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The underdog empowered? A case study of autistic policy influence in England (Alternative Format Thesis)

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The underdog empowered? A case study of autistic policy influence in England

Katharine Jane Precious

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Acknowledgements and Dedication

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Finally, these acknowledgements would not be complete without a recognition of the support that my Christian faith has given me. My knowledge that the aims of the thesis were aligned with my faith and values has spurred me on.

Nothing remains, then, but to dedicate this thesis to the people who I hope will benefit from it. This thesis is dedicated to underdogs everywhere.

Abstract

This multidisciplinary thesis by publication challenges the characterisation of marginalised groups as politically disempowered. While acknowledging their very real, structural disadvantage, it argues that dominant framings of marginalised groups, the actions of governments and researchers, and the actions of the groups themselves combine to systematically underestimate and under-measure policy influence in this context. This in turn impacts how others perceive marginalised groups, how they perceive themselves and how they behave.

Through two articles and a case study of the adult autistic community in England, I use process tracing of policy documents, Hansard records, stakeholder interviews and focus groups to track behaviours and outcomes during the lobbying process and to build my 'underdog theory' about the hidden potential of marginalised groups. The underdog theory states firstly that marginalised groups have a potential for a greater level of influence than is usually assumed; and secondly, that marginalised groups can maximise their policy influence by adopting a positive framing, learning about themselves and their policy environment (and using that knowledge strategically) and actively collaborating with others. The term 'underdog' reflects the disconnect between expectations of marginalised groups and what they can actually achieve.

This theory has implications for researchers and governments, who are urged to consider changes to the way they measure influence and design institutions and policy, but most importantly for underdogs. Through an article on policy design, it uses fuzzy set Qualitative Comparative Analysis to demonstrate the impact that governmental policy design has on autism policy decisions.

This thesis therefore makes a theoretical, methodological, and empirical contribution to the scholarship on empowerment, lobbying and policy processes. More importantly, it represents a first step in providing marginalised groups with the information they need about their policy environment to enable them to start their empowerment journey.

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1. Introduction

This thesis is founded on a simple premise: there is a democratic deficit in social policy (Norris, 1997; Pitkin, 2004; Fraser, 2009; Kingston, 2014; Fischer, 2019) - and we ought to try to do something about it. Or, more accurately, we ought to seek to facilitate the empowerment of those most excluded from the policy process, so that they can do something about it. As such, it is grounded in an epistemology based on critical social theory (Forst, 2014; Allen 2015): namely, that knowledge should be sought not for its own sake, but as ammunition to make the world a fairer place (Fraser, 1989b; Kemmis, 2006). Unapologetically empowerment-focused, it seeks to inform the lobbying strategy of groups which are traditionally assumed to lack the ability to influence policy in such a way as to enable them to exert maximal social policy influence. In so doing, it offers a critique of the unintended impact of the recent focus on power relations across a range of scholarships (Favre et al, 2019; Atkinson, 2020).

The notion of empowerment, which is more complex than its buzzword status implies (Cornwall and Brock, 2005), will be developed later in this chapter, and unpacked further in chapter 2. For the moment, however, I wish to draw attention to just two points. Firstly, em-power-ment is about realising one's capacity to exert power, which can be a synonym for influence (Bachrach and Botwinick, 1992; Wedel, 2017). Secondly, according to Dempsey and Foreman (Dempsey and Foreman, 1997), for a person to be empowered, they must have an awareness and understanding of the context in which they wish to exert power. This is not a new concept: the 'exploratory-diagnostic' phase of emancipation (Benhabib, 1985), where power relations are revealed (Béland and Cox, 2011; Scott, 2012), is widely accepted as an important part of the emancipation process in the emancipation scholarship (Taylor, 2011; Allen, 2015; Coole, 2015). Translated to the social policy arena, this means that, for marginalised groups to be empowered to exert policy influence, they must be aware of and understand the political opportunity structure which governs how likely they are to have the opportunity to exert influence (Gamson and Meyer, 1996; Meyer and Minkoff, 2004; McCammon, 2013), and, more generally, how the policy process and lobbying influence work (their policy environment).

Thus, this thesis poses exactly those research questions which will provide the answers needed by marginalised groups seeking empowerment to exert maximal social policy influence: **to what extent, under what conditions and to what effect do marginalised groups** (or, as I call them, 'the underdog') **exert social policy influence, and what can marginalised groups do to maximise their capacity to exert influence**? Over the course of the thesis, I use an iterative theory building process (Srivastava and Hopwood 2009) to build my 'underdog theory', a critical, explanatory framework of the social policy influence of marginalised groups, which draws together strands from the empowerment, lobbying, collective action, disability policy and policy process scholarships and is developed through a nested, outcome-explaining case study (Eckstein, 1992; Gerring, 2007; Levy, 2008) of the policy influence of autistic adults in England.

The 'critique' of this thesis is twofold: the unintended, reinforcing impact of the recent focus on power relations across a range of scholarships (Favre et al, 2019; Atkinson, 2020) and the democratic deficit that disempowers marginalised groups (Norris, 1997; Warren, 2009; Norris, 2011). It argues, firstly, that the social policy influence of marginalised groups is both underestimated and, perhaps as a result, under-measured: that it is not the 'rare case' (Lacy, 1997; Lowery, 2013) it would appear. This is largely due to the way in which marginalised groups and the issues concerning them are framed, which leads in turn to a range of both institutional and cultural barriers to influence (Schneider and Ingram, 1993; Nicolet, 2012; Jacoby, 2015). The barriers are real, not merely symbolic. This is about more than issue or target group frames that prioritise or minimise certain aspects of a policy issue. Framing is not even necessarily the most important reason for marginalisation. Nonetheless, just as framing contributed to the creation of these barriers, so, I argue, can it help to dismantle them. Marginalised groups often lack the tangible, external resources to do battle with tangible, external barriers to influence but can, I argue secondly, mobilise their internal resources – their strengths, skills, lived experience and learned expertise – in a positive, strengths-based reframing of themselves and of the issues which concern them (Kögler, 1996; Nicolet, 2012) to alter the dominant frames and help redress the balance of power relations.

Just as framing alone does not explain marginalisation, reframing alone is not, of course, sufficient to turn the tide of influence. However, when combined with other strategies as set out in the lobbying/collective action and disability policy scholarships, such as a strengths-based approach (Sullivan, 1992; Saleeby, 1993; Banducci, Donovan and Karp, 2004), forming alliances with other stakeholders (Riker, 1962; Mintrom and Vergari, 1996; Mahoney, 2007; Matti and Sandström, 2011; Pierce et al., 2017; Junk and Rasmussen, 2019; Luxon, 2019) and mobilising an understanding of how the policy system works (Kollman, 1998; Baumgartner et al., 2009; Binderkrantz and Pedersen, 2019; De Bruycker and Beyers, 2019), it can be the catalyst (Valsiner, 2019), or the "genie in the bottle" (John, 2013, p3) that facilitates empowerment and thereby enables the exertion of the influence that the marginalised group, and those around them, did not know they had. The input of the disability policy scholarship is particularly relevant here, and not just because of the nested case study on autism policy. It is also relevant because of the recent renaissance of the social model of disability (Priestley, 2010, Oliver, 2013, Lawson and Becket, 2021), which externalises barriers to influence and makes them combatable. The contribution of each of these scholarships is detailed later in this chapter.

It is also of paramount importance to note that marginalised groups cannot (and should not have to) do this alone. While the engagement and action of marginalised groups is undoubtedly a necessary condition for their empowerment and the maximisation of their influence, no group exists in a vacuum. The ability of marginalised groups to exert influence can be significantly constrained not just by how they are framed and by resultant institutional and cultural barriers, but also by the actions of two other actors in particular: governments and researchers. Governments constrain the influence of marginalised groups both through the institutions and political opportunity structures (Gamson and Meyer, 1996; Meyer and Minkoff, 2004) that they create and the way in which they design policies (Durose and Richardson, 2015; Schneider and Ingram, 2019). Researchers constrain the influence of marginalised groups because what they choose to research and how they choose to define, measure and research it determines what information is made available both to governments and wider society (Branham et al, 2014; Melissen and Koens, 2016). In this way, they both contribute to the framing of marginalised groups and potentially have an impact on institutional barriers. Thus, a change in the behaviour of either governments or researchers could help to facilitate the empowerment of marginalised groups, just as a denial of their duty to do so could result in a culture of responsibilising marginalised groups (Trnka and Trundle, 2014). This thesis, while prioritising the informing of a lobbying strategy for marginalised groups, as the underdogs at the heart of the underdog theory, also therefore considers the role of governments and researchers and makes recommendations as to how they could facilitate underdog empowerment in Articles 1 and 2, and in Chapter 8.

The word 'informing' is critical here: I do not seek to hand marginalised groups a ready-made strategy (nor would one strategy fit all contexts, in any case). Instead, across the thesis, I use an iterative process to build a theory, supported with evidence from a nested, outcome-explaining case study, which suggests behaviours which appear to be associated with lobbying success. Whether or not marginalised groups find this helpful and choose to use it is down to them. They must fill in the detail themselves, not least because the exact best strategy will be dependent on contextual factors. Empowerment is best achieved with marginalised groups at the helm (Goodley, 2005; Barnes, 2007) and it is paramount that those in a position of relative advantage do not inadvertently marginalise them further by seeking to speak or act for them (Alcoff, 1991) and thereby reinforce their framing as excluded and marginalised.

With this in mind, the remainder of this chapter will set out the evidence for the democratic deficit which motivates this thesis and retrace the steps of the beginning of my journey into the study of the social policy influence of marginalised groups, setting out why I decided to focus on influence and empowerment in the way that I did. It will also justify my potentially controversial choice to use the term 'underdog' to describe marginalised groups and indeed to name my theory using this term. The final section of the chapter will map the remainder of the thesis.

The democratic deficit

Getting back to basics, then, policy may be an interaction between state and society, but it is a predominantly one-sided interaction (Dahl, 1989; Banducci, Donovan and Karp, 2004; Fischer, 2019). The word 'democracy' means 'rule by the demos', or 'rule by the people', but in practice, 'the people' are excluded from the policy decision-making process. This exclusion is institutional, in terms of physical access to decision-making spaces (Miraftab, 2004; Cornwall, 2017; Hofman and Aalbers, 2017); cultural, in terms of the extent to which their views and opinions are taken into account (Aronson, 1993; McAdam and Tarrow, 2011; Schneider and Ingram, 2019) and normative in that it attempts to deter political participation by minimising the potential for influence (Dryzek, 1996; Halvorsen et al., 2017). This is the democratic deficit I refer to and the starting point of my critique.

As long ago as 1936, Harold Lasswell complained that policymaking was dominated by 'elites and experts' (Lasswell, 1936); over eighty years later, little has changed (Rawls, 2009; Richardson and John, 2012; Kingston, 2014; Flöthe and Rasmussen, 2019). Despite decades of research into various forms of collective action and citizen participation (Wright, 2009), combined with regular (if, at times, half-hearted) exhortations from governments for citizens to participate (Powell and Bingham, 2004), the ordinary citizen still finds themselves with limited voice and limited access to the policymaking process (Fischer, 2019; Junk and Rasmussen, 2019). Where they do have access, it is usually through participating in lobbying or collective action of some sort (McAdam, Tarrow and Tilly, 2001; Olson, 2009; Hardin, 2015; Junk and Rasmussen, 2019).

Specifically, the lobbying and collective action scholarships describe how lobbying success is qualified by a range of contextual factors, which vary according to the policy stage. At the agenda setting stage, influence is mainly restrained by the political opportunity structure, which determines how likely it is that a particular advocacy group will be given the opportunity to put their views forward, and a favourable hearing when they do so (Gamson and Meyer, 1996; Meyer and Minkoff, 2004; Jones and Baumgartner, 2005; McCammon, 2013). At the problem definition stage, framing congruence, where the aim of the game is to persuade the government to adopt your framing of a policy issue, is argued by some to represent the most effective way for advocacy groups to exert influence (Vanhala, 2010; Waldschmidt et al., 2015; Junk and Rasmussen, 2019). Beyond problem definition, at the decision-making stage, very few societal actors are given access to decision-making spaces, whether directly or by proxy (Bohman, 2012; Berry, 2015). Substantive representation at the decision-making stage therefore becomes of great importance, but is unfortunately elusive (Pitkin, 2004; Powell and Bingham, 2004; Pennock, 2017). Substantive representation requires both that the views (and frames) of the interested party are portrayed accurately, but also that the proxy acts in the best interests of that party (Pitkin, 2004).

Certain characteristics are held to be prevalent across the board in those who have been observed to achieve lobbying (or collective action) success – usually defined as either getting an issue on the government’s agenda or achieving their policy goals. We know that resources matter (not just financial, but also manpower, expertise, and reputation) (Kaplow, 2007; Leech et al., 2007; Toke, 2010; Rhodes, 2018; Fischer, 2019). These are characteristics not generally held by ‘the people’ – nor is the democratic deficit entirely overcome by pooling resources, which is a central tenet of the collective action argument (Olson, 2009; Wright, 2009; Laumann and Pappi, 2013; Hardin, 2015).

We also know that public opinion about the group and policy issue matter too (Baumgartner and Leech, 1998; Dür and Mateo, 2014; Flöthe and Rasmussen, 2019; Schneider and Ingram, 2019), meaning that large swathes of the population are effectively disenfranchised because they possess a characteristic which is seen as politically unpalatable. For example, teenage mothers and young black men are both examples of groups which have been negatively framed in public opinion and have subsequently found that policy decisions have not gone in their favour (Ellis-Sloan, 2014; Rowley et al., 2014; Taylor and Haider-Markel, 2014). Thus, all societal actors suffer from an institutional bias which limits their access to decision-making spaces. This, to a certain extent, is unavoidable – there are only so many seats at the policy table. However, certain societal actors – including marginalised groups - are further hamstrung by additional cultural and normative biases which reduce both their access to decision-making spaces and the likelihood that they will be listened to, and ultimately able to achieve their policy goals.

Introducing the underdog

The democratic deficit appears to be particularly pronounced when it comes to those groups of people commonly referred to as 'marginalised' (Baumgartner and Leech, 1998; Fraser, 2009). I use inverted commas deliberately, in recognition of the partially constructed nature of their marginalisation (Nordberg, 2006, Priestley, 2010). While I do not fully subscribe to a constructivist view of policy subjects, or indeed of the world in general, (Kögler, 1996; Bardon and Josserand, 2011), the word 'marginalised' is decidedly spatial. You can only be 'on the margins' of a (real or discursive) space which has been demarcated (constructed) with margins or barriers (Allen, 1999). Discourses of marginalisation focus heavily on moving these margins or overcoming barriers to move further into the space, but all too often end up reinforcing the barriers they set out to decry (Brown, 1993; Koselleck, 2002; Goodley, 2005; Coole, 2015). By focusing on structural barriers, on the resources that they do not have, on their victimhood, they risk missing the potential resources and positives which are to be found in the group dismissed as being marginalised (Chapin, 1995; Sen, 2005; Kaplow, 2007; Rawls, 2009; Jacoby, 2015). The strengths-based, or capabilities approach espoused by Amartya Sen and others (Sullivan, 1992; Chapin, 1995; Hamilton, 2003; Banducci, Donovan and Karp, 2004; Sen, 2005), complemented by the social model of disability, which externalises barriers and reinforces inner strengths (Priestley, 2010; Oliver, 2013), form a key part of the argument of this thesis – and a compelling counter-argument to the marginalisation framework - and are expanded upon in chapter 3.

Throughout this thesis, I prefer to use the term 'underdog', which the *Oxford English Dictionary* defines as 'one who is in a state of inferiority or subjection' (OED, 2020). To begin with, there were two main reasons for this: firstly, because it is a more intellectually and emotionally honest term: it recognises the psychological burden of not just being 'on the margins' but being maintained, by norms, by others and, to a certain extent by oneself, in a state of subjectivity. A focus on the subjectification of marginalised groups is not without its risks (Scott, 2012; Allen, 2015; Lettow, 2015), and due in part to concerns about promoting victimhood (Brown, 1993; Jacoby, 2015) most critical social scholars prefer to talk about power relations rather than a binary oppressor-victim approach (Kögler, 1996; Koselleck, 2002; Mckee, 2009). I concur entirely with their concerns and indeed promote the very opposite of an oppressor-victim approach. However, minimising the subjectification of marginalised groups also comes with its own risks, partly because the opposite extreme of the victimhood approach is responsibilisation, where marginalised groups are expected to empower themselves without any form of government (or societal) support (Garland, 2012).

Perhaps more importantly, and potentially controversially, I argue that an acceptance of the role a subject plays in maintaining their state of subjectification is required in order to identify those aspects of subjectification that the underdog is in a position to be able to change. This is something that is a mainstay of the strengths-based approach ((Sullivan, 1992; Chapin, 1995; Banducci, Donovan and Karp, 2004)) but remains unpalatable in the political and policy fields, partly due to the understandable fear of responsibilisation. However, if the negative framing of the underdog is *entirely* the doing of others, where is the agency of the underdog to change that framing? The underdog is most certainly *not* responsible for their own marginalisation. Rather, their marginalisation is the cumulative effect of centuries of cultural, institutional, and normative attitudes and behaviours towards those who do not 'fit in', and of course, the frequently consequent material deprivation. Despite their status 'on the margins' of society, the underdog is nonetheless part of the society which has constructed these attitudes and participated in these behaviours. A tightrope must be walked to recognise agency without slipping into responsibilisation, and I go more into detail in this in chapter 2.

The second reason why I initially chose to use the term underdog is because, in mythology, literature and popular culture, the underdog often defies expectations to come out on top (Vandello, Goldschmied and Richards, 2007; Goldschmied, Ruiz and Olagaray, 2017; Zamudio and Wang, 2018). There is a disconnect between what the underdog is *expected* to achieve and their *actual potential* to achieve. From the tortoise and the hare to David and Goliath, Cinderella marrying her prince to Erin

Brockovich winning her law case and even England winning the World Cup in 1966, popular culture recognises what politics and policy frequently does not, because it acknowledges that *an underdog is a state of being* (Dempsey and Foreman, 1997) *and a state can be changed*. It imparts hope. By invoking the imagery of the underdog triumphing against all odds, I hope to do my part to shift the framing of marginalised groups in a more positive direction.

What began as a simple choice of words emerged into something perhaps more akin to an ideological position. I realised that the underdog is characterised by two descriptors which, at first glance, appear at odds with one another. On the one hand, the underdog is anyone who approaches the policy decision making system from a position of disadvantage. They may be disadvantaged due to poverty, to characteristics such as age, gender, sexuality, disability, or any combination of these things. In many cases, the underdog is also the target group of social policy, i.e., they are expected to benefit from it (Schneider and Ingram, 1993; Van Oorschot, 2006; Heuer and Zimmermann, 2020). This widens the democratic deficit further for these groups: they arguably have the most to gain, or lose, of any stakeholder, and yet they are assumed (framed) and observed (as a result of the choice of indicators and topics in research) to lack the political influence to exert any control over the policy decisions which determine those gains or losses. Thus, the second part of my critique is that the democratic deficit is particularly unjust when it comes to marginalised groups.

However, the second descriptor which characterises the underdog is that, despite these challenges, despite being framed as a weak and dependent target group and maintained in a position of subjectification, they – in fiction and mythology at least - succeed against the odds. Therefore, they have a *hidden potential* – in an empowering inversion of the way that we often talk about hidden disabilities. Thus, the underdog evolved to be more than a descriptive term: the underdog represents the *potential for empowerment of marginalised groups*. By exhibiting certain ‘underdog behaviours’ theorised in this thesis, marginalised groups can both reframe themselves and take action to empower themselves. However, in order for this reframing and empowerment to take place and for these behaviours to become commonplace, marginalised groups must recognise and act upon their hidden potential. By highlighting the hidden potential of marginalised groups, governments, researchers, and indeed wider society can do their bit to facilitate the empowerment of marginalised groups and the development of underdog behaviours.

Influence: the elephant in the room

Despite marginalisation being, in essence, a lack of influence, policy influence remains the elephant in the academic conference room. The plight of the underdog has attracted much scholarly attention from many disciplines (Mowat, 2015). Disciplines such as feminist studies, gender and sexuality studies and disability studies have evolved to grapple specifically, if not exclusively, with the social and political empowerment of these groups (Fraser, 2009). A whole body of scholarship focused on emancipation has emerged (Ray, 1993; Koselleck, 2002; Scott, 2012; Coole, 2015) and remains divided as to the best route to social justice. The collective action scholarship was optimistically touted as a route out of the democratic deficit, but results remain mixed and highly context bound (Dür, 2008; Lowery, 2013). This is not to say that important inroads have not been made but simply that more needs to be done: the democratic deficit remains.

At the heart of the underdog dilemma is the disempowerment of these groups, and this is one important reason why I focus on empowerment rather than emancipation. While emancipation is defined as the act of being set free, which could be twinned with a paternalistic approach to imply that an underdog needs someone else to set them free, empowerment can only be achieved by the underdog themselves. Put simply, they are assumed (framed) and observed (reinforcing the framing) to lack the characteristics which are associated with the power to determine or alter the policy process and its outcomes, as outlined in the previous section. I query, however, whether a focus in the scholarship on those assumed to be more likely to achieve lobbying success (Robb, 1998; Lowery, 2013) has overstated some of these characteristics. In chapter 3, I demonstrate that many of the measures used to quantify influence are calibrated in a way that risks missing the influence of marginalised groups. Are we missing their influence because we don't have an appropriately calibrated measure for it? Are marginalised groups as disempowered as we think they are, or are scholars falling prey to (unconscious?) normative and methodological bias? Such questions are discussed further in chapter 3, and the case study that forms the bulk of the thesis will further illuminate the answer.

Lobbying influence is fundamental to the study of policy as an interaction between state and society (March, 1955) and yet, paradoxically, relatively few scholars have grappled with more than a narrowed and isolated aspect of it (Lowery, 2013). This is partly because it is difficult to grapple with something you cannot see (Winton, 2018). It is not as simple as lobbying success or failure: there are degrees of influence.

Influence is invisible and detectable only through its effects (Arts and Verschuren, 1999; Dür, 2008). Causation is particularly evasive and, as a result, most scholars either focus on a narrowed and incomplete definition of influence, where they feel they can establish causality, or avoid the topic altogether (Klüver, Heike, 2009; Schunz, 2010; Skodvin, Gullberg and Aakre, 2010; Richardson and John, 2012; Laumann and Pappi, 2013; Lowery, 2013). Scholars know it's there; they know it's important but they're reluctant to take on the methodological challenge of tackling it head-on.

The thorny issue of causality is approached in this thesis from the ontological perspective that, in the social sciences, causation can only ever be inferred (Gerring, 2010). Both the iterative nature of the theory building process used in this thesis, and the use of an established outcome-explaining process tracing method in the case study make it more likely that the theory built is generalisable to other contexts. However, this thesis can only state with confidence that the underdog theory is applicable within the case and circumstances studied. Further testing will be required to test the extent to which it is generalisable to other contexts.

Underdog influence is even less studied than policy influence in general because it is assumed to be minimal: the successful underdog is dismissed as a 'rare case' (Lacy, 1997). Underdogs have been framed in such a way that it is assumed that they cannot exert influence by themselves, but only by climbing on the shoulders of more influential giants. The common focus on alliances and collective action to overcome such social structures as ableism is important but has the unintended consequence of implying that the underdog cannot do anything on their own and reinforcing their framing as dependent. In chapter 2, I outline how these strategies can be used together with a concerted, strengths-based reframing to maximise influence.

I argue that it is only by tackling influence in its entirety – or as close to it as possible - that underdogs can complete Benhabib's exploratory-diagnostic phase (Benhabib, 1985) and gain the knowledge that they need to empower themselves. Empowerment is the antidote to disempowerment and at the heart of any approach to tackling the democratic deficit. Therefore, in this thesis, I propose a theoretically grounded and empirically developed calibration of observable indicators of influence adapted to the underdog which I hope will overcome both normative/methodological bias and some of the methodological challenges inherent in measuring it. This template for measuring influence, which triangulates existing indicators, forms the first claim that this thesis makes towards making a novel contribution to knowledge, and is developed and justified in chapter 3 and article 1 before being empirically developed further through the case study which follows.

The underdog empowered?

As stated earlier, empowerment has become something of a buzzword in many academic disciplines, and indeed in wider society (Banducci, Donovan and Karp, 2004; Cornwall and Brock, 2005). Confusing the issue further, it is understood to mean subtly different things in different contexts. In its simplest form it means the realisation of the capacity to exert power, but it can also mean to confer power on someone else in a paternalistic way. There are many different spheres of power, and while psychology and disability scholars, for example, often focus on personal power in daily life through self-determination, political scholars often focus on political representation. Empowerment to the disability studies scholar may be the power to redefine oneself and to overcome the normative and structural barriers in one's way.

In the context of this thesis, political self-empowerment is the desired outcome, and I turn to Dempsey and Foreman's (Dempsey and Foreman, 1997) very thorough definition of empowerment as an outcome of disability policy. There are two key strands to their definition. The first is that empowerment is a state of mind (much like being an underdog). This is a very important statement, because it puts control over one's empowerment directly in the hands of the person being empowered. True empowerment is not something that can be done to somebody else, but something that a person must do for themselves (Barnes, 2007). There is, of course, a risk that this framing of empowerment puts all the responsibility for empowerment on the underdog, which is neither necessary nor desirable. Nonetheless, the importance of the person to be empowered taking an active role is clear from this approach and supported by the strengths-based literature (Sullivan, 1992; Banducci, Donovan and Karp, 2004; Hornung, Bandelow and Vogeler, 2019).

The second is that, like influence, it is made up of different strands which all contribute to the strength of its thread: self-efficacy, participation, sense of control, meeting personal needs, understanding the environment, personal action, and access to resources. Unsurprisingly, the list is not so very different from qualifiers of influence. It is clear that resources, participation, or representation alone are not enough to empower. Nor is self-efficacy paramount. It is the last two strands of the thread that power the argument of this thesis: to empower themselves, the underdog must understand the policy system and environment *and* they must themselves take action.

If the underdog is to be empowered to develop a lobbying strategy that will enable them to exert influence, then just measuring influence is not enough. It is also necessary to understand what conditions favour influence, so that these conditions can be manufactured, or reproduced, insofar as is possible. This involves looking both at the decision-making process and at its output (policy decisions). (Outcomes, as in policy impact and implementation is outside the scope of this thesis but will form part of the wider research plan, as discussed in the Conclusion.) The second contribution to knowledge made by this thesis is therefore my 'exploratory-diagnostic' theoretical framework about the extent of underdog influence and the conditions which favour it, which was summarised earlier in this chapter and is set out in skeleton form using the scholarship, including in my pyramid of empowerment, in chapter 2, and further developed through the case study which follows.

The main empirical contribution to the scholarship is thus an in-depth single case study which explores, through a semi-inductive, iterative method (Srivastava and Hopwood, 2009), across two journal articles, the validity of my template for measuring influence, my underdog theory, and my pyramid of empowerment. In-depth case studies are an established method for exploring social behaviour (Seawright and Gerring, 2008; Yin, 2013) and are particularly important when exploring influence, which is highly context driven. Without thick description (Geertz, 1973), and, indeed, thick analysis (Evers, 2015), the context in which influence is exerted cannot be understood and empowerment remains out of reach. The semi-inductive, iterative approach allows for contextual differences to be recognised and acknowledged (Srivastava and Hopwood, 2009). Outcome-explaining process tracing is used to explore different explanations for the unexpected policy success of autistic self-advocates, as outlined in the next section, and utilises a range of qualitative data analysis techniques across documents (policy documents, Hansard documents) and people (stakeholder interviews, elite interviews, focus groups and survey). A thesis by publication enables this complex case study to be split into manageable parts and demonstrates its applicability to different disciplines (Merga, Mason and Morris, 2020).

The autistic empowered?

The case selected for investigation is that of the adult autistic community in England. Autism policy is a new and as yet under-researched policy area which has evolved from disability policy in response to criticisms from campaigners, supported by charities and intergovernmental organisations that autistic people were falling through the gaps of existing disability policies (Loynes, 2001; Duffin, 2009). Over the past twenty years, fifteen new autism-specific policies, by which I mean national policies which deal exclusively or mainly with autism, have sprung up across Western Europe (Della Fina, 2015; Baranger, Hammersley and Posada de la Paz, 2018; Roleska et al., 2018). These policies have evolved from disability policy to form a sub-policy area of their own and, crucially, autism is the only disability[1] to have done this (Della Fina, 2015).

This implies that those seeking policy change in the form of an autism-specific policy – likely to be societal rather than governmental actors, since there is no discernible benefit to government, beyond reputational, in doing so (Pross, 1992; Lindquist, 2001) – have succeeded in persuading governments that there is something additional and/or different about autism. If autistic people are behind this change – and nothing causal has been proven – then this is really a surprising level of influence, and worthy of evaluation. This remains an under-researched area of autism policy and therefore there is a 'gap' to be filled.

The case selection was further narrowed down to England, as one of the earliest European countries to implement an autism policy, in 2009, with the passing of the Autism Act 2009 and the first Autism Strategy (National Archives 2021). This decision predated pressure from the United Nations Resolution on Autism (UN, 2012), World Health Organisation Resolution on Autism (WHO, 2014) and European Parliament Declaration on Autism (EC, 2015), making it more likely that the actions of campaigners were pivotal. England was also the first country to pass an autism-specific law (Della Fina, 2015). My Masters of Research dissertation explored the campaign behind the Autism Act, which began in approximately 2006, and included interviews with key players in the campaign, all of whom underlined how the campaign was driven by autistic self-advocates, albeit with important support from the National Autistic Society (Precious, 2018). These interviews are incorporated into the chapter on case selection, to support the argument that the Autism Act 2009 was not only a watershed moment of change in policy but was also driven by a marginalised group. My second article further supports the selection of England as a case study for this thesis, since it demonstrates that the political opportunity structure in England is favourable to autistic empowerment (Precious, 2020). I choose to focus on autistic adults both because the Autism Act and Strategies, up until 2021, were focused exclusively on

[1] There is significant debate among the autistic community as to whether autism should be considered a disability (Krcek, 2013). However, autistic people are often disability policy beneficiaries (Knapp, Romeo and Beecham, 2009), therefore it is relevant that autistic people are the only group of such beneficiaries to break away and form their own policy area.

adults, and because they are more likely than children to be able to participate in lobbying.

The autistic community therefore appears to meet the underdog criteria. Although, in recent years, there has been a trend towards self-diagnosis or identification (Brosnan, 2020), autism remains clinically defined on the basis of perceived, clinician-observed deficits in social communication, restricted interests or thought patterns and sensory processing difficulties (APA, 2013). Thus, they are defined by what they lack and clearly constructed as disempowered, dependent target groups of policy. Globally, around 1% of the world's population are thought to be autistic, with some estimates putting the number higher and rates of diagnosis increasing (Elsabbagh et al., 2012). Autistic people are statistically over-represented among unemployed (Hendricks, 2010; Mavranezouli et al., 2014), under-employed (Nicholas et al., 2017) and prison populations (King and Murphy, 2014; Robertson and McGillivray, 2015), and those experiencing mental health difficulties (Cage, Di Monaco and Newell, 2018; Crane et al., 2019). Thus, they intersect with a range of other marginalised groups, ramping up their societal marginalisation.

Despite this marginalisation, the autistic community has also long been associated with the neurodiversity movement, which calls for a strengths-based approach to autism (Kapp et al., 2013; Arnold, 2017; Donaldson, Krejcha and McMillin, 2017; Kapp, 2020). There are several positive characteristics which have long anecdotally been associated with autism and, more recently, empirically tested and shown to be clinically evident (Meilleur, Jelenic and Mottron, 2015). These characteristics, which include a detail-orientated focus, the ability to retain large amounts of information and the ability to speak articulately and persuasively on a topic of interest, are potentially characteristics which would be beneficial in the lobbying arena. They could therefore be examples of 'hidden potential'.

Research questions and structure of the thesis

The overarching research question, as stated earlier, is concerned with the **extent** of underdog influence, the **conditions** within which it is exerted and the **effect** of its exertion. The rationale for answering these questions, beyond a desire to understand underdog influence, is to provide the necessary data to inform a lobbying strategy for underdogs and to enable governments and researchers to facilitate their empowerment. Therefore, a nested, outcome-explaining case study also applies these research questions specifically to the autistic community in England, as shown in the table overleaf.

<table>
<tr><td colspan="4">Overarching Research Questions:
1. To what extent, under what conditions and to what effect do underdogs exert social policy influence?
2. How can underdogs empower themselves to maximise their policy influence?
3. How can governments and researchers facilitate the empowerment of underdogs?</td></tr>
<tr><td colspan="4">Case Study Research Questions:
1. To what extent, under what conditions and to what effect did the English adult autistic community exert influence over national autism policy between 2006 and 2018?
2. How can autistic adults maximise their policy influence?
3. How can governments and researchers facilitate the empowerment of autistic people?</td></tr>
<tr><td></td><td>Article 1</td><td>Article 2</td><td>Article 3</td></tr>
<tr><td>Title</td><td>Marginalised or missed? The curious case of missed policy influence.</td><td>Informed, involved, or empowered? Three ideal types of autism policy design in Western Europe.</td><td>The autistic community empowered: towards a lobbying strategy for autistic adults in England.</td></tr>
<tr><td>Scope</td><td>Extent of influence; role of researchers</td><td>Conditions for influence; role of government.</td><td>Conditions for and effect of influence; role of autistic community.</td></tr>
<tr><td>Research Question</td><td>To what extent does the English adult autistic community exert</td><td>How do different Western European autism policies</td><td>Under what conditions and to what effect to autistic self-advocates exert</td></tr>
</table>

	influence over autism policy in England?	impact the political opportunity structure for autistic people?	policy influence in England?
Method	Process tracing	Fuzzy set qualitative comparative analysis.	Process tracing
Status	Conditionally accepted with revisions by *Politics and Policy.*	Published online and in print by *European Policy Analysis.*	Under review by *Journal of Autism and Developmental Disorders.*

Figure 1: Research Questions

Following this Introduction, Chapter 2 sees the opening stages of the building of my underdog theory. A literature review of the relevant sections of various interdisciplinary scholarships is used to assemble a skeleton theory about underdog influence. This chapter has been left as it was written at this initial stage of the thesis deliberately, in order to elucidate the development journey of the thesis. Changes are proposed and incorporated to this theory in Chapter 6.

Chapter 3 goes on to discuss the elephant in the academic conference room: policy influence and its measurement. This chapter contains a literature review of indicators of policy influence and the methods used to obtain them, viewed from the standpoint of marginalised groups. It goes on to propose specific indicators of influence which are better calibrated for such groups. It is followed by Article 1.

Chapter 4 discusses the case selection of the English adult, autistic community as an exploratory case study for this theory and is followed by Article 2. Chapter 5 contains the method for the case study, while Chapters 6 and 7 constitute the main body of the case study and are followed by Article 3.

Chapter 8 brings the thesis to its conclusion by drawing together the three strands of analysis: underdogs, governments, and researchers, and considering the next steps for underdog empowerment.

The articles are thus integrated into the overall flow of the thesis; each both contributes to the thesis and the case study but also stands as an independent research article in its own right.

Impact of the coronavirus pandemic

No introduction to this thesis would be complete without an acknowledgement of the timing of its development in the middle of the COVID-19 pandemic. This has necessitated adaptations to both the scope and methodology of the research. I had originally intended to compare English and Danish policy, but reverted to a single case study, following advice from my funding provider about international travel due to travel restrictions and the national lockdown. In addition, interviews and focus groups had to be moved online, which necessitated learning new technological platforms and additional training in conducting online research. Finally, arranging interviews with government representatives was more difficult than it might otherwise have been due to an understandable preoccupation in government with managing the pandemic. As a result, interview numbers were lower than I would have liked.

However, the impact of the pandemic was not entirely negative. Several of the autistic individuals I interviewed and spoke to stated that they were more comfortable with online interviews and focus groups than they would have been if they were held in person. As a result, it is possible that autistic engagement was better than it might otherwise have been, although of course I cannot say this with certainty. Evidently, moreover, this is not true for all autistic individuals.

A contribution to empowerment

To conclude this Introduction, this thesis aims to make four contributions to knowledge: two theoretical, in the form of my underdog theory and my pyramid of empowerment, one methodological in the form of my indicators of policy influence, and one empirical, which, more simply, aims to add to the nascent but growing scholarship on autism policy. However, most importantly, it aims to provide autistic people, and more widely, underdogs in other areas, with the tools to understand their policy environment so that they can take action and empower themselves to develop a successful lobbying strategy, which, ultimately, will result in them being able to have their needs met better by policy.

The key to this empowerment, I argue, lies in combining the strengths-based argument with a pragmatic approach. Focusing on what you *can* do to improve your situation, rather than on the barriers holding you back, is more likely to foster a state of mind where empowerment is possible. While resources have long been known to matter in lobbying influence, insufficient focus has been given thus far to the internal resources of marginalised groups. I argue, and I hope, that this may hold the key to unlocking hidden underdog potential, which may well have always been higher than we had assumed. When these internal resources, or hidden potential, are combined with the 'underdog behaviours' set out in this thesis, marginalised groups can climb the pyramid of empowerment and began to enact that potential by strategising themselves about the best way to maximise their influence. Governments and researchers, of course, also have a role to play here as well in facilitating the process of empowerment and should not be allowed to shirk their responsibilities.

Further analysis and testing are planned and required in the future to further develop and bolster my underdog theory, which is still a fledgling theory. Testing and further development will be required in different policy contexts, in different countries and with different underdog types. Nonetheless, this thesis represents the birthing, initial testing, and tentative foray of the underdog theory into the real world. I hope that it will be both interesting and successful.

2. The underdog empowered: beginning to build a critical, explanatory framework

Introduction: a critical explanation

In this chapter, I begin the iterative process of theory building (Srivastava and Hopwood, 2009, Howarth, Glynos and Griggs, 2016) by constructing a skeleton, critical, explanatory theoretical framework, which will be built upon and expanded as the thesis progresses. The skeleton framework begins with a multidisciplinary literature review, incorporating relevant aspects of the framing, empowerment, lobbying, policy process, disability studies and psychology scholarships, which aims to "explain and expose the contingency of processes and relations" (Howarth, Glynos and Griggs, 2016, p101). (The rationale for focusing particularly on the disability policy scholarship will be explained later in this chapter.) The process in this instance is the lobbying process and the relations of interest are those between the underdog and governmental decision makers. The framework is critical because it aims to address the imbalance of power in this relationship and explanatory because it seeks to illuminate the processes and relationships for the benefit of the underdog's learned expertise. Put simply, the framework critiques the lack of access to the policy making process for underdogs and explains how underdog lobbying is traditionally assumed to work, so that lessons can be learned by the underdog about how this limited access can be translated into maximal influence. However, as set out in the Introduction, it is also a critique of the unintended consequences of a long-term focus on power relations across a range of scholarships (Favre et al, 2019; Atkinson, 2020), which has reinforced a further disempowerment of already disempowered groups and created an excessively pessimistic outlook for these groups.

This approach fits both the critical and practical aims of the thesis - namely to expose the imbalance of power inherent in underdog policy influence with a view to empowering the underdog to alter it - as set out in the Introduction. As in the rest of this thesis, pragmatism (in the everyday rather than the philosophical sense) and the moral/normative imperative to be critical, i.e., to seek to right a wrong, trumps traditional ontological and disciplinary divides. For example, the framework places a high value on framing, which is a relatively constructivist concept, but acknowledges that there are 'real world' implications of this framing which require 'real world' solutions as well.

Similarly, the number of disciplines used in the literature review necessarily compromises the breadth of theories from that discipline that can be discussed in depth. Here, my deliberate approach is to cross-reference and focus on commonalities across the disciplines. Where theorists from different disciplines come to very similar conclusions about a particular topic, this boosts the reliability and generalisability of the conclusion. As a result, I consider that the requirement to analyse competing viewpoints within each discipline is lessened. This is therefore a focused literature review (for a focused and niche policy area) which highlights and builds upon commonalities rather than seeking to evaluate a wide range of ideas. To employ a metaphor, the thread of the theory is stronger because it is made up of numerous strands from different disciplines.

This chapter focuses mainly on what the underdog can do but does touch on the role of other parties. The role of other parties is discussed more in-depth in Chapter 8 and Articles 1 and 2. Finally, a reminder that this chapter represents the skeleton theory that *began* the thesis, at the beginning of the iterative process. It is adapted in light of the results of the case study in Chapters 6 and 7.

I begin by constructing the imbalance of power in underdog influence as a problem (a phase that Howarth, Glynos and Griggs call problematisation (Howarth, Glynos and Griggs, 2016)). It immediately becomes apparent that, in order to do so, aspects of different scholarships must be combined. We cannot understand underdog influence if we do not understand both how the underdog is (socially, politically, <u>and</u> psychologically) framed as disempowered (empowerment, framing and disability policy scholarships) and how policy influence works (policy influence and policy process scholarships). Similarly, we will not be able to offer a critique which proposes a potential redress if we do not understand the conditions which favour policy influence (lobbying, collective action, and disability policy scholarships). It is neither practical, possible, nor desirable to summarise these scholarships in their entirety in this chapter, or indeed this thesis. Therefore, I deliberately separate the strands that I consider to be theoretically relevant and combine them to make a new theoretical thread. This thread forms part of a skeleton theory and a skeleton lobbying strategy which will be deepened and embellished through the case study which follows.

I prefer the term proto explanation to the term hypothesis because proto, from the Greek πρωτοσ meaning 'first', reflects my ontological perspective that there is not a single 'truth' to be uncovered and, indeed, that even the softening of positivist causation into a causal mechanism (Bennett, 2010) is too blunt an instrument. As set out in the Introduction, the understanding of causation utilised in this thesis is that, in the social sciences, we can *infer* likely causation by using robust methods which have been shown over time to be effective in identifying causation, and by testing hypothetical causal links in different contexts (Levy, 2008; Valsiner, 2019). The outcome-explaining process tracing (Bennett, A., 2010; Collier, 2011; Beach and Pedersen, 2019) and Fuzzy Set Qualitative Comparative Analysis (Ragin and Pennings, 2005; Kvist, 2007) used in this thesis are established methods for exploring causation. Using these methods, I can infer a likely causal link between certain behaviours and conditions and policy influence in the context of the case study of autistic policy influence. The strength of the thread of the theoretical framework outlined in this chapter, which is constructed by cross-referencing commonalities across different scholarships and combining their learning, makes it more likely that the causal link theorised will be generalisable. However, this is by no means certain until it has been tested in other contexts.

Furthermore, there is no 'recipe' for increasing underdog influence. We cannot say that if you do x, y, and z, you *will* increase your influence. What we can say is that is that the explanatory framework suggests that there may be a causal link between certain actions or behaviours, which, importantly, are within the control of the underdog. These actions are neither necessary nor sufficient conditions for influence but may serve as a catalyst for maximising influence (Valsiner, 2019). This is not a deductive hypothesis to be tested, but the first step in a semi-inductive and iterative journey (Srivastava and Hopwood, 2009) which will be completed not by me, or even by other scholars (although we will move it along the way), but, most importantly of all, by the underdog.

This chapter is divided broadly into two sections. The first section begins with a problematisation (Glynos and Howarth, 2007) of the underdog as politically disempowered in policy influence terms, drawn from a critical literature review of first the framing and disability policy and then the empowerment and policy influence scholarships. It goes on to consider the factors which impact the capacity of the underdog to exert policy influence, linking the collective action/lobbying scholarship with the disability policy and empowerment scholarships. Throughout this first section, proto explanations are generated. In the interests of transparency and reproducibility, I am clear in the sections which follow which elements of the scholarship I have chosen to focus on and why.

The second stage, which will be further developed in Chapters 6 and 7, iteratively develops the proto explanations, and considers what the underdog can do to maximise their influence – what is practical? What is achievable? It is preferable to focus on what the underdog can do rather than what they cannot do. Here, I rely particularly on the empowerment and disability policy scholarships. I then combine the proto explanations generated in the previous section with the 'can do' list generated in this section to propose a critical, explanatory framework of underdog influence which both 'explores and diagnoses' the barriers to influence while identifying what the underdog can do to maximise their policy influence.

Thus, rather than proposing a deductive, hypothetical causal mechanism for influence, this thesis, in the tradition of many critical theorists (Kurki, 2007; Fletcher, 2017) will argue that:

a strengths-based approach – promoting a positive framing and capitalising on strengths/existing resources – is the catalyst which, in the right conditions (understanding of policy environment, maximisation of opportunities for participation, alliance with other groups), gives the underdog an opportunity to empower themselves to exert the influence they didn't know they had.

We must begin by understanding who the underdog is and why they are disempowered.

The underdog: disempowered from within and without

In the Introduction to this thesis, I explained why 'underdog' was my preferred terminology for referring to marginalised groups. In fact, my choice of terminology goes further than this, and forms an integral part of my 'underdog theory'. I shall expand on the reasons for this shortly but begin with a critical discussion of who we mean when we talk about marginalised groups. As stated in the Introduction, one element of the critique which motivates this thesis is that scholars and society have long focused on power imbalances and relations (Favre et al, 2019; Atkinson, 2020), which runs the risk of reinforcing an 'us vs them' approach (Crawford, 1977; Jacoby, 2015). For the purposes of this thesis, a marginalised group is any group which finds itself in a position of disadvantage in the policy process. The nature of this disadvantage will vary from group to group but the first commonality to highlight from the various disciplines reviewed is that the **disadvantage that hinders the marginalised group is situated both inside and outside the individual.**

Within political perspectives, this divide may be characterised as structural vs cultural disadvantages (Goodwin & Jasper, 1999; Koopmans et al, 2001; Howlett, 2019). Structural disadvantage, as the name implies, is conceptualised as a structure outside of the disadvantaged individual which impedes their progress. For example, if an individual is not permitted by the electoral system to vote, this would constitute a structural disadvantage. Cultural disadvantages, however, are situated both inside and outside of the individual since they refer to societally embedded norms and expectations. For example, if the societal expectation of women is that they are primarily homemakers, this constitutes a disadvantage both in the sense that it is internalised by women in society and because it is expressed by other members of society. Societal expectations are commonly based on internal characteristics, such as biological sex, race, or disability, which cannot be changed. This can lead to a sense of disempowerment from within, since one is disempowered by something inside of oneself, which one cannot change.

However, the expectations themselves are narratives, or stories which the society has built up around that characteristic. The characteristic cannot be changed, but the narrative around the characteristic can. This will not necessarily solve the problem – in the case of biological sex and disability, for example, there are innate disadvantages which cannot be removed by changing the narrative. Changing the narrative about women will not change the fact that someone who is biologically female has to consider the risk of pregnancy if they are heterosexually active. Changing the narrative about disability will not mean that a wheelchair user can suddenly get up and walk.

This important difference is picked up on by the psychology, empowerment, and disability policy scholarships, all of which highlight a similar divide between the internal and the external. Perhaps understandably, the psychology discipline tends to focus more on the internal. Maslow's hierarchy of needs (Maslow, 1943) (which will be returned to in more detail later in this chapter) highlights the internal needs which require meeting before an individual can begin to meet the external challenges outside of themselves. Where any of these needs are not met, the person becomes disempowered and less able to tackle their external disadvantages. The discipline of positive psychology highlights changing what are you able to change – your internal disadvantages – rather than focusing on the situation outside of you which you cannot change – your external disadvantages (Sheldon and King, 2001; Compton, 2005; Meyers et al, 2013).

When the psychology discipline segues into the empowerment discipline, the internal does battle with the external more explicitly. Empowerment, according to several scholars, consists of being aware of both one's internal advantages and disadvantages and the disadvantages in one's environment and acting strategically to maximise one's innate advantages (Perkins and Zimmerman, 1995; Dempsey and Foreman, 1997; Page and Czuba, 1999; Zimmerman, 2000; Maiorano et al., 2021). Several empowerment scholars focus specifically on empowerment for disabled people precisely because they are a powerful exemplar of a group for whom there is a usually unchangeable, internal disadvantage which is further reinforced by external disadvantages, both structural, such as inaccessible spaces (both physical and discursive) and cultural, such as ableism (Dempsey and Foreman, 1997; Goodley, 2005; Cascio, M.A., Weiss, J.A. and Racine, E., 2020). Indeed, this was the founding premise of the social model of disability, about which I will say more in more detail later in this chapter.

It is important to note here that all disability policy scholars, or social model adherents, would agree with my characterisation of internal versus external disadvantage. For some scholars, and some activists, the internal characteristic is only a disadvantage because society has decreed that it is so. Nonetheless, in recent times, many scholars concede that a full understanding of disability must include elements of both essentialist and constructivist approaches (Dirth and Branscombe, 2017; Olsen and Pilson, 2022). I consider the differentiation between internal and external to be important because there is a longstanding understanding that having both an internal and an external locus of control is important for disabled people (McDonald and Hall, 1969; Partridge and Johnson, 1989; Terras et al, 2018; Olsen and Pilson, 2022) and differentiating between internal and external disadvantages helps to crystallise this. In many ways, it does not matter for this theory what the 'cause', or 'location' of disability is so much as what can be done to mitigate what disabled people consider to be impeding their wellbeing and quality of life. Here, this is much evidence to suggest considering both internal and external factors is helpful.

Thus, there is agreement across several disciplines that marginalised groups are disadvantaged both by internal and external disadvantages. There is less agreement over how to tackle these disadvantages; however, there are two further, key, common threads which, again, run through the disciplines already discussed. The first is the importance of framing and the second is the power of a strengths-based approach.

The importance of framing

The concept of framing is ubiquitous across a wide range of disciplines, although different areas focus on different aspects of it (Hertog and McLeod, 2001; Carragee and Roefs, 2004). It is defined by Gitlin (1980, p7) as "the persistent patterns of cognition, interpretation and presentation, of selection, emphasis and exclusion, by which symbol-handlers routinely handle discourse". As such, it is about how narratives are created, presented, and reinforced (Lakoff, 2014) – and it is something which is universally agreed to be powerful and important (although the extent of its importance is debated).

In this section, I will discuss how framing has been applied in the lobbying, disability policy, psychology, and empowerment scholarships and what can be extracted from this to build the theoretical framework. Once again, disability policy is focused upon because disabled people are an exemplar of a group with both internal and external disadvantages, not all of which can be overcome. Therefore, anything which is shown to be helpful to the empowerment of disabled people is likely to be helpful to a wide range of groups.

Framing congruence in lobbying

Within the lobbying scholarship, there is a consensus that policy actors present different frames to the government as part of their lobbying activity, who make a decision as to which frame to use in their policy decisions (Mahoney, C and Kluver, 2012; Snow, 2013; Kangas, Niemelä and Varjonen, 2014). This dominant policy frame is reflected in policy documents and makes its way into government discourse. The dominant policy frame may be, but is not necessarily, the same as the dominant societal frame. While almost any aspect of policy can be described in framing terms, the main types discussed in the scholarship are issue frames (also known as problem definition) and target group frames.

Issue frames refer to which aspects of a problem are selected and highlighted (Baumgartner, F. et al., 2001; Jeon and Haider-Markel, 2001). For example, teenage pregnancy could be defined as a child health issue, a safeguarding issue, or a burden on the benefit system (Ellis-Sloan, 2014). Defining what the 'policy problem' is remains a key part of the policymaking process, since it determines in turn what the government is likely to do about it. Persuading the government to adopt your narrative around a particular policy issue therefore becomes a key lobbying tool (Baumgartner, F.R. et al., 2009; Baumgartner, F.R. and Jones, 2015; De Bruycker, 2017; Junk and Rasmussen, 2019).

The same applies to frames of the target group, which in this context is usually the expected beneficiaries (or targets, if the policy is punitive) of the policy (Schneider, A. and Ingram, 1993; Schneider, A.L. and Ingram, 2019). These frames are about people, not problems and consequently can become much more emotive and also develop moral connotations. Returning to the example of teenage pregnancy, pregnant teenagers could be framed as innocent victims, as sexually promiscuous or as deliberately trying to secure benefits. Frames of the target group are argued by some to be more authentic when they are presented by members of the target group themselves (Robertson, T. and Wagner, 2012).

Of particular relevance here is Schneider and Ingram's (1993) work on the social construction of target groups, which is largely synonymous with target group frames. Schneider and Ingram argue that governments treat target groups differently according to the extent to which they are framed as being weak or powerful, and positively or negatively viewed. This builds on research on the impact of public opinion on government decisions by combining it with framing. Four categories of target group are identified as shown below, where the vertical axis denotes ascending level of power and the horizontal access whether the group is positively or negatively viewed (positive on the left).

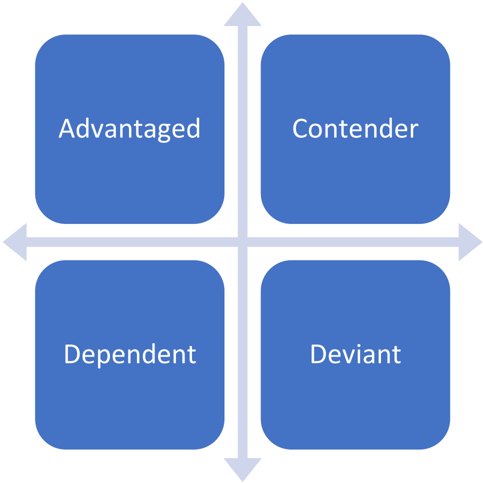

Figure 2: Schneider and Ingram's social construction of target groups

Schneider and Ingram argue that governments seek to appease target groups they perceive to be powerful and to punish those they consider to be negatively viewed. Thus, Deviants, who are seen as weak and negatively viewed, receive the most punitive policy, while Advantaged target groups, who are seen as powerful and positively viewed, find that policy decisions are made in their favour. Groups who are positively viewed but weak (Dependents) or negatively viewed but powerful (Contender) generally receive symbolic policy change which does not do a great deal to change their situation but equally is not punitive enough to incur public disapproval or negative action by Contenders.

Of particular relevance for marginalised groups are the two categories which are seen to be weak - Dependents and Deviants. This reflects the reality that marginalised groups are often offered either only symbolic policy change or are morally hounded and punished (Hvinden, 2003; Townsley and Ward, 2010). However, the most interesting thing to emerge from the lobbying scholarship on framing is that researchers have shown that persuading the government to change the dominant frame of a policy issue or target group to that put forward by a policy actor is an effective form of lobbying (Tarrow, 1999; Hertog and McLeod, 2001; Kangas, Niemelä and Varjonen, 2014; Werts and Brewer, 2015; De Bruycker, 2017; Junk and Rasmussen, 2019). This is referred to in the scholarship as framing congruence (Boräng and Naurin, 2015; Rasmussen, A., Binderkrantz and Kluver, 2021) . I will go into more detail on this later in this chapter but, for now, the important take-away is that policy frames can be changed and that doing so is a lobbying strategy which has been shown to work for even marginalised groups. Within lobbying so far, it has mainly been used to change societal framings, i.e., external disadvantages or barriers.

Framing in disability policy: models of disability

That policy frames can be changed is exemplified by the widespread success of the social model of disability in disability policy (Barnes, Colin, 2000; Priestley, 2005; Putnam, 2005). Models of disability are essentially frames of disability and disabled people. For several centuries, an individual (and therefore internalised) model of disability prevailed (Barnes, Collin, 2007; Campbell and Oliver, 2013). This model frames disability as an individual deficit and often medicalises disability as something to be cured, or, at best, mitigated. It focuses exclusively on the internal disadvantage and places a responsibility on the disabled person, or those that care for them, to seek to mitigate the impact of their disability – on themselves and others. It others the disabled person and frames them as ‘less than’, since most widely accepted definitions of disability define disabled people in terms of a deficit or lack (Oliver and Zarb, 1989; Danermark and Gellerstedt, 2004; Fulcher, 2015; Mladenov, 2016). (The UK Government’s definition of a disability is a “physical or medical impairment which has a substantial and long-term negative effect on your ability to carry out your day-to-day activities” (UK Government, 2010). The associated guidance actively encourages practitioners assessing disability to compare disabled and non-disabled people to assess the level of deficit (UK Government, 2018).) A deficit-led, individual model of disability used in isolation has been associated with in the institutionalisation of disabled people, in low expectations of their potential and in high levels of welfare dependency (Danermark and Gellerstedt, 2004; Campbell and Oliver, 2013; Fulcher, 2015; Calder, 2016; Fisher and Purcal, 2017).

In the 1980s, a disabled academic called Mike Oliver built on the work of a disability advocate led group (Union of the Physically Impaired Against Segregation, or UPAS) to propose a new way of looking at and talking about disability (Oliver and Zarb, 1989). This came to be known as the social model of disability. The social model disability situates disability outside of the disabled person (Dirth and Branscombe, 2017) and argues that a disabled person is disabled not by their body or mind but by socially constructed barriers – such as buildings which are designed to be inaccessible, the expectation to be economically active, or simply ableism. In response to later criticism that the social model ignored the internal aspects of disability, Mike Oliver responded that the social model was never intended to be a universal descriptor of disability but rather an alternative way of looking at it (Oliver, 2013).

The social model has been shown to have overtaken the individual model in large swathes of the Western world (Barnes, Colin, 2000; Hvinden, 2003; Putnam, 2005; Mladenov, 2016). It is evident in the wording used to talk about disability in policy documents from organisations such as the World Health Organisation (WHO, 2022), the United Nations (UN, 2022), and the European Parliament (European Parliament, 2022). The WHO explicitly states on its Disability webpages that "disability results from the interaction between individuals with a health condition … with personal and environmental factors", clearly referencing the social model. The United Nations Convention on the Rights of Persons with Disabilities similarly defines disabled people as "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others", while the European Parliament's Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030 makes no mention of the medical nature of any disability and focuses entirely on removing barriers.

While the extent to which the social model is actually reflected in policy is more open to debate – for example, in the UK, Personal Independence Payments may sound very social model focused, but the reality is that gatekeepers still assess deficit (Maschke, 2004; Prideaux et al., 2009; Rummery, 2017) -, it is clear that, even 40 years on, this is the dominant framing of disability (Oliver, 2013; Waddington & Priestley, 2021). While many other models have been offered and are used, the most widely accepted models in the scholarship today are those which build on the social model, such as the human rights model (Vanhala, 2015; Degener, 2017; Kakoullis & Ikehera, 2018). As such, it is a clear achievement for a target group-led advocacy group (UPAS) and clear evidence of reframing and the use of framing in lobbying. Both the social and the human rights models, however, have the weakness of being focused mainly on external disadvantage (Quinn et al, 2002; Dirth and Branscombe, 2017) – and we are looking for a way to combat both. The answer – to the extent that it is possible, since, as I have said, I would argue that some internal disadvantages cannot be changed – lies in the psychology and empowerment scholarships.

Framing in psychology and empowerment

The psychology scholarship adds to the discussion on framing by highlighting the impact of societal frames on self-esteem and wellbeing (Franks & Marolla, 1976; McElroy et al, 2007; Diener & Diener, 2009; Landau & Sullivan, 2009; de Lenne et al, 2021) and by introducing the idea that we have our own personal, internal frames of ourselves which affect how we behave. Many forms of psychological therapy focus on changing our frames of ourselves by challenging unhelpful narratives and ideas (Abbas et al, 2017; Abbey, 2019; Plakun, 2020). Similarly, a large body of work shows that negative societal frames frequently cause stigma, which, especially if internalised as frames of ourselves, negatively impact self-esteem and wellbeing (Coleman, 1986; Goffman, 1997; Link & Phelan, 2001; Bos et al, 2013). The most widely accepted way of stamping out stigma is to change societal and internal frames (Byrne, 2001; Miller, 2013; Sogg et al, 2018; Atkinson et al, 2020. Thus, once again, reframing is seen as a way of tackling disadvantages, but the psychology discipline shows that it can be used to tackle internal as well as external disadvantages.

This is further built upon in the empowerment scholarship which sees taking action to address internal and external barriers to agency (i.e., disadvantages) as a key way of promoting resilience and wellbeing. Maslow's pyramid of needs (Maslow, 2013) sees self-actualisation, the ability to exert agency in one's life, as the pinnacle to be attained; agency is restrained by disadvantage/need, so the journey to the top of the pyramid (empowerment) requires those disadvantages/needs to be tackled. Advocacy in particular (in other words, advocating your own frame) has been shown to be empowering for people with a learning disability (Goodley, 2005; Waldschmidt et al., 2015; Gardner and Brindis, 2017; McCoy et al., 2020; Petri, Beadle-Brown and Bradshaw, 2020).

As before, the detail of *how* this reframing happens will be delved into later in this chapter, but at this stage of the theoretical framework, the important thing is that there is cross-disciplinary agreement that marginalised groups can reframe themselves and that this can be a key lobbying tool.

The power of a capabilities or strengths-based approach

Another key theme which is reflected across the disciplines is variously known as the capabilities approach, as espoused by Amartya Sen in particular (Hamilton, 2003; Sen, 2005; Kaplow, 2007; Von Jacobi, Edmiston and Ziegler, 2017), and the strengths-based approach, which is used in social care and social work practice (Sullivan, 1992; Saleeby, 1993; Chapin, 1995; Hornung, Bandelow and Vogeler, 2019).

At the heart of both the capabilities and strengths-based approaches lie two key points. The first of these is that everyone has abilities and strengths. Social work and social care practice deal with not just the marginalised but those who have a high level of social need and those who are dependent on others to meet at least some of their needs, such as the disabled communities, the elderly, the infirm and children (Sullivan, 1992; Chapin, 1995). The strengths-based approach acknowledges this dependence in some areas of their lives but argues that this does not mean that they do not have strengths and abilities in other areas.

Secondly, these approaches argue that focusing on these strengths results in better outcomes. Much research has focused on people with a learning disability, as there is often significant societal stigma attached to this, as well as low expectations about their capacities. Goodley (2005) found that measures of wellbeing and resilience increased when people with a learning disability participated in advocacy. Halvorsen et al (2017) found that those who were politically active also became more socially active, reducing their levels of isolation. Dempsey and Foreman (1997) found that 'speaking truth to power', as Foucault termed it, increased the self-efficacy of disabled people. Saleeby (1991) and Chapin (1993) found that, when social workers focused on what clients could do rather than what they couldn't do, they achieved their targets more quickly. While less has been written about this in the lobbying scholarship, it is further supported by Junk and Rasmussen's work, which shows that advocacy groups which project a positive self-framing are more likely to achieve policy success (Junk and Rasmussen, 2019).

The underdog as a symbol of untapped potential

In summary, if we accept that marginalisation consists of a web of internal and external disadvantages which can be successfully tackled through a strengths-based, reframing approach, marginalised groups are conceptualised as being in a temporary state of disempowerment. They have untapped potential in the form of skills, abilities and strengths which are either overlooked or denied by society and by governments. This could be, as Schneider and Ingram elucidate (Schneider, A. and Ingram, 1993), because the group are socially constructed as victims, or it could be because they are socially constructed as 'bad' or 'dangerous' outsiders. Either way, the end result is that these strengths are minimised at best and blocked at worst. If these marginalised groups are able to reframe themselves, they have an opportunity to empower and emancipate themselves.

I propose and use the term ‘underdog’ in this thesis because it is a symbol of untapped potential. The underdog is in a position of subjectification and is not expected to succeed. They are constructed as marginalised. Nonetheless, throughout folklore, mythology, literature and film, the underdog is used as a symbol of hope and a reminder that marginalisation is temporary, not permanent. The apparent ‘victim’ wins against all odds (Goldschmied, 2007; Vandello, Goldschmied and Richards, 2007; Kim et al., 2008; Goldschmied, Ruiz and Olagaray, 2017; Zamudio and Wang, 2018). Thus, the underdog is also constructed as having a hidden potential. Of course, while we may root for the underdog, that doesn’t mean the underdog necessarily wins. But this too is important. The underdog has an uphill road to climb and may not succeed. I will argue later in this chapter, for example, that they are much more likely to succeed if they are able to form alliances with others. It appears self-evident that an underdog acting alone will rarely succeed – although Greta Thünberg could yet be the exception that proves the rule (Sabherwal et al., 2021). However, the underdog is a powerful symbol of hope and symbols matter. Symbols contribute to discourse. Discourse contributes to framing and social constructions (Gitlin, 1980; Schneider & Ingram, 2019). And therefore, the underdog, as a symbol, can contribute to its own emancipation.

Moreover, if emancipation, as stated earlier, is about rebalancing power relations, then the route to gaining more power can be termed em-power-ment. In the next section of this chapter, I will review what empowerment is, and what it looks like in practice.

Empowerment as personal, political power

Empowerment has become something of a buzzword in recent years, generating over 30,000 citations on Google Scholar in the last year alone. Beyond the obvious fact that it is about power, there is little consensus about how to define it (Rowlands, 1995; Page and Czuba, 1999; Zimmerman, 2000; Maiorano et al., 2021). It is variously described as a value orientation (Zimmerman, 2000), a theory (Perkins and Zimmerman, 1995), a practice (Lee and Koh, 2001) and a state of mind (Dempsey and Foreman, 1997). One of the reasons why there is such a plethora of definitions is because there are so many different types of power – e.g., personal, political – and so many spheres within which power can be exerted – e.g., domestic, community, policy, governmental (Maiorano et al., 2021).

In this thesis, the focus is on political power in a national policy context. However, it is also about personal power, because reframing is done by individuals, albeit in large numbers if it is to be successful (Kögler, 1996; Thompson, 2003; Bardon and Josserand, 2011; Nicolet, 2012). If marginalisation is a state of being, then empowerment is also a state of being. It is an outcome of emancipation. It is for this reason that I turn to Dempsey and Foreman (Dempsey and Foreman, 1997) for a definition of empowerment, since they specifically define empowerment as both a process (emancipation) and a desirable outcome for the learning-disabled community, i.e., a marginalised group. As an outcome, empowerment is a *state of mind*. This is not a 'hive mind' but, as more individuals within a group attain the state of mind, so group empowerment begins to emerge, as with reconstruction of the self (McCarthy, 1993; Thompson, 2003). This definition therefore fits well with assessing personal, political power in a policy context and with assessing the empowerment of marginalised groups. It also reflects the origin of the term empowerment in the psychology literature (Zimmerman, 2000).

Dempsey and Foreman use a literature review of many of the 'big names' in the psychological empowerment literature, namely Zimmerman, Rappaport, Solomon, Staples and Torre, to propose a definition of empowerment as a "multidimensional construct that can be expressed in attitudes, knowledge, and behaviour" (Dempsey and Foreman, 1997, p299) and which culminates in the person being appropriately resourced to exert personal power. They and other empowerment scholars acknowledge, in line with the strengths-based approach, which is closely allied with empowerment, that this personal power is inevitably restricted by a range of contextual factors and other people (Rappapon, 1984; Bachrach and Botwinick, 1992; Perkins, 1995; Tilley, Pollock and Tait, 1999; Zimmerman, 2000; Goodley, 2005). Empowerment does not create a superhero; the important measure is that the person is able to exert maximal personal power for the situation in which they find themselves. Adapting this to the exertion of policy influence, I propose the following definition of empowerment for the purposes of this thesis:

A is politically empowered if they possess appropriate resources to enable them to exert maximal policy influence in a given political situation.

It is important to note that these resources are not necessarily things that we would traditionally think of as resources, such as money, or even expertise. Instead, since empowerment is a psychological construct, many of the resources are internal. Dempsey and Foreman propose seven components of empowerment. They do not explicitly state whether all these components need to be present in order for the person to be empowered, but scholars using their framework have discussed certain components, such as understanding the environment, a sense of self-efficacy and feeling in control as being more important than others (Casagrande and Ingersoll, 2017). The components, all of which, excepting Action, can be seen as resources according to the definition above, are listed in Figure 3 below, in a pyramid form, ordered according to my own analysis, which is set out underneath the diagram.

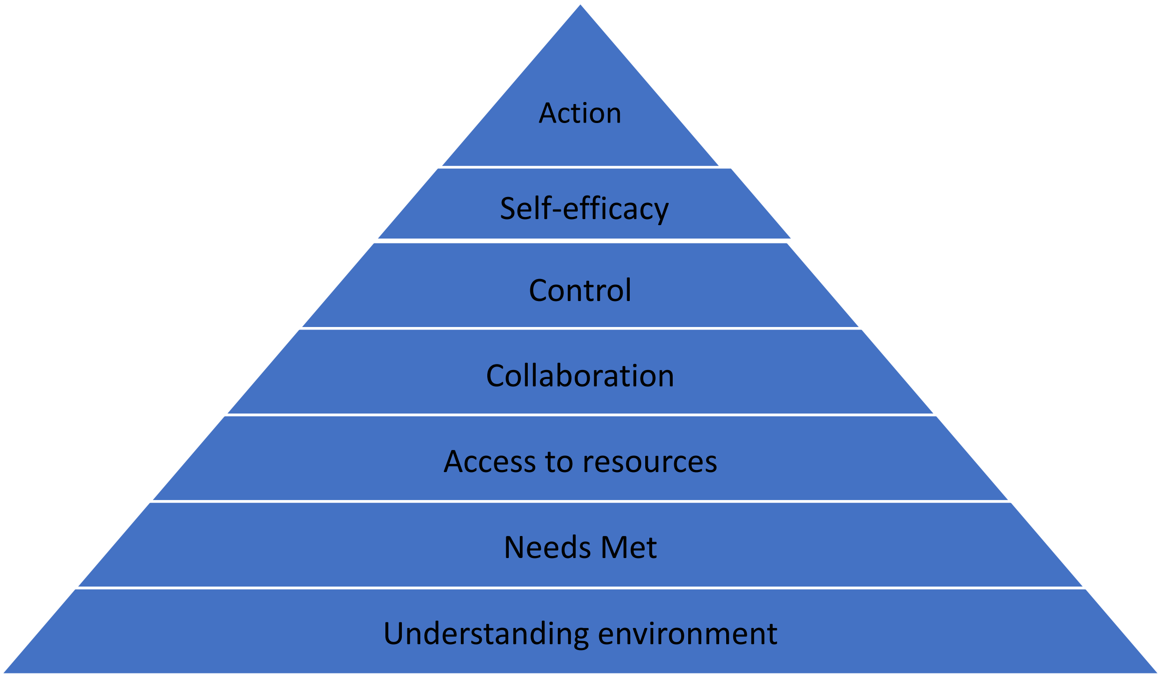

Figure 3: Political Empowerment for the Underdog, adapted from Dempsey and Foreman (Dempsey and Foreman, 1997, p289-294)

As in Maslow's seminal hierarchy of needs (Maslow, 1943), the base of the pyramid contains the foundations of empowerment, which build up to the higher-level components. In Maslow's pyramid, self-efficacy is at the top, but I place action at the top, to highlight that the underdog must take action if they wish to empower themselves. This is supported by both the literature on disability advocacy, which demonstrates that political participation of disabled people has a positive impact on both the self-confidence of those participating and the inclusivity of the policy which results (Goodley, 2005; Vanhala, 2010; Kingston, 2014; Waldschmidt et al., 2015; Halvorsen et al., 2017), and by Junk and Rasmussen's work on advocacy coalitions, which shows that coalitions where all parties are active are more effective than those with silent partners (Junk, 2019a). Nonetheless, it is important to note that an empowered underdog may choose not to take action. Inherent in empowerment is the ability to choose whether or not to act.

Below this is self-efficacy, which is placed here partly because of its similarity to self-actualisation, which tops Maslow' hierarchy, and partly because, as Dempsey and Foreman note, self-efficacy requires an understanding of one's environment, a sense of control and one's needs being met, which are all components which are further down the pyramid. Understanding is knowledge, and therefore a resource. It is mentioned separately from the more general 'access to resources' because of its importance to self-empowerment. Self-efficacy comprises self-awareness, including an understanding and acceptance of one's strengths and weaknesses, an understanding of one's environment and a sense that one is in control and can choose to act. Self-efficacy is thus a precursor to empowered action.

A sense of control comes directly below self-efficacy because it is such an important component of this. In terms of policy influence, a sense of control could be improved by opportunities for participation and feeling that one's voice is heard, both things that will be looked at in more detail later in the chapter. Again, feeling in control can be seen as a psychological resource.

Collaboration and access to resources (in general) are both factors which are known to affect the level of policy influence an actor has (Baumgartnerand Leech, 1998; Leech et al., 2007; Mahoney, 2007; Toke, 2010; Laumann and Pappi, 2013; Pierce et al., 2017; Junk and Rasmussen, 2019). Pooling resources (of all kinds) is at the heart of the collective action scholarship, which covers all forms of group-based lobbying (Laumann and Pappi, 2013; Hardin, 2015). I will go into this in more detail later in the chapter, where I will also highlight the links between the lobbying/influence and empowerment scholarships. For now, I simply note that possession of such resources (since collaboration is in itself a resource) boosts strength and adds to the sense of control necessary for self-efficacy.

The requirement for most physical needs to be met before an underdog can activate their resources for empowerment is at the heart of Maslow's hierarchy of need (Maslow, 1943) and supported by Hamilton (Hamilton, 2003) and Sen (Sen, 2005). It is logical that if a person is worrying about how to feed and clothe themselves, for example, that they are not going to have the internal resources to take political action. In addition, if a disabled person needs reasonable adjustments to be made for them to participate, these needs will need to be prioritised (Gimpel and Schuknecht, 2003; Kingston, 2014). The psychological state of feeling sated, that one's needs are met can, again, be seen as a resource.

This could be problematic for some underdogs, since those in marginalised groups are often more likely to experience poverty and poor mental health (Wolff, 2015), which are both factors which would make it less likely that a sufficient level of their needs was being met for empowerment. Arguably, in the Western world at least, social assistance programmes provide a minimal level of support that should meet basic needs, but in practice, this has often been found to be lacking (Gordon and Townsend, 2000; Cornwall and Brock, 2005; Mabbett, 2005; Barnes and Sheldon, 2010; Wolff, 2015; Leventi, Sutherland and Tasseva, 2019).

At the very base of the pyramid, and fundamental to any journey of empowerment, as made clear in Benhabib's exploratory-diagnostic phase of emancipation (Benhabib, 1985), is an understanding of the policy environment. Thus, the first proto explanation in this logic of explanation of underdog influence is:

Proto explanation 1 (from empowerment scholarship): **In order to politically empower themselves, underdogs must understand the policy environment within which they are to operate.**

Avoiding the risk of responsibilisation

Before we go on to discuss that policy environment in more detail, and consider what disempowers the underdog, it is first necessary to address a serious and valid concern that has been raised about both the strengths-based approach and empowerment. This concern is that, by highlighting the importance of the underdog taking action for themselves, and the impossibility of anyone ever being fully empowered by somebody else, we risk responsibilising the underdog (Garland, 2012; Trnka and Trundle, 2014). By responsibilising, I mean that we risk making the underdog wholly responsible for their own empowerment and subsequent influence, or lack thereof. This is not just a theoretical concern either: it is a requirement of the disability work assessment carried out by the UK Government that the disabled person has made reasonable attempts to mitigate the impact of their disability (DWP 2018). The corollary is that the government will only help you if you first reinforce your own lack of ability to help yourself.

In a sense, it is a potential get out of jail free card for governments: they can promote empowerment and make themselves look good, while divesting themselves of any responsibility to do anything themselves (Trnka and Trundle, 2014). In the meantime, the underdog is made to feel weak and powerless because they have not been able to achieve empowerment entirely on their own, reinforcing their social construction as dependent and powerless. Responsibilisation can go hand-in-hand with victim-blaming, for a truly toxic environment (Johnson, Mullick and Mulford, 2002; Jacoby, 2015).

The reality is more nuanced, with the underdog, governments and other civil society actors needing to work together (collaborate) for the best chance of empowerment (Martin and Carey, 2009; Milner and Kelly, 2009; Kingston, 2014; Bovaird et al., 2016; Ingold and Leifeld, 2016; Halvorsen et al., 2017), as we will discuss in more detail later. I borrow from Julie McLeod in suggesting that it is more helpful to reframe responsibility, at least in a situation where power relations are imbalanced, as relational (McLeod, 2017). Just as power relations are relational, so is empowerment. Disempowerment is shaped by power relations, which means that both sides, as said earlier, share responsibility for it. If empowerment is also relational, then both/all parties also share responsibility for empowerment.

My pyramid showing the components of political empowerment in Figure 3 reinforces this shared responsibility for empowerment. Yes, the underdog has to take action. However, *before* the underdog can be expected to take action, the foundations of the pyramid must be laid, and these include collaboration with others and, crucially for governments, the meeting of the underdog's basic needs, which is indisputably, in the majority of welfare state models (Esping-Andersen, 1990; Ciccia, Rossella and Javornik, 2019; Heuer and Zimmermann, 2020), a matter for the state through social policy. Thus, my thesis clearly states (and further highlights through Article 2, which focuses on what governments can do to foster empowerment) that responsibilisation needs to be explicitly guarded against – and this can be done through conceptualising empowerment as a pyramid which needs to be built up from below, and approached as a collaborative effort, which cannot reach its peak without the underdog's active participation.

The underdog disempowered

Having problematised why underdog influence needs to be addressed and provided a definition and conceptualisation of empowerment as a possible means of addressing this, I now move on to the logics stage of Glynos and Howarth's process (2004). In the context of this thesis, that requires an understanding of the factors which limit the policy influence of the underdog. For this, I will focus primarily on the collective action and lobbying scholarships. First, however, I must define what I mean by policy influence.

Defining underdog social policy influence

Etymologically, the word 'influence' stems from the Latin influere, which means to flow in. The Latin 'influentia' was used in the Middle Ages to mean 'influx' (OED, 2020). By the sixteenth century, the modern understanding of 'acting to cause a change' (or a new influx) had been established (OED, 2020). In a world where the term 'influence' has become synonymous with power in general, and, almost certainly, over-used (Banfield, 1961; Bachrach and Baratz, 1962; Kadushin, 1968; Lukes, 1974; Debnam, 1984; Lowery, 2013; Wedel, 2017; Wrong, 2017), a reminder of the importance of the influx of change is an encouraging start to creating a definition of policy influence for the underdog.

For at its heart, influence, as the sixteenth century definition makes clear, is about policy change. It can also entail retaining the status quo, where other stakeholders are seeking to change it (Baumgartner et al., 2009; Richman, 2011; Morisi, Colombo and De Angelis, 2019). This represents the first barrier for the underdog, since the scholarship is clear that is generally easier to retain the status quo than it is to achieve policy change (Mintrom and Vergari, 1996; John, 2003; Meijerink, 2005; Gardner and Brindis, 2017; Feldman, 2020). The underdog is marginalised by the status quo and therefore more likely to seek to change it than to retain it.

Policy change is also frequently gradual and incremental, although there can be periods of rapid change (True, Jones and Baumgartner, 1999; Boushey, 2012; Flink, 2017). This means that it is likely to take some time for change to become visible. Thus, if influence is defined, as many scholars have, in terms of achieving one's goal of policy change (Arts and Verschuren, 1999; Dür, 2008; Lowery, 2013), underdogs are once again at a disadvantage. It will take time for the influence they have exerted to become visible in policy change – but that does not mean that they have not exerted any influence at all. This highlights the importance of defining influence in terms of altering (or maintaining) a trajectory of policy change, rather than in terms of the end result. It further highlights that influence is not binary but a spectrum – there are degrees of influence (Lowery, 2013). However, even this does not cover all the bases, since an underdog may exert influence through laying the groundwork for altering the trajectory in the future, without managing to achieve any alteration in the present.

Having established that changes to the policy trajectory are not necessarily a complete way of defining underdog influence, I now consider how else influence could be manifested. Here, it is helpful to consider the stages of the policy process (Binderkrantz and Pedersen, 2019). While theories abound as to whether the policy process is best conceptualised as linear, cyclical, or stream-based (John, 2003; Jann and Wegrich, 2007; Howlett, McConnell and Perl, 2017), scholars agree on the broad categories that characterise the process. These include an agenda-setting stage (Kingdon, 1995; Jones and Baumgartner, 2004) and a problem-definition stage (Rochefort and Cobb, 1993; Dery, 2000; Barbehön, Münch and Lamping, 2015), both of which precede the making of decisions as to specifically how to tackle a policy problem, and therefore the alteration of any policy trajectory. An underdog's influence may be visible in getting an issue on the government agenda, even if the government subsequently decides to prioritise another issue.

An underdog's influence may also be visible in how a policy issue (or target group) is defined or framed: they may be able to alter the way that either the government, or public opinion, which has been shown to be an important factor in how governments choose to frame a problem (Kollman, 1998; Dür and Mateo, 2014), sees the issue. Sometimes, they may not succeed in influencing the dominant framing, but nonetheless add nuance to the framing that would not otherwise be there (Junk and Rasmussen, 2019).

Research suggests that altering the dominant framing of a policy issue or problem is one of the principal ways that interest groups, alliances and advocacy coalitions can influence policy (Croteau and Hicks, 2003; Kangas, Niemelä and Varjonen, 2014; Klüver and Mahoney, 2015; De Bruycker, 2017; Junk and Rasmussen, 2019). This indicates that it is likely to be one way in which the underdog, who may well belong to a group of this nature, exerts influence. However, it is possible that researchers (including emancipation scholars) pay too much attention to this form of influence because they are failing to measure influence exerted elsewhere. In other words, framing is undoubtedly part of the definition of influence, but only by measuring influence in as complete a way as possible can one be sure that it is the main way that the underdog exerts influence. This would not be the first time that the underdog had been underestimated, as the apocryphal tale of David and Goliath reminds us.

Finally, it is important to reflect also in the definition that influence can occur without an actor deliberately taking action to exert it. While direct influence follows a deliberate action designed to elicit influence, indirect influence does not (Crano and Alvaro, 1997; Marshall, 2012; Weiss-Gal et al., 2020). For example, public opinion influences governments without the public necessarily seeking to exert any influence (Schneider and Ingram, 2019). Similarly, the underdog may exert influence without taking action to do so. This form of underdog influence is well-explained by Schneider and Ingram's theory of social construction of target populations, which demonstrates that, where a target group is considered to be positively viewed by the public, governments are minded to make at least symbolic policy gestures towards them (Schneider and Ingram, 1993). Since the aim of this thesis is to inform a lobbying strategy for the underdog, it follows that the natural focus will be on actions that the underdog can take, i.e., direct influence. Nonetheless, no definition of influence would be complete if it did not include indirect influence.

Drawing together all these threads, then, my working definition of underdog social policy influence needs to cover altering the trajectory and/or outcome of the policy process, getting an issue on the policy agenda and altering a dominant framing. It also needs to cover both direct and indirect influence. Finally, it needs to reflect that influence is not binary but a spectrum. I express this definition as shown below:

Social policy influence is a spectrum which relates to the ability of a stakeholder, either directly or indirectly, to alter the trajectory of the policy process, to persuade the government to consider a policy issue or to alter the dominant framing of a policy problem or target group.

Having established a definition of influence, I must consider what the policy environment – the context in which the underdog seeks to exert influence – is. Specifically, I consider what policy scholars call the political opportunity structure, since this comprises both the policy environment and opportunities for exerting influence (Gamson and Meyer, 1996; Koopmans, 1999; Tarrow, 1999; Meyer and Minkoff, 2004). Emancipation scholars would consider this part of the exploratory-diagnostic phase and recognise, as policy scholars do, that marginalisation is contextual: it looks different in different settings (Steinberg and Kincheloe, 2010; Boltanski, 2011; De Proost and Coene, 2019). In doing this, I also bear in mind the components of empowerment as shown in Figure 3, as empowerment and influence are closely linked.

There are many different ways that this section could be organised since there are many different ways of categorising the political opportunity structure. However, I choose to divide this section into three categories: cultural, institutional and resources. The cultural v institutional dichotomy is a commonly used mechanism in discussions about political opportunity (Goodwin and Jasper, 1999; Koopmans, 1999; McCammon, 2013). It is also helpful for the purposes of this chapter because it provides a heuristic device to differentiate between discursive elements of the opportunity structure, which are likely to strongly contribute to the social construction of the underdog, and more tangible elements, such as institutional arrangements, which may need non-discursive means to tackle. As stated above, the collective action scholarship suggests that reframing is likely to be the most effective tool in the underdog's armoury (Van Gorp, 2007; Klüver, H and Mahoney, 2015; De Bruycker, 2017; Junk and Rasmussen, 2019), and it has certainly been seen as important by many cross-disciplinary scholars as a form of both resistance and reconstruction (Schneider, 1986; Tilley, Pollock and Tait, 1999; Allen, 2015) but we must assess all areas.

The third category of resources is included because of its well-attested importance to policy influence (Leech et al., 2007; Baumgartner et al., 2009; Toke, 2010; Rhodes, 2018), the strengths-based approach (Sullivan, 1992; Saleeby, 1993; Chapin, 1995; Banducci, Donovan and Karp, 2004; Donaldson, Krejcha and McMillin, 2017) and empowerment, as shown in Figure 3.

Cultural disempowerment

Cultural aspects of the political opportunity structure determine how receptive the government, stakeholders and wider society as a whole are to the idea of a particular policy trajectory (McAdam, Tarrow and Tilly, 2001; Meyer and Minkoff, 2004; McCammon, 2013; Meng, Pan and Yang, 2017). Essentially, this comes down to how marginalised groups are framed by each of these groups, and how the problems that concern marginalised groups are framed (Benford, 1988; Hertog and McLeod, 2001; Snow, 2013). Gitlin (Gitlin, 2003, p6) defines frames as "principles of selection, emphasis and presentation comprised of little tacit theories about what exists, what happens and what matters", building on Goffman's (Goffman, 1974) account of frames as a way of organising experiences. Thus, as people look for tacit theories to organise their experience, they select and emphasise certain aspects of reality to present in a certain way. The theories which inform their decisions, both on an individual and a societal level, are informed by historical, political, social, and cultural norms and also by their own experience. Selection and emphasis may be conscious and deliberate or unconscious.

There are three main types of framing which influence the receptivity of governments, stakeholders, and society to a policy trajectory: target group frames, issue frames and media frames. Since everyone's framing preference is shaped not just by their historical, political, social, and cultural context but also by their own lived experience (Cresswell and Hawn, 2011; Werts and Brewer, 2015; Voronka, 2016; McIntosh and Wright, 2019), several different frames are likely to co-exist within any group of stakeholders, within the government, and within society as a whole (Jones and Baumgartner, 2004; Laumann and Pappi, 2013; Boräng and Naurin, 2015; Junk and Rasmussen, 2019).

However, there tends to be a dominant frame within society (Croteau and Hicks, 2003; Boräng and Naurin, 2015) and governments have been repeatedly shown to take note of this dominant frame when making policy decisions (Hertog and McLeod, 2001; Mahoney and Kluver, 2012; Snow, 2013; Kangas, Niemelä and Varjonen, 2014; Boräng and Naurin, 2015; De Bruycker, 2017; Voltolini and Eising, 2017; Guaschino, 2019; Schneider and Ingram, 2019). This does not necessarily mean that they accept the framing: they may project a different frame in their ultimate decision. As stated previously, stakeholders in the policy process also put forward competing and often contested frames for government attention (Fraser, 1989a; Tarrow, 1999; McAdam, Tarrow and Tilly, 2001; Navneet, 2018). The government considers these frames in the light of dominant societal frames and makes a decision as to which trajectory to take, and which frame to favour.

Target group framing is of considerable importance. If the underdog succeeds in putting forward a reconstructed framing of themselves and this framing is accepted by the government for the purposes of this policy trajectory, that is a step towards achieving a societal reframing, since governmental policy framings help to construct these (Schneider and Ingram, 1993; Schneider and Ingram, 2019).

Following Schneider and Ingram (1993), the underdog is likely to be socially constructed as weak but may be constructed either as positively viewed (dependent) or negatively viewed (deviant), depending on the context. For example, the disabled are typically framed as dependent (Putnam, 2005), while drug addicts are typically framed as deviant (Brucker, 2009). This is not a new idea: the concept of 'deservingness' in relation to welfare policy has a long history (Van Oorschot, 2006; Heuer and Zimmermann, 2020). If the underdog is framed as dependent, then governments are likely to pay lip service to making policy change in their favour but limit such changes to largely tokenistic or symbolic changes. If the underdog is framed as deviant, then governments will be openly antagonistic and make policy changes that deliberately harm them. Being viewed as powerful appears to make more of a difference to government decisions than being positively or negatively viewed: both advantaged and contenders are more likely to receive policy largesse than dependent or deviants; however, governments are demonstrably more receptive to at least consulting dependents (Powell and Bingham, 2004; Townsley and Ward, 2010; Richardson and John, 2012), so there is an opportunity there for the underdog to make it inside the policy building, albeit not get as far as taking their seat at the policy table.

Issue framing, or issue definition is also an important component. Any policy 'problem' can be defined in a number of different ways (Baumgartner and Leech, 1998; Jeon and Haider-Markel, 2001; Boräng and Naurin, 2015; Junk and Rasmussen, 2019), which in turn results in a different framing of the target group. The underdog is more likely to be able to achieve framing congruence on issue definition if they are positively viewed and if the framing they put forward is shared by other, more powerful groups (Croteau and Hicks, 2003; Boräng and Naurin, 2015; Brisbois, Morris and de Loë, 2019; Junk, 2019a; Junk and Rasmussen, 2019; Luxon, 2019).

Finally, media frames, which are not always the same as the dominant, societal frame, have also been shown to impact governments' decisions about policy trajectories (Gitlin, 2003; Sobbrio, 2011; Bail, 2016). They can reinforce existing social constructions, or they can introduce and publicise new reconstructions. They are particularly useful for raising awareness of new viewpoints. As with other tools, most media frames are controlled by those with power, i.e., not by underdogs. However, if underdogs collaborate with a better-resourced power, they may be able to disseminate a new reconstruction through a media campaign (Hertog and McLeod, 2001; Binderkrantz and Krøyer, 2012; Bail, 2016).

Thus, the receptivity of the policy environment to policy change which favours the underdog is heavily impacted by the framing of the underdog. This is the product not just of the historical, political, cultural, and social context in which the underdog lives, but also of the deliberate framing proposals put forward by policy stakeholders, the media, and the government. Since the underdog is framed as weak, they are not anticipated to possess much policy influence and governments treat them accordingly as being politically disempowered and are less inclined to listen to them beyond tokenistic consultations.

Stigma, -isms and phobias

Before moving onto institutional disempowerment, it is important to mention a frequent consequence of negative frames of the underdog, which in itself forms a cultural disadvantage and barrier. Negative frames of target groups frequently come with stigma attached and this has been shown to result in culturally embedded discriminatory behaviour and even hate activities, commonly described as either '-isms', e.g., racism, sexism and ableism, or phobias, e.g., homophobia, xenophobia (Haider-Markel & Joslyn, 2005; Howarth, 2006; Corrigan, 2014). This forms a barrier in two ways. Firstly, it contributes to the overall frame of the target group, which influences how others behave towards them (Flöthe and Rasmussen, 2019; Schneider, A.L. and Ingram, 2019). But secondly, it also makes it harder for underdogs to act, since not only do they have to battle negative frames, but they also have to put themselves at risk of discrimination and hate activities.

History has shown us that the framing of and stigma attached to certain social groups can be changed over time (Goldman, 2010; Casados, 2017; Roe et al, 2017). For example, while homophobia has certainly not gone away, it has become more societally acceptable to be openly LGB (Subhrajit, 2014; Lewis & Flores, 2017). Similarly, racism has not gone away, but it is more likely to be covert than overt (Coates, 2011; Bowser, 2017). Reframing therefore can help with these cultural barriers but it is important to note that they are formidable barriers that will not go away quickly or easily, and that there is potentially a danger in seeking to tackle them.

Institutional disempowerment

Underdog policy influence is also impacted by the number of different opportunities which are open to them to participate in the policy process. This is related to the spatial component of marginalisation. Policy decisions are made in policy spaces, which underdogs usually have limited access to (Miraftab, 2004; Milner and Kelly, 2009; Cornwall, 2017; Hofman and Aalbers, 2017). At various stages of the policy process, there are different opportunities for stakeholders to participate. Some of these opportunities entail access to the decision-making space, while others are more peripheral and keep stakeholders at arms' length. A stakeholder may have unfettered access to the decision-making space, or only by invitation (invited spaces); similarly, some democratic spaces are not government-controlled and instead allow for civil society actors to protest (popular spaces) (Cornwall, 2017). Figure 4 below provides a visual representation of the proximity of different lobbying activities to decision-making spaces. Only in the case of Citizens' Assemblies, co-production and Advisory Groups are citizens actually allowed into decision-making spaces. I have deliberately placed consultation quite far out, as governments may use consultation in a tokenistic way and ignore the results in their decision-making (Halvorsen et al, 2017). Similarly, protest is some distance from the decision-making space since its primary effect is usually to raise awareness (Feinberg et al, 2017; Coombs et al, 2020). Advocacy is closer because it increases the chances of being invited into the space (Gaventa, 2006), but organised, collaborative advocacy is more likely still to result in an invitation (Sabatier, 1988). This is due in part to the United Nations Convention on the Rights of People with Disabilities, to which the UK and many other countries have signed up. The Convention requires that signatory countries actively involve advocacy groups representing people with disabilities in the decision-making process (Articles 4.3 and 33.3 and General Comment 8) (UN, 2012).

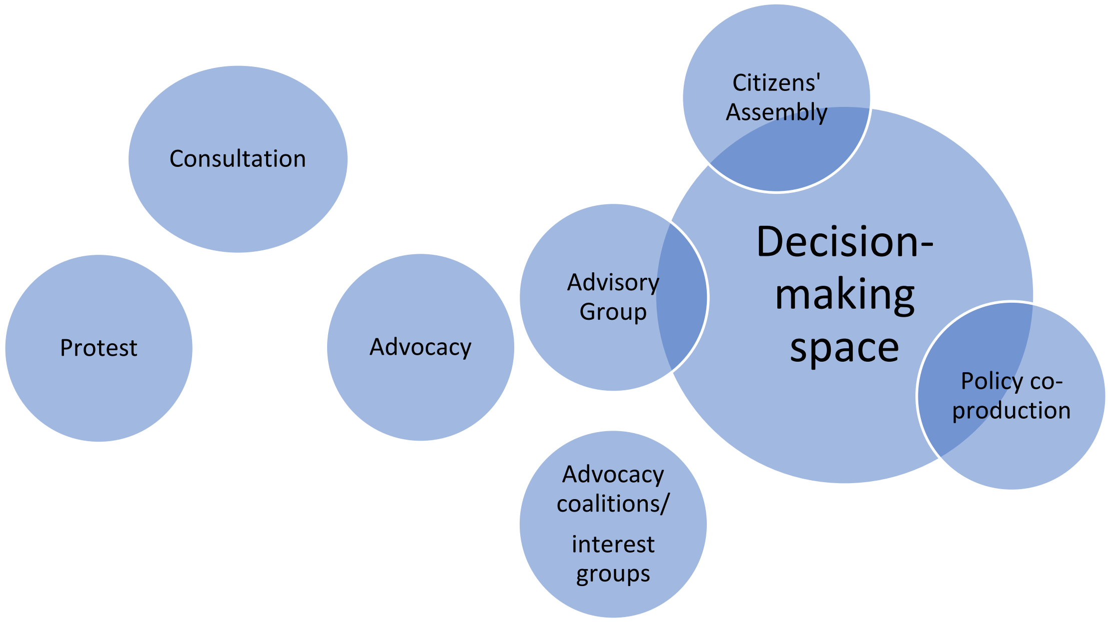

Figure 4: Democratic spaces in the policy process

Policy co-production and citizens' assemblies remain relatively rare at national policy level, although they are used in some situations in Ireland and Scandinavia, and there are regional assemblies in Canada (Lindbom, 1998; Lang, 2007; Warren and Pearse, 2008; Suiter, Farrell and O'Malley, 2016). Even where they exist, accessibility for the underdog may be limited by lack of resources, as we shall see below. Advisory groups are more common but vary in the extent to which their advice is taken into consideration (Brown, Lentsch and Weingart, 2005; Christiansen and Larsson, 2007; Princen and Kerremans, 2008; Eichenberger, 2020); these do sometimes specify that a certain number of seats must be allocated to underdogs belonging to a particular group, such as the disabled community, but such appointments have been criticised as tokenistic (Barnes, 2007; Campbell and Oliver, 2013; Halvorsen et al., 2017).

Moving further away from the decision-making space, consultation is common, but again differs in the extent to which advice is heeded (Cook, 2002; Kröger, 2008; Fraussen, Albareda and Braun, 2020). Most collective action scholars would argue, as we will see in more detail later, that protest, advocacy, coalitions, and interest groups represent the underdog's best chance of lobbying success (Baumgartner and Leech, 1998; Olson, 2009; Weible et al., 2011; Hardin, 2015; Junk and Rasmussen, 2019); however, it is notable that they are the furthest from the decision-making space.

Underdogs therefore have very limited opportunities to enter the decision-making space and when they do, it is usually invitation only and tokenistic. Those measures widely considered to hold their best chance of lobbying success are at a distance – although this may be a straw man argument. If underdogs are rarely given access to decision-making spaces, then their opportunities for influence will be greater at a distance, where the government has less ability to limit them (popular spaces) and their greater success at a distance may simply be a function of a higher number of opportunities being available at a distance.

Institutionally, the underdog is frequently also under-represented, partly due to their under-representation within society as a whole and partly due to barriers to accessibility (Anderson, 1977; Hirst, 1990; Norris, 1997; Pitkin, 2004; Powell and Bingham, 2004; Bohman, 2012; Pennock, 2017). For example, almost all minority groups are under-represented in the UK Parliament (Banducci, Donovan and Karp, 2004; Barnes, 2007) and it is a truism that business interests are dominated by older, white 'elite' men (Maume Jr, 1999; Fairlie and Robb, 2007; Feagin and Ducey, 2017). Since the preferred framing of policy decision-makers will be determined in part due to their lived experience (Werts and Brewer, 2015; McIntosh and Wright, 2019), this makes it less likely that there will be framing congruence with the underdog, whose lived experience will be very different from their own.

Thus, institutional barriers combine with a negative framing of the underdog to create a political opportunity structure which is minimally receptive to underdog influence. There are opportunities for political participation, but both cultural expectations and a reduced number of invitation-only and distanced, popular spaces for this ensures that the balance of power relations remains weighted against the underdog.

Or, perhaps more accurately, this is what the theory tells us … but the theory has historically been written by scholars who do not belong to any marginalised group and who, like policy decision-makers, are likely to have an unconscious bias (Swedlow, 2014; Flöthe and Rasmussen, 2019). In addition, many of the indicators traditionally used to assess influence, such as goal attainment, reputation, and substantive representation (March, 1955; Banfield, 1961; Arts and Verschuren, 1999; Dür, 2008; Lowery, 2013; Wedel, 2017) are calibrated in such a way as to risk missing underdog influence – as I will show in more detail in Chapter 3.

In recent years, more scholars belonging to marginalised groups have written, particularly on subjects such as emancipation and empowerment, and some are optimistic about the potential of the underdog (cf Gillespie-Lynch et al., 2017; Alkhaled and Berglund, 2018). Indeed, there are examples in recent history of occasions where the underdog has scored an unexpected policy win: the last fifty years has seen an increase in policies guaranteeing the rights of marginalised groups, from the decriminalisation of homosexuality (Sexual Offences Act 1967) to same-sex marriage (Marriage (Same Sex Couples) Act 2013), the decriminalisation of abortion (Abortion Act 1967), to gender-affirming approaches to gender incongruence (Gender Recognition Act 2004). While some of these could be argued to be symbolic wins, or due to cultural changes, the shift implies that reframing of the underdog is possible, despite the odds.

Lack of resources

For this reframing of the underdog to result in empowerment, we must also consider the role of resources. The word 'resource' simply means something that can be utilised to produce a benefit (OED, 2020). Traditionally, the underdog has been considered to be under-resourced (Bochel et al., 2008; Toke, 2010; Wolff, J., 2015). The underdog is more likely to experience poverty and unemployment or underemployment, meaning that they lack financial resources. It could be argued that they have time as a resource, but Maslow's hierarchy of needs (Maslow, 1943) shows that a lack of physical resources can hinder the motivation of an actor to maximise other resources. Similarly, the scholarship on protest and social movements shows that underdogs' lack of financial resources and social status is likely to limit their involvement in successful protest (Jasper, 2014; Quaranta, 2015). Financial resources and social status have also been shown to be linked to lobbying success for interest groups and advocacy coalitions (Baumgartner and Leech, 1998; Leech et al., 2007; Weible et al., 2011; Berry, 2015; Dür and Mateo, 2016), although they are not necessarily the most important factor.

However, financial resources and status are not the only resources that can be used for empowerment. As the empowerment and strengths-based scholarships show, knowledge/expertise, connections/networks, lived experience and personal skills and attributes can all be counted as resources (Marsh and Smith, 2000; Alam and Lawrence, 2009; Laumann and Pappi, 2013; Cairney, 2019; Fischer, 2019). Indeed, the whole premise of the collective action scholarship is that collaboration allows for the pooling of diverse resources for the benefit of all (Olson, 2009; Laumann and Pappi, 2013; Hardin, 2015). The importance of collaboration is highlighted in all the scholarships that have been discussed: lobbying/collective action, empowerment, emancipation, and influence. Collaboration is particularly important for the underdog because it provides a route to obtaining important resources to which they would not otherwise have access (Olson, 2009; Laumann and Pappi, 2013; Hardin, 2015; Junk and Rasmussen, 2019), including an understanding of how the policy process works from 'insiders' (Binderkrantz and Krøyer, 2012; Dür and Mateo, 2016). It also promotes empowerment because it engenders a sense of greater control and self-efficacy (Dempsey and Foreman, 1997).

One resource which all underdogs have in abundance is lived experience of their personal situation. Increasingly, this lived experience is being recognised by policymakers as a form of expertise, even if it is not yet accorded the same consideration as professional or technical expertise (Cresswell and Hawn, 2011; Werts and Brewer, 2015; Voronka, 2016; Fischer, 2019; McIntosh and Wright, 2019). Personal skills and attributes and the ability to gain knowledge/expertise and form connections/networks will vary according to the personal circumstance of the underdog: for example, a person who has a learning disability may have a reduced ability to retain learning and a person from a low socioeconomic background may be less likely to achieve educationally.

A particularly powerful resource at the underdog's disposal is that of narrative (Tilley, Pollock and Tait, 1999; DePauw and Doll-Tepper, 2000; McLeod, 2017). The underdog is in the unique position of being able to put forward an authentic framing of the policy target group. Evidence from the collective action scholarship, as we have seen, suggests that altering the framing of the target group and policy issue (possibly slowly over time, and possibly by altering dominant social framings first) is the underdog's best chance of influence (Carragee and Roefs, 2004; Kangas, Niemelä and Varjonen, 2014; De Bruycker, 2017; Junk and Rasmussen, 2019).

Thus, despite a minimally receptive political opportunity structure, the underdog is not as poorly resourced as they first appear. They possess lived experience, can promote authentic discourse which has been shown to have the power to influence framing, are likely to possess skills and attributes which make them useful as coalition partners, and can access other resources through collaboration to maximise their influence. The balance of power relations can be tipped if the underdog makes use of these internal resources. The next question is what is the best way for them to do this?

What options for the underdog?

To guard against 'victim culture' (Brown, 1993), responsibilisation (Garland, 2012) and unrealistic anticipatory-utopian perspectives (Allen, 2015), the underdog is best served by a pragmatic approach. We must ask the question 'what can the underdog realistically do to alter the balance of power?' I review the areas of underdog disempowerment as described in the previous section (cultural, structural and resources) to see where the opportunities lie in the political opportunity structure.

Cultural strategies

As stated above, target group framing is the area where the underdog is uniquely placed to make a real difference by putting forward an authentic reconstruction of the self. This is particularly effective when promoted through advocacy, where the authenticity of the person standing before policymakers pleading their case is undeniable. Advocates also tend to have certain strengths in terms of skills and attributes which enable them to effectively propound their discourse (Vanhala, 2010; McCoy et al., 2020; Petri, Beadle-Brown and Bradshaw, 2020); this means that certain members of the target group can act as ambassadors of a sort. It can also be done through social media campaigns and, via collaboration to access the necessary resources, through media and charity campaigns. Authenticity gives the underdog power. To a lesser extent, underdogs can also influence the way policy issues are viewed (issue definition) through narratives. While underdog influence is measured as low by scholars in general, it is accepted that framing of social problems is where they possess the greatest influence (Hertog and McLeod, 2001; Kangas, Niemelä and Varjonen, 2014; De Bruycker, 2017; Junk and Rasmussen, 2019), therefore this must be maximised.

Proto explanation 2 (collective action/lobbying): Underdogs are uniquely placed to alter the framing of the target group and can also alter the framing of policy issues.

Structural strategies

Since the political opportunity structure allows limited opportunities to access the policy process, underdogs must maximise those opportunities they do have. There is evidence from the empowerment, and particularly the disability studies scholarships to show that where underdogs engage in political activity, it increases their resilience, sense of control and sense of self-efficacy (Dempsey and Foreman, 1997; Goodley, 2005), which boosts their empowerment according to Figure 3.

Proto explanation 3 (disability studies, empowerment): Underdogs can make the most of the structural opportunities available to them by being as politically active as possible.

Resource strategies

However, I argue that it is internal resources which are the catalyst which, in a context where opportunities have been maximised, underdogs have the best chance of reconstructing themselves, attaining empowerment and increasing their policy influence. Each underdog's resources will be unique and able to be used in a different way. These resources can be maximised, according to both the premise of collective action and the empowerment pyramid, through collaboration.

Proto explanation 4 (collective action/lobbying, empowerment): Underdogs can pool resources with other groups by forming alliances or collaborative frameworks.

Junk and Rasmussen's work in the collective action scholarship (Junk and Rasmussen, 2019) combines with the principles of the strengths-based approach (Saleeby, 1993; Banducci, Donovan and Karp, 2004; Donaldson, Krejcha and McMillin, 2017) and the importance of self-efficacy in empowerment (Dempsey and Foreman, 1997) to argue that underdogs will have more influence if the reconstruction of the self that they propose focuses on their strengths and resources more than their weaknesses. This contributes to a positive framing, which Schneider and Ingram have shown to be important (Schneider and Ingram, 1993; Schneider and Ingram, 2019), as well as highlighting their resources and improving their reputed influence. It also ties in with the anticipatory-utopian strand of the emancipation scholarship (Benhabib, 1985; Allen, 2015): self-efficacy is the pinnacle of Maslow's hierarchy of need (Maslow, 1943) and very nearly the pinnacle of the pyramid of empowerment.

By acting collectively, underdogs also make themselves more likely to be heard, not just because they amplify their voice, but also because advocacy organisations frequently have superior access to government, as shown in Figure 1 on page

Proto explanation 5 (empowerment, influence): Underdogs will have more influence when they adopt a strengths-based approach.

It is, however, crucial to remember the limitations of the strength-based approach, in the spirit of pragmatism. The strength-based approach does not refute the existence of weaknesses and self-efficacy requires an acceptance of both strengths and difficulties (Dempsey and Foreman, 1997; Goodley, 2005). Without this self-awareness, there is a risk of 'anticipating utopia' (Allen, 2015) then falling into victimhood (Brown, 1993). Empowerment is the exertion of maximal influence for the context. The influence of the underdog is highly likely, if not certain, to remain low relative to other actors in the policy process. However, this does not mean either that it cannot be increased or that the underdog should not try.

The underdog theory is born

Drawing together, then, the threads from the different scholarships that have been reviewed, we can assemble an explanatory framework - an exoskeleton, or suit of Iron Man-esque armour, if you will - of underdog influence for the underdog to put on and transform from David to Goliath. We know that the balance of power is weighted against the underdog, who is framed as weak and dependent and further barred from political action by a political opportunity structure which is minimally receptive. On the surface, they lack both resources and opportunity and, crucially, they are framed as having minimal influence.

However, all things are relative, and the underdog can increase the receptivity of the political opportunity structure through discourse, maximise their opportunities for political action and, crucially, reframe themselves as empowered and influential by mobilising their internal resources through a strengths-based approach. I return to my opening thesis statement:

A strengths-based approach – promoting a positive framing through discourse and capitalising on strengths/existing resources – is the catalyst which, in the right conditions (maximisation of opportunities for participation, alliance with other groups), gives the underdog an opportunity to empower themselves to exert the influence they didn't know they had.

Conclusion

This explanatory framework helps identify opportunities for influence and therefore provides a toolbox for a skeleton strategy to increase influence which can be developed by the underdog to suit their own particular strengths and context. This toolbox can assist the underdog to climb almost to the top of the pyramid of empowerment, in collaboration with other policy actors. However, it is only by the underdog choosing to take action that the pinnacle can be achieved. As Colin Barnes, disability scholar said, empowerment is not something that can be done to you by another person, but something you must do for yourself (Barnes, 2000). This is the paradox of the theory: the underdog cannot empower themselves alone, but nor can empowerment be achieved without their active involvement and buy-in.

In the remainder of this thesis, I will explore the usefulness of the framework in relation to explaining the apparently rare case of an influential underdog in autism policy. The next chapter looks in more detail at how influence can be measured.

3. Policy influence: the elephant in the room

In this chapter, I begin where the journey of my thesis began: with the knowledge that I wanted to talk about social policy influence, juxtaposed with an understanding that this posed a methodological challenge. Here, I provide a critical literature review of existing indicators of influence and methods used to capture these indicators in the scholarship. Lowery (Lowery, 2013, p1) says of influence that “we all look for it, but rarely find evidence of it”. Social policy influence is undeniably important because it determines how governments behave towards different societal groups and who does or does not get their needs met (March, 1955; Banfield, 1961; Dür, 2008; Lowery, 2013). Indeed, sixty years before Lowery, March accurately summarised the problem with influence, when he wrote:

> The interest in influence stems, in turn, from its conception as the fundamental intervening variable for the analysis of decision-making. Influence is to the study of decision-making what force is to the study of motion - a generic explanation for the basic observable phenomena.
>
> (March, 1955, p432)

There are three main points to unpack in this summary. The first is that influence is ‘fundamental’ to the study of decision-making – and therefore to social policy, which is, after all, a series of political decisions. The second is that it is an ‘intervening variable’, which means that it moderates or mediates the outcome but is not only partially observable and, crucially, that we can only observe *indicators* of influence, not influence itself. The third is that it is a ‘generic explanation’ for what can be observed: it lacks nuance.

This chapter therefore begins by motivating the need for a recalibration of the indicators for influence to effectively capture underdog influence and reduce researcher bias. It goes on to critically review the main methods and indicators used by scholars to date, before proposing and explaining a new set of indicators and an outline method, which will be expanded upon in Chapter 5.

Measuring underdog influence: an exercise in recalibration

Influence is something which political and policy (and other) scholars believe to be important in helping us understand why governments make particular decisions. However, there are problems with measuring it, because it can only be partially observed, and subsequent difficulties with nuance, or sensitivity. As a result, scholars have tended to describe it in general terms, which are insufficiently nuanced to measure influence in a specific context.

Lowery demonstrated that many of the problems March raised remained unsolved (Lowery, 2013). He argued that scholars are almost afraid to tackle the methodological problem posed by influence. It is not just that it cannot be fully observed – many social phenomena can only be partially observed. It is because the indicators that have been designed to measure it, to move from the generality of March's definition to the specificity of a means of measurement, remain poorly calibrated for measuring underdog influence (perhaps in part because it is assumed to be a rare event).

Nor is Lowery alone in noting that scholars measuring influence tend to respond to the methodological mountain in front of them by choosing to measure only one or two indicators of influence (Arts and Verschuren, 1999; Dür, 2008; Lowery, 2013). We know from both the policy change and emancipation scholarships that the underdog is not theorised to exert (much) policy influence (Baumgartner and Leech, 1998; Fraser, 2009; Laumann and Pappi, 2013). On all the factors which have been associated with policy influence, as will be described in Chapter 3, the underdog scores low. The underdog is institutionally and culturally excluded by the political opportunity structure (Meyer and Minkoff, 2004; Fraser, 2009), under-represented among decision-makers (Norris, 1997; Pitkin, 2004; Pennock, 2017) and is perceived to lack resources, since they are typically defined by what they are assumed not to have (Hamilton, 2003; Fraser, 2009).

If the methods and measures used to assess influence are not calibrated in a sufficiently sensitive way, this could lead to a situation where any influence the underdog does have is missed. This reinforces the theory – possibly erroneously – and makes it more likely that future methods and measures will similarly discount underdog influence. Perhaps more importantly, it also leads to an assumption that the underdog will lack influence, which could colour public opinion and the opinion of governments and negatively affect policy decisions (Dür and Mateo, 2014; Schneider, and Ingram, 2019). It could also discourage the underdog from seeking influence, which would reinforce their existing marginalisation (Von Jacobi, Edmiston, and Ziegler, 2017) – and the cycle begins again.

Thus, even though I agree that, if the scholarship is fully correct, underdog influence is likely to be limited, I consider it to be important that a method is chosen which is able to capture multiple indicators of influence, as well as lower levels of influence so that these can be acknowledged and built upon. At the heart of any multi-measure method is the triangulation principle (Flick, 2018), which argues that empirical and theoretical gaps can be filled by using a range of different measures or methods. Thus, gaps in the measurement of influence can be filled by combining different indicators. These gaps can be, and often are filled by using a different method for each indicator (Hofman and Aalbers, 2017), such as a survey for reputed influence and document analysis for representation (Dür and De Bièvre, 2007). However, where there is not a unifying multi-measure method, the analysis of the results becomes piecemeal and is not optimal. Particularly where one indicator does not pick up underdog influence and another does, the lack of a unifying framework could mean that this influence is overlooked. A systematic, analytical method which combines results from all measures but allows the researcher freedom to weight certain indicators more heavily than others is optimal for measuring underdog influence.

The thorny issue of researcher bias

A less methodological but equally important reason for seeking a recalibration of measures of influence is the need to minimise researcher bias (Chenail, 2011). This bias can creep in on a number of levels (Onwuegbuzie and Leech, 2007). Firstly, researchers base their choice of what to research partly on what has already been researched (Van de Ven, 2007), whether to 'plug a gap' or explore a novel area. Therefore, through their own contributions to the scholarship, researchers influence what research is done in the future. While the peer review process serves as a safeguard against erroneous assumptions, it is an imperfect method (McGrail, Rickard and Jones, 2006) and, should a poorly calibrated measure of influence be used, and cited and reused, this provides a veneer of reliability for a measure which may not in fact be reliable for the underdog. In essence, it risks 'baking in' errors.

Secondly, it is widely accepted that researchers bring their own lived experience to their research and that this includes any biases they may have absorbed (Chenail, 2011). Researchers are part of society and are therefore likely to have low expectations of the level of influence that underdogs can exert. These biases may well be reinforced by what has already been written in the scholarship. As a result of these biases, the researcher is likely to choose methods that they believe to be suited to these expectations. If the expectations are inappropriately low, then the methods (and indicators) chosen may also be inappropriate.

Finally, researchers produce research which is taken into consideration by governments when they make policy decisions (Start and Hovland, 2004). Therefore, what researchers choose to research – and their findings – have an impact on how governments frame the underdog, which this thesis argues is a crucial factor in their underestimation. For all these reasons, it is clear that indicators for influence must be as free from bias as is feasible. The role of researchers is discussed in more detail in Chapter 7.

Process tracing as a means of measuring influence

It is surprising but true that there are only two main multi-indicator methods of measuring influence in the scholarship (Dany, 2012). The first, process tracing, is a generic method which has been adapted to assess influence in the policy process (Betsill and Corell, 2001; Dür, 2008; Lowery, 2013; Jacobs, A.M., 2015), while the second, Art and Rasmussen's EAR instrument (Arts and Verschuren, 1999), was designed specifically to tackle policy influence.

Process tracing seeks to uncover intervening variables (such as influence) and infer causality (i.e. who has influence) by systematically examining the observable variables in a process (Bennett, A., 2010; Collier, 2011; Beach and Pedersen, 2019). As an established method for analysing complex social mechanisms (Mahoney, J., 2012), it appears an obvious choice for the study of influence. It allows for the observable effects of influence (indicators) to be noted at all stages of the policy process (Betsill and Corell, 2001; Dür, 2008; Lowery, 2013) and has successfully been used to combine multiple measures of influence by a range of different scholars (cf Rasmussen, M.K., 2012; Voltolini and Eising, 2017; te Lintelo et al., 2019) .

Process tracing is theory-driven, which improves its reliability but allows for researcher discretion in exploring new ideas (Mahoney, J., 2012). This is important since the majority of existing theory about underdog influence assumes that the underdog will exert either no or minimal influence. My underdog theory goes against the grain on this, so it will be doubly important for me to be very transparent in all my decisions. The stated aim of this thesis is to inform an underdog lobbying strategy which will increase influence, which is challenging to those who occupy the status quo. It is important that the methods used are open to as little challenge as feasible.

Process driven is traditionally associated with causal mechanisms (Mahoney, J., 2012; Beach and Pedersen, 2019), which I eschew in favour of a broader explanatory framework. However, process tracing is flexible and can be combined with other methods. In this case, I assess each indicator of influence in the same way as I would assess each stage of a causal mechanism, but I do not seek to infer causation from it, since the purpose of this stage of the method is simply to measure influence, not to identify what causes it. A causal mechanism approach would make it difficult to assess indirect influence and favour influence which results in an observable consequence. This would risk missing underdog influence, which may be indirect and is certainly more likely to make only small changes to the policy trajectory, which may not be noticeable if the focus is entirely on the output.

While process tracing is a generic tool that has been used by scholars to assess multiple measures of influence, the EAR instrument developed by Arts and Verschuren (Arts and Verschuren, 1999) was specifically created for this purpose. The EAR instrument uses a heuristic formula, which combines self-reputed influence, reputed influence by others, goal attainment and political relevance. Political relevance is a function of the importance of the issue, its degree of controversy and its potential impact on stakeholders. The EAR instrument assigns an ordinal code of 0 – 4, where 0 = no influence and 4 = great influence, to each case to reflect its score on each of these factors. These ordinal scores are multiplied together to give a final influence score between 0 and 27.

The benefits of this instrument include its notable inclusion of self-reputed influence, which is missing from most analyses, and its heuristic formula which gives a clear way to rate the relative influence of different stakeholders (Dür, 2008; Lowery, 2013; Hofman and Aalbers, 2017; Cole, Epstein and McGinnis, 2019). The coding system allows for the researcher to take a flexible approach and weight some measures more heavily than others – indeed Arts and Verschuren specifically state that “the best judge is the researcher” (Arts and Verschuren, 1999, p419), while the multiplication formula ensures that lower levels of influence are not missed. It is a solid multi-indicator method – but it is not well-adapted to underdog influence.

Firstly, the instrument uses indicators which are poorly suited to capturing underdog influence: goal attainment, reputed influence, and political relevance (more on this below). The underdog is unlikely to exert enough influence to attain their goals and is unlikely to be expected by others to be influential. They are certainly not considered politically relevant. While the policy issue in question will be of high importance to the underdog, it is unlikely to be of high political relevance overall. Therefore, this method is highly likely to miss underdog influence.

Secondly, the process is highly subjective, as acknowledged by Arts and Verschuren (Arts and Verschuren, 1999). Unless the researcher is expecting and seeking to capture underdog influence – and historically, more have focused on NGOs, interest groups and institutions (Lowery, 2013) – it seems unlikely they will notice it using this method which uses indicators already biased against the underdog.

Thus, I select process tracing as the method most likely to successfully capture underdog influence and most able to combine deductive and inductive approaches to coding, but I include the reputed influence highlighted by the EAR method. In lieu of stages of a causal mechanism, I assess the presence or absence of observable indicators of influence.

Indicators of influence

The policy influence scholarship describes five main ways in which influence can be measured – some of which are more useful for measuring underdog influence than others. These are, broadly in the order in which they are first discussed in the scholarship, goal attainment; reputed or attributed influence; representation and framing congruence. Some of these measures focus exclusively on direct influence, others on indirect, while some cover both. Similarly, some measures focus on the beginning of the policy process, others the end and yet others cover influence at all stages. A summary can be found in Figure 5 below.

Measure	**Direct or Indirect**	**Policy Stage observed at**
Goal attainment	Either	Policy output
Reputed influence	Indirect	Any
Representation	Either	Any
Framing congruence	Either	Problem definition
Agenda control	Either	Agenda-setting

Figure 5: Summary of Measures of Influence

Each sub-section will give an overview of what this measure looks like, followed by an evaluation of how useful it is for measuring underdog social policy influence.

Goal attainment

Goal attainment is the longest-standing measure of influence in the scholarship, dating back to at least the 1950s/1960s (March, 1955; Bachrach and Baratz, 1962). It is sometimes also referred to as lobbying success (cf Heinz, Laumann and Nelson, 1993; Baumgartner, F.R. et al., 2009; Klüver, Heike, 2009; Bernhagen, Dür and Marshall, 2014; De Bruycker and Beyers, 2019) or, more recently, preference attainment (cf Weiler, 2012; Bunea, 2013; Junk, 2019b; Romeijn, 2020). In all contexts, it refers, to borrow Laswell’s famous words, to ‘who gets what’ (Lasswell, 1936) – influence is measured by whether you get what you want out of the policy process. As such, it focuses on the final stage of the policy process: policy output. Although there is often assumed causality between action taken in pursuit of a goal and achieving that goal (Goodwin and Jasper, 1999), goal attainment can be a measure of indirect influence as well as direct influence. However, to succeed in altering policy output, comparatively high levels of influence are generally required (De Bruycker and Beyers, 2019).

Goal attainment remains a frequently used measure, despite widespread acknowledgement that its binary nature (you either achieve a goal/preference/success or you don’t) is too blunt an instrument for measuring a complex phenomenon (Mahoney, Christine, 2007; Lowery, 2013; Bernhagen, Dür and Marshall, 2014). Attempts have been made to nuance this binarity: Verschuren and Arts propose paired comparisons, which compare the degree of goal attainment between two stakeholders (Verschuren and Arts, 2005); Klüver uses quantitative text analysis of policy and campaign documents (Klüver, Heike, 2009); Bunea uses an ordinal scale (Bunea, 2013) and Vannoni and Dür propose spatial models (Vannoni and Dür, 2017). However, while this allows for a pluralist approach which compares degrees of influence, it remains biased towards those with more influence due to its continued focus on policy output. It will miss those (like the underdog) who are still building influence and have not yet succeeded in achieving their goals/preferences. In addition, this measure favours experienced lobbyists over underdogs, since they are more likely to either support the status quo or to understand how to formulate policy issues and goals in such a way as to garner government support (Salisbury et al., 1989; Leech, 2014; De Bruycker and Beyers, 2019).

Thus, goal attainment is poorly suited to measuring underdog influence, which is likely to be most strongly manifested in earlier stages of the policy process than in policy output (Weiler and Brändli, 2015; De Bruycker and Beyers, 2019). Nonetheless, it is an inescapable fact that goal attainment matters: there is arguably no point in lobbying for something that there is no possibility of attaining. It is important, therefore, to measure goal attainment for the underdog, in as nuanced a way as possible, but to do so with an awareness that, as a measure, it is biased towards experienced lobbyists and established actors, and to combine it with other measures which capture influence at an earlier stage in the policy process.

Reputed influence

Reputed influence, also referred to as influence reputation (cf Knoke, 1983; Heaney, 2014) and attributed influence (cf Heinz, Laumann and Nelson, 1993) has its roots in the psychology scholarship (cf Zander and Cohen, 1955; Larsen and Minton, 1971) but mainly entered the social policy scholarship through network analysis theory in the 1980s (cf Knoke, 1983; Laumann, Knoke and Kim, 1985), seeing some interest in the 1990s (cf Fernandez and Gould, 1994; Smith, R.A., 1995), and experiencing a renaissance in the past decade (cf Young, Lewis and Sanders, 2010; Hojnacki et al., 2012; Ingold and Leifeld, 2016; Schneider, A.L. and Ingram, 2019). It refers to the impact of how much influence an actor is perceived to have on how other stakeholders and the government treat them, which, in turn, impacts upon how likely they are to be able to alter the policy trajectory. Policy actors with high levels of reputed influence are more likely to be listened to, and more likely to actually exert influence (Ingold and Leifeld, 2016). Governments also treat policy actors differently according to how much influence they perceive them to have, with groups perceived to be powerful more likely to be given what they ask for (Schneider, A. and Ingram, 1993; Schneider, A.L. and Ingram, 2019). It is an indirect measure and can be observed at any stage of the process but is perhaps most visible in the agenda-setting and problem definition stages.

The obvious criticism of this measure is that it is measuring opinions and not actual influence (Heinz, Laumann and Nelson, 1993; Arts and Verschuren, 1999; Dür, 2008; Lowery, 2013). This measure, perhaps more than any other, needs to be paired with other measures to give it some empirical clout. Schneider and Ingram's theory of the social construction of target populations (Schneider, A. and Ingram, 1993) also makes it clear that power is not the only factor which determines how a policy actor is viewed: whether they are viewed positively or negatively is also important. In addition, whose opinion do you prioritise? A group may be viewed differently by the public, the government or other policy actors. Public opinion is known to be important

(May, 1991; Kollman, 1998; Dür and Mateo, 2014; Schneider, A.L. and Ingram, 2019) but it is self-evident that governments do not always do what public opinion suggests (Jacobs, L.R. and Shapiro, 2000; Goot, 2005). Finally, the factors governing how much influence an actor actually has are much more complex than how much influence they are perceived to have.

One type of reputed influence which is often ignored in the scholarship is self-reputed influence, or, to put it another way, how much confidence an actor has in their own ability to influence. (The EAR instrument proposed by Arts and Verschuren is an important exception (Arts and Verschuren, 1999) and will be discussed in more detail later in this chapter.) It is recognised to a certain extent in political psychology studies of political leaders (cf Kaarbo, 2018) but considered less often when it comes to studies of other stakeholders (Arts and Verschuren, 1999). I consider this to be an unfortunate omission, due to the large body of literature in both the psychology and empowerment scholarships which supports the argument that self-belief increases a person's self-efficacy and resilience and thereby their ability to empower themselves (Saleeby, 1993; Perkins, 1995; Dempsey and Foreman, 1997; Banducci, Donovan and Karp, 2004; Cornwall and Brock, 2005; Goodley, 2005).

It is clear that reputed influence is an indicator which is heavily biased against the underdog. It remains a useful measure for tracking change in the reputation of the underdog over time but needs to be paired with at least another more empirical method if it is to be of use. Finally, I would argue for the addition of self-reputed influence as a component of reputed influence for the underdog, so that the underdog theory detailed in Chapter 3 can be explored.

Participation as a form of substantive representation

Representation is at the heart of the representative democracy system that holds sway through much of the Western world (Dahl, 1989; Hirst, 1990). It is accepted to be an important, if imperfect, way of holding governments to account, both in the scholarship (Norris, 1997; Pitkin, 2004; Bohman, 2012; Pennock, 2017) and more generally in society, where the notion that everyone should be able to 'make their voice heard' is ubiquitous (Aronson, 1993; Nordberg, 2006; Smith, M.K., 2013; Flöthe and Rasmussen, 2019). It has gained traction as a measure of influence through studies about the representation of women, people of colour and other minorities (underdogs) since the 1970s (cf Peterson, 1970; Anderson, 1977) – although it has been spoken of as a political mechanism since much earlier (Fairlie, 1940; Seitz, 1995), and remains a popular area of study today (Vieira, 2017). However, it is a truism that just because a voice is heard does not mean it is listened to (Aronson, 1993). Therefore, representation needs to be unpacked further to understand how it can be used as a measure of influence.

For representation to lead to influence, it must constitute substantive representation (Banducci, Donovan and Karp, 2004; Powell and Bingham, 2004), which means that the voice of the actor is not just heard but listened to and reflected in policy decisions. Political participation is one way of achieving representation, and some scholars have argued that it is a pre-requisite for substantive representation (Dür and De Bièvre, 2007; Luxon, 2019). Others argue that, while participation may make it more likely you will be heard, it does not mean you will be listened to (Jones and Baumgartner, 2004; Pitkin, 2004). However, this assumes a binary success – either you are listened to, or you are not; either you 'get what you want' or you don't, and this has already been shown to be a blunt instrument that misses lower levels of influence.

Political participation has been shown to be a useful tool for underdogs to increase both their visibility and their influence (Dempsey and Foreman, 1997; Banducci, Donovan and Karp, 2004; Goodley, 2005; Mabbett, 2005; Milner and Kelly, 2009; Kingston, 2014; Halvorsen et al., 2017), but by itself it is not necessarily enough to alter the policy trajectory. This may be because the underdog is more likely to participate earlier in the political process than the decision-making stage, through advocacy, social movements, or consultations rather than sitting on policy boards or citizens' assemblies (Miraftab, 2004; Milner and Kelly, 2009). It has demonstrably succeeded on a number of occasions at getting an issue on the policy agenda (Dery, 2000) or altering the way a problem is framed (Kangas, Niemelä and Varjonen, 2014; De Bruycker, 2017; Junk and Rasmussen, 2019) – cf the women's suffrage movement, LGBT rights movement, civil rights movement – but assessing participation on its own wouldn't tell the researcher any of this.

In addition, there is a body of literature in the disability studies and empowerment scholarships which highlights the inequality of different methods of participation (Banducci, Donovan and Karp, 2004; Kingston, 2014; Halvorsen et al., 2017). Certain modes of participation are criticised as being more symbolic than others: for example, completing a survey as part of a consultation is a far cry from being invited to sit on a committee making policy decisions (Mabbett, 2005; Barnes, Collin, 2007; Waldschmidt et al., 2015). Halvorsen and others differentiate between active participation – where the citizen has a tangible stake in the decision-making process, even if they do not have veto power – and passive participation – where the citizen takes the role of an informant (Mahoney, Christine, 2007; Halvorsen et al., 2017; Junk, 2019a). Thus, substantive representation can only be measured by pairing an assessment of political participation with an assessment of the type of participation and at least one additional measure of influence – such as goal attainment, or as I will discuss in the next section, framing congruence.

Representation can also take place by proxy, such as through the use of lobbyists or advocates (Majone, 1997; Baumgartner, F. et al., 2001; Meijerink, 2005; Gardner and Brindis, 2017; Luxon, 2019). While, similarly to citizen participation, the presence or absence of an actor representing a particular interest can increase the likelihood the voice is heard (Dür and De Bièvre, 2007; Papadopoulos and Warin, 2007; Romeijn, 2020), it cannot guarantee the voice is listened to. It presents additional ethical and methodological complications for underdogs as well: how can you determine whether any alteration in the policy trajectory, or change in the policy agenda or problem definition is down to the underdog or their proxy? How can you determine if a proxy is accurately representing the interests of the underdog? These are all thorny issues which cannot be entirely resolved but must be acknowledged and addressed as far as possible in the context of each individual research project (Robertson, T. and Wagner, 2012).

It is clear that representation is a useful measure for the underdog. It is a topical issue which is understood by society to be important, and it can assess something tangible (unlike reputed influence) at an earlier stage and in a more nuanced way (unlike goal attainment). Arguably, if the underdog feels that they have 'had their say', they may feel more empowered, and this may increase their self-reputed influence. However, it is an incomplete measure: it is only really useful if it is paired with other measures. In addition, care must be taken to isolate the influence of the underdog from the proxy insofar as is possible and to avoid allowing the proxy to speak for the underdog in research (McCoy et al., 2020). More detail on how this will be enacted in relation to my own research can be found later in this chapter.

Framing congruence

Framing congruence allows the user to measure influence at the problem-definition stages of the policy process, which other measures struggle to do (Boräng and Naurin, 2015; Klüver, H and Mahoney, 2015; De Bruycker, 2017). Although framing as a concept has been accepted since the advent of social constructionism (Van Gorp, 2007), its use to measure policy influence is a more recent arrival, with most studies taking place in the past thirty years (Goodwin and Jasper, 1999; Kangas, Niemelä and Varjonen, 2014; De Bruycker, 2017) and a focus from the beginning on minority interests.

Framing ties in with the extensive literature on problem definition (Rochefort and Cobb, 1993; Dery, 2000; Baumgartner, F.R. and Jones, 2015) for issue framing, and the social construction of target groups and anticipatory policy for target group framing (Schneider, A. and Ingram, 1993; Schneider, A.L. and Ingram, 2019). There are several different ways of approaching any policy problem, and several different ways of viewing any target group or other stakeholder. Each policy actor or interest coalition puts forward a particular framing, or viewpoint of a policy problem and its stakeholders, particularly the target group (Boräng et al., 2014). Only one framing of the policy problem and each stakeholder will be selected by the government as the dominant frame which will, in turn, colour the political decisions that are made and the policy output (Mahoney, C and Kluver, 2012; Kangas, Niemelä and Varjonen, 2014; Junk and Rasmussen, 2019). A shift in framing may not be enough for the policy actor to ‘get what they want’ and attain their goals, but it still represents the exertion of influence. The degree of congruence between the frames put forward by each actor or interest and the dominant framing chosen by the government is a measure of the influence of that actor or interest (Klüver, H and Mahoney, 2015; Junk, 2019b).

Valid criticisms of framing congruence include that frames are inevitably subjective, and it is difficult to measure them in an objective way (Arts and Verschuren, 1999; Goodwin and Jasper, 1999). In addition, it is difficult to demonstrate causal inference between the actions of an actor and a shift in framing (Kangas, Niemelä and Varjonen, 2014; Junk and Rasmussen, 2019). While researchers have sought to overcome these difficulties (Klüver, H and Mahoney, 2015; De Bruycker, 2017), framing is by nature constructivist and subjective, and this cannot be negated entirely.

Framing congruence is evidently a useful measure for the underdog because it has been developed with the underdog in mind and it captures influence at the earlier stages, which is where the underdog’s influence is more likely to be visible. However, to minimise the risk of researcher bias in identifying frames (Boräng et al., 2014), it is best combined with another, more empirical method such as goal attainment.

Agenda control

Agenda-setting is a sub-discipline of policy sciences (Dery, 2000; Jones and Baumgartner, 2004; Birkland, 2007) but its outcomes are also of relevance as an indicator of influence, since tabling an issue for discussion is frequently a pre-requisite for it being given due consideration. Therefore, agenda *control* defined as the ability to determine the policy agenda during the agenda-setting process is, in fact, a key indicator of social policy influence, even though it is rarely discussed as such in the scholarship. It is another indicator which captures influence in its earlier stages.

Studies of agenda-setting show that it can be an area where marginalised groups are able to exert some influence through raising awareness of certain issues or highlighting inequalities (Ahmed and Rogers, 2016; Scior et al, 2016; Finn et al, 2021). Often this is through consultation (Halvorsen et al, 2017), but it can also be through petitions (Earl and Schusmann, 2008) and forms of protest (Aaslund and Chear, 2020). However, the government does not act on every issue it considers and agenda-setting on its own is therefore an incomplete indicator of influence.

Agenda control was not on my original list of indicators of influence at the theory-building stage but made it on as a result of the iterative process, when it became clear from interviews with stakeholders that they perceived control of the agenda to be an important facet of influence. Like many of these indicators, agenda-setting on its own is not evidence of influence, but when taken cumulatively, helps to build a fuller picture.

A template for influence

The literature review has shown that there are several, valid indicators of social policy influence but that many of them are calibrated in such a way that they risk missing or minimising underdog influence. Taking inspiration from the EAR instrument (Arts and Verschuren, 1999), I propose to assess cumulative influence across six measures: goal attainment, self-reputed influence, reputed influence, active participation (as a component of substantive representation), framing congruence and agenda control.

Learning from the shortcomings of the EAR method, an ordinal system will not be used but instead the researcher will use their own expertise and knowledge of the subject area to combine the measures cumulatively according to such weightings as they feel to be appropriate. This allows the political and cultural context to be taken into account and for theoretical innovation where, as in the example of the underdog, existing theory assumes low levels of influence which have not been fully tested due to theoretical assumptions. Coding decisions and their rationale must be made explicit to ensure reproducibility (Christensen, Freese and Miguel, 2019). Rather than an influence ‘score’, the researcher will provide a thick description (Geertz, 1973) of the relative influence of each stakeholder, based on observations of each measure and thematic analysis, as described later in this chapter.

Figure 6 below describes the indicators and the pre-selected codes for analysis.

Measure	**Data required**	**Codes**
Goal attainment	Goals; policy output	For each goal: Fully attained; mostly attained; slightly attained; not at all attained.
Self-reputed influence	Opinions of each stakeholder	For each stakeholder: As a group, we have a lot of influence; quite a lot of influence; a little influence; no influence.
Reputed influence	Opinions of each stakeholder	For each stakeholder: Stakeholder X has a lot of influence; quite a lot of influence; a little influence; no influence.
Active participation	For participation: opportunities for political participation and presence or absence of actor at each opportunity. For active nature: feedback from actor and stakeholders.	For each stakeholder: participates; does not participate and, if participates = true, participates very actively; quite actively; a little actively; not at all actively.
Framing congruence	Issue and target group frame proposed by each actor; dominant issue and target group frame in final output.	For each stakeholder: framing identical; highly congruent; quite congruent; a little congruent; not at all congruent.
Agenda control	Issues; policy agenda.	For each stakeholder: has a lot of; quite a lot of; a little; no control over the policy agenda.

Figure 6: Indicators of influence

As the table shows, participation is recorded whether it is active or not, but active participation is of particular interest when looking at underdog influence because of the correlation in the empowerment scholarship between active participation and self-belief, which will in turn feed into self-reputed influence (Dempsey and Foreman, 1997; Goodley, 2005; Halvorsen et al., 2017). Both issue and target group framing are recorded, due to the importance of the framing of the target group, as described in Schneider and Ingram's theory of social construction of target groups and anticipatory policies (Schneider, A. and Ingram, 1993; Schneider, A.L. and Ingram, 2019). Although I have pre-selected certain codes to ensure consistency in analysis, I will also add additional codes on an inductive basis if they are indicated by the data: for example, if it is necessary to qualify influence in a more graded way, or if interviews reveal an additional measure of influence that I had not considered. Thematic codes will also be added inductively to support the creation of a thick description about the influence of each stakeholder.

Following Seawright and Gerring (Seawright and Gerring, 2008), I use data from both documents and people to assess these indicators. Stakeholder interviews are combined with focus groups and a survey of the wider autistic community to capture a wider range of data, and policy documents and Hansard records of government discussions. The detail of this is set out in Chapter 5, which is the Methodology chapter. Process tracing is used to assess the presence or absence of each indicator shown in Figure 7 overleaf; this is supplemented with thematic coding as described in Article 2 and Chapter 5.

A has cumulative policy influence to the extent that A:

succeeds in obtaining their policy goals

and

has a positive opinion of their own level of policy influence

and

actively participates in the policy process

and

succeeds in getting an issue on the agenda

and

puts forward a framing of the policy issue which is congruent with the dominant framing

and

other stakeholders have a positive opinion of A's level of policy influence.

Figure 7: Influence Template

This template is cumulative, in that no one indicator is either necessary or sufficient, but together they combine to pool their resources in one. It is pluralist, accepting that there are levels and degrees of influence, and that all influence is relative. It includes all empirical measures of influence; therefore, it should be suited to measuring all observable forms of influence at all stages of the policy process. It allows the researcher space to use their expertise to explore a policy process but provides a systematic and structured framework to ensure that all bases are covered.

Thus, in this chapter, I have retraced the earliest steps of the journey of this thesis by getting back to basics: what is policy influence and how do we measure it? I have shown that influence is difficult to measure and that scholars usually do so incompletely and using indicators which are poorly calibrated for underdog influence. I have theorised that this may be partly due to expectations about influence. In Article 1, which follows, I test these indicators on the adult autistic community in England.

Appendix 6B: Statement of Authorship

This declaration concerns the article entitled:									
Marginalised or missed? The curious case of autistic policy influence in England.									
Publication status (tick one)									
Draft manuscript		**Submitted**		**In review**	X	**Accepted**		**Published**	
Publication details (reference)	Provisionally accepted pending revisions by *Politics and Policy*.								
Copyright status (tick the appropriate statement)									
I hold the copyright for this material	X	Copyright is retained by the publisher, but I have been given permission to replicate the material here							
Candidate's contribution to the paper (provide details, and also indicate as a percentage)	This is a sole author article. The candidate carried out all of the research and writing of the article, with advice only from supervisors. Formulation of ideas: 100% Design of methodology: 100% Experimental work: 100% Presentation of data in journal format: 100%								
Statement from Candidate	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature.								
Signed	[redacted]	**Date**	11.04.22						

Article 1: Marginalised or missed? The curious case of missed policy influence.

Preamble

This article was originally intended to contain the results of the case study as they pertained to autistic self-advocates in England. It became apparent when starting to write it that there was simply too much material to do justice to within the word count of a single article. The decision was therefore made to make this a method-focused article and to dedicate a chapter of the thesis to the full case study.

Within the thesis, this article serves as part of the case study on the autistic community: it tackles the 'to what extent' part of the research question. As such, it also contributes to building the underdog theory by providing empirical evidence for the 'to what extent' part of the overarching research question. In its own right, this article stands as an original methodological article.

This article was also incorporated into a paper presented at the International Public Policy Association Conference in Barcelona on 8 July 2021, where it received positive feedback, and was revised to provide further justification of the indicators and a more detailed explanation of the importance of treating autistic people and families/carers as separate groups.

This article has been provisionally accepted following revisions by *Policy and Politics* journal.

Abstract

This article challenges the dominant societal framing of marginalised groups as lacking policy influence and argues that said influence is at risk of being underestimated, in the scholarship, policy communities and wider society. It proposes a triangulated approach to measuring influence with a wider set of indicators than usually attempted. These indicators, which are designed to include influence in its early stages, are explored through a case study of the autistic community in England. Surprisingly, the results show not just that autistic people have more policy influence than they or others expect, but that influence is also being missed in its later stages, indicating both a methodological problem and potentially an issue with researcher bias (Chenail,

2011). This methodological and empirical contribution to the scholarship has particular implications for social researchers but is also of interest to governments and marginalised groups everywhere.

Introduction

There is a democratic deficit in social policy: those who need it the most are the least able to influence it (Norris, 1997; Warren, 2009; Maiorano et al., 2021). Marginalised groups experience physical exclusion from both democratic and social spaces (Milner and Kelly, 2009; Cornwall, 2017; Hofman and Aalbers, 2017), limiting their opportunities for political participation (Meyer and Minkoff, 2004; McCammon, 2013), and are also socially constructed as weak target groups (Schneider, A.L. and Ingram, 2019), which contributes to a dominant, societal framing of the group as lacking influence.

This article acknowledges the very real constraints placed upon marginalised groups but challenges their framing as disempowered. It argues, instead, that the policy influence of marginalised groups is at risk of being underestimated and, as a result, under-measured, and that marginalised groups are able to exert higher levels of influence in relation to other stakeholders than both the scholarship and their own perceptions would lead them to expect.

This underestimation derives from the dominant, societal framing of marginalised groups, which, like any framing, is the product of many different and interacting factors (Benford, 1988; Hertog, 2001; Kangas et al, 2014). Framing is an ongoing process, where historical and culturally embedded frames are often reinforced, but where there is also the possibility for new frames, introduced by societal actors, and even by marginalised groups, to become dominant (Snow, 2013; Klüver, 2013; De Bruycker, 2017). Indeed, framing congruence, i.e., getting an alternative frame to be accepted by governments, is argued by several scholars to be an important tool for marginalised groups (Börang et al, 2015; Junk and Rasmussen, 2018).

In this article, I demonstrate, using process tracing and thematic analysis of documents, stakeholder interviews, an online survey and focus groups relating to my case study of autistic adults in England, that autistic people have more policy influence than the scholarship would lead us to expect, or they themselves believe themselves to have. The article opens by building a theoretical framework to demonstrate how expectations of influence are derived, and then how they are typically measured. I go on to critique these measures as incomplete before proposing my own recalibrated indicators which are designed specifically to capture the influence of marginalised groups. While no generalisability can be claimed at this stage, it nonetheless raises the possibility that the influence of other marginalised groups is being similarly missed.

The underestimation of marginalised groups: a theoretical framework

At the heart of this theory is the disconnect between what marginalised groups are expected to achieve and what they actually achieve. It is essential then to understand how those *expectations* are formed, and how their *achievements* are measured. Since the focus of this case study is social policy *influence*, I examine what the scholarship says about the anticipated social policy influence of marginalised groups, and how said influence is measured.

Expectations of influence

Lowery (2013) says of influence that many scholars look for it, but few find it – a comment on the methodological difficulties inherent in measuring influence, on which I will say more shortly. However, this is even truer for marginalised groups because expectations of their influence are that much lower.

Explanations for the policy marginalisation of certain groups emerge from several disciplines, most notably the emancipation and collective action scholarships (Boltanski, 2011; Scott, 2012; Coole, 2015), but converge on certain points. Firstly, marginalised groups rarely possess the resources associated with lobbying success (Lowi, 1954; Baumgartner and Jones, 2007). These resources are not necessarily financial, although money can be used to buy other resources, but also include expertise and access to key people and networks of contacts. Secondly, marginalised groups are generally excluded from the decision-making phase of the policy process and limited to agenda-setting, issue definition or framing: processes which are lengthy and take time to show results (Cornwall, 2017; Hornung, Bandelow and Vogeler, 2019; Junk and Rasmussen, 2019). Thirdly, common lobbying strategies assume that marginalised groups lack influence: they are advised to pool resources (since they are assumed to lack them) (Junk, 2019a), protest (since they are assumed to be outsiders) (Quaranta, 2015) and focus on agenda-setting/framing (since they are assumed to have no access to decision-making spaces) (De Bruycker, 2017). What if some of these assumptions are wrong?

Formation of expectations

Expectations about influence are formed using information from a variety of sources. Of particular interest to this article, since it will be read primarily by social science researchers, is how the scholarship develops. Every researcher, whether inductive or deductive, begins their research process with a review of what other researchers have already written: the literature review (Rozas and Klein, 2010; Carver et al, 2013). Each book and article within the scholarship has in turn been written by a researcher who began their research project in the same way. Over time, therefore, the choices made by researchers as to what to research and how to research it determine what makes up the scholarship and what other researchers choose to research in the future. This has many benefits in ensuring the robustness of research and allowing new researchers to ‘stand on the shoulders of giants’ – but it also represents a risk. Something that has been repeated many times in the scholarship can be accepted with little questioning and errors may creep into the scholarship, despite the best efforts of the peer review process, and be ‘baked in’ (Milner, 2007).

Moreover, researcher bias is a known artefact (Chenail, 2011). Researchers are individuals with their own life experiences, biases, and preferences. These can be acknowledged and mitigated as far as possible, but not removed entirely. Researchers are therefore likely to be impacted by dominant societal framings of marginalised groups. This will have an impact on their expectations of the influence of marginalised groups and how they set out to measure it. Dominant societal framings of marginalised groups expect that they will not have high levels of influence, therefore the researcher is likely to treat any example of influence as a ‘rare case’ (Lowri, 2013).

Finally, dominant societal framings of marginalised groups will impact not just researchers but also governments, as shown in Schneider and Ingram’s (2019) anticipatory feedback strategy work and how marginalised groups view themselves, with a corresponding effect on their self-worth and behaviour (Goodley, 2005).

Indicators of influence

As an intervening variable, influence can only be measured by identifying observable indicators (March, 1955; Lowery, 2013). Unavoidably, this means that influence in its very early stages is likely to be missed, simply because it is not yet observable. However, let us look at the most commonly used indicators of policy influence.

Goal attainment is the longest-standing measure of influence in the scholarship (March, 1955). It refers to 'who gets what' (Lasswell, 1936), or whether you get what you want out of the policy process. As such, it focuses on policy output. Although there is often assumed causality between action taken in pursuit of a goal and achieving that goal (Goodwin, Jasper and Khattra, 1999), goal attainment can be a measure of indirect influence as well as direct influence. However, to succeed in altering policy output, comparatively high levels of influence are required (De Bruycker and Beyers, 2019). Goal attainment remains a frequently used measure, despite widespread acknowledgement that its binarity is problematic (Lowery, 2013; Bernhagen, Dür and Marshall, 2014). Attempts have been made to nuance this binarity (Verschuren and Arts, 2005; Klüver, Heike, 2009; Vannoni and Dür, 2017); however, while this allows for a pluralist approach which compares degrees of influence, it will still miss those who are building influence and have not yet succeeded in achieving their goals, e.g. marginalised groups. This measure also favours experienced lobbyists, who are more likely to either support the status quo or understand how best to formulate policy issues and goals to garner government support (Leech, 2014; De Bruycker and Beyers, 2019).

One way that this emphasis on the later stages can be mitigated is by including agenda control as an indicator of influence. While agenda-setting as a topic has a broad following in the scholarship (Barbehön, Münch and Lamping, 2015), and the link between agenda-setting and political influence is well-established (Birkland, 2017), methodological discussions of measuring policy influence ignore it (cf Dür, 2008; Lowery, 2013). Assessing the degree of congruence between the claims made by a marginalised group (McAdam and Tarrow, 2011) and the issues discussed in Parliament and on decision-making bodies can also be used as an indicator of influence (Birkland, 2017) – and more likely to capture the influence of marginalised groups than goal attainment.

Reputed influence, also referred to as influence reputation (Heaney, 2014) and attributed influence (cf Heinz, Laumann and Nelson, 1993) refers to the impact of how much influence an actor is perceived to have on how other stakeholders and the government treat them, which, in turn, impacts upon how likely they are to be able to alter the policy trajectory. Policy actors with high levels of reputed influence are more likely to be listened to (Ingold and Leifeld, 2016). It is an indirect measure and can be observed at any stage of the process but is most visible in the agenda-setting and problem definition stages.

One type of reputed influence which is often ignored in the scholarship is self-reputed influence, or how much confidence an actor has in their own ability to influence. It is recognised to a certain extent in political psychology studies of political leaders (cf Kaarbo, 2018) but considered less often when it comes to studies of other stakeholders (Arts and Verschuren, 1999). This is an unfortunate omission, since self-belief is known to increase a person's self-efficacy and resilience (Dempsey and Foreman, 1997; Banducci, Donovan and Karp, 2004; Goodley, 2005). It is unlikely that marginalised groups would score highly using this indicator, given that they have been socialised to expect minimal influence.

Political participation is one way of achieving representation, and some scholars have argued that it is a pre-requisite for substantive representation (Dür and De Bièvre, 2007; Luxon, 2019). Others argue that while participation may make it more likely you will be heard, it does not mean you will be listened to (Jones and Baumgartner, 2004; Pitkin, 2004). Political participation has also been shown to be a useful tool for marginalised groups to increase both their visibility and their reputation (Dempsey and Foreman, 1997; Banducci, Donovan and Karp, 2004; Goodley, 2005; Milner and Kelly, 2009; Kingston, 2014; Halvorsen et al., 2017), but by itself it is not necessarily enough to alter the policy trajectory. This may be because they are more likely to participate earlier in the political process than the decision-making stage, through advocacy, social movements, or consultations rather than sitting on policy boards or citizens' assemblies (Miraftab, 2004; Milner and Kelly, 2009). Marginalised groups have demonstrably succeeded on a number of occasions at getting an issue on the policy agenda (Dery, 2000) or altering the way a problem is framed (De Bruycker, 2017; Junk and Rasmussen, 2019) – but assessing participation on its own would not tell the researcher any of this.

In addition, there is a body of literature in the disability studies and empowerment scholarships which highlights the inequality of different methods of participation (Banducci, Donovan and Karp, 2004; Kingston, 2014; Halvorsen et al., 2017). Halvorsen and others differentiate between active participation – where the citizen has a tangible stake in the decision-making process, even if they do not have veto power – and passive participation – where the citizen takes the role of an informant (Halvorsen et al., 2017; Junk, 2019a). Like other measures of influence, active participation is only really useful if it is paired with other measures.

Framing congruence allows the user to measure influence at the agenda-setting and problem-definition stages of the policy process, which other measures struggle to do (Boräng and Naurin, 2015; Klüver, H and Mahoney, 2015; De Bruycker, 2017).
Each policy actor or interest coalition puts forward a particular framing of a policy problem and its stakeholders, particularly the target group (Boräng et al., 2014). Only one framing of the policy problem and each stakeholder will be selected by the government as the dominant frame which will, in turn, colour the political decisions that are made and the policy output (Mahoney, C and Kluver, 2012; Kangas, Niemelä and Varjonen, 2014; Junk and Rasmussen, 2019). A shift in framing may not be enough for the policy actor to attain their goals but may nonetheless alter the trajectory. The degree of congruence between the frames put forward by each actor or interest and the dominant framing chosen by the government is a measure of the influence of that actor or interest (Klüver, H and Mahoney, 2015; Junk, 2019b). Framing congruence is evidently a useful indicator for marginalised groups because it captures influence at the earlier stages, which is where influence is more likely to be visible. However, to minimise the risk of researcher bias in identifying frames (Boräng et al., 2014), it is best combined with another method.

Recalibrating the indicators

As the above analysis shows, the most commonly used indicators for influence are not calibrated in such a way as to detect the influence of marginalised groups. I propose a specific definition of policy influence and a new way of assessing indicators which builds on the work of Arts and Verschuren (1999) – still the only multi-indicator method in the scholarship - while maintaining tried and tested methods for assessing influence. Rather than viewing influence as binary success or failure, I define it as a spectrum which determines the trajectory of the policy process.

Policy influence consists of the ability to alter or maintain the trajectory of the policy process.

Arts and Verschuren (1999) refer to their EAR Instrument as an instrument based on triangulation; I extend this triangulation to encompass all indicators of influence. The EAR instrument measures goal attainment, reputed influence, and self-reputed influence using process tracing. It uses an ordinal algorithm to determine the extent of influence, reinforcing the existence of influence on a spectrum; however, it also relies heavily on researcher knowledge. However, its focus on the indicators of influence least likely to be observable for underdogs means that it needs some recalibration.

I retain the spectrum focus and use of process tracing as an established method but, instead of using an algorithm, I deliberately leave it to the researcher to assess influence according to a sliding scale.

Marginalised groups have cumulative policy influence to the extent that they: succeed in obtaining their policy goals and/or succeeds in getting an issue on the policy agenda and/or have a positive opinion of their own level of policy influence and/or actively participate in the policy process and/or propose a framing of the policy issue which is congruent with the dominant framing and/or succeed in getting an issue on the policy agenda and/or other stakeholders have a positive opinion of their level of policy influence.

Figure 1: Influence Template

This template covers influence at all stages of the policy process. It is cumulative, in the sense that the more indicators that are observed, the higher level of influence. It is also relative and pluralist; it is of most use when compared with the relative influence of other stakeholders.

Case Selection

To test for missed influence, I selected a case where there appears to be a disconnect between how the target group is constructed and what they achieve. Autism policy is a contested area which is a sub-group of disability policy (Feinberg and Vacca, 2000; Orsini, 2016). Autism is clinically defined as a neurodevelopmental disorder (Falkmer et al., 2013; NICE, 2016; Hayes et al., 2018) and most autistic people with a clinical diagnosis would meet the legal definition of a disability (Baron–Cohen, 2000; Krcek, 2013; O'Reilly, Karim and Lester, 2015). Thus, autistic people are framed as weak; they are also statistically over-represented among the unemployed, underemployed (Hendricks, 2010) and those involved with the mental health (Maddox and Gaus, 2019) and criminal justice systems (King and Murphy, 2014). On the other hand, the neurodiversity movement argues that autism is a difference, not a deficit and calls for autistic people to be defined what they can do rather than by what they cannot do (Kapp et al., 2013; Donaldson, Krejcha and McMillin, 2017). Strengths commonly associated with autism, such as attention to detail and a strong work ethic, have been empirically demonstrated in the psychology scholarship (Meilleur, Jelenic and Mottron, 2015).

In parallel with a rapid evolution in understanding of autism and the growth of the neurodiversity movement (Dillenburger et al., 2013; Donaldson, Krejcha and McMillin, 2017), Western Europe has seen 15 new autism-specific policies – national policies that deal exclusively with autism – spring up over the past twenty years (Precious, 2020). I focus on England as the first country to pass an autism-specific law, the Autism Act 2009 (Della Fina, 2015; Baranger, Hammersley and Posada de la Paz, 2018) and one of few countries to make institutional changes to the political opportunity structure to facilitate autistic participation (Precious, 2020), making participation, as an indicator of influence, more likely

Methodology

The first methodological challenge is how to determine if autistic policy influence is 'higher than expected'. I measure this in two ways. Firstly, I compare autistic people's perception of their influence with the perceptions of other stakeholders and with the overall level of influence. Secondly, I consider that this criterion has been met if there is evidence of goal attainment, or reputed influence, since both are shown by the scholarship to be unlikely for marginalised groups.

I use process tracing to assess the presence or absence of the various indicators of influence at different stages of the policy process. Process tracing requires the generation of observable indicators for each element being assessed; the researcher then assesses the presence or absence of each indicator at pre-determined stages in the identified process (te Lintelo et al., 2019). Here, the process is divided into the following traditional policy stages: agenda-setting, issue-definition, deliberation, and formulation (Shanahan, Jones and McBeth, 2011; Howlett, M., McConnell and Perl, 2017). I stop at the formulation stage, which means that my data is limited to what makes it into policy output. I do not attempt, in this article, to assess the implementation of the policy, although this is something which merits further investigation. This is because other factors outside of policy influence may determine the extent to which a policy is effectively implemented. This does have implications for goal attainment, in that I am assessing goal attainment in terms of getting something written into policy, rather than in terms of a specific outcome actually being achieved.

Data Sources

Data for analysis is obtained from stakeholder interviews, including some elite interviews, an online survey of autistic people, online focus groups involving autistic people, policy documents and Hansard records of parliamentary debates. A copy of the interview questions and transcripts can be found in the data repository. Interviews were conducted online using Microsoft Teams and Zoom due to COVID-19 restrictions. In some cases, elite interviewees requested written questions and responded by email.

I carried out an actor mapping exercise to inform sampling, using Hansard transcripts of Parliamentary debates, policy documents and publicly available websites. A list of sources and the subsequent mapping data can be found in the data repository. As a result of this mapping exercise, I identified two deliberation bodies for national autism policy in England (the Adult Autism Programme Board and the All-Party Parliamentary Group on Autism Advisory Group) and eleven categories of stakeholder: autistic self-advocates – by which I mean, in this context, those autistic people who sit on decision-making bodies as official representatives of autistic people -, the wider autistic community; families/carers of autistic people; charities; researchers; professional bodies; NHS bodies; local government bodies; national government bodies, civil servants, and MPs/Lords. Demographic information was not collected.

Membership of the deliberation bodies is publicly available information; therefore, I began with a mixture of direct and gatekeeper-facilitated contact with members of these bodies. Gatekeeper-facilitated contact was made possible through existing contacts within the National Autistic Society, which provides the secretariat for the All-Party Parliamentary Group on Autism. Snowball sampling was then used to facilitate further introductions. In total, I conducted 29 interviews: 5 with autistic self-advocates and 2-4 with stakeholders from each of the other groups. A breakdown by stakeholder type can be found in the data repository. The total number of members of the Adult Autism Programme Board and All-Party Parliamentary Group on Autism Advisory Group at the time was 38; therefore, this was good saturation. Transcripts of all interviews are available in the data repository; interviewees were given the option of being anonymous if they chose, while retaining their stakeholder category for analytical purposes.

The data obtained from stakeholder interviews was supplemented with an online survey and focus groups targeting autistic adults resident in England, to gather data from the wider community about their perceptions and experiences of autism policy (De Vaus and de Vaus, 2013; Berinsky, 2017). These were held online due to the coronavirus pandemic. In addition, policy documents and Hansard records of parliamentary discussions were used (Freeman and Maybin, 2011). The online survey was created on the OnlineSurveys.ac.uk platform, which is owned by JISC, and contained a mixture of Likert scale questions, multiple choice tick box questions and free text responses. The survey and focus groups were advertised to members of the University of Bath's Centre for Applied Autism Research's volunteer database, and also on Twitter. All responses were anonymised, and a copy of the questions can be found in the data repository. 118 survey responses were received. Online focus groups were held on Zoom with between 3 and 5 people present at each focus group in addition to facilitators; a total of 24 people participated. Again, data was anonymised, and demographic information was not collected. Three questions for discussion were emailed to attendees a week before the focus group to allow them time to consider them; the focus groups lasted one hour each and were facilitated by an autistic person.

Method

I assessed the presence or absence of each indicator of influence at each stage of the policy process according to the evidential markers shown in Figure 2 below. These codes were recorded in a master spreadsheet which can be found in the data repository.

Measure	Data required	Data source	Codes
Goal attainment	Goals; policy output	Goals from stakeholder interviews; policy output from policy documents.	For each goal: Fully, mostly, slightly, or not at all attained.
Agenda-setting	Issues; policy agenda	Issues from stakeholder interviews; policy agenda from stakeholder interviews and Hansard records of committee and Parliamentary discussions	For each issue: high, medium, low, or not at all on the agenda.
Self-reputed influence	Opinions of each stakeholder	Stakeholder interviews, survey and focus groups.	For each stakeholder: As a group, we have a lot of, quite a lot of, some or no influence.
Reputed influence	Opinions of each stakeholder	Stakeholder interviews, survey and focus groups.	For each stakeholder: Stakeholder X has a lot of, quite a lot of, some or no influence.
Active participation	For participation: presence or absence of actor. For active nature: feedback from actor and stakeholders.	For participation: stakeholder interviews, survey, focus groups and Hansard records of committee and Parliamentary discussions. For active nature: stakeholder interviews, survey and focus groups.	For each stakeholder: participates; does not participate and, if participates = true, participates very, quite, a little or not at all actively.
Framing congruence	Issue and target group frame proposed by each actor; dominant issue and target group frame in final output.	Proposed frames from stakeholder interviews, survey and focus groups; dominant frame from policy documents.	For each stakeholder: framing identical; highly, quite, a little or not at all congruent.

Figure 2: Indicators of influence

The decision as to how to code each indicator of influence for each stakeholder is necessarily a moderately subjective one since we are not dealing with numeric data or an algorithm. Interviewees and focus group members were asked to choose the classification they thought most relevant for each one and this was recorded (along with additional detail to provide a thick description); however, I then corroborated this with data from policy documents and Hansard records. Where I decided to change a code, I recorded the rationale for my decision. If evidence suggested any codes needed to be altered inductively, I also recorded this, together with the rationale.

Finally, a note on researcher bias. I was conscious throughout the research that, as a neurotypical researcher, I was likely to have internalised certain stereotypes about autistic people. I was careful not just to base my hypotheses and theory on commonalities found across different scholarships, to reduce the likelihood of ‘baked in’ errors but also to ask questions which challenges those ideas. I actively sought to minimise power imbalances by following AASPIRE guidelines for working with autistic participants.

Results and Discussion

The results, as shown in Figure 3 overleaf, support my hypothesis that the autistic people sampled would have higher than expected influence, as measured both by their overall scores, reputed influence, and goal attainment scores.

	Goal attainment	Agenda-setting	Reputed influence	Self-reputed influence	Active Participation	Framing Congruence
Autistic self-advocates	High	High	High	Medium	High	High
Wider autistic community	Medium	High	High	Low	Medium	Low
Families and carers	Low	Low	Low	Low	Medium	Low
Charities	Medium	Medium	High	High	High	Medium
Professional Bodies	Medium	Low	Medium	Medium	Low	Medium
Academics	Medium	Low	Low	Low	Low	Medium
Government Bodies	Medium	Medium	Medium	Medium	High	Medium
Government Departments	High	High	High	High	High	High
MPs	Low	Low	Medium	Medium	Medium	Medium
Secretaries of State	High	High	High	High	High	High

Figure 3: Relative influence of autism policy stakeholders

There is a clear difference between the level of influence of autistic self-advocates and the wider community. In this context, autistic self-advocates are those autistic people who had a seat on a decision-making body regarding autism policy. Advocates scored 'high' on all indicators of influence except for self-reputed influence, which is what they and others think of their levels of influence. Their level of influence is second only to government departments (civil servants) and Secretaries of State. Among other interviewees, i.e., those stakeholders involved in the policy decision-making process, reputed influence of the wider autistic community was high. Those involved in the process appear to believe that autistic people are in the driving seat – or at least report that they believe this, which indicates that they believe the involvement of autistic people to be important.

Nonetheless, the wider community do meet the criteria for 'higher than expected influence'. They score 'Medium' or 'High' on four out of six indicators, 'High' on reputed influence and their overall level of influence is clearly higher than the 'low' that they ascribe themselves. This is reinforced by the survey data – although a specific question about influence was not asked, the following quotes make it clear that those surveyed had a negative opinion of their own influence. While not a big enough sample to be argued to be representative of the autistic community as a whole, this evidence nonetheless corroborates the evidence from the interviews.

> "Nobody listens, they are thought of as being disabled and unintelligent."
> "Autistic people are not seen as able to make good decisions / give good advice."

Agenda control

Agenda control is high for both autistic self-advocates and the wider autistic community. This was assessed by a mixture of asking interviewees directly about the topics discussed at meetings and observing the extent to which policy issues raised as a priority by autistic people were reflected in governmental discussions and policy documents. (Interviewees were asked if any group dominated the agenda, how agendas were determined and whether they could describe a time when they had succeeded in getting an issue on the agenda).

The main issues raised by both autistic self-advocates and the wider autistic community were better public understanding of autism, mental health support, employment support and availability of local services. NVivo coding showed that at least three of these four goals were mentioned in all interviews and each of the focus groups. These are all also headline statements in the most recent Autism Strategy, which has as its goals "improving understanding and acceptance of autism within society", "building the right support in the community and supporting people in inpatient [psychiatric] care" and "supporting more autistic people into employment" (DHSC, 2021). They also appear with frequency in governmental discussions, with 'understanding autism' being tagged 174 times since 2018 on the Hansard database, 'autism and mental health' 454 times, 'autism and employment' 147 times and 'autism and local services' 101 times (Hansard, 2021). All of this suggests that the goals put forward by autistic self-advocates both reflect those of the wider community and make it onto the governmental agenda. While this is not proof of influence, it is corroborating evidence. Supporting this further are the quotes below from stakeholder interviews:

"Autistic people definitely drive what we talk about, we are always going back to ask, 'what do you need', 'what do you want'. We can't always give it to them, but we do ask."

Civil Servant

"Oh, I'm only called in to discuss issues when autistic people have raised them. I wouldn't get a look-in if I didn't have some kind of expertise they thought they could use".

Professional Body Representative

"Obviously, the government has the final say, and sometimes we have to follow their agenda but most of the time, yeah, they do listen to us, and we do get to discuss what we want. And we always make sure we are speaking to our networks, so we're not just reflecting our views but what other autistic people think too".

Autistic self-advocate

Finally, levels of agreement within the wider autistic community surveyed with the stated goals of autism policy are extremely high (between 75% and 90% for all governmental goals), as shown in the chart overleaf. Agreement with the goal of public understanding is highest at 90%. While the number of respondents is not sufficient enough to render it representative of the wider community as a whole, this is helpful in contributing to understanding agenda-setting as a form of influence.

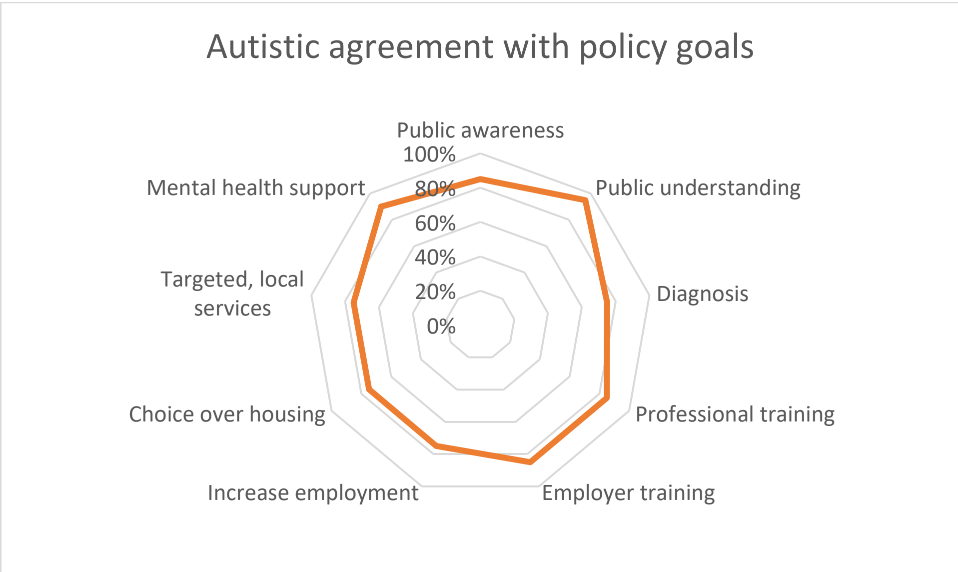

Figure 4: Autistic agreement with policy goals

Active Participation

Both goal attainment and active participation are high for autistic self-advocates but medium for the wider autistic community. It is not surprising that active participation is higher for autistic self-advocates, since they by definition seek to get involved in policy. However, it is noteworthy that it is medium for the wider autistic community, who, despite stating very clearly that they do not think they have much influence, (as shown by the chart showing self-reputed influence below), still come out and try to make a difference.

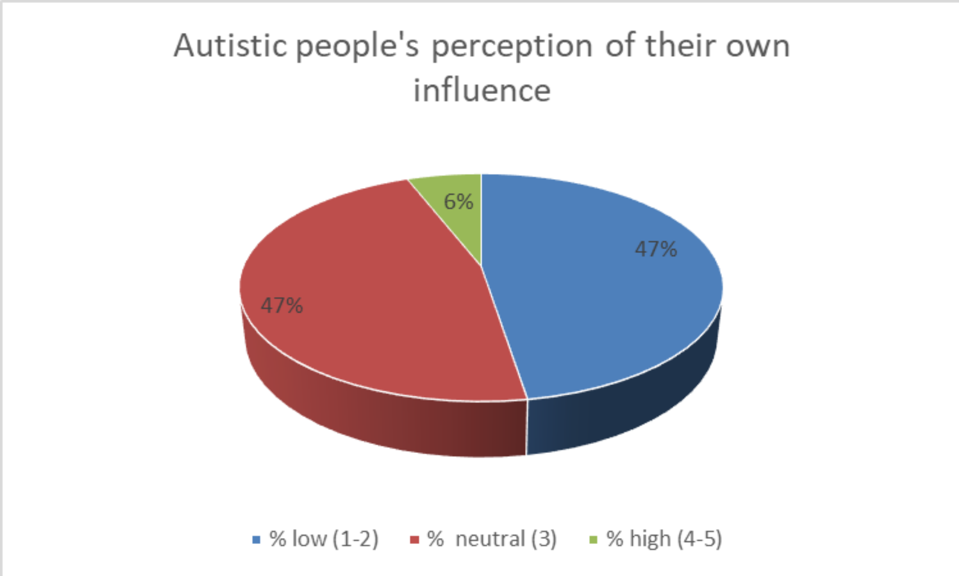

Figure 5: Autistic people's perception of their own influence

Despite their low perceptions, the charts below show that those autistic people who responded to the survey are at least moderately politically active. Although overall levels of participation are low, when data about awareness of methods of participation is combined with data about participation, it is clear that these autistic respondents do engage with those participation methods of which they are aware.

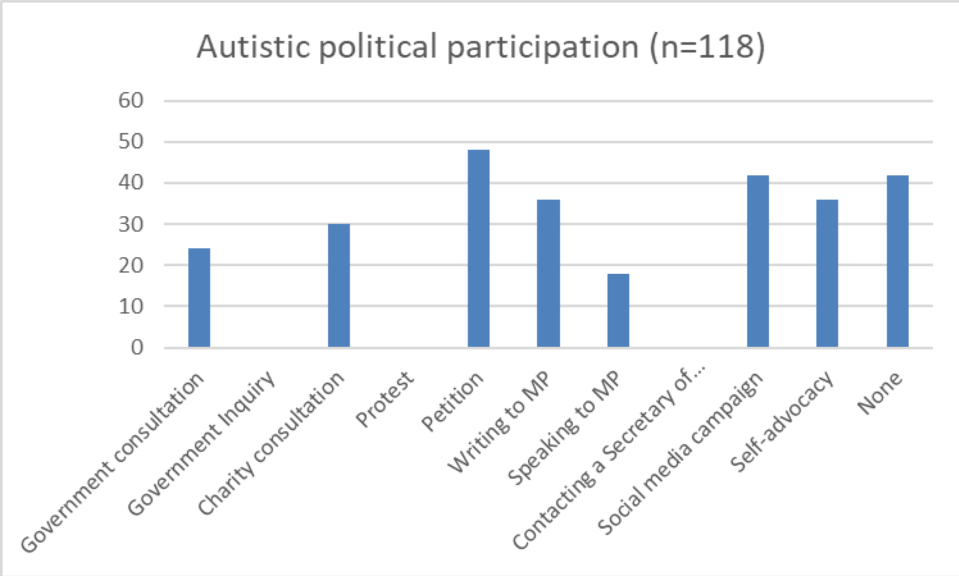

Figure 6: Autistic political participation

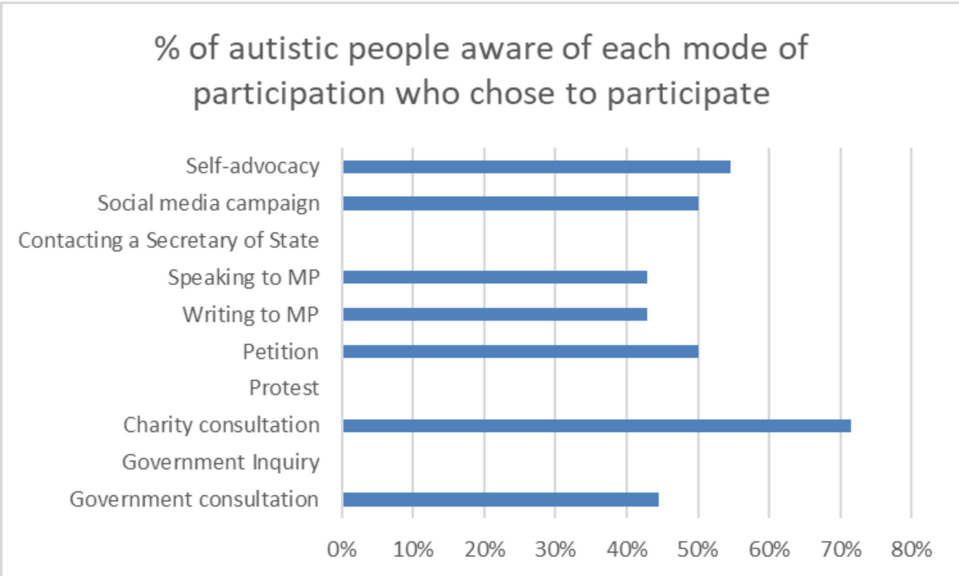

Figure 7: % of autistic people aware of each mode of participation who chose to participate.

Goal attainment

The autistic community surveyed may agree broadly with governmental policy goals but they have a relatively low opinion of how far they have been achieved, as shown in Figure 8 overleaf.

Goal attainment	% not at all (1)	% entirely (5)	% partially (2-4)
Public awareness	16%	8%	75%
Public understanding	17%	14%	69%
Diagnosis	48%	0%	52%
Professional training	14%	7%	80%
Employer training	25%	0%	75%
Increase employment	47%	0%	53%
Choice over housing	37%	0%	63%
Targeted, local services	27%	8%	64%
Mental health support	36%	6%	58%

Figure 8: Autistic views on goal attainment

The autistic self-advocates interviewed broadly agree with this assessment, stating that there has been progress towards meeting governmental goals (as shown in the quotations below), but they have not yet been fully achieved. Indeed, this view is shared by other stakeholders interviewed.

"We've come such a long way, twenty years ago no-one knew about autism and now everyone does. There's a lot more to do but I really think we should recognise the progress too."

Autistic self-advocate

"Progress has definitely been made, especially in public awareness and understanding, but there's more to be done, for sure."

Civil Servant

"Oh, the whole landscape has changed. Working together, we've achieved a lot. But of course, there is a mountain to climb yet."

Charity Representative

There is more of a difference in the extent to which the goals proposed, rather than supported, by autistic people and by autistic self-advocates are achieved. These are much less likely to have been achieved than the government's stated goals. However, it is notable that the goals as articulated by the wider autistic community are in fact much harder to achieve and to measure, because they tend to be much more general in nature, and to involve changing things which are beyond the power of the government to change, as shown in the quotations below taken from the survey and focus groups. These responses were in relation to a specific question "What does the government need to do differently to help you?" but were generic in their response. While this may be down to a misunderstanding, the chances of this were minimised as the questions were approved by three autistic consultants for accessibility before being used.

> "the general public need to change their attitude towards us"
> "society needs to change"

Conversely, autistic self-advocates were very aware of the importance of promoting goals which were achievable, measurable and which could be framed in a way which made them attractive to the government.

> "I think that with experience of working with people, in government, you know, you get to understand what might work and what doesn't, and you pick your time and you put things a certain way".
> "You have to take the long view; you have to be able to see the steps that take you to your end goals. You can't jump straight to your end goal; it doesn't work like that."

Framing congruence

Framing congruence is one of the two areas which shows the greatest discrepancy between the influence of autistic self-advocates and the wider autistic community, indicating that this is a factor in goal attainment. Specifically, it can be noted that autistic self-advocates propose a much more positive, strengths-based framing of autistic people than the wider autistic community: they focus more on their potential than on their difficulties. This is reflected in the thematic analysis of policy documents and Hansard discussions used in Article 3, which found that 67% of references to autism were framed positively as opposed to 22% framed negatively, as well as in the updated language used in on government websites, which is very clear that autism is a difference not a deficit, and that autistic people can 'lead fulfilling lives', as stated in the preamble to the Autism Act (AutismAct, 2009).

This difference can be seen in the quotations below taken from the online survey of autistic adults and contrasted with the interviews with autistic self-advocates and wording used on government websites.

"Only a minority of autistic people actually have the necessary understanding of our own brains to become self-advocates"
"Getting autistic people to agree on anything is like herding cats"
Quotes from Online Survey

"I feel like we focus on the wins more than the losses. People will have a good success story, people will be the ones that, you know, if I get access to this, or these things change, I can be the best and I can excel, I can be brilliant. And I think that when you've got like an audience around that people love to hear those stories."
"That's kind of the problem with policy, because in order to get change, you have to make something out to be really bad. But then when you make something out to be really bad, you create a negative image of yourself. And it just goes in a cycle. So, it's a balancing act. You have to include the negatives but also keep reminding them of the positives, the potential, that it's not the end of the world if you're autistic."
Quotes from autistic self-advocates

NHS definition of autism: "Being autistic does not mean you have an illness or disease. It means your brain works in a different way from other people." (NHS, 2021)
"Autistic people see, hear and feel the world differently to other people. […]
Some autistic people will need very little or no support in their everyday lives while others may need high levels of care." (HM Government, 2021).

This indicates that the framing of autism in public documents has shifted to a more positive framing, when compared with previous wording (Kenny et al, 2016; Vivanti, 2020). While this cannot be attributed conclusively to self-advocates, it is noteworthy that this positive framing is shared by self-advocates but not by the wider community. The measure of framing congruence would therefore suggest that autistic self-advocates have more influence.

Conclusion

In conclusion, I have demonstrated in this article that using a triangulated approach to measuring policy influence, which incorporates indicators sensitive to influence in its early stage, reveals missing influence in the context of the sampled autistic community in England. Despite low societal and personal expectations, and confounding the expectations of the scholarship, autistic people actually exert influence at all stages of the policy process and represent the primary form of expertise taken into account by policymakers. This influence is higher for autistic self-advocates, who are able to exert direct influence through their role on decision-making bodies, than for the wider community. Nonetheless, it remains higher than would be expected for the wider community sampled.

This research forms part of a larger body of research into the influence of marginalised groups which considers not just the extent of influence, as outlined here, but also the conditions in which it is exerted. While evidence from one case is not sufficient to be generalisable, this raises the question of whether the influence of other marginalised groups is being inadvertently missed. Expectations about the influence of marginalised groups are impacted both by researcher choices (and therefore prey to bias) and by dominant societal framings, to which all of us, including marginalised groups, as members of society, contribute. Changing the dominant societal framing of marginalised groups is an important task for which there is much work being done in the scholarship.

One way in which researchers in particular can seek to reduce the risk of missed influence in their research is to practise self-reflexivity, to question the dominant ideas in the scholarship and to use a multi-indicator method to determine influence. This research will be of interest to researchers focusing on other marginalised groups where dominant societal framings tend to be negative, and to members of those groups themselves. It will also be of interest to methodological scholars seeking new ways of measuring influence.

Evaluation of article

Feedback on this article from the journal review process and the paper discussion revealed some changes which were easy to make, and others which were either impractical or beyond the scope possible in this article. These are acknowledged here.

Firstly, while not practical for this article, it may be helpful for future research to consider intersectional factors, since these are known to increase social marginalisation in autism (Woods et al., 2018) and therefore it would be helpful to include these as variables in the analysis.

Secondly, it became apparent that, to those with a more limited knowledge of the history of the autistic community, the rationale for separating autistic self-advocates from autistic people, and autistic people from family members and carers was unclear. This is important because, historically, autistic people have been infantilised and it has been assumed that all autistic people are unable to express their opinions independently and need others to speak on their behalf (Chamak, 2008; Milton, DE and Bracher, 2013; Orsini, 2016). This has since been demonstrated to be a false assumption (McCoy et al., 2020), with the majority of autistic people being able to communicate if suitable adaptations are made. Sometimes this may include support from trusted family members and/or carers, but this should not be assumed to be the default option. There have also historically been strained relationships between groups representing autistic people and those representing families/carers of autistic people, indicating a difference in goals, and framing of autistic people between these two groups (Harrington et al., 2006; Chamak and Bonniau, 2013; Rowley et al., 2014; Casagrande and Ingersoll, 2017). Therefore, it cannot be assumed that these two groups have the same goals or promote the same frames and it is vital that they are treated as separate policy actors. This rationale has been strengthened in the article but would benefit from being strengthened further and so is developed in more detail in Chapter Four on case selection.

Finally, the paper presentation in particular revealed the importance of being specific about language and definitions when speaking to an international audience. For example, ‘autistic community’ can be assumed to refer to an epistemic community, and terms such as marginalisation and empowerment require careful definition. I’ve tried to address this in the article as far as possible, within the word count, but also to ensure that definitions are clear in the body of the thesis.

4. The autistic empowered? Case selection

Introduction

In this chapter, I will explain and justify my selection of the autistic community in England, firstly as an ‘underdog’ and secondly as a ‘crucial case’. Autism itself is a relatively new concept, although autistic people have always existed (Wolff, S., 2004). Autism was first described by Kanner (Kanner, 1943) and Asperger (Asperger, 1943) in 1943 as an “affective disorder” or “psychopathology” of childhood. In short, it was considered to be a mental illness caused by maternal neglect (Fombonne, 2003). With subsequent research, which was particularly fast-moving in the 1960s and 1970s (Wolff, S., 2004), autism has been redefined today as a lifelong, neurodevelopmental difference diagnosed on the basis of the clinical observation of differences in social communication, restricted interests, rigidity of thought and sensory sensitivities, which can present either with or without a learning disability (O’Reilly, Karim and Lester, 2015; Walker, 2017). While its aetiology remains contested, both parenting and vaccines have been thoroughly discredited as potential causes (Rutter, 2005).

Although it is still diagnosed in many countries on the basis of the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM5), autism is not now generally considered to be a mental disorder. With recent research in the 1990s and 2000s, researchers have shown that autism is not a childhood condition but, instead, a lifelong difference in the way the brain processes information and responds to social and sensory stimuli (Wolff, S., 2004). Particularly in the last few years, as the concept of an autistic identity has grown (MacLeod, A., Lewis, A. and Robertson, C. , 2013; Parsloe, 2015), the possibility of self-identification as autistic as a valid alternative to diagnosis has begun to be discussed (Brosnan, 2020).

As researchers have grown to understand autism better, it has become a ‘hot topic’, both for academic research and in political terms (Baker, 2011). The World Health Organisation (WHO, 2014), United Nations (UN, 2012) and EU (EC, 2015) all state that supporting autistic people through policy is a priority. However, autism policy, and particularly policy for autistic adults, remains an area which has been under-researched by policy or politics scholars. This is not to say that nothing has been written: applied psychologists, disability and autism studies and special education scholars have been prolific in their articles and books about autism which contain either recommendations for or evaluations of aspects of autism policy (cf Crane, J.L. and Winsler, 2008; Shepherd and Waddell, 2015; Keenan and Dillenburger, 2018). However, a holistic approach is lacking, with most policy recommendations being fragmented and piecemeal: non-policy scholars stick to their specialism. Meanwhile, relatively few policy or politics scholars have written about autism policy as a separate issue to special education policy or disability policy, although there is relevant material to be found in these scholarships.

Where policy scholars have focused on autism, this has tended to be in relation to North America (Feinberg and Vacca, 2000; Baker and Steuernagel, 2009; Orsini and Smith, 2010; Orsini, 2012; Baker and Steuernagel, 2013; Orsini, 2016), with most European-based studies focusing on education (Della Fina, 2015; Roleska et al., 2018) or policy in relation to children (Chamak, 2008; Chamak and Bonniau, 2013). This scholarly focus does not reflect the stated policy priorities of many autistic people, who highlight the importance of public awareness and understanding, employment, mental health and concerns about the criminal justice system (Pellicano, E., Dinsmore and Charman, 2014). However, what has been useful from the perspective of this thesis is the way that policy scholars have highlighted the competing framings of autism and autistic people put forward by different stakeholders (Feinberg and Vacca, 2000; Orsini, 2016), the diversity of ways in which autism is treated by policy makers (Della Fina, 2015; Baranger, Hammersley and Posada de la Paz, 2018; Roleska et al., 2018) and the rapid evolution of how autism is perceived over the past few years (Caruso, 2010; Chamak and Bonniau, 2013).

I argue that the autistic community is a crucial case for a successful reframing of what it means to be autistic, due to the rapid evolution of framings of autism, the variety of ways in which governments choose to frame it and the live debate about what it means to be autistic. The case is further strengthened by the consensus across different stakeholders that an improved understanding and awareness of autism is a necessary precursor to a better quality of life for the autistic community (Dillenburger et al., 2013; Pellicano, L., Dinsmore and Charman, 2013; DeVilbiss and Lee, 2014; Pellicano, E., Dinsmore and Charman, 2014; Mac Cárthaigh and López, 2020).

Autism as a contested subject

The contested nature of autism means that there are many different framings of what autism is and what it means to be autistic in the public domain, due in part to recent interest in intersectionality and self-identification (Feinberg and Vacca, 2000; MacLeod, Andrea, Lewis, Ann and Robertson, Christopher, 2013; Garen, 2014; Orsini, 2016; Cooper, Smith and Russell, 2017). This means both that there are many different potential reframings of autism and autistic people to be considered, and that several of them are 'authentic' framings which have been put forward by autistic people themselves.

Dana Lee Baker (Baker, 2011) proposes four categories of disability policy inspired by her research into policy for autism and other similar neurodevelopmental differences (neurodiversities): Cure, Care, Cause and Celebrate. The first three of these categories are closely linked to established models and typologies of disability policy (Esping-Andersen, 1990; Waldschmidt, 2009; Tschanz and Staub, 2017), but the fourth, 'Celebrate' is a novel addition which is particularly relevant and useful for the strengths-based approach espoused in this thesis. These categories, although not specific to autism policy, reveal much about the different ways that autism can be framed and are reflected in the wider scholarship on autism.

'Cure' broadly conforms to the medical, or essentialist model of disability (Barnes, Colin, 2000; Campbell and Oliver, 2013), which has fallen out of favour in much of Western Europe (Hvinden, 2003; Danermark and Gellerstedt, 2004; Halvorsen et al., 2017) but remains an undercurrent in North America (McGuire, 2012) and most developing countries (Barnes, Colin and Sheldon, 2010). This approach is usually, but not always, deficit-led and focuses on 'treatment' or mitigation of behaviours perceived as 'problematic'. It is linked with the social protection axis of welfare policy (Tschanz and Staub, 2017).

It is now generally accepted that autism cannot be 'cured' (Bagatell, 2010; Walker, 2017) and indeed the suggestion greatly angers those autistic people who feel that being autistic is part of their identity (Parsloe, 2015). A true 'cure' framing is rarely, if ever, put forward by autistic people, although some have said that if a cure were possible, they might consider it (Barnes, R.E. and McCabe, 2012). However, clinical mitigation of the effects of autism remains a topic of interest to autistic people who are experiencing distress as a result of the impact of autism (Mazefsky, 2015) and to parents who are struggling with the experience of parenting an autistic child (Casagrande and Ingersoll, 2017). A significant amount of autism research still focuses on 'treatment' (Bodfish, 2004; Harrington et al., 2006; Volkmar and Wiesner, 2017), although this meets with anger from some of the autistic community, who perceive a 'war on autism' as a war against autistic people (McGuire, 2016).

'Care' broadly conforms to the early iterations of the social model of disability (Barnes, Colin, 2000; Danermark and Gellerstedt, 2004; Brucker, 2009). It is of particular interest to this thesis because of its foundational belief that disability is a social construct – that disabled people are disabled by society rather than by their disability. Like ‘cure’, it comes under the social protection axis of welfare policy (Tschanz and Staub, 2017). However, the earlier iterations of the social model were criticised as being overly paternalistic – there was a sense that disabled people were dependent on others to help them overcome barriers to equality (Barnes, Colin, 2000; Brucker, 2009; Campbell and Oliver, 2013; Calder, 2016). This is reflected in the term ‘care’, which implies that they need to be ‘cared for’. Thus, it is a conceptual match for the epistemology of the thesis but not for a theory of empowerment.

This model used to be proposed by autistic people but has fallen out of favour in recent years (Bumiller, 2008; Bagatell, 2010; Krcek, 2013; Donaldson, Krejcha and McMillin, 2017). Nonetheless, the provision of services for autistic people (Jacobson and Mulick, 2000; McConachie et al., 2018; Maddox et al., 2020) remains an area which many autistic people consider to need significant improvement (Thomas et al., 2007; Jordan, 2009; Ravet, 2015), and many of these services are operated by social care providers and could reasonably be described as ‘care’. Care policies are therefore vitally important, but we should be careful not to adopt ‘care’ as a policy framing of autism to avoid infantilising autistic people.

‘Cause’ refers to the idea of disability activism and advocacy. This could be but does not have to be carried out by autistic people themselves, but, in practice, the autism advocacy movement across the world, including in the UK, is an active one (Ne'eman, 2010; Itkonen and Ream, 2013; McCoy et al., 2020). The autistic community can, however, also be used as a ‘cause’ by other groups in a way which is not beneficial for them, so ‘cause’ is not necessarily a helpful framing, although it can be. Certainly, the adoption of autism as a cause by many intergovernmental bodies such as the WHO, UN, and EU, has been helpful in shaping the evolution of autism policy as a policy in its own right. It is linked with the social rights axis of welfare policy (Tschanz and Staub, 2017), although there is widespread acceptance that ‘rights-based’ policy does not further emancipation unless it is also paired with other measures (Vanhala, 2010; Kingston, 2014; Waldschmidt et al., 2015).

Where ‘cause’ can be a particularly helpful framing is where it is combined with the fourth framing: ‘Celebrate’. ‘Celebrate’ is an unashamedly strengths-based approach to disability which has its roots in the neurodiversity movement (Robertson, S.M., 2009; Orsini, 2012; Kapp et al., 2013; Krcek, 2013; Garen, 2014; Arnold, 2017; Donaldson, Krejcha and McMillin, 2017; Walker, 2017; Kapp, 2020) and is linked with later iterations of the social model of disability. It could be linked to the activation, or labour market integration axis of welfare policy (Tschanz and Staub, 2017), but it goes further than this. It is not enough just to have a job – it is necessary to have a job which brings satisfaction, supports wellbeing and is an appropriate match for one's skills and abilities.

The neurodiversity movement argues that autism is a difference, not a deficit or a disability. Proponents vary in how positive they are about autism, with some going so far as to call autism a 'superpower' (Kitson-Reynolds et al, 2015) and others being more nuanced. This framing of autism, particularly when paired with activism and advocacy through the addition of the 'cause' framing, makes an excellent test case for my underdog theory.

The autistic community as an underdog

Nonetheless, if the underdog theory is to be tested on the autistic community, I must first explain why they fit the criteria of being 'an underdog'. There are two strands to this: are they in a position of subjection and marginalisation, and do they have untapped potential? Firstly, autistic people are diagnostically defined according to the widely used DSM-5 by "persistent deficits in social communication and social interaction across multiple contexts" and "restricted, repetitive patterns of behaviour, interests, or activities" (APA, 2013). Thus, they are diagnostically defined, according to the most commonly used diagnostic measures (Falkmer et al., 2013) by what they lack. The requirement for this to be persistent links with the most commonly used definition of disability as a functional difficulty which has an impact on everyday life (Calder, 2016) and means that many formally diagnosed autistic people would meet the legal criteria to be described as disabled: a group already clearly identified as an underdog by the existing literature (Bochel et al., 2008; Polack, 2008; Von Jacobi, Edmiston and Ziegler, 2017). (This is not necessarily true of all autistic people: some choose to remain undiagnosed; some are misdiagnosed as not being autistic and others prefer self-identification due to difficulties in obtaining a diagnosis (Hayes et al., 2018; Brosnan, 2020; Fusar-Poli et al., 2020).

The Autism Diagnostic Observation Schedule (ADOS), and Autism Diagnostic Interview Revised (ADI-R) which are also widely used, similarly refer to difficulties in "functional" communication and interaction, meaning that these differences make daily life difficult and, similarly would be classed as a disability. Furthermore, the restricted interests and activities diagnostically required of autistic people would indicate that they are marginalised in terms of social inclusion – although some might argue that if an autistic person chooses to live a relatively isolated life, they are not truly excluded or marginalised (Armstrong, 2010). The social model of disability is strongly linked with the neurodiversity movement in autism which argues that autism should not be seen as something inherently bad; however, most activists would argue that society needs to stop marginalising them.

More compelling than the diagnostic criteria, however, which do not necessarily cover all autistic people, is the evidence that autistic people are statistically significantly more likely to be unemployed or under-employed (Hendricks, 2010; Mavranezouli et al., 2014; Nicholas et al., 2017), to experience mental health difficulties (Cooper, Smith and Russell, 2017; Cage, Di Monaco and Newell, 2018; Crane, L. et al., 2019; Maddox and Gaus, 2019) and to be involved with the criminal justice system (King and Murphy, 2014; Maras et al., 2017; Helverschou et al., 2018). This demonstrates the intersection of the autistic community with other groups considered to be marginalised and at risk of not reaching their potential. Research has also shown that autistic women and girls are at risk of being under-diagnosed and not receiving the appropriate support because they present differently to men and boys and services have been primarily determined according to the needs of men and boys (Bargiela, Steward and Mandy, 2016; Gould, 2017; Fusar-Poli et al., 2020), putting them at further risk of marginalisation. Autistic people also appear to be over-represented among trans and LGB populations (Glidden et al., 2016; Walsh et al., 2018; Adams and Liang, 2020), further intersections which put them at a cumulatively increased risk of marginalisation (Saxe, 2017).

The evidence above shows that autistic people are structurally placed in a position of subjectification. The diagnostic rules which, in many cases, serve as a gatekeeper to services (Thomas et al., 2007; Jordan, 2009) define them by what they lack, while high levels of intersectionality with other marginalised groups amplify this subjectification (Cascio, M., Weiss, J. and Racine, E., 2020). Low levels of employment suggest that both job application and continuous professional development infrastructures are poorly suited to autistic people and form a structural barrier. If autistic people are less likely to be employed (and therefore more likely to be dependent on government benefits and to live in poverty) but more likely to be sectioned or put in a police holding cell than their neurotypical peer, this suggests a definite imbalance of power.

However, autistic people are also framed as underdogs – and not just because they are framed as dependent. Studies on public awareness and understanding of autism, and of how autism is portrayed in the media, show that, while awareness of autism has grown, a nuanced understanding of autistic diversity has generally not (Dillenburger et al., 2013; DeVilbiss and Lee, 2014; Mac Cárthaigh and López, 2020). Public opinion is influenced by stereotypes of autism and by media reporting (Rasmussen, A., Binderkrantz and Kluver, 2021). For example, newspaper reports on Jonty Bravery stated that his autism diagnosis contributed to his decision to deliberately throw a young boy off the viewing gallery of the Tate Modern (Wilkinson, 2020). In fact, psychiatric reports had referenced the combination of his autism with a personality disorder – a diagnosis which received much less media attention than the autism. Following two high profile cases of autistic hackers (Gary McKinley and Lauri Love), a research article found little evidence to support strongly-held public opinion that autistic people are more likely than neurotypical people to be involved in cybercrime (Payne et al., 2019). Even locally in Bristol, much was recently made of the autism diagnosis of a woman who apparently threatened police officers with a knife in a (successful) deliberate attempt to be given a custodial sentence (Bennett, G., 2021).

The autistic person is typically framed in one of three ways. The first category amalgamates the autistic community with the intellectual disability community, even though only 50% of autistic people have a co-morbid learning disability (MacLeod, A., Lewis, A. and Robertson, C. , 2013). This stereotype is assumed to be weak and dependent, incapable of meaningful employment and often as functionally mute. It is accepted that they are 'needy' and marginalised, but their potential is not acknowledged. Examples in popular media of this stereotype include Warren in *There's Something About Mary* (Sandahl, 1999) and Arnie in *What's Eating Gilbert Grape (*Conn and Bhugra, 2012*)*.

The second category portrays the autistic person as a brilliant but socially awkward savant who is the source of much amusement (but is assumed not to need autism policy to do anything for them) (Walters, 2013). This stereotype is currently the dominant stereotype when it comes to films and television series (Nordahl-Hansen, Øien and Fletcher-Watson, 2018), and includes films such as *Rain Man* and series such as *The Big Bang Theory*. This portrayal is potentially harmful for policy as it can mean that the general public assumes that the majority of autistic people are like this, and that they need only light-touch support. It downplays the extent to which they are perceived to be marginalised.

The third stereotype, however, is undoubtedly the most harmful and this is the category of dangerous and deviant (Gillespie-Lynch et al., 2020). This is a common framing in the news media, as detailed in the paragraph above. In all stereotypes, autistic people are othered and subjectified, even if the second stereotype is subjectified through humour rather than necessarily being viewed as dependent or deviant (Schneider, A. and Ingram, 1993).

The other side of the coin of the underdog theory is, of course, that underdogs have untapped potential, and this is strongly demonstrated by the neurodiversity movement's promotion of strengths typically associated with autism. Restricted interests are reframed as encyclopaedic knowledge, a difficulty in seeing the bigger picture as a laser focus and bluntness as honesty (Donaldson, Krejcha and McMillin, 2017). A sub-group of autistic people who were previously described as 'having Asperger Syndrome' or 'having high-functioning autism' (Baron‐Cohen, 2000), often possess strengths which would make them excellent advocates. They are single-minded, prolific researchers, retain facts and figures well, are highly articulate when speaking on a subject which interests them and are exceptionally determined (Donaldson, Krejcha and McMillin, 2017). They also appear to be drawn to advocacy (McCoy et al., 2020). While all autistic people therefore have untapped potential, it appears that 'Aspies', as some like to call themselves (Walters, 2013) are particularly well-suited to advocacy, and, in many cases, already participating.

Neurodiversity: a mixed blessing

At this point, it is important to note that, while the strengths-based approach associated with the neurodiversity movement is an integral part of my underdog theory, the neurodiversity concept is a mixed blessing (Krcek, 2013; Garen, 2014; Milton, Damian, 2015). The spirit of the neurodiversity movement is pivotal. Portraying autism as a difference, not a deficit and highlighting the strengths and potential of autistic people (Orsini, 2012; Kapp et al., 2013; Krcek, 2013; Armstrong, 2015; Donaldson, Krejcha and McMillin, 2017) is a key part of changing their framing, and one that I have argued can best be done by autistic self-advocates, who, according to McCoy et al (McCoy et al., 2020), are more likely to be at the 'higher functioning' end of the spectrum.

Nonetheless, my pyramid of empowerment described in chapter 2 makes it clear that an awareness of one's own strengths and weaknesses is a pre-requisite for empowerment; thus, focusing exclusively on the strengths of autistic people without acknowledging the difficulties they also face would not be empowering. Just as empowerment rhetoric risks responsibilisation, so does neurodiversity rhetoric such as 'autism is my superpower' (Kitson-Reynolds, Kitson and Humphrys, 2015) risk downplaying the needs of autistic people to such an extent that they are no longer deemed 'needy' enough to require policy change. This risk can be seen in the response to autistic 'savant' figures in film and television, who, unrealistically, seemingly just need good, tolerant friends around them to be able to manage perfectly well (Conn and Bhugra, 2012).

However, the term neurodiversity also applies to the fact that autistic people are heterogeneous and have different needs and priorities. This presents an impossible challenge to policymakers, who must seek to craft policy which is all things to all autistic people (Feinberg and Vacca, 2000; Orsini, 2012). It also presents a challenge to autistic advocates, who must seek to represent as many different autistic viewpoints as they can, while recognising the need to be specific in their lobbying requests (Junk and Rasmussen, 2019). Finally, it presents a challenge to autistic people and their families, who must recognise the limitations of policy and advocacy in meeting the needs of every person. The autistic tendency to see the detail rather than the bigger picture, and possible limitations in social imagination, may make this more difficult than for neurotypical people (Cascio, M.A., Weiss, J.A. and Racine, E., 2020).

Given these challenges, the method described in the next chapter must gather sufficient information to capture these varying goals and needs, how they are presented and the extent to which those proposing them can be said to have exerted influence. It is also paramount to isolate the influence of autistic self-advocates (those who actively seek to involve themselves in policy as representatives of other autistic people) from that of the wider autistic community. There are ethical considerations as to the extent to which any advocate is able to represent all autistic people (McCoy et al., 2020), but especially those who, by virtue of being less visibly disabled and benefiting from a more benevolent media framing (Walters, 2013; Harbour, 2015; Rourke and McGloin, 2019), are arguably in a position of relative privilege within the autistic community, and these will be addressed in the Ethical Considerations section of the Methodology chapter.

The autistic community as a successful reframing?

The final justification for the selection of the adult autistic community as a crucial case is a question of timing. I have shown that autistic people are structurally marginalised and framed as being in a position of subjectification, but also that they possess well-documented potential, including skills which are particularly well-suited to advocacy. I have also shown that there are many different framings of autism and an increase in interest in reframing what it means to be autistic.

However, across Western Europe in the past twenty years, fifteen autism-specific national policies have been brought in, despite autistic people, by virtue of the functional disability-led nature of the diagnostic process, being able to benefit from existing disability policies. This implies that the autistic may have already undergone a successful reframing: no longer just part of the 'disabled community' but set apart as different – maybe even stronger?

Although no peer-reviewed research has been carried out into why the campaign for the Autism Act was successful, or indeed who was responsible for its success, my Masters of Research dissertation (included in the data repository for this thesis[2]) did attempt to dig into this. Specifically, I carried out elite interviews with key members of the campaign and then used process tracing to assess the extent to which autistic advocates were involved at each stage of the campaign. The results suggested both that autistic advocates were closely involved with the campaign (albeit with the significant financial and political support of the National Autistic Society (NAS) and Baroness Browning) and that those working on the campaign considered it to be autistic-driven, as the quotations below show.

I think the autism campaign and voice, like families and individuals with autism as activists, is really strong. I still think they're the strongest campaigning part of the disabilities sector.

Amanda Batten, Chair of the NAS at the time of the campaign.

Everything we were trying to do was not to present autistic adults, it was to get people with autism themselves to present it.

Matthew Downie, Campaigns Manager at the NAS at the time of the campaign.

One of the things I said to the board when I put forward the case for increasing investment, was that we needed to involve much more people with autism in the organisation, in the way we shaped our campaigns and the way we delivered our campaigns.

Benet Middleton, Communications Director at the NAS at the time of the campaign.

While my MRes dissertation cannot be taken as demonstrating a causal link between the actions of the autistic community and the success of the campaign, it certainly

[2] The interviewees gave specific informed consent for their transcripts to be used in my PhD research.

supports the selection of the adult autistic community as a crucial case at this time of rapid change in autism policy.

The autistic community in England: a crucial case

The case selection is further narrowed to England as an example of a country which was one of the pioneers of autism-specific policy. The very first autism-specific law was enacted in England in 2009 (AutismAct, 2009), which led to the creation of an Autism Strategy which, by law, must be regularly reviewed and brought in statutory guidance for local authorities and health authorities. (It was not the first national policy, but France, the first country to produce a national autism policy, has been strongly criticised for the lack of inclusivity of its autism policy (Davidson, 2014), making it unsuitable as a crucial case at this time.) The campaign for the Autism Act was headed up by the National Autistic Society, who claimed to have worked closely with the autistic community and who employ a number of autistic people (NAS, 2019). In just the past year, the NHS webpages on autism have been updated to reflect a framing which is noticeably influenced by the neurodiversity approach. For example, they open with “Autistic people may act in a different way to other people” and explicitly state that autism is “not a disease” and that autistic people “can live a full life” (NHS, 2021).

In Article 2, fuzzy set Qualitative Comparative Analysis (fsQCA) (Ragin and Pennings, 2005; Kvist, 2007; Ciccia, R. and Verloo, 2012) is used to further test the suitability of the autistic community in England as a most-likely case. fsQCA uses existing theory to create criteria for fuzzy sets, which are then used to determine fuzzy set membership for comparative cases. Since fsQCA effectively tests the extent to which the theoretical framework expressed through the fuzzy sets is valid for the cases studied, it can also be used to assess the political opportunity structure in different countries and was therefore relevant as contributory data for a more in-depth case study of one of the comparative cases.

I created sets which would assess the extent to which different governments considered the autistic community as being capable of being empowered. Further detail as to how I constructed the set criteria can be found in the Method section of Article 1. The results of the fsQCA supported the selection of England as a most-likely case by demonstrating that England was among the three countries which met the set membership criteria for a policy design which facilitated the framing of the autistic community as ‘Empowered’ (Precious, 2020). This article was peer-reviewed and published by *European Policy Analysis* journal in 2020.

Conclusion

In this chapter, I have explained how autistic people are framed not just as marginalised but as *underdogs*: they are subjectified, but they also show potential for empowerment. The success of the neurodiversity movement, the agenda-setting success of autistic advocates and their allies and the possible reframing of autism policy as separate and different from autism policy all point to a potential for the autistic community to exert more policy influence than existing theory would suggest. In addition, the existence of certain personality traits and characteristics associated with autism which appear to be particularly well-suited to advocacy is supportive of the hypothesis that autistic advocates may have an inherent advantage.

It is thus my contention that the autistic community is a most-likely case for testing the usefulness of my underdog theory. A focus on England further ensures a political opportunity structure which is, in relative terms, more welcoming to autistic participation than other countries, as supported by my second article, which follows this chapter. In Chapter 5, I set out how I will go about measuring autistic influence and testing my underdog theory.

Appendix 6B: Statement of Authorship

This declaration concerns the article entitled:									
Informed, involved, or empowered? Three ideal types of autism policy design in Western Europe									
Publication status (tick one)									
Draft manuscript		**Submitted**		**In review**		**Accepted**		**Published**	X
Publication details (reference)	https://doi.org/10.1002/epa2.1092								
Copyright status (tick the appropriate statement)									
I hold the copyright for this material		Copyright is retained by the publisher, but I have been given permission to replicate the material here	X						
Candidate's contribution to the paper (provide details, and also indicate as a percentage)	This is a sole author article. The candidate carried out all of the research and writing of the article, with advice only from supervisors. Formulation of ideas: 100% Design of methodology: 100% Experimental work: 100% Presentation of data in journal format: 100%								
Statement from Candidate	This paper reports on original research I conducted during the period of my Higher Degree by Research candidature.								
Signed	[redacted]	**Date**	11.04.22						

Article 2: Informed, involved or empowered? Three ideal types of autism policy design in Western Europe.

Preamble

This article was originally intended to set the scene for the thesis (as the first article in the sequence) and to provide justification for the case selection of countries. It became evident when trying to put the article together that this was not sufficient for it to stand as an original research article in its own right. A comparative policy analysis was not enough without a 'hook' to make it original and different. At the same time as planning this article, the underdog theory was emerging, along with its links with empowerment, and therefore it made sense to design this article around empowerment.

This article also served to highlight what governments can do to facilitate empowerment, and so it serves an important role in the overall thesis as well as justifying the case selection. It provides much of the detail for the discussion of what governments can/should do in Chapter 8 and emphasised the importance of thinking about actors other than the underdog to avoid the risk of responsibilisation.

Abstract

Governments which design policies to empower marginalized groups contribute to reducing the democratic deficit in public policy and improve their efficacy, efficiency, and democratic credentials. This article uses fuzzy set ideal type analysis to propose three ideal types of policy design for political empowerment, according to whether the government views the target group as capable only of being Informed by experts, or of being Involved in policy, or even Empowered to co-govern. An analysis of Western European autism policy illustrates and confirms the usefulness of the ideal types. England, Wales, and Denmark emerge as countries where governments have the highest expectations for political empowerment. Surprisingly, traditional disability policy groupings seem not to apply, with the UK split across Empowered and Involved, while Spain leaves its Informed Southern European counterparts to join the Involved cohort. This paper is a timely reminder of the importance of lived experience as a policy resource lived experience as a policy resource.

Introduction

Governments have an important role to play in tackling the democratic deficit that characterises the public policy decision-making process (Dahl, 1989; Jones, 1994;

Fraser, 2009; Norris, 2011; Threlfall et al., 2012). While citizen participation is often encouraged through symbolic policy instruments (Irvin and Stansbury, 2004; Bochel et al., 2008) policy designs which make concrete changes to facilitate participation are rarer (Hill et al., 2004; Smith, G., 2009; Warren, 2009; Cornwall, 2017). Thus, substantive representation of the public remains elusive (Urbinati, 2000; Pitkin, 2004; Wampler, 2012). Many marginalised groups, who are already in a position of political disadvantage due to exclusion from social spaces (Nordberg, 2006; Milner and Kelly, 2009), are further disempowered by being excluded from democratic spaces as well (Fraser, 2009; Cornwall, 2017).

The antidote to disempowerment is empowerment but these terms are both overused and under-defined (Bachrach and Botwinick, 1992; Perkins, 1995; Sørensen, 1997; Tilley, Pollock and Tait, 1999; Cornwall and Brock, 2005). Traditionally, in policy studies, empowerment as a policy outcome equates to one of the following: making one's voice heard (achieving substantive representation) (Urbinati, 2000; Pitkin, 2004; Fraser, 2009; Wampler, 2012); being given resources to overcome artificially constructed barriers to social inclusion (Sullivan, 1992; Milner and Kelly, 2009; Cornwall, 2017); increasing life choices (Kaplow, 2007; Rawls, 2009) or increasing autonomy (Balcazar, Keys and Suarez-Balcazar, 2001; Hamilton, 2003; Halvorsen et al., 2017). Meanwhile, the concept of empowerment as a function of liberal democracy has evolved as being something that governments can gift through institutionalised changes to political structures (Bachrach and Botwinick, 1992; Sørensen, 1997; Fung and Wright, 2003).

Dempsey and Foreman (Dempsey and Foreman, 1997), however, define empowerment as a psychological construct which enables an actor to exert maximal power and comprises self-efficacy, self-knowledge, active participation and access to resources. It is a central component of the strengths-based approach to disability (Saleeby, 1993; Chapin, 1995; Hornung, Bandelow and Vogeler, 2019) and encompasses the definitions put forward by both policy and liberal democracy scholars in a cohesive way. I argue that this definition of empowerment is more useful than the more outcome-focused definitions that are used in most public policy research (Cornwall and Brock, 2005), or the structural focus that dominates liberal democratic theory (Fung and Wright, 2003) since it reinforces that, whatever a government may do or not do to emancipate or resource a group, empowerment is a state of mind and, as such, is not within their gift (Barnes, M. et al., 2003).

Nonetheless, governments can, as liberal democracy scholars have noted, create a political opportunity structure which fosters empowerment through citizen participation in democratic processes and social spaces, and a receptive policy environment (Sullivan, 1992; Chapin, 1995; Goodley, 2005; Dunn, Clare and Holland, 2008; Milner and Kelly, 2009; Cornwall, 2017).

This article conceptualises policy design as a means of enacting a governmental goal of politically empowering marginalised groups to actively participate in and co-determine policy. Using Ciccia's two-step approach to building a policy typology (Ciccia, Rossella, 2017), it identifies three ideal types of policy design based on governmental perceptions of the maximal capacity of the marginalised group: are they capable only of being Informed, or can they be Involved or even Empowered? A marginalised group already lacks external resources, such as money and reputed influence (Polack, 2008; Wolff, J., 2015; Rhodes, 2018), but the extent to which governments recognise their internal resources – expertise, capacity and self-efficacy (Chapin, 1995; Dempsey and Foreman, 1997; Fischer, 2019) – varies more significantly (Schneider, A. and Ingram, 1993; Schneider, A.L. and Ingram, 2019). A government who considers the marginalised group to lack all three internal resources will see them as needing to be Informed, to be educated by the experts, to be 'done to'. A government who recognises their lived experience as expertise may Involve them, but limited expectations of capacity and self-efficacy will curtail the opportunities they offer. Only a government who sees the group as Empowered will recognise all three resources.

The typology is illustrated through fuzzy set ideal type analysis (FSITA) (Kvist, 2007) of a new policy area: Western European autism policy. Autism policy has evolved as a discrete subset of disability policy in Western Europe over the past twenty years, with fifteen new autism policies arriving on the policy scene in response to concerns that autistic people were 'falling through the gaps' of disability policy (Ravet, 2015). The neurodiversity movement argues that autistic people have untapped potential which remains unrealised due to a hostile environment (Kapp et al., 2013; Arnold, 2017; Donaldson, Krejcha and McMillin, 2017; Kapp, 2020). If this is true, the autistic community has much to gain from empowerment, and their statistical over-representation among the under-employed, unemployed (Mavranezouli et al., 2014) and those involved with the mental health (Maddox and Gaus, 2019) and criminal justice systems (King and Murphy, 2014) is all the more concerning.

This article contributes both to the scholarship on emancipatory policy design by proposing a typology of policy designs for empowerment and to the nascent autism policy scholarship by answering the research question 'how do different Western European autism policies impact the political opportunity structure for autistic people?'. Ciccia's two-step method (Ciccia, Rossella, 2017) begins with a conceptual framework and the identification of Weberian ideal types (Psathas, 2005), which are operationalised through varying combinations of set membership (Kvist, 2007).

Designing policy for citizen empowerment: a conceptual framework

All policy is designed with a goal or goals in mind (Howlett, Michael, 2019). Governments select a mix of policy instruments, actors, and social constructions of the target group which they believe will enable them to achieve those goals (Schneider, A. and Ingram, 1993; Elliott and Salamon, 2002; Veselý and Petrúšek, 2020). Any goal could be achieved using a range of policy mixes or designs (Salamon, 2000).

Empowerment is often referred to as a desirable outcome (Dempsey and Foreman, 1997) for policies relating to marginalised groups (Balcazar, Keys and Suarez-Balcazar, 2001), but less frequently conceptualised as part of policy design and output (Dunn, Clare and Holland, 2008). Despite this, research in social care and disability studies shows that empowered groups participate more in governance (Goodley, 2005; Halvorsen et al., 2017). Participatory governance in turn leads to more efficient public services and greater governmental responsiveness (Speer, 2012). A goal of political empowerment could therefore be beneficial for governments by reducing their expenditure on inefficient public services and improving their democratic credentials. Even when empowerment is only a subsidiary goal, it can influence the policy design and output.

While empowerment may be an outcome without ever having been a goal, by tracing back through the policy process from putative outcome to putative goal (as shown in Figure 1), it is possible to hypothesise what empowering mechanisms (policy instruments) might make up a policy design for empowerment. This analytical framework therefore begins at the micro level and progresses to the macro level not just to enable generalisability (Acciai and Capano, 2018) but also to ensure rigour. The 'big picture' must be built up from below (Bosch et al., 2007) – and the building blocks of policy are policy instruments (Elliott and Salamon, 2002).

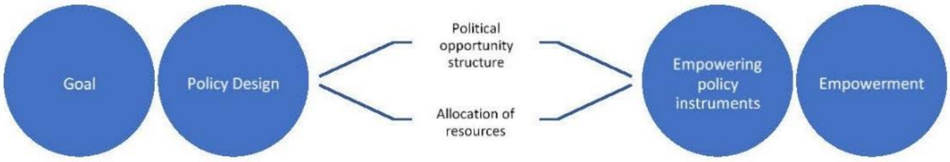

Figure 1: Empowerment as a policy outcome

If empowerment is to be conceptualised as an outcome, it must be conceptualised in terms of its effects. Empowerment as a construct is the capacity to exert power; as an outcome, it is the exertion of power. Political power is constrained by the political opportunity structure and actor resources (Bachrach and Botwinick, 1992; Meyer and Minkoff, 2004; Baumgartner, F.R. et al., 2009; Lowery, 2013). Since governments cannot alter the psychological components of empowerment, which are within the control of the citizen alone (Barnes, M. et al., 2003), they can only alter the political opportunity structure and allocation of resources through empowering (or disempowering) policy instruments.

A policy design which has a goal of empowerment is likely to seek to alter the political opportunity structure and/or allocate resources to the target group; a policy design which sees a group as lacking full capacity for empowerment will make no or fewer and mainly symbolic changes. The political opportunity structure determines how and when actors are given structured opportunities to participate in policy and how much weight is given to their representations (Gamson and Meyer, 1996; Koopmans, 1999; Meyer and Minkoff, 2004). In short, it consists of structural and cultural elements which either limit or facilitate political power – which either disempower or empower. The focus on participation in the policy process rather than in social spaces is deliberate; while empowerment in terms of autonomy and self-efficacy is important, I argue that it is the extent to which a government permits citizens to determine their own policy (and thereby their own lives) that is the most accurate marker of political empowerment.

Structurally, the political opportunity structure consists of opportunities (or lack of) for citizens to participate in the policy process (Smith, G., 2009; Wampler, 2012). Governments can use policy instruments to make changes to state apparatus or institutions to provide additional opportunities for participation. They can also use policy instruments to mandate or encourage citizen participation (Stutzer and Frey, 2006; Fraser, 2009; Warren, 2009).

Policy instruments are mechanisms used by governments to change (or maintain) public or professional behaviour (Howlett, Michael, 2005). Instruments combine with other policy components such as goals and framing to produce a policy mix (Flanagan, Uyarra and Laranja, 2011). Typologies are often used to categorise instruments (Acciai and Capano, 2018). Each typology approaches instruments from a different perspective; however, they share commonalities, such as the omnipresence of coercion, suasion, and financial and information elements.

I use Schneider and Ingram's instrument typology (Schneider, A. and Ingram, 1990) in this framework, because it specifically conceptualises instruments on the basis of behavioural assumptions. Within this typology, Authority instruments permit, prohibit or require actions; Incentives offer tangible rewards and/or sanctions to encourage compliance; Capacity instruments seek to overcome barriers caused by lack of information, knowledge, or resources; Symbolic instruments change seek to change perceptions by appealing to values or symbolic images and Learning instruments allow citizens to determine the best technique for themselves.

Governments can use Authority tools to make structural changes. An Authority tool of any level of coercivity which creates an opportunity for citizens to participate indicates a goal of empowerment. However, the strongest structural indicator would be a Learning tool which puts the power to determine policy in the hands of the citizen through such instruments as citizen assemblies and advisory boards (Polack, 2008; Smith, G., 2009; Cornwall, 2017).

Structural changes may facilitate citizen participation, but this will only result in empowerment if the policy environment is also receptive to the idea that their participation will result in useful and valuable information. Culturally, political opportunity structures refer to the extent to which different citizens are considered capable of participating and/or worthy of attention. The link to structural elements goes both ways: governments who perceive a group as being capable of participating are more likely to create opportunities for participation, but structural elements will be of little use if the representations of the group are ignored.

This is closely linked to the social construction of the target group, as described by Schneider and Ingram (Schneider, A. and Ingram, 1993), and informed in turn by sociocultural norms, political systems and public opinion. How a group is socially constructed (how capable and valued they are perceived to be) impacts how likely they are to participate – and the policy design (Schneider, A. and Ingram, 1993).

Governments can use Capacity and Symbolic instruments to influence social construction through educating others or sermonising (Bemelmans-Videc, Rist and Vedung, 2011). However, not all such instruments are empowering: the group which needs educating or sermonising to is paramount. If it is the marginalised group who is perceived to lack information/knowledge, they are viewed as disempowered. If it is professionals who need to be educated, the balance of power swings back towards the marginalised group.

This requires analysis of elements beyond instrument selection and can be inferred from a variety of factors. The choice of language in policy documents, particularly in the wording of goals, is important (Freeman and Maybin, 2011). Goals give insight into how the target group is viewed (Schneider, A. and Ingram, 1990; Guaschino, 2019). Does the policy seek to change the behaviour of the target group (implying that there is something about them that needs to change) or the behaviour of others towards them? What is the expectation ceiling for this target group? For example, a goal to increase employment assumes capacity for employment, while a goal to increase availability of financial support for carers would assume a lack of capacity for employment. What actors are involved in delivering the policy? A focus on Health actors would imply that the group are defined by their medical diagnosis, while a focus on Social Care actors might imply dependency on social care support. When a marginalised group are involved in delivering the service, this implies both a desire to contribute to their empowerment and a capacity for empowerment. The lead Government department can similarly reveal a lot about what 'category' the policy is perceived to fall under and thereby how the group are viewed.

To assess the extent to which a policy design aims to empower citizens, then, an analysis of the mix of policy instruments, language, actors, and goals is required – but how might these coalesce into policy design clusters?

Three ideal types: Informed, Involved, Empowered

Since empowerment is not a binary concept, at least three ideal types are needed to capture degrees of empowerment. At one end of the spectrum, governments may see a target group as fully capable of being empowered and co-governing in the policy area in question (Fung and Wright, 2003). I call this cluster 'Empowered'. A government which sees the value of a group's participation and expertise will activate them (Bovaird et al., 2016) by creating opportunities for them to co-govern, as well as using a variety of policy instruments to facilitate and encourage receptivity to their participation (Bochel et al., 2008), such as information campaigns and training programmes designed to upskill the group.

At the other end of the spectrum, governments may see a target group as lacking capacity entirely. This group need the government to act on their behalf and educate or inform them (Voronka, 2016; Fischer, 2019). I call this cluster 'Informed'. The government makes little more than symbolic adjustments to the political opportunity structure: they may, for example, assert the right for this group to be free from discrimination without attempting any re-education of the public to facilitate this (Mabbett, 2005).

The third cluster falls in between these two views. There is an acknowledgement of untapped capacity for empowerment, but the expectation ceiling is still low. This group are encouraged to be involved in policy, but not considered fully capable of co-governance. They may be consulted, which gives the impression of participation, but their representations are then given less weight than other actors (Barnes, Collin, 2007). I call this cluster 'Involved'.

Having set out the theoretical grounding, I now explain for the purposes of reproducibility how I selected cases for analysis and how I applied the method.

Method

Fuzzy set ideal type analysis (FSITA) (Kvist, 2007; Ciccia, Rossella, 2017) assesses the extent to which a case corresponds to the criteria that constitute an ideal type. Based on fuzzy set theory as outlined by Ragin (Ragin, 2000; Guaschino, 2019), it can use any qualitative coding data. It is relevant as an initial exploration of the usefulness of the ideal types hypothesised. FSITA is only as reliable as the configuration of its sets, which must be theoretically grounded, and the coding of the cases, which must be systematically applied (Kvist, 2007).

FSITA requires the ideal type to be operationalised in terms of membership of different sets (Kvist, 2007). This forms the property space within which the policy is located, with each set characterising a different dimension (Ciccia, R. and Verloo, 2012). In the case of policy design for political empowerment, I identify four constitutive elements: Capability (which refers to the group's perceived capacity for empowerment), Expertise (which refers to whether the group is perceived as possessing expertise that the government or others can learn from), Value (which refers to whether the group's contribution is perceived as valuable) and Opportunity (which refers to whether the government provides structured opportunities for participation over and above that of the average citizen). In order to be a member of the ideal type, each case must confirm to the proscribed membership or non-membership of all sets, since empowerment is a cumulative function of the four elements. The property space for a policy design for empowerment is shown in Figure 2.

	Capability (C)	Expertise (E)	Value (V)	Opportunity (O)
Informed (~C*~E*~V*~O)	~C	~E	~V	~O
Involved (~C*E*V*~O)	~C	E	V	~O
Empowered (C*E*V*O)	C	E	V	O
A capital letter denotes set membership; a capital letter preceded by ~ denotes membership of the negated set (i.e. non-membership). * denotes combination of the sets.				

Figure 2: Property space for a policy design for empowerment

Set membership will be determined according to the context of the cases being examined (Kvist 2007); thus, I turn now to case selection.

Case selection

Autism policy was selected because it has evolved from disability policy, where complaints of disempowering policy are commonplace (Jeon and Haider-Markel, 2001; Kingston, 2014; Fulcher, 2015; Halvorsen et al., 2017). Autism policy is 'new' but the extent to which it is 'different' remains to be seen. Autism policy is also linked to the neurodiversity movement, which is one stream of the autism advocacy community (Kapp et al., 2013; Milton, Damian, 2015; Arnold, 2017) and promotes autistic empowerment (Baker, 2011).

This is narrowed to Western European autism policy due to the recent flurry of new policies being enacted in this part of the world. Western Europe is often called the birthplace of the welfare state (Blum, Kuhlmann and Schubert, 2009) and European Union regulations require that EU member states, which make up the bulk of Western European countries, have some form of welfare state and disability policy (Waldschmidt, 2009). There is thus a solid basis from which autism policy can evolve. Article 29 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2006), which promotes political participation of people with disabilities, has also been ratified by the majority of Western European countries. The principle of autistic political participation is further reinforced by the European Parliament's Declaration on Autism (EC, 2015), the United Nations Resolution on Autism (UN, 2012) and Autism Europe (AutismEurope, 2020), an EU-funded body which promotes autism research and seeks to inform national and international autism policies.

There were three qualifying criteria for inclusion of a national autism policy in the sample. I defined national policy as a policy (either legislative, statutory, or simply a strategy or plan of action) emanating from a government with devolved powers over education, health, and social care. Firstly, the government had to be in a country classified as Western European, defined as included in the United Nations Western European and Others Group (WEOG) dataset. This dataset was chosen because it is determined in terms of political similarities, rather than geography or EU membership. Secondly, it had to have a current, autism-specific policy (a policy dealing exclusively with autism). This was to isolate autism policy from disability policy and ensure reliability. Thirdly, there had to be sufficient detail in the policy to enable the instrument types and other details to be coded. Twelve policies met these criteria and are outlined in Figure 3.

Country	Executive Body	Policy Documents
Belgium	Wallonia & Brussels-Capital Region	Transversal Autism Plan 2017
	Flanders	Flemish Action Plan for Autism 2017
Denmark		National Autism Plan 2008
France		4th Autism Plan 2018-2022
Greece		National Greek Social Policy for Autistic People 2017
Italy		Autism Act 2015
Spain		Strategy for Autistic Spectrum Disorders 2015
Switzerland		Measures for improving the diagnosis, treatment and monitoring of people with autism in Switzerland 2018
United Kingdom	England	Autism Act 2009 Think Autism - Autism Strategy 2014 - 2018 Statutory Guidance for Local Authorities and NHS organisations 2010
	Wales	Autism Act 2009 Autism Spectrum Disorder Strategic Action Plan 2016
	Scotland	Strategy for Autism 2018-2021
	Northern Ireland	Autism Act Northern Ireland 2011 Autism Strategy 2013-2020

Figure 3: Autism-specific policies in Western Europe

To ensure that no autism policies were accidentally omitted, email contact was made with the lead autism charity in each country to confirm the absence of a national policy. Systematic document coding was used to produce the data required for fuzzy set analysis. Policy documents provide written, dated evidence of the policy instruments, actors and goals selected by governments (Freeman and Maybin, 2011) and are valuable tools for language analysis. Documents were downloaded directly from government websites where available, and from autism charity websites where not available. The researcher is fluent in English, French and Italian and translations were obtained for documents not available in any of these languages.

Step 1: Document coding

Policy documents were coded systematically in four stages. Firstly, I used Schneider and Ingram's instrument typology (Schneider, A. and Ingram, 1990) as the basis for a list of possible instrument categories, as shown in Figure 4. This list was informed by my professional knowledge of autism policy and existing scholarly analyses of European autism policy, which highlight the importance of services for autistic people, awareness campaigns and staff training, as well as the omnipresence of some form of welfare benefits and legal safeguards against discrimination (Chamak, 2008; Della Fina, 2015; Bolte, 2017; Baranger, Hammersley and Posada de la Paz, 2018; Roleska et al., 2018).

Category	Instrument Type	Description
Authority	Regulation	Legislation, regulations or requirements – 'must do'. E.g. statutory guidance.
	Responsibilities	Duties to carry out a prescribed action. E.g. duty to appoint an Autism Champion.
	Monitoring	Oversight, monitoring, review. E.g. monitoring body.
Incentives	Payments	Payment made to any third party outside the target group (distributive). E.g. additional funding for schools.
	Benefits	Welfare payment made to an autistic person or their family (redistributive). E.g. Access to Work payments.
	Sanctions	Sanctions of any kind. E.g. financial penalty for failure to adhere to regulations.
Symbolic	Recommendation	Encouragement or recommendations – 'should do'. E.g. encouragement to employ autistic people.
	Autism Awareness	Raising awareness of autism in the general public. E.g. autism awareness campaign
Capacity	Professional Capacity	Training for professionals. E.g. training school staff to recognise autism.
	Research	Research into autism. E.g. researching what autistic people want from policy.
	Autistic Capacity	Training for autistic people and/or their families. E.g. interview training to support job applications.
Learning	Family Consultation	Consulting with families/carers of autistic people. E.g consulting families on services desired.
	Autistic Consultation	Consulting with autistic people. E.g. consulting autistic people on services desired.
	Autistic co-governance	Involving autistic people in the policy decision-making process. E.g. Partnership Board or Citizen's Assembly.
	Pilot	Piloting a new initiative. E.g. piloting personal budgets.
	Innovation	Calling for innovative responses from third parties. E.g. innovation fund.

Figure 4: Instrument Categories

Within Authority, 'Regulation' is reserved for legal or statutory requirements, whereas duties would be classed under 'Responsibilities'. 'Recommendation' is placed in Symbolic because of the value-laden nature of governmental expectation that an 'autistic-friendly' company, for example, 'should' behave in a certain way. 'Autism awareness' refers to public campaigns designed to raise awareness of what autism is and how autistic people see the world; this is something that autistic people consider highly important (Pellicano, E., Dinsmore and Charman, 2014; Kenny et al., 2016).

Having created a list of possible instruments, the next step involves identifying each of the 552 policy instruments from the policy documents and assigning it a code from Figure 4. I also coded any conditions that were applied to Authority instruments, such as time limits, including autistic people or collaborating with other actors. For example, a duty to include autistic people in the development of local policy would be coded as a Responsibility with a condition of Inclusion.

To determine membership of the sets detailed in Figure 2, a deeper analysis than that of instrument categories is needed. I focus on services for autistic people, as these provide the greatest insight into how they are viewed and services make up a large tranche of autism policy (Baranger, Hammersley and Posada de la Paz, 2018). For each service, I coded the goal according to one of Baker's four categories of disability policy goal (Baker, 2011): cause, care, cure and celebrate. 'Cause' refers to a rights-based approach which seeks to assert a right or protect against discrimination. 'Cure' refers to a medicalised approach, which focuses on mitigating the health impact or curing a disease. 'Care' refers to an approach which sees the group as dependent and needing to be looked after by a benevolent other. 'Cause' and 'Care' are frequently seen in disability typologies, which typically distinguish between rights-based and social protection policies (Esping-Andersen, 1990; Maschke, 2004; Tschanz and Staub, 2017), while the 'cure' versus 'care' debate is well known in disability policy (Barnes, Collin, 2007; Fulcher, 2015). The fourth category, 'Celebrate', is more novel and describes an approach which highlights the strengths and abilities of the individual rather than their difficulties or disabilities (Saleeby, 1993; Chapin, 1995).

I coded 'Cause' if the goal of the service was to assert rights (including by diagnosis, which often acts as a gatekeeper to other services (Birkland, 2007) or protect against discrimination and 'Cure' if it was to mitigate the health impact of autism (it is accepted that autism cannot be 'cured' (Bagatell, 2010)). I used Maslow's hierarchy of needs as the basis for differentiating between 'Care' and 'Celebrate' services, since the pinnacle of the pyramid, self-actualisation, is equivalent to capacity for empowerment (Hamilton, 2003). I coded a service as 'Care' if it did not fit 'Cause' or 'Cure' and its aim was to meet the physiological and safety needs of the autistic person and 'Celebrate if its aim was to meet higher level needs. For example, an employment support service would be coded as 'Celebrate', while a residential care home would be coded as 'Care'. I also coded the actors who were tasked with delivering the service – including autistic people where this was specified - and the lead Government department. Where available, the funding allocated to autism policy was also recorded.

The fourth and final stage of document analysis was a language analysis of the policy documents using NVivo to determine how many of the top ten most frequently used words (ignoring conjunctions and neutral words such as 'autism' or 'policy') were words which describe autism, or autistic people in a positive, negative, or neutral light. For example, in different countries, autistic people are described as being ‘afflicted’ by autism, ‘having an autistic spectrum disorder’ or just being ‘autistic’ (McGuire, 2012). The first two are negative; the third is neutral. An autistic person might be ‘treated’ or ‘cared for’, which is negative, or ‘facilitated’, which is positive. A spreadsheet showing all coding results is available in the data repository.

Fuzzy set ideal type analysis

Having identified the ideal types and operationalised them in terms of set membership, as shown in Figure 2, the next step in fuzzy set ideal type analysis is to determine the parameters for membership of each set. The conditions for membership of each set, in relation to autism policy, are set out in Figure 5.

	Policy instruments	Goals	Named Participants	Language analysis
Capacity (C)	Presence of Education instruments directed at autistic adults.	Presence of 'Celebrate' goals	Presence of autistic people as named participants	-
Expertise (E)	Presence of Autistic Consultation instruments.	-	-	-
Value (V)	Presence of Symbolic instruments encouraging autistic participation.	-	-	Positive language appearing in top ten meaningful[1] high frequency words.
Opportunity (O)	Presence of CoGovernance instruments. Presence of Authority instruments with a participation condition	-	-	-

1 Articles, conjunctions and other words patently not contributing to the social construction of autistic people, such as 'policy' or 'autistic', are ignored. A full list of ignored words and the words classified as positive is included in the data repository.

Figure 5: Set membership conditions

For each policy, the number of instances of each instrument, goal, or named participant (or the number of high frequency words) was used to determine the fuzzy set score. Due to the difference in number of policy instruments per case, which ranged from 18 in Greece to 84 in France, this was then converted into a percentage of all instruments for that case. The range of non-zero percentages (since zero percentage equates to non-membership) was then established and divided by 9 to produce a range of scores which correspond to 0.1 to 0.9. No case was assigned a 1, on the basis that membership of the set is not binary. A case is a member of the set if it scores 0.5 or higher for all of the set criteria (where there is more than one criterion).

Results

The fuzzy set ideal type analysis reveals that all but one of the twelve cases (Scotland) studied correspond to one of the ideal types, with Informed being the most prevalent. Interestingly, the clusters do not correspond to traditional clusters of disability policy (Tschanz and Staub, 2017), with the United Kingdom split across different clusters and Spain, which usually clusters with other Southern European countries such as Italy and Greece, joining Northern Ireland in the Involved group.

Figures 6, 7, 8 and 9 show set membership for each of the constituent sets, while Figure 10 shows the resultant ideal type membership. The number of instances and percentage of total policy instruments is given alongside the fuzzy set score for that category. This corresponds to clusters of ideal types as shown in Figure 11, with Scotland as an outlier.

	Education instruments			Celebrate goals			Named autistic participants			Capacity Set member?
	No.	%	Score	No.	%	Score	No.	%	Score	
Brussels-Capital Region and Wallonia	1	3	0.2	1	3	0.2	0	0	0	N
Denmark	9	17	0.9	14	24	0.9	9	17	0.9	Y
England	7	16	0.8	7	16	0.8	6	14	0.7	Y
Flanders	1	3	0.2	0	0	0	1	3	0.2	N
France	2	2	0.1	2	2	0.2	1	1	0.1	N
Greece	0	0	0	0	0	0	1	5	0.3	N
Italy	1	6	0.3	1	6	0.3	0		0	N
Northern Ireland	5	10	0.5	8	17	0.8	3	6	0.3	N
Scotland	4	12	0.6	5	15	0.8	3	9	0.5	N
Spain	3	9	0.5	10	20	0.9	5	12	0.6	Y
Switzerland	3	8	0.4	2	6	0.3	0	0	0	N
Wales	7	10	0.5	6	9	0.5	5	7	0.5	Y

Figure 6: Capacity Set membership

	No.	%	Score	Expertise Set member?
Brussels-Capital Region and Wallonia	1	3	0.3	N
Denmark	5	6	0.8	Y
England	5	7	0.9	Y
Flanders	1	2	0.2	N
France	2	2	0.2	N
Greece	0	0	0	N
Italy	0	0	0	N
Northern Ireland	2	4	0.5	Y
Scotland	1	5	0.6	Y
Spain	3	6	0.7	Y
Switzerland	0	0	0	N
Wales	6	8	0.9	Y

Figure 7: Expertise set membership

	Symbolic Participation			Positive language in top ten words			Value set member?
	No.	%	Score	No.	%	Score	
Brussels-Capital Region and Wallonia	1	3	0.4	0	0	0	N
Denmark	4	7	0.9	7	12	0.9	Y
England	3	4	0.5	5	6	0.6	Y
Flanders	1	2	0.3	0	0	0	N
France	1	1	0.1	2	2	0.2	N
Greece	0	0	0	0	0	0	N
Italy	0	0	0	0	0	0	N
Northern Ireland	1	2	0.3	2	4	0.5	N
Scotland	1	3	0.5	2	6	0.6	N
Spain	2	4	0.5	4	8	0.7	Y
Switzerland	0	0	0	1	3	0.3	N

Figure 8: Value set membership

	Co-governance instruments			Instruments mandating political participation			Opportunity set membership?
	No.	%	Score	No.	%	Score	
Brussels-Capital Region and Wallonia	0	0	0	0	0	0	N
Denmark	3	5	0.7	2	3	0.7	Y
England	4	6	0.8	3	4	0.9	Y
Flanders	0	0	0	0	0	0	N
France	1	1	0.1	1	1	0.4	N
Greece	0	0	0	0	0	0	N
Italy	0	0	0	0	0	0	N
Northern Ireland	0	0	0	0	0	0	N
Scotland	0	0	0	0	0	0	N
Spain	1	1	0.1	0	0	0	N
Switzerland	0	0	0	0	0	0	N

Figure 9: Opportunity set membership

	Constituent set membership				Ideal type membership		
	C	E	V	O	Informed	Involved	Empowered
Brussels-Capital Region and Wallonia	~C	~E	~V	~O	Y	N	N
Denmark	C	E	V	O	N	N	Y
England	C	E	V	O	N	N	Y
Flanders	~C	~E	~V	~O	Y	N	N
France	~C	~E	~V	~O	Y	N	N
Greece	~C	~E	~V	~O	Y	N	N
Italy	~C	~E	~V	~O	Y	N	N
Northern Ireland	~C	E	V	~O	N	Y	N
Scotland	C	E	V	~O	N	N	N
Spain	~C	E	V	~O	N	Y	N
Switzerland	~C	~E	~V	~O	Y	N	N

Figure 10: Ideal type membership

Informed	Brussels-Capital Region and Wallonia Flanders France Greece Italy Switzerland
Involved	Northern Ireland Spain
Empowered	England Denmark Wales

Figure 11: Countries by ideal type

I now use the results to illustrate in more detail what these ideal types look like in practice when it comes to autism policy. Autism policies in Western Europe share several similarities with disability policies. They all assert the right to freedom from discrimination and provide some level of welfare support. They all provide diagnostic services and care services which aim to meet at least the basic needs of autistic people, although the range and availability of services varies considerably. They all pay lip service to participation and empowerment. However, on the ground, they look very different.

Informed policy designs

This is the most common design within the sample, and particularly prevalent in Southern European countries which were traditionally slower to move away from the medical to the social model of disability (Barnes, Colin, 2000). The policies in this group make no or limited changes to the political opportunity structure: they are very similar to existing disability policies. They focus primarily on using professional expertise to meet the basic needs of autistic people, who are constructed as lacking capacity and needing others to advocate for them. For example, in France, parents of autistic people are offered training in how to ‘manage’ their child and autistic people are offered ‘behaviour management’ training.

All consider the needs of autistic people from cradle to grave but focus more on support for autistic children than adults. Families of autistic people are consulted on policy change and support, but autistic people are rarely given that opportunity. In Switzerland, local services are determined exclusively by parents and professionals.

Professional expertise is king: professionals are encouraged to collaborate, and academic research is encouraged, such as in France's 'centres of excellence'. Autism awareness campaigns are informed by professional opinions about autism. Where the needs of autistic people are represented at all, they are represented by professionals and by family members. Symbolic tools, such as recommendations and awareness campaigns, are used more frequently than Authority tools, such as duties; where Authority tools are used, they are directed at professionals and have low levels of coercivity and no sanctions for non-compliance. Participation is encouraged through Symbolic tools but not mandated or facilitated.

The receptivity of the policy environment to participation is limited: autistic people are not considered to have the capacity or expertise to contribute to the debate. Their representations are not valued, and so minimal changes are made to the political opportunity structure to facilitate participation, since empowerment is not anticipated.

On the ground, these autism policies provide a range of housing, education, residential care, and medical services but limited services aiming to upskill autistic people. Employers are given quotas or financial incentives to employ autistic people, but autistic people are not supported into appropriate employment. In some cases, such as in France, which, until a few years ago, treated autism as a psychiatric disorder caused by maternal neglect (Davidson, 2014), programmes are available to 'normalise' autistic people by teaching them how to 'pass' as non-autistic. Welfare payments are available in line with payments for other disabled people. Spending on these policies varies but some of the highest spending on autism can be found in this category.

Involved policy designs

This group contains just two countries – Northern Ireland and Spain, although Scotland shares many characteristics with it and its membership scores on the sets which excluded it from this group were borderline. In these countries, some cultural design changes have been made to the political opportunity structure. It is interesting to note that this in-between category, which marks a departure from traditional disability policy but not yet arrival at a full design for empowerment, contains both some parts of the United Kingdom – where other parts are Empowered- and Spain – where its Southern European counterparts remain Informed.

These policies pay equal attention to adults and children. Autistic people are consulted on policy change, alongside their families, and asked to contribute to research but not involved in planning or delivering policy. For example, in Northern Ireland, autistic people are invited to contribute to consultations but not involved in any of the boards which make decisions or determine provision. Professional expertise is still prioritised, and professionals lead on the planning and delivery of services. They are encouraged to involve autistic people but not sanctioned if they do not. Authority tools are used more frequently than Symbolic tools but usually simply require professionals to provide certain services.

The receptivity of the policy environment is mixed. Autistic people's contributions and representations are encouraged and given symbolic value. Their expertise is recognised. It is accepted that they have a degree of untapped potential. Nonetheless, their capacity is still considered to be limited and, as a result, structural changes are not made to the political opportunity structure.

On the ground, these autism policies still provide medical, education and housing services, but are more likely to offer supported living in the community than residential care homes. There are some services which aim to upskill autistic people but most focus on removing barriers to social inclusion, in line with the social model of disability (Barnes, Colin, 2000). For example, Northern Ireland provides an advocacy service for autistic people and Spain provides sheltered employment services, where autistic people are guaranteed employment on minimum wage but only with high levels of supervision. Employment support programmes aim to give autistic people the skills to get into work but encouragement to employ autistic people remains symbolic and there are no services which aim to support autistic people to stay in work or achieve a promotion. Working is seen as an achievement in itself rather than a means to empowerment. These policies do not make any new welfare payments available to autistic people but remind autistic people that they are entitled to them. Funding is generally not specified.

Empowered policy designs

This ideal type includes the only Nordic country in the sample, Denmark, and also England and Wales. This group is the only one to make changes to both cultural and structural elements of policy design to facilitate participation and empowerment.

The Danish and Welsh policies consider adults and children, paying more attention to adults, while English policies to date only consider adults, although this is set to change in the next iteration of the Autism Strategy. This focus on supporting adults sets this group clearly apart from the other types. Autistic people are both consulted on policy and structurally included in the decision-making process. In England and Wales, autistic people are involved in determining policy at the regional level, through regional partnership boards, whereas in Denmark, they are involved at the national level as well, through citizen's assemblies. Authority instruments mandate the involvement of autistic people and Symbolic instruments are a minority.

The policy environment is receptive to autistic involvement with autistic people recognised as being capable, expert, and valuable representatives. Structural changes reinforce the opportunities for participation.

On the ground, these policies consist of a range of medical, housing and employment and social support services, with supported living and even personal assistants prioritised over residential care services. In Denmark, individualised support plans are available which allow targeted support to be given to upskill autistic individuals. In England and Wales, services are more generic but still seek to upskill. Funding varies and autistic people are encouraged to apply for welfare support if it is needed.

Conclusion

In conclusion, this research has conceptualised and illustrated three ideal types of policy design for empowerment, revealing that autism policy still has much to do in the majority of countries to make meaningful progress towards addressing the democratic deficit. The majority of countries in Western Europe consider autistic people to lack capacity, expertise, and value and, as a result, do not make concrete changes to the political opportunity structure to facilitate their participation or empowerment. Some countries, such as Spain and Northern Ireland, are beginning to make changes but still need to address their low expectations of maximal capacity. Denmark, England, and Wales lead the pack at the moment, in terms of the political opportunity structure for autistic people – but whether this has actually resulted in an outcome of empowerment is a subject for another study. It would be interesting to extend this study to Eastern Europe and beyond to see if the ideal types still apply.

Governments have much to gain from designing citizen-empowering policies. In practice, however, preconceptions about the maximal capacity for empowerment of marginalised groups limit the changes made to policy design to facilitate this. Empowering policy designs require structural and cultural changes to existing policy templates. Citizens whose empowerment is desired must be socially constructed as not just valued contributors but experts in their field and, crucially, capable. In an age in which lived experience is becoming ever more important, governments need to move on from the Informed category which negates this lived experience. They can and should do more to empower their citizens – and the starting point is policy design.

Evaluation of article

As an original research article in its own right published by *European Policy Analysis*, it has already shown itself to be of interest to other autism scholars, three of whom have cited it in their own work at the time of writing. Indeed, the article received a certificate from Wiley as the most-cited article in the journal in the year of its publication. It is also of interest to anyone interested in policy design for marginalised groups. As a result of this article, I've been invited by Routledge to submit a book proposal on completion of the thesis.

5. Methodology for a case study of autistic policy influence

In this chapter, I set out how I intend to measure the ‘extent, conditions and effect’ of autistic policy influence, as set out in the research questions outlined in Chapter 1. In order to do this, I need to combine data from different sources and different indicators. For the extent of autistic influence, I use the indicators of influence set out in Chapter 3. For conditions and effect, I rely on in-depth qualitative analysis, through process tracing and thematic analysis of policy documents, Hansard records, stakeholder interviews and focus groups. The nature of both types of analysis is such that, in order to retain transparency and reproducibility, it is important to be very clear about the method used.

To recap what has already been said about influence in Chapter 3, for the purposes of this thesis, social policy influence is defined as ‘the ability to alter or maintain the trajectory of the policy process’. Since autism policy appears to have resulted in a reframing of what it means to be autistic, it is likely that autistic people want to alter the trajectory, i.e., achieve policy change, but this should not be assumed. Effectively, I need to ask what did autistic people want to achieve and to what extent did they achieve it? This is one stage of the method. A subsequent stage of the method entails gathering data to explain the influence exerted through examining the conditions and effect.

I begin this chapter by tackling the question of how to isolate autistic influence, before going on to explain the multi-stage method in more detail. The chapter closes with an analysis of the ethical considerations taken into account.

Isolating autistic influence

Methodologically, it is important to address how the influence of autistic people will be isolated from that of other actors, and how the influence of autistic self-advocates, who are able to exert direct influence, will be isolated from the influence of the autistic community as a collective, who are less able to exert direct influence. If influence cannot be sufficiently isolated, it cannot be analysed effectively. The first point to make is that each kind of influence will be isolated insofar as is possible – it is not feasible to entirely isolate an intervening variable because of the degree of intertwining.

The scholarship on autism policy is clear that there are many competing actors and frames (Feinberg and Vacca, 2000; Orsini, 2012) and this provides an opportunity for isolating certain aspects of influence. For example, if the different stakeholders in policy can be identified, it is possible to assess reputed and self-reputed influence by speaking to these stakeholders. If different frames can be identified, and attributed to certain actors, then framing congruence can be assessed. Similarly, participation and goal attainment can be assessed through information gleaned from interviews and focus groups. Thus, the first stage in the Method, which will be outlined shortly, is to carry out a stakeholder mapping exercise using publicly available government websites, policy documents and records of government debates. This will allow the relevant stakeholders to be identified, contacted, and interviewed.

There is a risk in any interview that the interviewee is not giving accurate information (Aberbach and Rockman, 2002; Goldstein, 2002; Harvey, 2011); therefore the information gleaned from interviews and focus groups will need to be supplemented with thematic and content analysis of policy documents and records of government debates, in order to flag any assertions which appear out of place. This approach also allows for autistic self-advocates to be isolated from family advocates and from the autistic community as a whole, which is important for the reasons outlined in Chapter 4.

Assessing the extent of influence

A detailed rationale for my indicators of influence is set out in Chapter 3, so I will just recap them briefly here. I measure cumulative influence for each stakeholder (as identified in the first stage of the Method, which will be detailed later) across the indicators shown in Figure 7 overleaf which have been selected to assess influence across as many means of measurement as is feasible:

Measure	Data required	Data source	Codes
Goal attainment	Goals; policy output	Goals from stakeholder interviews; policy output from policy documents.	For each goal: Fully, mostly, slightly, or not at all attained.
Agenda-setting	Issues; policy agenda	Issues from stakeholder interviews; policy agenda from stakeholder interviews and Hansard records of committee and Parliamentary discussions	For each issue: high, medium, low, or not at all on the agenda.
Self-reputed influence	Opinions of each stakeholder	Stakeholder interviews, survey and focus groups.	For each stakeholder: As a group, we have a lot of, quite a lot of, some or no influence.
Reputed influence	Opinions of each stakeholder	Stakeholder interviews, survey and focus groups.	For each stakeholder: Stakeholder X has a lot of, quite a lot of, some or no influence.
Active participation	For participation: presence or absence of actor. For active nature: feedback from actor and stakeholders.	For participation: stakeholder interviews, survey, focus groups and Hansard records of committee and Parliamentary discussions. For active nature: stakeholder interviews, survey and focus groups.	For each stakeholder: participates; does not participate and, if participates = true, participates very, quite, a little or not at all actively.

Framing congruence	Issue and target group frame proposed by each actor; dominant issue and target group frame in final output.	Proposed frames from stakeholder interviews, survey and focus groups; dominant frame from policy documents.	For each stakeholder: framing identical; highly, quite, a little or not at all congruent.

Figure 8: Influence codes

The decision as to how to code each indicator of influence for each stakeholder is necessarily a moderately subjective one since we are not dealing with numeric data. Interviewees and focus group members were asked to choose the classification they thought most relevant for each one and this was recorded (along with additional detail to provide a thick description); however, I then corroborated this with data from policy documents and Hansard records. Where I decided to change a code, I recorded the rationale for my decision. If evidence suggested any codes needed to be altered inductively, I also recorded this, together with the rationale. The interview and focus group questions, as well as all the responses and coding decisions, can be found in the online data repository detailed in the Appendices.

Assessing conditions for influence

As well as measuring the extent of influence using the indicators set out in Chapter 3, I also need to capture the political opportunity structure for autistic people – both institutionally and culturally – so that I can assess the conditions which favour autistic influence and therefore provide a skeleton lobbying strategy structure. The institutional opportunity structure is detailed using data from thematic and content analysis of government policy documents and legislation combined with a thematic and content analysis of stakeholder interviews and a survey and focus groups of autistic people, as well as using the data about the English political opportunity structure gleaned from Article 1. The cultural opportunity structure is similarly detailed using data from thematic and content analysis of stakeholder interviews, survey and focus groups and data from article 1. This method examines the underdog theory in its entirety, including the pyramid of empowerment. In both cases, the priority is thick description (Geertz, 1973) and rich analysis so that a narrative can be created which can be absorbed and put into action by the autistic community.

As with the coding for indicators of influence, I combine pre-determined, theory-driven codes with the opportunity to include additional codes determined on an inductive basis during the data analysis phase. The pre-determined codes are based on the pyramid of empowerment described in Chapter 2, augmented with additional codes based on my literature review of factors which qualify influence. In each case, codes are applied to documents, or transcripts of survey responses, focus groups and interviews and the frequency, pattern and spread of the various codes analysed using NVivo® in relation first to the pyramid of empowerment and then to four quadrants relating to the receptivity of the political opportunity structure, as detailed in Figure 5 overleaf.

Pyramid of Empowerment Codes			
Understanding of environment	Needs met	Access to resources	
Collaboration	Control	Self-efficacy	
Political Opportunity Structure Codes			
Codes indicating receptivity		***Codes indicating hostility***	
Institutional	***Cultural***	***Institutional***	***Cultural***
Invitation	Positive framing	Exclusion	Negative framing
Consultation	Awareness	Tokenism	Lack of awareness
Mandated representation	Understanding		Lack of understanding
Financial allocation	Intersectionality		Stereotypes
Legal changes	Pluralism		

Figure 9: Pyramid of Empowerment and Political Opportunity Structure Codes

The pyramid of empowerment codes will be assessed in relation to all stakeholders, both to test the efficacy of the pyramid of empowerment as a measure of necessary precursors to influence and to provide information on the political opportunity structure for autistic people. Other codes are assessed in relation only to autistic people. Each code is either Present or Not Present. Some codes are mutually exclusive, such as positive and negative framing, whereas others may coexist. At the end of the process, a score of 1 is given for each Present code from the Pyramid of Empowerment or Receptive Policy Environment codes and a score of 0 for every Present code from the Hostile Policy Environment codes. The higher the end score, the more receptive the policy environment to autism policy change. The quotations attached to each code also yield data for a thicker description of the conditions.

An initial explanation of each code is given in the table overleaf; however, as with the influence codes, these codes may be added to, or revised inductively, during the data collection and data analysis process and any changes will be detailed in Articles 1 or 3, or in Chapter 6.

Code	How measured	Data Source	Rationale
Understanding of environment	Respondent shows understanding of policy process and opportunities for influence	Stakeholder interviews, focus groups and survey of autistic people.	Present – any understanding shown. Not Present – no understanding shown.
Needs met	Data shows deprivation for that stakeholder. Respondent mentions an unmet need.	Publicly available data sources, e.g., ONS/OECD/DWP. Stakeholder interviews, focus groups and survey of autistic people.	Present: deprivation shown or respondent states unmet need. Not Present: deprivation not shown, and no unmet need stated.
Access to resources	Divided into financial, expertise and manpower. Financial resources assessed from publicly available data sources. Expertise assessed by respondent demonstrating expertise (lived or learned). Manpower assessed by respondent mentioning contacts or networks.	Publicly available data sources, e.g., ONS/OECD/DWP and Companies House for financial resources. Stakeholder interviews, focus groups and survey of autistic people.	Present: any resources demonstrated. Not Present: no resources demonstrated.

Collaboration	Respondent mentions collaborating with others.	Stakeholder interviews, focus groups and survey of autistic people.	Present: any collaboration mentioned. Not Present: no collaboration mentioned
Control	Respondent belongs to a group with high or medium self-reputed influence OR asserts that they feel they have some control over the policy process OR mentions controlling themselves.	Data on self-reputed influence. Stakeholder interviews, focus groups and survey of autistic people.	Present: high or medium self-reputed influence or assertion of control. Not Present: low or no self-reputed influence and no assertion of control.
Self-efficacy	Respondent belongs to a group with high or medium self-reputed influence OR is able to explain a way they have exerted influence.	Data on self-reputed influence. Stakeholder interviews, focus groups and survey of autistic people.	Present: high or medium self-reputed influence or explanation of influence exerted. Not Present: low or no self-reputed influence and no explanation of influence.

Invitation	Respondent belongs to a group which was invited to contribute by government.	Hansard records and minutes of All Party Parliamentary Group and Autism Programme Board.	Present: respondent belongs to a mandated representation group, or to a group which has been invited to contribute or mentioned in Parliamentary discussion. Not Present: none of the above are true.
Consultation	Respondent belongs to a group which was consulted by government.	Autism Act and Autism Strategy Consultations (publicly available online).	Present: respondent belongs to a group which was consulted. Not Present: respondent belongs to a group which was not consulted.
Mandated representation	Respondent belongs to a group which has mandated representation.	Minutes of All Party Parliamentary Group and Autism Programme Board.	Present: respondent belongs to a mandated representation group. Not Present: respondent does not belong to such a group.

Financial allocation	Respondent belongs to a group allocated autism policy funding.	Autism Strategies and minutes of Autism Programme Board.	Present: respondent belongs to a group named as receiving funding. Not Present: respondent does not belong to such a group.
Legal changes	Respondent belongs to a group which benefited from a legislative or statutory policy decision.	Autism Strategies.	Present: respondent belongs to a group which benefited from a legislative or statutory decision. Not Present: respondent does not belong to such a group.
Positive framing	Respondent belongs to a group positively framed by government or other stakeholders.	NVivo analysis of policy documents, interview and focus groups transcripts and free text from the survey to code frames as positive or negative.	Present: more positive frames coded than negative. Not Present: more negative frames coded than positive.
Awareness	Respondent shows awareness of autism in others.	Stakeholder interviews, focus groups and survey of autistic people.	Present: respondent shows awareness. Not Present: respondent does not show awareness.

Understanding	Respondent shows accurate understanding of autism.	Stakeholder interviews, focus groups and survey of autistic people.	Present: respondent shows accurate understanding. Not Present: respondent does not show accurate awareness.
Intersectionality	Respondent shows awareness of intersectionality of autism.	Stakeholder interviews, focus groups and survey of autistic people.	Present: respondent shows awareness. Not Present: respondent does not show awareness.
Pluralism	Respondent shows awareness of plurality of different presentations of autism.	Stakeholder interviews, focus groups and survey of autistic people.	Present: respondent shows awareness. Not Present: respondent does not show awareness.
Exclusion	Respondent belongs to a group which is neither invited, consulted nor a mandated representative.	Coding data on invitation, consultation, and mandated representation.	Present: respondent belongs to such a group. Not Present: respondent does not belong to such a group.

Tokenism	Respondent belongs to a group which is consulted but not invited or a mandated representative.	Coding data on invitation, consultation, and mandated representation.	Present: respondent belongs to such a group. Not Present: respondent does not belong to such a group.
Negative framing	Respondent belongs to a group negatively framed by government or other stakeholders.	Nvivo analysis of policy documents. Interview and focus group transcripts and free text from surveys to code frames as positive or negative.	Present: more negative frames coded than positive. Not Present: more positive frames coded than negative.
Lack of awareness	Respondent does not show awareness of autism in others.	Stakeholder interviews, focus groups and survey of autistic people.	Present: respondent does not show awareness. Not Present: respondent shows awareness.
Lack of understanding	Respondent does not show accurate understanding of autism.	Stakeholder interviews, focus groups and survey of autistic people.	Present: respondent does not show accurate understanding. Not Present: respondent shows accurate awareness.

Stereotypes	Respondent uses a stereotype of autism as if it is true.	Stakeholder interviews, focus groups and survey of autistic people.	Present: respondent uses stereotypes. Not Present: respondent uses stereotypes.

Figure 10: Coding Rationale for Pyramid of Empowerment and Political Opportunity Structure

The key difference between coding for these codes and coding for the indicators of influence is that, while questions about influence are asked directly, these codes are obtained indirectly. Respondents are asked general questions rather than being specifically asked to discuss e.g., intersectionality or pluralism. This is to ensure as far as possible that what is top of their agenda is noted.

Assessing effect of influence

The effect of autistic influence is assessed through direct questions asked of both stakeholders and autistic people through focus groups and a survey. Inductive coding is carried out using NVivo to organise the data. The codes chosen are detailed in Article 3 and Chapter 6. It is also important to differentiate between autistic self-advocates and the wider autistic community, since, as detailed in Chapter 4, they experience different opportunities and receptivity. If autistic self-advocates show influence but this does not translate to influence for the wider autistic community, it is debatable whether their influence has actually been effective.

NVivo® is a widely used software package which assists with the coding and thematic analysis of documents (Welsh, 2002; Bazeley and Jackson, 2013; Zamawe, 2015). It consists of a variety of analytical tools which can be used to assist the researcher in identifying patterns more quickly than would be possible if the researcher were to work manually (Bazeley and Jackson, 2013). However, it is dependent on coding decisions made by the researcher and as such is a tool rather than an intrinsic part of the research design (Zamawe, 2015). Analysis was carried out under the University of Bath's licence, on University computers.

Data sources

Documents

Documents are frequently used in triangulation with other data sources (Flick, 2018) and are a staple of traditional policy analysis (Karppinen and Moe, 2012), since governmental policymakers frequently produce large amounts of documentation (Freeman and Maybin, 2011). Policy documents are particularly useful to this case study because they represent the considered and deliberate choice of framing made by governmental decision-makers. Policy documents are a form of communication (Freeman and Maybin, 2011; Karppinen and Moe, 2012) and represent what the government wants to communicate to autistic people and the public about what autism is, and how autistic people 'should' be viewed and treated. Other documents of interest include transcripts of government debates, such as those provided by Hansard, and minutes of relevant committee meetings. Documents can be analysed in a range of different ways under the general heading of document analysis (Bowen, 2009; Karppinen and Moe, 2012): they can be searched for specific evidence or using quantitative or qualitative textual analysis. (McKee, 2003; Fürsich, 2009).

The documents used in this research are listed in full in the data repository and include the Autism Act 2009 (AutismAct, 2009) , the first two Autism Strategies (Fulfilling Lives in 2010 (DHSC, 2010) and Think Autism! in 2014 (DHSC, 2014)), local authority and NHS statutory guidance between 2010 and 2018 (DHSC, 2010; DHSC, 2014; NHS, 2010; NHS, 2014) and the governmental review of Think Autism! (DHSC, 2018). While only documents up to 2018 are formally assessed in this research, reference and consideration are also given to the latest iteration of the Autism Strategy (the National Strategy for autistic children, young people, and adults 2021-2026) (DHSC, 2021), which was issued after data analysis had been completed. In addition, searches were made of Hansard records of parliamentary debates and APPGA and other deliberation body decisions between 2009 and 2018. Finally, publicly available data such as from the ONS, OECD, DWP and Companies House is also incorporated. All the search terms used can be found in the data repository.

Stakeholder interviews

Stakeholder interviews (Darnall and Jolley, 2004) are a useful technique of targeting interview questions directly at the people who are able to tell us the most about the policy process: those who are directly involved in it. Because of their depth of knowledge, these questions are usually open questions to elicit maximal information (Aberbach and Rockman, 2002; Harvey, 2011). I take a semi-structured approach, to ensure that all indicators for influence are covered but allow for the introduction of new ideas and the investigation of interesting side topics.

Questions were devised with the aim of gathering evidence for each indicator of influence, but also exploring the nature of the decision-making process, the conditions in which decisions were made, the effects of these decisions and the opinions of the interviewee. Care was taken to maintain the same wording of each question to ensure that the same core questions were answered by each interviewee. The wording of the questions was matched to the coding rationale, but open questions were also used. A full list of the core interview questions can be found in the data repository.

Stakeholder interviews are sometimes called ‘elite’ interviews, a terminology I eschew because of its exclusionary nature (Goldstein, 2002; Harvey, 2011). In the autism policy process, non-elite actors, such as autistic self-advocates are stakeholders with a seat at the decision-making table, as is shown by their inclusion on such bodies as the Adult Autism Programme Board and All-Party Parliamentary Advisory Group on Autism. However, the challenges associated with elite interviews, such as potential power imbalances between the interviewer and interviewee (such as in the case of MPs or Ministers) and difficulties with accessing people to interview remain valid.

I use a combination of gatekeeper (via the National Autistic Society), scattergun (by contacting all board members) and snowball sampling (by asking each interviewee if they can make introductions) to access as many interviewees as possible (Goldstein, 2002). The potential imbalance of power varies from one interviewee to another: MPs, for example, would be in a position of power in a relation to the interviewer, whereas autistic self-advocates may consider themselves in a subjective position in relation to the interviewer. In both cases, maintaining a semi-structured approach allows for maximal control over the interview process. This was also facilitated by the virtual nature of the interviews: a video interview is an equaliser of sorts, since it means that nobody has to travel to anybody else and backgrounds can be hidden (Salmons, 2014). I blurred my background and adapted my choice of clothing to the interviewee. Demographic information was not collected for interviewees since the focus of this research was their stakeholder role.

Online survey

Surveys (Fink, 2003; De Vaus and de Vaus, 2013) allow for questions to be posed to a much larger sample of people than can realistically be interviewed. Questions need to be carefully phrased and, where supporting interviews, as in this case, should be worded as close to the interview questions as possible. Surveys do not allow for follow-up questions or an inductive approach but can contain a mix of open questions with ranking, scale, and multiple-choice questions for easy statistical analysis. Surveys are often used to complement other data collection methods and can be carried out online to maximise reach (Sue and Ritter, 2012). A potential challenge with surveys is that it is not always possible to verify the identity of the respondent in the same way as in an interview, which could lead to inauthentic or even irrelevant or malicious responses if the person does not belong to the appropriate sampling group (Van Selm and Jankowski, 2006; Sue and Ritter, 2012). This can be minimised with screening questions and careful advertising but not avoided entirely. Surveys also do not allow for the same richness of analysis as in-depth interviews.

I created an online survey to maximise reach and facilitate involvement during the pandemic. This was created on the JISC platform using www.onlinesurveys.ac.uk. A mixture of Likert scale and tick box questions linked to the indicators for influence and more open, free-text questions about behaviour and conditions were included. The survey questions were sent to three autistic consultants prior to going live to check that they were accessible. One of the consultants was an academic and the other two were not. The consultants were paid for their time. Demographic information was not collected as it was not the focus of this research. 118 responses were received. A full list of questions can be found in the data repository.

The criteria for taking part in the survey were that the respondent was aged 18 or over, had a formal diagnosis of autism and was able to express their views, either independently, with support or using a proxy. (While there is scholarly debate about whether self-identification as autistic is accurate (Brosnan, 2020), I judged that there was not yet a sufficient consensus to justify eschewing the need for a formal diagnosis.) A tick box required respondents to confirm this before proceeding to the main survey. The survey was advertised to the database of autistic people who had volunteered to participate in research that is managed by the University of Bath's Centre for Applied Autism Research. It was also advertised on Twitter using an advert approved by both the Social Sciences and Psychology Ethics boards.

Focus groups

Focus groups (Finch, Lewis and Turley, 2003; Stewart and Shamdasani, 2014) are a participatory method of data collection which allows for respondents to play a greater role in determining the direction of discussion. The facilitator traditionally intervenes as little as possible, provided that the topic is broadly relevant, and allows the discussion to evolve. Focus groups therefore allow respondents to feel that they have more control over their contribution than they might have in an interview or survey situation. They are also useful for assessing the degree of consensus, although true consensus cannot be assumed just because a group comes to an agreed conclusion. Since focus groups consist of several people, they cover more people in less time than an interview but still allow for a semi-inductive approach. The challenge of focus groups is that they may not end up answering the question you wish them to answer (although this can it itself provide useful data) and that groups of people can be difficult to manage. Focus groups, like surveys and interviews can be carried out online.

The focus groups were advertised at the same time as the online survey and to the same group of people in the same way. As before, the questions, which were designed to elicit perceptions of autistic people in the policy process, were sent to three autistic consultants before being approved. The consultants were paid for their time. All questions can be found in the data repository. Focus groups consisted of between 5 and 6 people to allow for an in-depth discussion of 3 questions and lasted one hour. A total of 24 people took part. Microsoft Teams was used as the medium of discussion. The focus groups were facilitated by an autistic person, who was paid for their time. All focus group participants were also paid for their time with a £10 Amazon voucher.

Method: a two-stage case study

This case study is split into two parts, separating autistic self-advocates from the wider autistic community as two groups experiencing different opportunities for influence and different levels of receptivity. The first part of the case study will focus on autistic advocates, since they are more likely to have access to policy spaces and, according to my theory, therefore more likely to have higher levels of influence. This case study is discussed in Article 2 and uses documents and stakeholder interviews.

However, the autistic community is so diverse and the cumulative effect of intersectionality so great that there are problems of representation – are advocates really representing a broad enough section of the autistic community? Thus, the second part of the case study, in Chapter 6, combines this data with data about the influence of the wider autistic community to assess effectiveness and begin to build a lobbying strategy. This case study combines information from the first case study with a survey and focus groups.

Figure 10 overleaf sets out the method in more detail, as well as how the three articles relate to each other. Article 2 constitutes the first stage of the method for Articles 1 and 3, as well as being a research article in its own right, and provides data to be used in the third and fourth stages. The second stage involves mapping stakeholders to ensure accurate isolation of the relative influence of different parties, while the third entails measuring relative influence and the fourth stage investigates the conditions in which that influence is exerted (the political opportunity structure, including the pyramid of empowerment). The fifth stage assesses the effect, while the sixth and final stage draws together learning from all the stages to produce a thick, narrative description of how autistic influence measures up against the influence of other stakeholders and the conditions which favour it, so that a skeleton lobbying strategy can be assembled. Article 3 draws together the learning about a lobbying strategy for the autistic community and follows Chapter 6.

	Article 1 and Chapter 6	Article 3
Stage 1	Article 1: Justifies case selection and provides data on political opportunity structure in England using fsQCA. Data sources: policy documents.	
Stage 2	Stakeholder mapping. Data sources: policy documents, government websites, Hansard records of parliamentary debates.	
Stage 3	Measuring relative influence of all stakeholders using process tracing and my template for influence. Measuring relative influence of autistic community using process tracing and my template for influence. Data sources: coded policy documents from Article 1, text from Hansard records of parliamentary debates and online stakeholder interviews and focus groups.	

Stage 4	Assessing conditions for autistic self-advocates and the autistic community using content and thematic analysis. Data sources: as above.	
Stage 5	Assessing effect of autistic influence using content and thematic analysis. Data sources: as above	
Stage 6	Combining analysis to produce a lobbying strategy.	

Figure 11: Research Method

More detail on this method and the stages involved can be found in each of the three articles.

Ethical Considerations

There are four areas of caution when it comes to ethical considerations for this research. The first relates to assuring that the data collection process is as accessible as possible to as many autistic people as possible. The second relates to the moral imperative widely accepted by autism researchers and autism journals that research involving autistic people should be co-designed and co-researched insofar as possible (Pellicano, E. and Stears, 2011; Pellicano, L., Dinsmore and Charman, 2013; Milton, D.E., 2014). The third and fourth relate to managing potential imbalances of power: firstly, between autistic self-advocates and the wider autistic community and secondly between the researcher and the underdog.

Accessibility is maximised by following the AASPIRE Guidelines (Nicolaidis et al., 2019) for “the inclusion of autistic adults as co-researchers and research participants”. In keeping with these guidelines, I took the following actions:

- ✓ I made a video introduction to the research as an alternative to a written information sheet.

- ✓ I created an online consent form using Google Forms (which allows the questions to be spoken aloud) as an alternative to a printed consent form, which has a high cognitive load due to the stages involved in returning it.
- ✓ I offered multiple ways of engaging with the interview on different platforms.
- ✓ I had the questions reviewed by an autistic consultant and piloted on autistic people prior to roll-out.

For the most part, autistic people are research participants rather than co-researchers in this project. This is partly due to the nature of a PhD, which is necessarily a predominantly solo endeavour (Felner, 2020) and partly because the importance of co-design became progressively evident and much of the project had already been designed. However, the survey and focus group questions for Article 3 were reviewed by three paid autistic consultants, including Dr. Damian Milton, an autistic researcher who specialises in participatory action research. These three consultants also provided feedback on my analysis of the findings. If I could begin the PhD over again, I would attempt a higher degree of co-research.

The potential imbalance of power between autistic advocates and the wider autistic community is managed by keeping these two strands of the research separate but directly questioning perceptions of power and representation through the interview and focus group questions. The potential imbalance of power between the researcher and the autistic community is mitigated through conscious awareness of the possibility that the interviewee/survey respondent/focus group participant may feel uncomfortable and doing my best to provide a neutral environment. In online interviews and focus groups, I blur my background so that no conclusions can be drawn from my physical environment, and I dress in smart but casual clothes. I am clear that my aim is to provide autistic people with the data needed to make changes and with suggestions as to how to make that change, but not to tell them what to do or to try to make changes on their behalf.

Conclusion

As stated in the Introduction, the aim of this thesis is to inform a lobbying strategy for autistic people and, more widely, for underdogs everywhere. My underdog theory, set out in Chapter 3, argues that underdogs have untapped potential for influence and can empower themselves to exert more influence than they or others would think possible. The first stage in this is to ascend the pyramid of empowerment, which is dependent in part upon the actions of others, such as governments in ensuring basic needs are met, and to make the decision to take action. An important stage in ascending the pyramid of empowerment is an awareness of the political opportunity structure in which one operates and an awareness of one's own strengths and weaknesses. The pyramid ascended, I argue that the underdog can maximise their influence by actively participating in politics/policy, collaborating with others and, crucially, adopting a strengths-based approach.

In this chapter, and also in Article 1, I have set out indicators for influence calibrated for the underdog and have described how process tracing can be used to assess the relative influence of different stakeholders. I have also shown how content and thematic analysis can be used to detail the conditions in which that influence is exerted and to assess how far the pyramid of empowerment has been ascended. By combining what I hope to be a higher-than-expected level of autistic influence with an assessment of the conditions which facilitated it, I hope to be able to provide the autistic community with a skeleton outline of a lobbying strategy based on my underdog theory, which they can build upon and develop.

In Chapter 6, which follows, I draw together the analysis from the full case study to further build both our understanding of autistic influence, and my underdog theory. Article 3 follows Chapter 6 to elucidate the lobbying strategy for the benefit of the autistic community.

6. The underdog empowered Part 1: how much influence does the autistic community in England actually have?

Introduction

In this chapter, and the one that follows, I begin to build a case study of the policy influence of the autistic community in England and the extent to which they fit my skeleton theory of the empowered underdog. Through this case study, which combines data from all three articles, and is split across two chapters, I continue the theory building process by fleshing out the skeleton theory assembled from the scholarship in Chapter 2 with empirical evidence. The end result is a deepened theory and thick description (Geertz, 1973) of underdog empowerment and policy influence, with empirical evidence from the case of the autistic community in England. The first chapter focuses on the extent of autistic influence (as outlined in Article 2), while the second chapter covers the conditions and effects associated with influence, the behaviour of successful autistic advocates and the extent to which the underdog theory is supported by the evidence (Articles 1 and 3). The reason for this divide is that demonstrating that autistic people have a significant (relative) level of influence is crucial for supporting the later elements of the underdog theory.

Chapter 4 has already set out the reasons why the autistic community were selected to help build this theory. There was evidence, in the form of the trailblazing Autism Act 2009, and the findings from my article on autism policy design, that suggested that autistic people might have more opportunities for influence and be framed in a more powerful way than some other marginalised groups.

However, there is also evidence, in the form of the most recent iteration of the Autism Strategy for 2021-2026 (DHSC, 2021), itself the product of a governmental review (APPGA 2021), that suggests that autistic people still feel themselves to be very much disenfranchised and disempowered. While awareness of autism has increased, the review highlights that awareness is not understanding, and 76% of autistic adults feel misunderstood, while 79% feel socially isolated. Indeed, the review showed that only 38% of autistic people were aware of the Autism Act and their rights under it, let alone the opportunities to get involved in policy decision-making that it offers (APPGA 2021). With 66% of autistic people experiencing suicidal thoughts over unmet needs, it is clear that, despite many inroads, there is much still to do in autism policy (APPGA 2021).

To avoid unnecessary repetition of the data in Article 2, this chapter, while summarising the data and, in places, going into more detail on it, will be structured around the research process and how the underdog theory evolved through the semi-inductive and iterative process outlined in Chapter 5.

When the underdog theory was first outlined in Chapter 2, there was not really a specific proto-explanation about the extent of influence, but it did form part of the main research question. Implied but not explicitly hypothesised was that autistic people did have policy influence, despite the fact that evidence from the scholarship and societal explanations would lead one to believe they would not. The underdog theory itself outlines a disconnect between expectations and reality, therefore an analysis of the reality of influence was essential.

However, while I had anticipated that the autistic self-advocates interviewed would have more influence than the wider community, given that they sit on decision-making bodies, I had not anticipated how wide the differential would be: this was the first evolution. The second evolution emerged from an analysis of how both influence and conditions differed: the key difference was in the behaviour of self-advocates, something that, in keeping with the premises of the underdog theory, is under their control. The third evolution was therefore that the wider community could learn from their more influential members – in this case, self-advocates, but in other underdog communities, this might vary.

This chapter begins then with a summary of the data outlined in Article 2 and moves on to consider these three evolutions in more detail.

The extent of autistic influence

I begin my analysis of the results with the data relating to the first research question: the extent of the influence of autistic self-advocates and the wider autistic community. There are two aspects to this: what proportion of the indicators outlined in Chapter 3 are evidenced, and how strongly they are evidenced, and whether this constitutes a 'higher than expected' level of influence. I consider the level of influence to be 'higher than expected' if it meets the following conditions:

1. The level of influence is 'medium' or 'high' on the majority of indicators
2. 'Reputed influence' is 'medium' or 'high'
3. The level of overall influence is higher than the level of self-reputed influence.

The table overleaf, reproduced from Article 1, shows the relative influence of autistic self-advocates and the wider community compared to other actors.

	Goal attainment	Agenda control	Reputed influence	Self-reputed influence	Active Participation	Framing Congruence
Autistic self-advocates	High	High	High	Medium	High	High
Wider autistic community	Medium	High	High	Low	Medium	Low
Families and carers	Low	Low	Low	Low	Medium	Low
Charities	Medium	Medium	High	High	High	Medium
Professional Bodies	Medium	Low	Medium	Medium	Low	Medium
Academics	Medium	Low	Low	Low	Low	Medium
Government Bodies	Medium	Medium	Medium	Medium	High	Medium
Government Departments	High	High	High	High	High	High
MPs	Low	Low	Medium	Medium	Medium	Medium
Secretaries of State	High	High	High	High	High	High

Figure 11: Relative influence of autism policy stakeholders

The specific question posed was asking interviewees to classify the influence of each group as either low, medium, or high. Most interviewees gave additional detail, which is used in the deeper analysis which follows later in the chapter. What is immediately apparent from the raw results is that autistic self-advocates scored 'high' on all indicators of influence except for self-reputed influence, which is what they and think of their levels of influence. Their level of influence is second only to government departments (civil servants) and Secretaries of State. Most interestingly, among the interviewees, i.e., those actually involved in the policy decision-making process, reputed influence of the wider autistic community was high. Evidently, those involved in the process believe that autistic people are in the driving seat – or at least report that they believe this, which indicates that they believe the involvement of autistic people to be important.

While there is a difference in the extent of the influence exerted by autistic self-advocates and the wider community, the wider community do meet the criteria for 'higher than expected influence'. They score 'Medium' or 'High' on four out of six indicators, 'High' on reputed influence and their overall level of influence is clearly higher than the 'low' that they ascribe themselves. This is reinforced by the survey data – although a specific question about influence was not asked, the following quotes make it clear that those surveyed had a negative opinion of their own influence. While not a big enough sample to be argued to be representative of the autistic community as a whole, this evidence nonetheless corroborates the evidence from the interviews.

"Nobody listens, they are thought of as being disabled and unintelligent."

"Not being taken seriously by the Government and the general public."

"Lack of awareness/confidence that their thoughts could be influential or might be valued."

"Autistic people are not seen as able to make good decisions / give good advice."

Agenda control

Drilling down into more detail than was possible in the articles in terms of data, we can see that agenda control is high for both autistic self-advocates and the wider autistic community. This was assessed by a mixture of asking interviewees directly about the topics discussed at meetings and observing the extent to which policy issues raised as a priority by autistic people were reflected in governmental discussions and policy documents. (Interviewees were asked if any group dominated the agenda, how agendas were determined and whether they could describe a time when they had succeeded in getting an issue on the agenda.)

The main issues raised by both autistic self-advocates and the wider autistic community were better public understanding of autism, mental health support, employment support and availability of local services. NVivo coding showed that at least three of these four goals were mentioned in all interviews and each of the focus groups. These are all headline statements in the most recent Autism Strategy, which has as its goals “improving understanding and acceptance of autism within society”, “building the right support in the community and supporting people in inpatient [psychiatric] care” and “supporting more autistic people into employment” (DHSC, 2021). They also appear with frequency in governmental discussions, where ‘understanding autism’ is tagged 174 times in Hansard records since 2018, while ‘autism and mental health’ is tagged 454 times, ‘autism and employment’ 147 times and ‘autism and local services’ 101 times. (Hansard, 2021)). All of this suggests that the goals put forward by autistic self-advocates both reflect those of the wider community and make it onto the governmental agenda. While this is not proof of influence, it is corroborating evidence. Supporting this further are the quotes below from stakeholder interviews:

“Autistic people definitely drive what we talk about, we are always going back to ask, ‘what do you need’, ‘what do you want’. We can’t always give it to them, but we do ask.”   *Civil Servant*

“Oh, I’m only called in to discuss issues when autistic people have raised them. I wouldn’t get a look-in if I didn’t have some kind of expertise they thought they could use”.   *Professional Body Representative*

> "Obviously, the government has the final say, and sometimes we have to follow their agenda but most of the time, yeah, they do listen to us, and we do get to discuss what we want. And we always make sure we are speaking to our networks, so we're not just reflecting our views but what other autistic people think too".
>
> *Autistic self-advocate*

Finally, on the subject of agenda control, it is noteworthy that levels of agreement within the wider autistic community surveyed with the stated goals of autism policy is extremely high (between 75% and 90% for all governmental goals), as shown in the chart overleaf. Agreement with the goal of public understanding is highest at 90%. (Raw data can be found in the data repository.) While the number of respondents is not sufficient enough to render it representative of the wider community as a whole, this is helpful in contributing to our understanding agenda control as a form of influence. Autistic people may not be happy with the detail of policy, as the focus group results will show, but those surveyed/spoken to were in agreement with the policy goals. Unfortunately, many of the wider community are unaware of what governmental goals are, however, as we will see later, which presents another learning point.

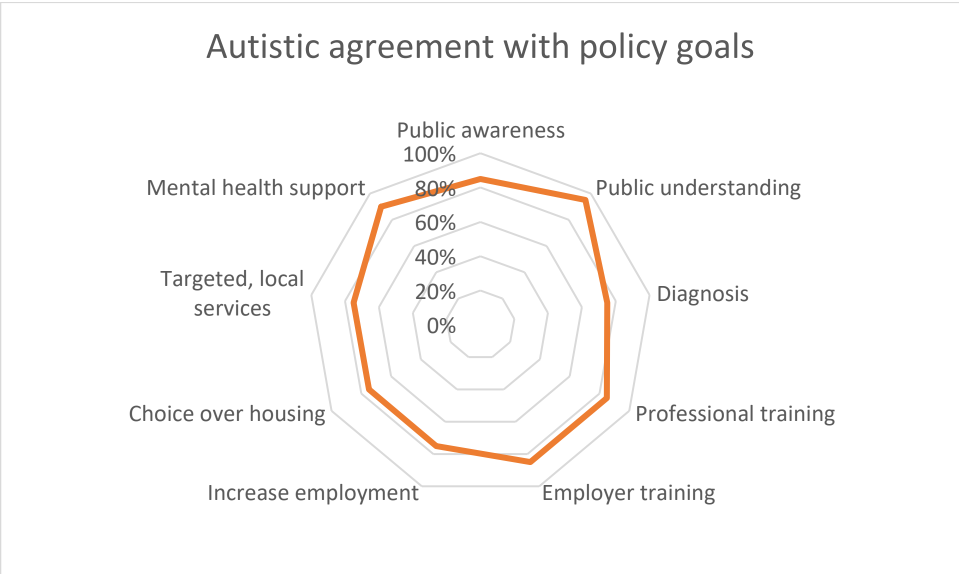

Figure 12: Autistic agreement with policy goals

Agenda control is essential for influence to be exerted at later stages. While it is not entirely surprising that it is demonstrated here, since the scholarship does suggest influence is more likely during the agenda setting and problem definition phases (Baumgartner and Jones, 2009; Junk and Rasmussen, 2018; Schneider and Ingram, 2019), it is crucial for the underdog theory that it is demonstrated here for both advocates and the wider community. This is because it shows that autistic self-advocates are effectively representing the wider community – more on this later in the chapter.

Active Participation

Both goal attainment and active participation are high for autistic self-advocates but medium for the wider autistic community. It is not surprising that active participation is higher for autistic self-advocates, since they by definition seek to get involved in policy. However, it is noteworthy that it is medium for the wider autistic community, who, despite stating very clearly that they do not think they have much influence (as shown by the quotations below taken from the online survey and the chart showing self-reputed influence below), still come out and try to make a difference.

"Nobody listens, they are thought of as being disabled and unintelligent."

"Not being taken seriously by the Government and the general public."

"Lack of awareness/confidence that their thoughts could be influential or might be valued."

"Autistic people are not seen as able to make good decisions / give good advice."

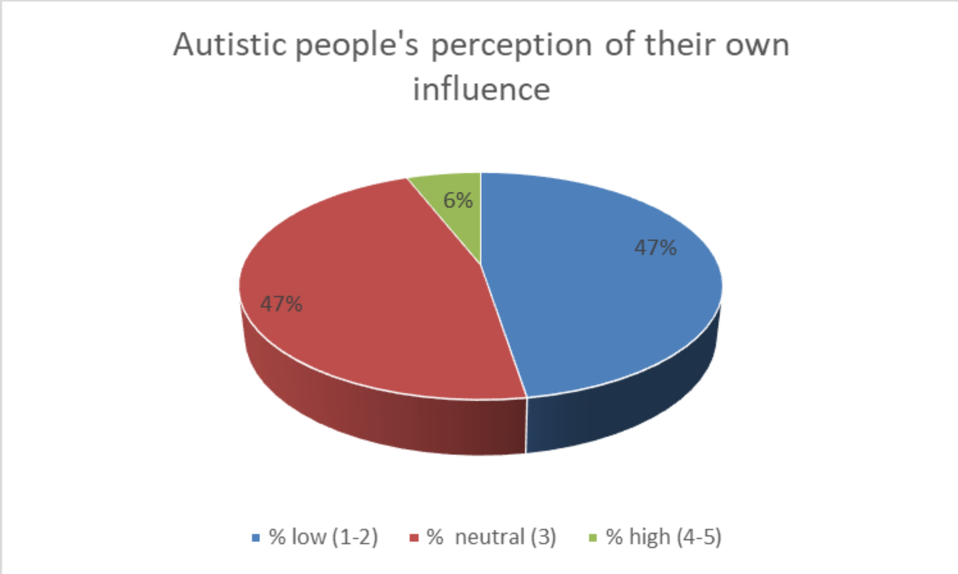

Figure 13: Autistic people's perception of their own influence

Despite these low perceptions, the charts below show that those autistic people who responded to the survey are at least moderately politically active (which is possibly unsurprising, since responding to surveys is a means of political engagement). Although overall levels of participation are not high, when data about awareness of methods of participation is combined with data about participation, it is clear that these autistic respondents do engage with those participation methods of which they are aware.

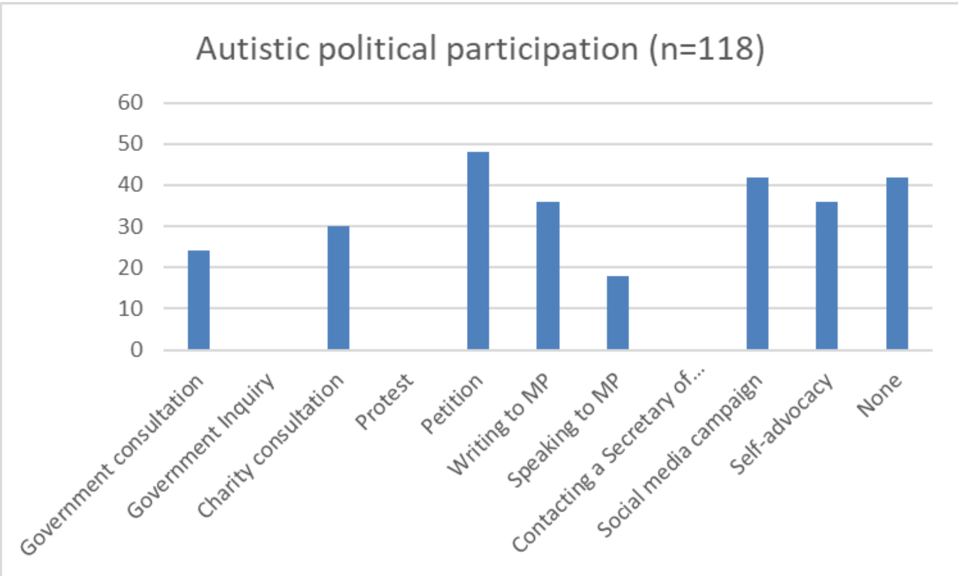

Figure 14: Autistic political participation

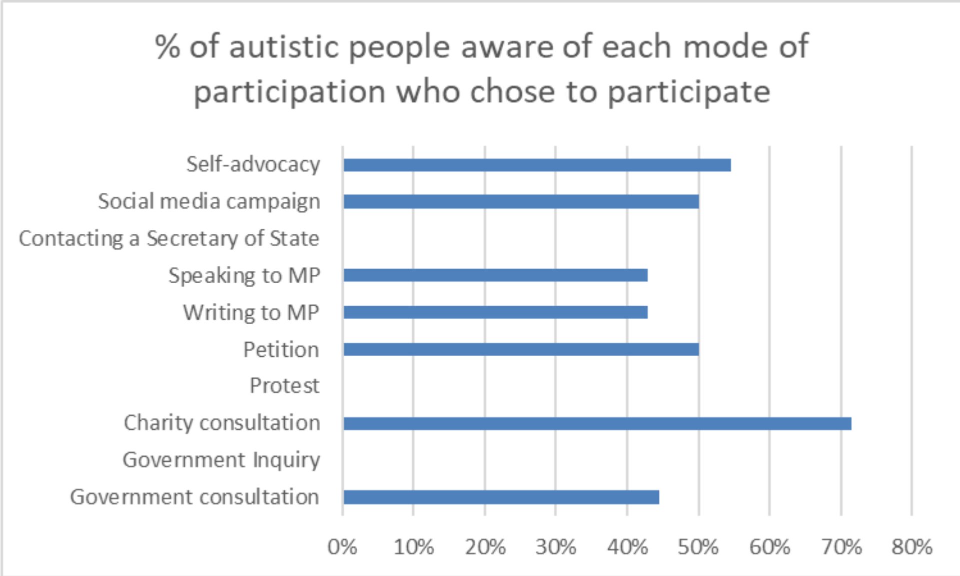

Figure 15: % of autistic people aware of each mode of participation who chose to participate

Also of note is the nature of the modes of participation that are more popular. Charity consultation is by far the most popular, with responding to government consultations, signing petitions, and participating in social media campaigns also popular. These are all relatively passive modes of participation (Halvorsen et al., 2017; Junk, 2019a): they are easy to do from home and, with the possible exception of social media campaigns, entail little risk. Protest, the highest-risk strategy (Jasper, 2014; Quaranta, 2015) is notably entirely absent – although this may be partly explained by the sensory hypersensitivity experienced by many autistic people (Pellicano, E., 2013), which would likely make protesting a difficult experience. This is against a backdrop of levels of people protesting increasing on a global scale (Bailey, 2020). However, self-advocacy remains strong, indicating that encouraging more autistic people into self-advocacy and upskilling them in the behaviours demonstrated by influential self-advocates could be an effective route to lobbying success. This raises another learning point: that raising awareness of available methods of participation would likely result in higher levels of active participation.

Goal attainment

We have already seen that the autistic community agrees broadly with governmental policy goals – however, they have a relatively low opinion of how far they have been achieved, as shown in the table overleaf.

Goal attainment	% not at all (1)	% entirely (5)	% partially (2-4)
Public awareness	16%	8%	75%
Public understanding	17%	14%	69%
Diagnosis	48%	0%	52%
Professional training	14%	7%	80%
Employer training	25%	0%	75%
Increase employment	47%	0%	53%
Choice over housing	37%	0%	63%
Targeted, local services	27%	8%	64%
Mental health support	36%	6%	58%

Figure 16: Goal attainment

The autistic self-advocates interviewed broadly agree with this assessment, stating that there has been progress towards meeting governmental goals (as shown in the quotations below), but they have not yet been fully achieved. Indeed, this view is shared by other stakeholders interviewed.

“We’ve come such a long way, twenty years ago no-one knew about autism and now everyone does. There’s a lot more to do but I really think we should recognise the progress too.”

Autistic self-advocate

“Progress has definitely been made, especially in public awareness and understanding, but there’s more to be done, for sure.”

Civil Servant

“The training for professionals makes such a difference and it’s easier to get a diagnosis. I didn’t say it’s easy, mind. We’ve still a way to go.”

Professional Body Representative

“Oh, the whole landscape has changed. Working together, we’ve achieved a lot. But of course, there is a mountain to climb yet.”

Charity Representative

However, the real difference comes in the extent to which the goals proposed, rather than supported, by autistic people and by autistic self-advocates are achieved. These are much less likely to have been achieved than the government’s stated goals, partly of course because they do not form part of government policy. However, the reasons why they do not form part of government policy are potentially explicable by the difference in how those goals are articulated. The goals as articulated by the wider autistic community are in fact much harder to achieve and to measure, because they tend to be much more general in nature, and to involve changing things which are beyond the power of the government to change, as shown in the quotations below taken from the survey and focus groups. These responses were in relation to a specific question “What does the government need to do differently to help you?” but were generic in their response. While this may be down to a misunderstanding, the chances of this were minimised as the questions were approved by three autistic consultants for accessibility before being used.

“less diatribe and extremist politics in the autism world”

“the general public need to change their attitude towards us”

“society needs to change”

“we need to become visible, and to be enabled by society”

“the public not electing a Conservative government”

Conversely, autistic self-advocates were very aware of the importance of promoting goals which were achievable, measurable and which could be framed in a way which made them attractive to the government.

“I think that with experience of working with people, in government, you know, you get to understand what might work and what doesn’t, and you pick your time and you put things a certain way”.

“You have to take the long view; you have to be able to see the steps that take you to your end goals. You can’t jump straight to your end goal; it doesn’t work like that.”

This offers another potential area where the wider community could learn directly from the policy experience of autistic self-advocates about more effective ways to frame their goals.

Framing congruence

Indeed, framing congruence is one of the two areas which shows the greatest discrepancy between the influence of autistic self-advocates and the wider autistic community, indicating that this is a factor in goal attainment. Specifically, it can be noted that autistic self-advocates propose a much more positive, strengths-based framing of autistic people than the wider autistic community: they focus more on their potential than on their difficulties. This is reflected in the thematic analysis of policy documents and Hansard discussions used in Article 3, which found that 67% of references to autism were framed positively as opposed to 22% framed negatively, as well as in the updated language used in on government websites, which is very clear that autism is a difference not a deficit, and that autistic people can ‘lead fulfilling lives’, as stated in the preamble to the Autism Act (AutismAct, 2009).

This difference can be seen in the quotations below taken from the online survey of autistic adults and contrasted with the interviews with autistic self-advocates and government websites.

From the survey:

"Only a minority of autistic people actually have the necessary understanding of our own brains to become self-advocates"

"Impaired ability to communicate in a manner that is considered OK by our type of society"

"People with ASD are not the golden ticket they don't know about anyone's autism except their own"

"Getting autistic people to agree on anything is like herding cats"

From interviews with autistic self-advocates:

"I feel like we focus on the wins more than the losses. People will have a good success story, people will be the ones that, you know, if I get access to this, or these things change, I can be the best and I can excel, I can be brilliant. And I think that when you've got like an audience around that people love to hear those stories."

"That's kind of the problem with policy, because in order to get change, you have to make something out to be really bad. But then when you make something out to be really bad, you create a negative image of yourself. And it just goes in a cycle. So, it's a balancing act. You have to include the negatives but also keep reminding them of the positives, the potential, that it's not the end of the world if you're autistic."

From government websites:

NHS definition of autism: “Being autistic does not mean you have an illness or disease. It means your brain works in a different way from other people.” (NHS, 2021)

“Autistic people see, hear and feel the world differently to other people. Autism varies widely […] While autism is not a learning disability, around 4 in 10 autistic people have a learning disability (Autistica). Some autistic people will need very little or no support in their everyday lives while others may need high levels of care.” (HM Government, 2021).

This indicates that the framing of autism in public documents has shifted to a more positive framing (Kenny et al, 2016; Jordan, 2020). Previously, autism was described by the government and the NHS as ‘a neurodevelopmental disorder’ and ‘a disability’ (DHSC, 2010; NHS, 2011). This shift in framing is important for a number of reasons beyond the fact that it is a measure of influence. Firstly, it is noteworthy that this positive framing is shared by self-advocates but not by the wider community. The measure of framing congruence would therefore suggest that autistic self-advocates have more influence than the wider community. Secondly, the fact that the positive framing has not reached the wider community is indicative that it is not yet normalised in society (this is also supported by the analysis in Chapter 4 on case selection). This highlights the influence of autistic self-advocates further and makes it more likely that the shift in framing can be attributed to them, since governments rarely go against public opinion (Schneider and Ingram, 2019). Thirdly, it is supportive of the idea that will be explored in the sections that follow on the evolution of the theory, that this is an area where the wider community can learn from autistic advocates. Fourthly and finally, it supports my original prediction that a strengths-based approach, i.e., a positive framing, would be beneficial for increasing underdog influence. This is therefore a key component of both the case study and underdog theory for a number of reasons.

In conclusion for this section on the extent of autistic influence, it is clear that autistic people do have influence over autism policy to an extent which can be considered surprising given the scholarship on underdog influence, as outlined in Chapter 2, and societal expectations about this particular underdog community of autistic people, as outlined in Chapter 4. They also clearly have more influence than autistic people in general consider themselves to have. This is supportive of the implicit predictions inherent in the underdog theory. However, it is now important to highlight the evolutions in the development of this theory that emerge from the data.

The evolution of the underdog theory

As previously outlined, there are three main evolutions that emerged from my analysis of the extent of underdog influence. These are the extent of the differential between autistic self-advocates and the wider autistic community, the importance of behavioural choices and the learning opportunity that this differential presents.

The differential between autistic self-advocates and the wider community

The first evolution arose from the realisation that the differential between autistic self-advocates and the wider community was quite significant in some areas. This was a potential threat to the validity of the underdog theory and therefore needed to be examined to ensure that autistic self-advocates were not simply part of the government system or another elite. In fact, my analysis showed that the areas where autistic self-advocates and the wider community shared similar levels of influence and where they differed were evidence of both effective representation by autistic self-advocates (not generally associated with an elite) and highlighted that the main difference was in behaviours, which led to the second evolution which actually reinforces the underdog theory.

To reiterate first the a priori reasons for methodologically differentiating autistic self-advocates from the wider autistic community, there is the obvious reason that certain autistic self-advocates (and they are a very small number) are given direct access to the autism policy decision-making process (AutismAct, 2009) and this increases the likelihood that they will be able to exert influence (Lowery, 2013; Cornwall, 2017). However, McCoy et al (McCoy et al., 2020), amongst others, argue that it is impossible for autistic self-advocates to fully represent all autistic people. This raises the question of whether an increase in influence in the small number of autistic self-advocates with direct access to the policy decision-making process can be considered to equate to an increase in the influence of the wider autistic community.

It is possible that autistic self-advocates are just another form of an 'elite' (Wedel, 2017) and there has certainly been some tension and distrust between autistic self-advocates, the wider community and particularly parents and carers, over the years (Bertilsdotter Rosqvist, Brownlow and O'Dell, 2015; Petri, Beadle-Brown and Bradshaw, 2020). As a result, it cannot be assumed that the goals and aims of the autistic self-advocates who sit on decision-making bodies, and the wider community are the same, or indeed that the representation of the wider community by autistic self-advocates is effective. For all these reasons, it was important to design the research in such a way as to capture these actors separately.

The evidence shows that the differential between autistic self-advocates and the wider community is widest when it comes to framing congruence and smallest when it comes to agenda control, on which the two are equal. In the other areas the difference is either between High and Medium, or Medium and Low. The fact that the wider community has a high level of control of the agenda, i.e., that government is discussing the issues and seeking to meet the goals that they desire, is evidence of effective representation of policy goals and priorities by autistic self-advocates and high levels of indirect influence by the wider community. This strongly suggests that autistic self-advocates are not just another form of elite.

Elites by definition possess influence, but just possessing influence does not make one a member of the elite: there is also an ideological component as well as a material one (Marvick, 1977; Cohen, 2020). Cohen argues that elites are “particularistically” (Cohen, 2020, pxiv) organised and use shared symbols to maintain their power. There is nothing in the data that I have gathered to suggest that there is any significant organisation to the autistic self-advocates working on the decision-making bodies. They acknowledge participating in online forums and networks (“I’ll go and make a post or send an email round a WhatsApp group”) but there is no evidence of central organisation of policy response. The networks and forums appear to be more for support than activism (Bagatell, 2010; Jordan, 2010). While national and supranational advocacy organisations do exist, they are not directly associated with any of the autistic self-advocates interviewed (beyond the National Autistic Society which is a charity rather than an advocacy organisation). There is also no evidence in the data I have gathered for any shared symbolism. Each of the advocates talked about autism and their priorities in a very individual way (the only terminology that was repeated by different advocates referred to autism being a “difference”) and indeed acknowledged that they were only really able to speak about their own autism.

> “I can talk about my own struggles and needs and I can report what others say their struggles are but that’s the limit of it, we’re not all the same.”
>
> “I do my best to report what others say because I know their experience might not be the same as mine”.

One would expect an elite, seeking to reinforce their power (Cohen, 2020) to be more explicit in the use of shared symbols and more organised in nature; therefore, I do not think it is appropriate to consider autistic self-advocates an elite simply because they have more influence. The conditions section of this chapter reveals that while advocates are usually economically better off than the average autistic person (in the sense that they are usually employed and live independently), they report high levels of stress from daily life and an emotional toll from their advocacy work. It is hard to view them as elites on reading the quotations below.

"Even with all the skills and strategies I've learned, even with a supportive boss, even with supportive friends, a supportive fiancée, I still have meltdowns and just go to ground for days."

"I don't think people understand just how much work it takes to look like you're functioning. How hard I have to think just to hold a conversation. How hard advocacy is. I think that's why a lot of people don't stay advocates for long – it takes an emotional toll."

Having established, then, that autistic self-advocates are effectively representing policy priorities and goals, I turned to question why framing congruence was so diverse, and specifically why the wider community had adopted a negative rather than a positive framing of autism. Framing is an interesting concept in that it can be a deliberate choice, but it can also be the product of one's experiences or societal context. Framing congruence tends towards viewing the projection of a particular framing as a deliberate choice (Börang et al, 2017). Autistic self-advocates are part of the wider community and operate in the same societal context, which favours the more negative framing adopted by the wider community. Self-advocates, then, are the group who are departing from the norm and more likely to be making a deliberate choice, whereas the wider community are more likely to be simply reflecting the framing they see around them. The quotes below from interviews with self-advocates support this idea and offer some explanation of why they chose a positive framing.

"It is a balancing act, it is tricky. You have to demonstrate the need while showing the potential. If you make it all seem bright and breezy and positive then, well, why should there be a policy change? But if you are all doom and gloom then you paint yourself into a corner. So, you have to acknowledge the need but show the potential."   *"Fundamentally I'm just expressing what I believe. There are certain problems that a lot of autistic people face in daily life but that doesn't mean that being autistic has to be a bad thing. If you look at autism differently you can see it as an opportunity not a death sentence."*   *"It's about helping autistic people help themselves, is how I see it. We can do a lot more than we think we do if we only open our eyes."*

This evidence both supports the underdog theory's proto-explanation about the ability to alter framing and demonstrates that proactive action can be taken to increase influence. As a result of this evolution, I moved on to the second evolution which looked at how much else was down to deliberate action.

The importance of behaviour

Even before this evolution emerged, I had expected that behaviour would be a key component of the underdog theory because taking action tops the pyramid of empowerment and was shown in the analysis in Chapter 2 to be associated with higher levels of self-efficacy and empowerment. However, I was surprised to note that the indicators of influence which aligned most strongly with a need to take a deliberate action were also associated much more strongly with autistic self-advocates than the wider community. In other words, the association between behaviour and influence was stronger than I had anticipated. This both reinforced the fundamentals of the underdog theory and shaped its evolution towards a recommendation for less influential underdogs to learn from more influential underdogs in developing a lobbying strategy.

I have already discussed framing congruence as a result of a deliberate action and, as previously noted, this was the indicator of influence where the differential between self-advocates and the wider community was highest. Conversely, agenda control, where the differential was smallest, is associated with direct action by advocates but no direct action by the wider community. The data for active participation, meanwhile, shows that the wider community lack awareness of opportunities for participation but do participate in those activities of which they are aware. This highlights the importance of building awareness. The other indicators are much more loosely linked to deliberate actions – goal attainment is subject to many factors outside the actions of advocates, for example. The likelihood of a goal being attained can be increased by wording or framing the goal in a certain way and this, as will be discussed in the next chapter, may be one reason why advocates score more highly here. Reputed influence is almost entirely beyond the control of the underdog, and self-reputed influence, while partially under their control, takes a lot of self-awareness to be able to change.

Thus, it became evident from the data that an in-depth exploration of behaviour was needed, and this is discussed in Chapter 7 and also in Article 3. The third evolution, which followed on from this recognition of the difference in behaviour between autistic self-advocates and the wider community, relates to the learning opportunity that this differential creates.

A learning opportunity: learning from more influential underdogs

The combination of recognising the breadth of the differential between advocates and the wider community and recognising the role of active and deliberate behaviours opens up the opportunity for less influential underdogs to learn from more influential ones. This is ethically preferable to lobbying strategies being recommended by a researcher who does not belong to the underdog community, for a number of reasons. Firstly, the very fact of seeing somebody who belongs to the same group as you and who is in a position of power, or influence, has been shown to be beneficial to empowerment (Watson et al, 2007; Depper, Fullagar and Frampton-Webb, 2019). Therefore, being taught or guided by someone from the same underdog community is likely to be empowering. Secondly, it enables the strategy to be mapped to the specific context. Thirdly and finally, it puts the underdog in the driving seat, which is psychologically important for their empowerment. Exactly what the behaviours that need to be taught might be, and what the lobbying strategy might consist of will be developed in Chapter 7, which follows.

Conclusion

It is clear from the data that autistic people possess policy influence of a sufficient level to support the utility of investigating the underdog theory further. Whereas the existing scholarship would lead us to believe marginalised groups have low levels of influence, the wider autistic community have been shown to have medium direct levels of influence and, potentially, through the more influential autistic self-advocates, even high indirect levels of influence.

This chapter has answered the first part of the research question, but in order to fully test my underdog theory, we must go on to assess the conditions and effect of this influence, to see the extent to which my proto-explanations and pyramid of empowerment are supported by the evidence and to further assess both underdog behaviours and the outline of a strategy. This is covered in Chapter 7, which follows to complete the case study.

7. The underdog empowered - Part 2: The autistic community on a journey to underdog empowerment.

Introduction

This chapter continues the analysis and case study begun in Chapter 6. Having established that the autistic community and autistic self-advocates sampled do demonstrate a higher level of influence than expected but that there is a divergence between advocates and the wider community in both influence and behaviour, this analysis proceeds to assess the conditions in which influence is exerted in order to identify elements which could be used to build a lobbying strategy. Thus, it answers the second part of the first case study research question by looking at the conditions and effect of influence, and it goes on to discuss the later case study research questions, namely the ways in which influence can be maximised and how this might be incorporated into a lobbying strategy. The final part of the chapter assesses the extent to which the autistic community in England can be considered to support my underdog theory. Once again, the data is presented first, followed by the analysis.

The conditions in which influence is exerted

This section of the data is split into two sub-sections which I will call conditions and behaviours. Conditions is used to refer to those elements which are outside the control of autistic self-advocates and the wider community – the external conditions which regulate their opportunities for and ability to influence. Behaviours is used to refer to actions or choices taken by autistic people.

Conditions

Beginning with conditions, data from Article 1 showed that the Autism Act 2009 and first Autism Strategy had created opportunities for autistic self-advocates to sit on decision-making bodies in relation to autism policy. In theory, any autistic person could apply for a seat, but in practice, only those self-advocates involved in the process are aware of the opportunity. When asked, nobody in any of the focus groups, who by definition were politically interested, were aware that they could apply to sit on one of these bodies. Therefore, the conditions for autistic self-advocates are more advantageous than for the wider community because they have an easier access to decision-making spaces.

When asked about barriers to participation in decision-making spaces, the autistic self-advocates interviewed agreed that money and the ability to take time off work might limit who was able to attend such meetings; however, they also felt that the move to online meetings occasioned by the COVID pandemic was overcoming some of those barriers.

"I'm lucky to have a supportive employer but you can claim back your expenses so there is help".

"A lot is online today, which makes it easier".

However, it is in their financial/employment status – a factor in autism advocacy which has also been noted by other scholars (Ne'eman and Bascum, 2020; Petri, Beadle-Brown, and Bradshaw, 2021) that any noticeable variation between the conditions for autistic self-advocates and the wider community ends. Autistic self-advocates by definition are able to communicate their opinions, and this places them at the more advantaged end of the spectrum; however, there are many who share these advantages who do not choose to be self-advocates (Caldora and Coghill, 2020; Ne'eman and Bascum, 2020). In addition, the self-advocates interviewed were clear that they continued to experience many difficulties in carrying out their advocacy work– advocacy at the national level carries a toll, both financial and emotional (see quotes in Chapter 6). It is undeniable, however, that all the self-advocates interviewed experienced a relatively high level of privilege in the sense that they were all employed in permanent roles and living independently. Their advocacy work was carried out as a 'hobby' almost alongside their paid work, and the time/money to be able to do this is a privilege in itself. Much has been written about the cost of self-advocacy (Itkonen and Ream, 2013; Gardner and Brindis, 2017; Petri, Beadle-Brown and Bradshaw, 2020) and it would be neither realistic nor fair to suggest that advocacy should be an expectation of any autistic person. However, for those with the resources and willingness to do it, advocacy clearly helps advance the autistic cause and, I will argue here, can be used to help engage and empower other autistic people who are unable or unwilling to commit to advocacy.

It is helpful here to refer back to the proto-explanations with which I started my explanatory framework. The first two relate to conditions and the final three to behaviours.

Proto explanation 1:

In order to politically empower themselves, underdogs must understand the policy environment within which they are to operate.

Proto explanation 2:

Underdogs are uniquely placed to alter the framing of the target group and can also alter the framing of policy issues.

The data on conditions suggests that both of these proto-explanations are supported. An understanding of the policy environment was evident for autistic self-advocates, who spoke with confidence of how to navigate 'the system', but not for the wider community, who were often unaware of the opportunities available to them. This is therefore a potential explanation for the difference in their level of influence. It is unclear from the data whether the advocates gained their knowledge of the policy system from their advocacy work or possessed it prior; however, what is clear is that this knowledge is beneficial. Moreover, the knowledge can be shared with the wider community for wider benefit.

Secondly, data from the interviews supported the idea that those sitting on decision-making bodies felt that they benefited from the presence of autistic self-advocates in decision-making spaces. All of the stakeholders interviewed reported the influence of self-advocates as high or medium, with a majority reporting it as high. They valued the expertise of the advocates and their ability to provide an experiential perspective. Damian Milton's (2013) 'double empathy problem' demonstrates that miscommunication, which is common between autistic and neurotypical people, is a two-way misunderstanding. It is not that the autistic person does not have empathy but that neither side find it easy to understand the other's perspective. As a result, there is a responsibility on both sides to facilitate two-way communication and this is something that the stakeholders clearly felt to be helpful in helping them understand the perspective of autistic people – a perspective which doesn't necessarily come naturally to them.

"It definitely helps to have autistic people in the room, you get to hear about real experiences".

"Well, the advocates are just brilliant, it helps you see the potential."

"They keep us on our toes!"

This supports the idea that seeing someone from a marginalised group who is living up to their potential in spite of marginalisation (an underdog empowered) is a powerful symbol. This is particularly true in those cases where autistic people have reached a position of authority – for example, the Chair of both decision-making bodies at the time of the interviews was autistic. This adds a gravity to their perspective, in the same way as autistic celebrities can help normalise autism (MacLeod, A., Lewis, A. and Robertson, C. , 2013)

Thirdly, the level of framing congruence was higher for autistic self-advocates than for any other group, but low for the wider community. While framing congruence does not prove that a particular actor altered a framing, it is accepted as a form of influence over framing. The high level of congruence between the framing put forward by autistic self-advocates and the framing in policy documents is indicative that they have contributed to a reframing of autism and autistic people.

Behaviours

The difference in behaviour between autistic self-advocates and the wider community is much more pronounced than the difference between external conditions, indicating that this may well be an explanatory factor for the difference in their levels of influence. There is a very clear difference between the way that the wider community interacts with stakeholders and the government, and the way that autistic self-advocates interact. Crucial to the development of a lobbying strategy is the fact that autistic self-advocates have been shown to have a higher level of policy influence; therefore, while we cannot claim clear causality from the sample assessed, we can say that their behaviours are associated with increased policy influence. We can also assess the extent to which they embody the 'underdog behaviours' described earlier in this thesis.

This assessment begins with analysing the extent to which each group demonstrates the attributes shown in the pyramid of empowerment. If the underdog theory is supported by the evidence, and can be built upon, then we would expect autistic self-advocates to have ascended further up the pyramid. The table overleaf shows the results of the analysis.

	Stage of pyramid	Autistic self-advocates	Wider autistic community
Bottom	Understanding Environment	High	Low
	Needs Met	Variable but more likely to be met than for wider community	Low
	Access to Resources	High	Very low
	Collaboration	High	Very low
	Control	High	Low
	Self-efficacy	High	Very low
Top	Action	High	Variable

Figure 17: Ascending the Pyramid of Empowerment

The first thing to note here is that, because the wider autistic community is so diverse, these characteristics will necessarily vary among the population. However, within the sample population from the survey and focus groups, these were the results of the analysis

Starting with the bigger picture, it can clearly be seen that autistic self-advocates demonstrate more of the attributes of empowerment than the wider autistic community. The only attribute which was slightly problematic for autistic self-advocates was the extent to which their needs are met. This was also problematic for the wider autistic community. In both cases, answers varied due to differences in how the question was interpreted. Autistic self-advocates were more likely to be employed and therefore financially secure than the wider autistic community; however, it is overly simplistic to say their needs are 'met' because of this. In retrospect, this element of the pyramid needs further development, since the extent to which needs are met is subjective (Fraser, 1989; Hamilton, 2003; Sen, 2005). In addition, consideration would need to be given as to which needs were deemed more important, in order to produce a sliding scale, and this would become complex. Therefore, I decided to adjust the pyramid by removing this element. While, theoretically, this is an important part of the pyramid, it is both methodologically hard to pin down and empirically shown to be variable.

The other element which was problematic for the wider autistic community was that of action. Autistic people are taking action, as shown in the data presented earlier about political participation, but they are tending to use more passive methods, such as responding to petitions, filling in surveys or contributing to social media campaigns, and these are not really resulting in meaningful change. Therefore, it seems that 'action' is not an appropriate word to use for the pinnacle of the pyramid. I decided to rename action 'Active Participation'.

Beyond that, the order of the elements of the pyramid seemed to be broadly correct, even if autistic people didn't necessarily score in a linear way, with scores varying between 'low' and 'very low'. Although the pyramid is a usual visual aid, with its connotations of 'climbing' to the 'summit', it seems that the order in which the elements are achieved is not necessarily paramount.

Understanding Environment

This was assessed through a mixture of direct questions about what avenues of involvement respondents were aware of and more indirect analysis of what was said in response to other questions. Autistic self-advocates clearly stated that they felt that they had developed an understanding of and expertise in the autism policy environment, as shown in the quotations below.

"Over time, you get to know who will be on side with something and who won't, who to talk to, what the counter arguments will be, and it helps you prepare. It's like a computer game strategy!"

"I'm well-known in autism policy now, people know my name, they respect that I know what I'm talking about, both about autism and about policy."

"It's like anything, there's a system and you just have to learn it."

Conversely, the wider autistic community had much less 'insider' knowledge. Data from my survey and focus groups showed that only 5% of respondents were aware of mandated autistic representation on decision-making bodies and the option to attend government inquiries. Their lack of awareness extended to wider policy, as they called for changes to be made which have already been made. For example, autism training for professionals has been a requirement since the 2010 Autism Strategy but this was raised as something the government needed to do by 44% of survey respondents and 57% of focus group respondents. Two survey respondents said the government should include autistic people in decision-making, while being unaware of the existence of decision-making bodies. In general, both survey and focus group respondents showed frustration that they felt they were not being listened to, while simultaneously demonstrating that they were not taking up avenues of participation available to them because they were unaware of them. The first set of quotations are taken from the survey, and the second from the focus groups.

"lack of a voice to be heard in government"

"I wouldn't know how to get involved"

"we need autistic people to be involved in government decision-making"

"the government isn't interested in what we have to say"

"why can't they have autistic people chairing these meetings" (NB the current chairs of both APPGA Advisory Group and the Autism Programme Board are autistic)

"we aren't allowed to get involved"

There was also evidence that autistic people wanted to know more about the policy environment, as shown below from quotations taken from the survey.

"GPs should inform autistic people about how to get more involved"

"Letters about updated policy changes"

"Send out information to autistic people if they are interested in government policy for example via email."

My data is further corroborated by data from a recent APPGA survey (2021) which showed that only 38% of autistic people surveyed were even aware of the existence of the Autism Act and Strategies and believed there was no coordinated governmental response at all.

Since autistic self-advocates were shown to have a higher level of influence, this corroborates the pyramid of empowerment.

Access to Resources

All the autistic self-advocates interviewed had an employment in addition to their advocacy work. While those surveyed and participating in focus groups were not asked about employment, data collected by the Office for National Statistics in 2021 suggests that only 21.7% of autistic people are employed (ONS, 2021). Therefore, it seems likely that autistic self-advocates are better resourced in financial terms than the wider community; however, I do not have the data to be able to state this definitively.

Where I do have clear data showing a difference between autistic self-advocates and the wider community surveyed is in access to network of contacts. The autistic self-advocates interviewed spoke explicitly about using their networks of contacts to pursue their policy goals.

> "Through the board we have access to a lot of professional experts – some more helpful than others but you get to know the good ones."
>
> "I'm very connected with other autistic people, I participate in a lot of forums, WhatsApp groups etc. We talk and I use the information they give me."

However, the wider autistic community surveyed have no such access to networks of contacts and reported feeling isolated, both in the quotations from the survey shown below, and in data collected by APPGA in 2021, which showed that 79% of autistic adults consider themselves to be socially isolated.

> "no-one makes an effort to talk to us"
>
> "they should write to us about policy changes"
>
> "we can't communicate with people who aren't autistic"

Thus, there is clear evidence to corroborate this element of the pyramid of empowerment since those with a higher level of influence show more evidence of this attribute.

Collaboration

Linked to the idea of networks of contacts is the concept of collaboration. Again, autistic self-advocates speak explicitly about the need to do this, while the wider community surveyed tend to focus on what others can do for them, rather than considering what they could either do themselves, or work with others to achieve. This in itself shows a lack of awareness of their own potential, in line with the underdog theory. The first set of quotations below are from interviews with autistic self-advocates, while the second set are taken from the survey of the wider autistic community.

> "To get autism policy right, you need autistic expertise for sure, but you also need other kinds of expertise from other people. You can't expect to get a bunch of autistic people together and work it all out yourself".
>
> "It's best to work together. It's not an us and them situation, although I know a lot of people feel like it is. You find the common ground and you build on that."
>
> "I work with other people all the time. It's never just me. Sometimes other autistics, sometimes NTs [neurotypical people], sometimes professionals, sometimes MPs. But you need the power of the collective."

> "How would we have the power to influence policy?"
>
> "We don't communicate how others expect so they don't communicate with us"
>
> "We don't get true compensation"
>
> "The public should stop electing a Conservative government"

Thus, again, this behaviour is evidenced for the autistic self-advocates interviewed but not for the wider community surveyed. This ties in with the APPGA statistics saying that autistic people feel isolated – someone who is isolated would find it difficult to find people to collaborate with (NAS, 2018).

Control

This element of the pyramid, as explained in Chapter 3, does not necessarily mean that the person is fully in control, but that they have the sense of some autonomy and agency. In the context of autism policy influence, this would mean feeling that one has the ability to make a difference, even if that difference is small, and that one is not unreasonably restricted in putting forward their views. Here, once again, autistic self-advocates strongly demonstrate a sense of agency, whereas the wider community surveyed speak of feeling excluded and disempowered. The first set of quotations are from interviews with autistic self-advocates, and the second from the wider community surveyed.

> "There are definitely times I've felt I made a difference. For example, I raised concerns about train travel, and I was put in touch with train companies, and they listened and a lot of them now have an autism policy – that was down to me."
>
> "It's all about the little wins. You can't change the world overnight, but you can make a difference and we do. You only have to look at the changes in autism policy to see that."
>
> "Yeah, I've not got a direct line to the PM, I don't always get what I want but they do listen, they do make changes based on what I and others say. We make a difference."

> "No voice in government."
>
> "Autistic people are seen as disabled and stupid, and they aren't interested in what we have to say."
>
> "We live in a top down, patriarchal and racist system ruled by an elite who prize self-interest over protecting the people."

Again, then, this attribute is evidenced for autistic self-advocates but not for the wider community, indicating that the pyramid of empowerment correlates with higher levels of influence.

Self-efficacy

The final element of the pyramid to discuss is self-efficacy. As described in chapter 3, this relates to an awareness of one's own strengths and weaknesses and a willingness to play to and compensate for these respectively. As with other elements of the pyramid, these are conspicuously more evident for autistic self-advocates than the wider autistic community surveyed. Those autistic self-advocates interviewed were asked specifically what their strengths and weaknesses are and were able to speak clearly to these, as shown in the quotations below.

"I'm really detail-focused and I'm good on stats so I'm able to bring lots of evidence to the table and governments like evidence. I'm not so good at the persuading part but there are other people on board who can do that."

"I think it's because I'm so bull-headed! [laughs] Once I have a goal in mind, I keep at it, I don't let it drop. Eventually people have to address the goal even if they might not do exactly what I want them to do with it. Sometimes I can annoy people though, so I've learned to watch for signs I need to give it a rest for a bit."

"I'm really passionate about autism because it's my life and I think this comes through. It means being vulnerable, which is the downside, when I talk about the bad times as well as the good but it's all about making them see the potential we have."

In contrast, those surveyed spoke primarily of their difficulties and weaknesses rather than their strengths. NVivo analysis of the text of the survey and focus groups showed negative words made up 78% of the text, while positive words were only 8%.

This evidence therefore combines to support the hypothesis that the elements of the pyramid of empowerment are associated with higher levels of influence – i.e., that greater empowerment leads to greater influence.

Moving on to look at how these behaviours were expressed in the proto-explanations, these are all also evidenced for autistic self-advocates but not for the wider community.

Proto explanation 3:

Underdogs can make the most of the structural opportunities available to them by being as politically active as possible.

Proto explanation 4:

Underdogs can pool resources with other groups by forming alliances or collaborative frameworks.

Proto explanation 5:

Underdogs will have more influence when they adopt a strengths-based approach.

The autistic self-advocates interviewed were able to evidence all of the behaviours set out in the proto-explanations, both supporting the theoretical framework proposed and strengthening the argument that they ‘behave like underdogs’.

Autistic self-advocates showed a good understanding of the policy system – who to speak to about what, what priorities were, what pitfalls might be and the best way to bring attention to a particular problem. This understanding was built over time through involvement in the system and contacts and relationships made. The wider community, however, showed very little understanding of the policy system and many were not even aware of the opportunity to contribute to or sit on decision-making bodies. Linked to this was the ability of each group to make the most of structural opportunities – autistic self-advocates were both more likely to be aware of such opportunities and more likely to take action.

There is good evidence, as shown in Chapter 6, to support the idea that autistic people have altered the framing of autism, as shown both in the congruence between the framing put forward by autistic self-advocates and government framing, and the shift in public attitudes to autism which has been well-documented in the scholarship (Kenny et al, 2016; Jordan, 2020)/.

Autistic self-advocates were also more likely to be proactively seeking to form alliances and collaborate with others. They very much saw themselves as part of a policy team and the other policy actors as colleagues, even though they recognised that there were, at times, competing priorities. They also proactively sought collaborations with the autistic community – although autistic people more generally were more likely to fill in a survey or respond to a consultation than to actively collaborate.

This brings us to the final proto-explanation, which really does seem to be the catalyst which crowns the empowerment of the underdog. When the underdog has mastered the other behaviours set out in the proto-explanations – when they have an understanding of the environment, they are making use of all opportunities and collaborating with others – then they can mobilise a strengths-based approach to both alter their framing and increase their influence. Autistic self-advocates were consistent in their focus on the potential of people with autism and the use of positive frames and language to describe autism, while the wider community took a much more negative approach.

Therefore, we can see that the behaviours which correlate with the pyramid of empowerment and the proto-explanations are associated with the higher levels of influence recorded for autistic self-advocates. This tells us that autistic self-advocates are more empowered than the wider community – and that the wider community can learn from them. This is particularly important because learning from other autistic people will reinforce autistic people's understanding of and belief in their strengths more than learning from a neurotypical person would. This chapter sets out the bare bones of a potential lobbying strategy for underdogs, which includes the wider autistic community – but autistic self-advocates have already worked this out for themselves. The value of this chapter, of this thesis, lies more in using autistic self-advocates as an exemplar for other marginalised groups, than it does in informing a lobbying strategy for autistic people.

Nonetheless, before we move on to look at what that lobbying strategy for underdogs might look like, we must first address the final component of the first research question: what has the effect of such influence been?

The effect of autistic lobbying influence

The effect of lobbying influence, as set out in the Methodology chapter, is assessed both through the perceptions of those interviewed and surveyed and through use of governmental and charity evaluations of autism policy – specifically the APPGA survey published in 2021 and the overview to the new Autism Strategy also published in 2021. These all broadly converge on the same key points:

- The goals of UK autism policy align with the wishes of the autistic community: this is a very important point as it suggests that the government has been listening to what autistic people want, and in itself, is a measure of influence.
- There has been progress towards achieving these goals, especially in awareness of autism.
- Much more still needs to be done, especially in understanding of autism and changing stereotypical framings and in reducing the 'postcode lottery' that currently applies to services.

Of the autistic community surveyed, a majority (expressed as more than 50%) felt that there had been progress in all governmental goals except for reducing diagnosis times. Diagnosis times is a problematic statistic to look at, as Russell et al (2021) point out, since the increase in awareness of autism has resulted in an increase in the number of requests for assessment. NHS data shows that 41% of referrals received a diagnosis within the target period of 13 weeks (NHS 2021). This time has shown a steady reduction over the period since 2010, when the first Autism Strategy came into force (NHS 2021). Therefore, the evidence suggests that this goal has been partially met, even though those surveyed appeared to have had a negative experience.

Those surveyed also supported the viewpoint expressed in the most recent Autism Strategy that autism awareness had improved but understanding needed more work. ("We've never had a greater public awareness of hidden disabilities like autism … 99.5% of people have now heard of autism. While this is an important change, evidence from the APPGA's *The Autism Act, 10 Years On* report found that there is still a significant lack of understanding about autism among the public." DHSC, p1 and p7).

"I think there is already sufficient public awareness of autism - what needs to be increased is understanding and acceptance of it, as awareness alone doesn't necessarily lead to a reduction in discrimination." "There's much awareness of autism but little understanding. There are many popular myths that still need correcting." "Autism is a scale; overall understanding is what is needed."

This view was shared by those interviewed as well:

"Oh, we've come a long way, everyone knows what autism is now. But is there more to do? Oh yes, so much more." (Medical professional) "It's changing hearts and minds. We've raised the awareness, now we need to show people what autism really is, that it isn't the stereotypical view they've formed." (Self-advocate) "There's been lots of positive changes but autistic people on the ground, as it were, can't necessarily see it until it's started having an impact on their lives." (Civil Servant)

Combined with the previous data, this shows us that there has been progress towards autism policy goals which are aligned with the goals of the wider community, as expressed not just within my sample, but within other datasets. This progress is associated with a higher-than-expected level of policy influence, across a range of measures, for both the wider community and autistic self-advocates. The level of influence is significantly higher for autistic self-advocates, who also demonstrate behaviours and benefit from conditions in line with my underdog theory. While causation cannot be proven from this data, it does suggest that autistic people have had a positive influence on autism policy. The majority of this influence has been exercised by self-advocates, who appear to have been representing the interests of the wider community as best they can. Nonetheless, there is a need to increase the influence of the wider community through a targeted lobbying strategy – the key aim of this thesis -, which I will turn to now.

Towards a lobbying strategy

What, then, would a lobbying strategy for autistic people look like? The biggest recommendation to come from my research is that those within an underdog community who are less empowered should seek to learn from those who are more empowered, and that those who are more empowered should seek to teach those who are less empowered. The very act of learning from others who are like you but more successful is much more empowering than being told what to do by a researcher, politician or academic (Goodley, 2005; Dunn, Clare and Holland, 2008; Cascio, M.A., Weiss, J.A. and Racine, E., 2020). It also needs to be acknowledged that not all underdogs will be physically capable of all the behaviours outlined, and that therefore there needs to be a degree of everyone acting according to their own individual strengths and weaknesses, with those able to implement the behaviours in the vanguard.

Secondly, there needs to be an acceptance that there are no guarantees with any lobbying strategy and that even with a successful strategy, progress is likely to be slow and bumpy. It has taken two or three decades at least for autistic self-advocacy in the UK to build to its current level (Itkonen and Ream, 2013; Gardner and Brindis, 2017; Petri, Beadle-Brown and Bradshaw, 2020). This is not an overnight fix. This is not going to reverse their underdog status – they will still, more than likely, be marginalised in more ways than is acceptable. However, they are likely to increase their influence, albeit slowly … and every little helps.

Finally, it is important to remember, as the next section will explore in more detail, that the lobbying success or failure of the underdog is not a product of only their actions but also the multi-layered actions of other parties and that a hostile policy environment, political opportunity structure, government or other actors will make the task much harder and longer.

With all this said, let us move on to identify key underdog characteristics which form the basis of a lobbying strategy for the underdog. These can be summarised under three headings: Knowledge, Resources and Behaviours.

Knowledge

An underdog who wishes to empower themselves needs to develop their knowledge and understanding of the policy environment, policy system and political opportunity structure in which they operate. This includes what current policy does or doesn't include, the history of the policy area and an understanding of the main debates. This knowledge enables them to identify opportunities for action and to develop achievable goals.

They also need to develop their knowledge and understanding of themselves as individuals and as part of a wider community. In particular, they need to be able to identify their own strengths and weaknesses and the extent to which they are shared by others in the community. Technical or scientific knowledge may be useful here in the case of a disability, for example. This knowledge is used to inform what skills and strengths should be mobilised as part of the strengths-based approach, and which weaknesses may need to be mitigated through alliances and collaboration.

Resources

There is also no escaping the fact that underdogs who wish to empower themselves need resources in a variety of forms. We have already talked about mobilising one's internal resources in the form of skills and knowledge, but external resources are needed to. In order to physically access decision-making spaces, whether in person, virtually or by proxy, a financial outlay, in the form of travel or equipment costs, or a financial cost, in the form of missed work, is likely to be required. Underdogs who seek to empower themselves need to understand that a certain amount of time and effort will have to be expended to achieve results and there are likely to be costs involved: they must weigh up the cost-benefit ratio.

In addition to internal resources and financial resources, underdogs also need access to networks of key contacts in order to access resources that they do not have and mitigate their areas of weakness by pooling resources.

Behaviours

Most important, however, are the actions or behaviours which the underdog must take when they have acquired sufficient knowledge and resources. (Acting without knowledge or resources is unlikely to result in significant lobbying success; the three areas must be combined.)

The underdog must use this knowledge and their resources to form collaborative alliances with others, to propose achievable policy goals that form part of a longer-term strategy and, crucially, to propose a positive framing of themselves as a target group. Evidence from the autistic community suggests that if underdogs adopt this lobbying strategy and adapt it to their own circumstances, they are more likely to increase their policy influence and thereby achieve lobbying success.

What role for governments and researchers?

The final research question addresses not just what the underdog can do but what governments and researchers can do to support the empowerment and increased influence of the underdog. For governments, Article 1 emphasised two key points: the importance of a positive framing that emphasises potential over current limitations, and the importance of making institutional changes to mandate or enable greater political participation by the underdog. This materially alters the conditions in which the underdog operates and makes it more likely that they will be able to exert influence. If the government frames the underdog positively, this filters through into societal expectations and ultimately contributes to the changes in 'hearts and minds' that are needed. Increasing the number of opportunities for the underdog to become politically involved and allowing them greater access to decision-making spaces also ensures better representation of their views and ideas. A move towards co-production of policy would be the ideal, but any increase in opportunities for meaningful participation is a bonus.

Article 2 similarly highlighted how researchers can contribute to the empowerment of the underdog by making mindful choices about what they research, how they research it and what indicators of influence they use. The snowball effect where research on 'hot topics' gathers momentum and attracts both funding and attention can be to the detriment of underdog and can also 'bake in' misconceptions. This is in no way a deliberate act by researchers against the underdog, but the potential for one's research to negatively impact a group should be borne in mind. For pure methodological reasons, using the indicators of influence that I have suggested would allow researchers to capture more wide-ranging data on influence.

The underdog theory: the end of an iterative process

At the end of this iterative process, which has addressed in turn each of the research questions with which I began, we are left with a rich description from the case study of both an underdog who is fully-empowered and an underdog who is partially empowered.

The underdog fully-empowered: autistic self-advocates

The underdog empowered, as embodied in this case study by autistic self-advocates, is characterised by a combination of awareness and confidence, which are closely linked. Firstly, they have a good understanding of their policy area: the key issues, the key players and how the system works. This means that they can readily identify opportunities for action as they arise and act upon them. They use this understanding to propose SMART goals (Specific, Measurable, Attainable, Relevant and Time-based) (Bjerke and Renger, 2017) and to propose them in a way which is more likely to get attention. This understanding has been built over time and cannot be assimilated rapidly (Fischer, 2019) … but it can be shared through collaboration, networks, and alliances, in which the underdog empowered participates with ease. These alliances allow them to pool resources – to access financial resources, to make useful contacts, to make themselves known as somebody to be listened to (Hardin, 2015). Networking is a skill which can be learned (van Asselt-Goverts et al., 2015), and the underdog empowered is willing to learn new skills and new information: they do not stand still. Autistic people are often assumed to lack communication skills, since they are diagnostically defined by perceived deficits in this area (Parsloe, 2015). However, autistic self-advocates are clear that they have learned networking skills over time

> "I've learned who I need to talk to and why. Once I know why and how, it's easy. It's a skill you can learn. People think autistic people can't learn but we can!"
>
> Autistic self-advocate

Secondly, they have a good understanding of themselves. They have made a realistic assessment of their strengths and weaknesses. They are ready to utilise the strengths and to mitigate the weakness through collaboration with others who have strengths that they do not. They also have a good understanding of common strengths and weaknesses of others within the underdog community. Even though all people are, of course, individuals, there may be traits or characteristics which are commonly found within the community – this is certainly true for autistic people (Putnam, 2005; Payne et al., 2019; Rourke and McGloin, 2019).

Finally, the underdog empowered uses this understanding and knowledge to propose a new social construction of themselves as a target group, a construction that they are uniquely placed to embody, and they use this new construction to not just alter how people see their community, but, in subtle other ways, to increase their influence. A more positive social construct does not just increase influence because it has altered the framing. It also changes how governments treat the group, how the public views the group and how other actors view the group. It can change how the group view themselves. When combined with SMART goals which have been adapted to the specific policy environment and situation, and widely disseminated by allies and collaborators, it is truly a force – or empowerment – to be reckoned with.

The underdog partially-empowered: the wider autistic community

The underdog not-yet-empowered shares the potential of the underdog empowered. Like the underdog empowered, they are uniquely placed to reframe how they, as a community, are viewed. Like the underdog empowered, they have strengths which can be utilised in a positive social construction. However, unlike the underdog empowered, they have not yet developed the understanding necessary to give them the confidence to act.

This is not surprising, since any underdog has spent their life entangled in a narrative which says that they are ‘less than’ and which defines them by what they cannot do rather than what they can do. Underdogs are a product of the society in which they live and the narratives which they hear. It requires a belief in a new narrative – best proposed by others in the same community – for this to belong to change. This is why underdogs not-yet-empowered learning from underdogs empowered is so important.

The wider autistic community are a strong example of this. Despite the evidence showing that they have a higher level of influence than expected, they show a poor awareness of the policy environment and policy systems and believe erroneously that there are no opportunities for them to make a difference. They believe they will not be listened to – and yet other autistic people, self-advocates, are being listened to.

They lack an awareness of their own strengths and weaknesses in relation to policy and they tend to focus on the negative when they talk about policy.

This combination of a lack of understanding and a lack of confidence prevents them from becoming fully empowered. Nonetheless, I argue that they can become empowered if they learn from underdogs who have already achieved this.

The Underdog Theory defined

Thus, the underdog theory, at the end of the iterative process recorded through this thesis, can be defined as follows:

- **Underdogs embody the disconnect between what marginalised groups are expected to achieve and what they can actually achieve.**
- **This disconnect is the product of a co-creation of a framing of the underdog as a target group by various actors, including the underdog, governments, and researchers, over an extended period of time.**
- **All these actors have the power to act to reframe the underdog.**
- **Underdogs have more policy influence than they or others expect.**
- **Underdogs can maximise their policy influence by developing an understanding of their policy environment and themselves, forming alliances, acting strategically, and promoting a positive framing of themselves.**
- **Underdogs can and should be supported in this endeavour by allies, which should include researchers and the government.**

How this learning can be developed into a lobbying strategy, and the next steps in developing the underdog theory further, can be found in the Conclusion which follows Article 3.

Appendix 6B: Statement of Authorship

<table>
<tr><th colspan="10">This declaration concerns the article entitled:</th></tr>
<tr><td colspan="10">The autistic community empowered: towards a lobbying strategy for autistic people.</td></tr>
<tr><td colspan="10">Publication status (tick one)</td></tr>
<tr><td>Draft manuscript</td><td></td><td>Submitted</td><td></td><td>In review</td><td>X</td><td>Accepted</td><td></td><td>Published</td><td></td></tr>
<tr><td>Publication details (reference)</td><td colspan="9">Under review by Journal of Autism and Developmental Disorders.</td></tr>
<tr><td colspan="10">Copyright status (tick the appropriate statement)</td></tr>
<tr><td colspan="3">I hold the copyright for this material</td><td></td><td colspan="5">Copyright is retained by the publisher, but I have been given permission to replicate the material here</td><td>X</td></tr>
<tr><td>Candidate’s contribution to the paper (provide details, and also indicate as a percentage)</td><td colspan="9">This is a sole author article. The candidate carried out all of the research and writing of the article, with advice only from supervisors.

Formulation of ideas: 100%

Design of methodology: 100%

Experimental work: 100%

Presentation of data in journal format: 100%</td></tr>
<tr><td>Statement from Candidate</td><td colspan="9">This paper reports on original research I conducted during the period of my Higher Degree by Research candidature.</td></tr>
<tr><td>Signed</td><td colspan="5">[redacted]</td><td colspan="2">Date</td><td colspan="2">11.04.22</td></tr>
</table>

Article 3: The autistic community empowered: towards a lobbying strategy for autistic people

Preamble

Originally, the intention was to use this article to present the full ‘underdog theory’ to the autistic community through an autism-related journal. This fairly swiftly became revised for a number of reasons. Firstly, autism journals are mainly read by autism professionals rather than autistic people – therefore a more accessible medium will need to be considered. Secondly, autism journals follow the medical/scientific journal format and tend to be shorter in length, which makes fitting all of the research in very difficult. Thirdly, the theoretical framework would be difficult to explain to those with no background in policy or politics within the space allowed.

The article was therefore reworked to focus on the behaviours to be used in a lobbying strategy. Following the format of autism journals, it is written in the third person and follows a scientific format. It stands in its own right as an independent research article but also contributes to the case study outlined in this thesis. Article 3 is currently under review by *Autism and Other Developmental Disorders* journal.

Abstract

Autistic people in England have the opportunity to exert influence over autism policy through mandated autistic representation on decision-making bodies. This article uses process tracing of stakeholder interviews, an online survey, online focus groups and documents to identify key behaviours demonstrated by autistic self-advocates which are theoretically and, in the example of this case, empirically associated with high levels of policy influence. The article argues that these behaviours could be the key to greater policy influence for the wider autistic community. Furthermore, it proposes that these behaviours, namely developing and applying knowledge, active collaboration and a positive, strengths-based approach should be incorporated by the autistic community into a lobbying strategy to maximise autistic policy influence in the future.

Introduction

In 2009, England and Wales made history by being the first countries to introduce a law to differentiate autism policy from disability policy (Della Fina, 2015; McCarthy, Chaplin and Underwood, 2015; Parkin, 2016; Bölte, 2017). That law was the Autism Act, which created a structure and a framework within which to enact a Strategy to enable “adults with autism to live fulfilling lives” (NationalArchives, 2020). Almost 12 years on from the Autism Act, the English government has produced the latest iteration of the Autism Strategy (NAS, 2019). At a hiatus of just over ten years, it is now possible to begin to assess the impact and success of the Autism Act and its Strategies to date (McConnell, 2010). There are many ways to define policy impact and success (Jørgensen, 1997; McConnell, 2010; Precious, 2020) but this article focuses on the extent to which autistic people have been enabled by the Act and its Strategies to exert policy influence (Dempsey and Foreman, 1997; Sørensen, 1997; Goodley, 2005; Halvorsen et al., 2017). Policy influence is here defined as the power to alter (or maintain) the trajectory of policy change in one’s favour, even if one falls short of achieving one’s final goal (March, 1955; Arts and Verschuren, 1999; Dür, 2008; Lowery, 2013; Ban and You, 2019).

In fact, it is precisely participation in policy decisions which sets English (and Welsh) autism policy apart from the autism policies of most other Western European countries (Precious, 2020) . The first Autism Strategy mandated representation of autistic people through their inclusion on the Adult Autism Programme Board and All-Party Parliamentary Group on Autism Advisory Group, as well as on local Partnership Boards (Precious, 2020). This potentially creates a dual system of policy influence whereby a minority of autistic self-advocates, i.e., those officially representing the autistic community on advisory bodies, possess a high level of influence but this is not shared by the wider community. In the worst-case scenario, such advocates could even become a form of elite. There is therefore a democratic mandate to ensure effective representation of the wider autistic community and develop a lobbying strategy co-produced with the wider community.

This article aims to explore the behaviours of autistic self-advocates in the autism policy context in England, as examples of demonstrably influential autistic people, with a view to identifying elements which could form a lobbying strategy to be shared with the wider autistic community. Such a lobbying strategy could enable the wider community to increase and maximise their policy influence (Binderkrantz and Pedersen, 2019; Romeijn, 2020). It is the explicit aim of this article that the research should provide only a list of behaviours associated with higher levels of influence in the policy context. The lobbying strategy itself must be a project which is led by autistic people and combines the policy expertise of self-advocates with the wider lived experience of the community (Kingston, 2014; Milton, Damian, 2017; McCoy et al., 2020).

The process began with a critical literature review of the lobbying, policy influence, disability studies, autism studies and empowerment scholarships. By cross-referencing these scholarships, common themes were able to be identified which suggested certain behaviours associated with either lobbying success or policy influence. It is important to note that the only study to date to assess autistic policy influence in England identified high levels of autistic influence among autistic self-advocates and medium levels among the wider community (Precious, in draft). These were used to put together proto explanations (possible hypotheses) about the behaviour of autistic self-advocates, as follows:

Proto-explanation 1: Autistic people are uniquely placed to alter the framing of autism and autistic people.

This proto-explanation draws on the literature on policy frames (De Bruycker, 2017; Junk and Rasmussen, 2019), the social construction of target groups (Schneider, A. and Ingram, 1993) and framing congruence (Boräng and Naurin, 2015; Rasmussen, A., Binderkrantz and Kluver, 2021), which argue that policy trajectories can be changed by persuading the government to adopt a specific framing of a policy issue or target group. This has been shown to be a particularly effective method for lesser-resourced groups (Junk and Rasmussen, 2019). It also draws on the advocacy, autism studies and empowerment scholarships, which are clear that advocacy is particularly effective because of the lived experience of advocates (Goodley, 2005; Itkonen and Ream, 2013; Werts and Brewer, 2015; Voronka, 2016; McIntosh and Wright, 2019; McCoy et al., 2020).

Proto-explanation 2: Autistic people can make the most of the structural opportunities available to them by being as politically active as possible.

This proto-explanation draws on theory from the lobbying scholarship about the importance of capitalising on opportunities in the political opportunity structure (Koopmans, 1999; Meyer and Minkoff, 2004; McCammon, 2013; Mintrom and Norman, 2019) and Kingdon's theory of policy entrepreneurs (Kingdon, 1995). It also draws on data from the disability studies and empowerment scholarships which demonstrates that political activism is beneficial to the wellbeing and self-esteem of disabled people (Goodley, 2005; Kingston, 2014; Halvorsen et al., 2017).

Proto-explanation 3: Autistic people can pool resources with other groups by forming alliances or collaborative frameworks.

This proto-explanation reflects the current learning of the collective action scholarship, which has shown that active co-operation across networks, alliances or other collaborative framework is associated with lobbying success for lesser-resourced groups (Weible et al., 2011; Pierce et al., 2017; Junk, 2019a). It also reflects the strengths-based approach in social work/social policy (Saleeby, 1993; Chapin, 1995), which has been widely applied to autism studies (Meilleur, Jelenic and Mottron, 2015; Donaldson, Krejcha and McMillin, 2017; Urbanowicz et al., 2019), since it recognises that autistic people have resources to pool. Finally, it reflects the importance of self-efficacy in the empowerment scholarship (Dempsey and Foreman, 1997; Mitchell, Rieger and McMillan, 2017).

Proto-explanation 4: Autistic people will have more influence when they adopt a strengths-based approach.

This proto-explanation reflects the strengths-based and neurodiversity element of the autism studies scholarship (Donaldson, Krejcha and McMillin, 2017; Urbanowicz et al., 2019) and the correlation between empirically identified clinical strengths of autistic people, such as persistence, laser focus and attention to detail (Meilleur, Jelenic and Mottron, 2015) and behaviours associated with lobbying success (Baumgartner, F.R. et al., 2009; Hornung, Bandelow and Vogeler, 2019).

Through a semi-inductive, iterative and theory-driven process (Glynos and Howarth, 2007; Srivastava and Hopwood, 2009), this article uses process tracing of stakeholder interviews, an online survey, online focus groups and document analysis, to demonstrate that autistic self-advocates exhibit three key behaviours that are not in evidence for the wider community. Firstly, they are committed to developing their knowledge about autism, the policy context and environment and themselves. Secondly, they actively collaborate with others and reject an ‘us and them’ approach. Thirdly, they promote a positive, strengths-based approach to autism and autistic people. While these behaviours cannot be causally proven to result in increased policy influence, the correlation is theoretically grounded and worthy of further exploration.

Method

Participants

Interviews

An actor mapping exercise was conducted to inform sampling, using Hansard transcripts of Parliamentary debates, policy documents and publicly available websites[3]. As a result of this mapping exercise, two decision-making bodies for national autism policy in England were identified (the Adult Autism Programme Board and the All-Party Parliamentary Group on Autism Advisory Group), along with eleven categories of stakeholder: autistic self-advocates , the wider autistic community; families/carers of autistic people; charities; researchers; professional bodies; NHS bodies; local government bodies; national government bodies, civil servants, and MPs/Lords.

Membership of the deliberation bodies is publicly available information; therefore, direct and gatekeeper-facilitated contact was made with members of these bodies. Gatekeeper-facilitated contact was made possible through existing contacts within the National Autistic Society, which provides the secretariat for the All-Party Parliamentary Group on Autism. Snowball sampling was then used to facilitate further introductions. In total, 29 interviews were conducted: 5 with autistic self-advocates and 2-4 with stakeholders from each of the other groups. A breakdown by stakeholder type can be found in the data repository. The total number of members of the Adult Autism Programme Board and All-Party Parliamentary Group on Autism Advisory Group at the time was 38; therefore, this was good saturation.

Online survey and focus groups

Autistic adults aged 18 and over were invited to take part in an online survey and/or online focus groups. An invitation was sent to all registrants on the University of Bath's Centre for Applied Autism Research volunteer database; this was complemented by an advert posted on Twitter. Demographic information was not collected. Participants were required to be able to express their views, either verbally, in writing or via a trusted proxy. AASPIRE guidelines were followed (Nicolaidis et al., 2019). 118 survey responses were received and 24 people in total participated in focus groups.

Design

Drawing on guidelines for critical, qualitative research as set out by Glynos and Howarth (2007) and Srivastava and Hopwood (2009), the design for this research was

[3] A list of sources and the subsequent mapping data can be found in the data repository.

theory-driven but iterative and semi-inductive in nature. An outline theoretical framework was refined through an empirical case study. This approach enables the rich detail and thick description (Geertz, 2008) of qualitative research and the flexibility of an inductive approach but is strengthened by the theoretical underpinning and the robustness of going through different iterations.

As outlined in the Introduction, the process began with a critical literature review which cross-referenced the scholarship from different disciplines to identify key threads of a hypothetical, theoretical framework. These threads were then converted into behavioural indicators which could be tested for using process tracing. Following established guidance for process tracing, a range of different sources were used to provide data: documents, interviews, an online survey and focus groups. The more times that a particular behaviour is evidenced in the data, and the more stages of the policy process that it is evidenced in, the more supportive the data is of the theoretical framework. This data is then used to strengthen and build upon the theoretical framework and produce a stronger theory which can subsequently be tested in other contexts.

Materials

Documents

Documents used for analysis included a range of policy documents, text from government websites and Hansard records of Parliamentary debates and discussions (including full transcripts). Policy documents provided written, dated evidence of governmental policy goals, instruments and frames (Freeman and Maybin, 2011) which are essential for assessing the extent to which the claims of autistic people are being listened to. For the purposes of this research, the text of the Autism Act 2009 (AutismAct, 2009), the first and second Autism Strategies (2010 and 2014) (DHSC, 2010; DHSC, 2014) and an evaluation of the 2014 strategy published in 2018 (DHSC, 2018) were used. At the time of analysis, the third Autism Strategy had not been published.

Interviews

Interviews were semi-structured in nature and a list of the core questions asked can be found in the data repository, along with transcripts of all interviews, anonymised where requested. The stakeholder category is always retained for the purposes of analysis. All interviews were carried out on Microsoft Teams due to restrictions occasioned by the coronavirus pandemic and took place between October 2020 and April 2021.

Survey and focus groups

The online survey was created on the OnlineSurveys.ac.uk platform, which is owned by JISC, and contained a mixture of Likert scale questions, multiple choice tick box questions and free text responses. Online focus groups were held on Zoom, with between 3 and 5 people present at each focus group in addition to facilitators. Three questions for discussion were emailed to attendees a week before the focus group to allow them time to consider them; the focus groups lasted one hour each and were facilitated by an autistic person, who was paid for their time. The online survey ran for 8 weeks. In advance of both the survey and focus groups being launched, the questions and research plan were sent to three autistic people who were paid to be consultants on this project for their feedback and amended accordingly. A copy of all the questions can be found in the data repository. Coding was completed using NVivo. Since coding is always a subjective decision, all coding decisions on NVivo are attached to a specific quotation in the interests of maximal transparency (Bazeley & Jackson, 2013; Welsh, 2002; Zamawe, 2015). All coding decisions can be found in the data repository. Analysis of the frequency of each code was then recorded in an Excel spreadsheet, which can be found in the data repository to build an overall picture and thick description (Geertz, 1973).

Procedure

Process tracing was used to assess the presence or absence of each behaviour outlined in the proto-explanations at each stage (Bennett, A., 2010; Collier, 2011; Mahoney, J., 2012; Jacobs, A.M., 2015; Beach and Pedersen, 2019; te Lintelo et al., 2019) in the cycle of policy change (Jann and Wegrich, 2007; Howlett, Michael, Ramesh and Perl, 2009). The stages used were agenda setting (getting an issue on the agenda), issue definition (defining the 'problem' to be solved), policy formulation (choosing the goals and tools) and policy implementation.

Rather than asking directly about these behaviours, more general questions were asked about aims and hopes for autism policy, what needed to change and how the respondent saw their role in this process. A list of all questions can be found in the data repository.

The codes were recorded as shown in Figure 1.

Behaviour	Description	Possible Codes
Framing congruence	The autistic person uses a framing of autism or autistic people which is congruent with that used in government documents.	Framing is highly congruent, slightly congruent, or not at all congruent.
Active participation	The autistic person is politically active by contributing where opportunities allow.	Very politically active, slightly politically active, participates passively, does not participate at all.
Active collaboration	The autistic person actively seeks to collaborate with others, both within and outside the autistic community.	Actively collaborates with all; passively collaborates with all; actively collaborates with autistic community; passively collaborates with autistic community; does not actively collaborate at all.
Positive framing	The autistic person uses a positive framing of autism or autistic people or otherwise demonstrates a strengths-based approach.	Framing is highly positive, slightly positive, neutral, slightly negative, or highly negative.

Figure 1: Behaviour Codes

A quotation is attached to every code in the data repository. Since an iterative and semi-inductive approach was taken, there was the option to add additional codes should an unexpected addition be needed. Three rounds of coding were carried out altogether, with additional codes around development of knowledge about oneself, autism and the policy process being added in the second round. These codes were as shown in Figure 2.

Behaviour	Description	Possible Codes
Develops knowledge of self	The autistic person shows awareness of their own strengths and weaknesses and a desire to develop/use this knowledge.	Actively uses knowledge; is aware and beginning to use knowledge; is aware but does not use knowledge; is not aware.
Develops knowledge of autism	The autistic person shows an awareness of the need to know more about autism than their own experience of it.	Actively uses knowledge; is aware and beginning to use knowledge; is aware but does not use knowledge; is not aware.
Develops knowledge of policy context/environment	The autistic person is aware that they need to understand 'the system' and seeks to learn and apply that knowledge.	Actively uses knowledge; is aware and beginning to use knowledge; is aware but does not use knowledge; is not aware.

Figure 2: Additional Behaviour Coding

All procedures were approved by the institutional research committee and were in accordance with the ethical standards of the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study. AASPIRE guidelines were also followed when planning the research (Nicolaidis et al., 2019) and autistic people were consulted in the development of the questions and supporting materials.

Results

The results show that the autistic self-advocates in the sample demonstrated all of the behaviours, while the situation was much more mixed among the wider autistic community sampled. A full breakdown can be seen in Figure 3.

Behaviour	% Autistic self-advocates (n=5)	% Wider autistic community (n=142)
Framing congruence	Highly congruent: 80% Slightly congruent: 20% Not at all congruent: 0%	Highly congruent: 1% Slightly congruent: 4% Not at all congruent: 95%
Active participation	Very politically active: 80% Slightly politically active: 20% Participates passively: 0% Does not participate at all: 0%	Very politically active: <1% Slightly politically active: 1% Participates passively: 24% Does not participate at all: 74%
Active collaboration	Actively collaborates with all: 100% Passively collaborates with all: 0% Actively collaborates with autistic community: 0% Passively collaborates with autistic community: 0% Does not actively collaborate at all: 0%	Actively collaborates with all: <1% Passively collaborates with all: 6% Actively collaborates with autistic community: 3% Passively collaborates with autistic community: 31% Does not actively collaborate at all: 60%
Positive framing	Highly positive: 80% Slightly positive: 20% Neutral: 0% Slightly negative: 0% Highly negative: 0%	Highly positive: 0% Slightly positive: 15% Neutral: 21% Slightly negative: 35% Highly negative: 30%
Develops knowledge of self	Actively uses knowledge: 80% Is aware and beginning to use knowledge: 20% Is aware but does not use knowledge: 0% Is not aware: 0%	Actively uses knowledge: 0% Is aware and beginning to use knowledge: 11% Is aware but does not use knowledge: 24% Is not aware: 65%
Develops knowledge of autism	Actively uses knowledge: 100% Is aware and beginning to use knowledge: 0%	Actively uses knowledge: 11% Is aware and beginning to use knowledge: 15%

	Is aware but does not use knowledge: 0% Is not aware: 0%	Is aware but does not use knowledge: 35% Is not aware: 39%
Develops knowledge of policy context/environment	Actively uses knowledge: 100% Is aware and beginning to use knowledge: 0% Is aware but does not use knowledge: 0% Is not aware: 0%	Actively uses knowledge: 0% Is aware and beginning to use knowledge: 1% Is aware but does not use knowledge: 0% Is not aware: 99%

Figure 3: Results of Behaviour Coding

The difference between n in relation to autistic self-advocates and the wider community mean that the percentages should be interpreted with caution, but, when combined with the richer, qualitative data, remain striking. The results demonstrate that the autistic self-advocates in the sample demonstrate all of the behaviours to a high degree, but the behaviours are much more mixed among the wider autistic community sampled, with the majority demonstrating them only to a low level. The areas with the greatest discrepancy between autistic self-advocates and the wider community were framing congruence, active collaboration, and knowledge of policy context/environment. While more autistic people did put forward a negative framing of autism than a positive one, the number of slightly positive or neutral framings was nonetheless encouraging. The numbers passively collaborating with the autistic community also suggest that collaboration outside of the autistic community could be increased if the importance of active collaboration were understood. More detail on the qualitative findings can be found in the sections which follow.

Framing congruence

Figure 4 shows the differential between autistic self-advocates and the wider community in achieving framing congruence.

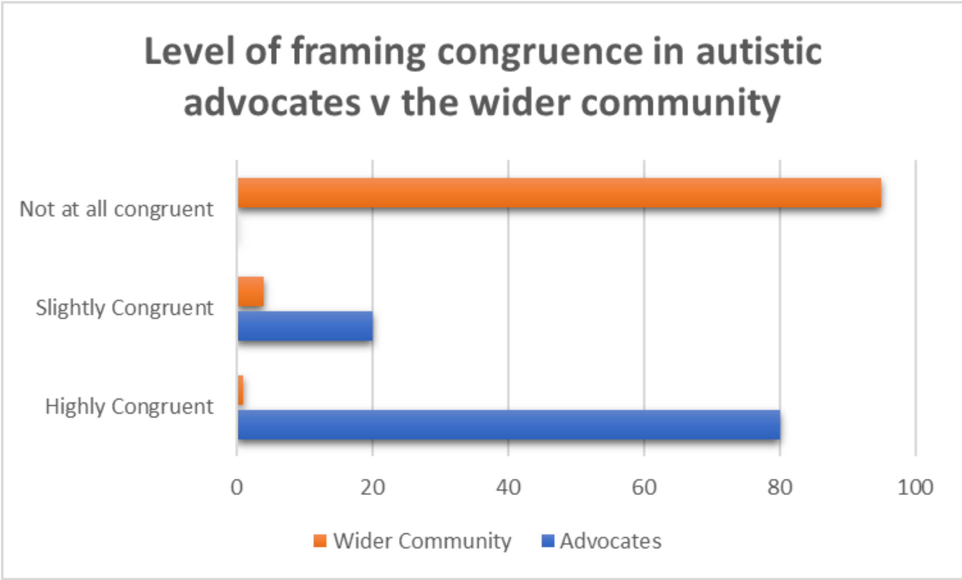

Figure 4: Level of framing congruence in autistic advocates vs wider autistic community

It is clear from this data that, while the majority of autistic adults achieve framing congruence, the majority of the wider community do not. In simple terms, this means that advocates are putting forward a framing of autism/autistic people which is adopted by the government in its autism policy documentation, whereas the framing used by the wider community is rejected. This can also be seen in a shift in language used to describe autism in NHS and government documentation over time, from describing autism as a "neurodevelopmental disorder" (NHS, 2010) to stating that "Being autistic does not mean you have an illness or disease. It means your brain works in a different way from other people" (NHS, 2021).

Qualitative data from the interviews with self-advocates reveal that, for the advocates sampled, this framing is a deliberate choice.

“It is a balancing act, it is tricky. You have to demonstrate the need while showing the potential. If you make it all seem bright and breezy and positive then, well, why should there be a policy change? But if you are all doom and gloom then you paint yourself into a corner. So, you have to acknowledge the need but show the potential.”

“Fundamentally I’m just expressing what I believe. There are certain problems that a lot of autistic people face in daily life but that doesn’t mean that being autistic has to be a bad thing. If you look at autism differently you can see it as an opportunity not a death sentence.”

Conversely, the wider community surveyed and spoken to in focus groups expressed powerlessness to make a change and did not seem to be aware that they could alter how other people see them.

“Other people need to change how they see us.”

“Nobody listens to us; we’re thought of as stupid and disabled.”

“What’s the point? No-one cares.”

There is therefore a clear correlation between a deliberate attempt to put forward a specific framing by the autistic community and the adoption of a similar framing by the government during the same timeframe. This is not just evidence of influence by autistic advocates (Börang and Naurin, 2017; Junk and Rasmussen, 2018) but support for the behaviour of deliberately putting forward a specific framing being linked to increased influence.

Active Participation

Figure 5 shows how levels of active participation vary between autistic self-advocates and the wider community.

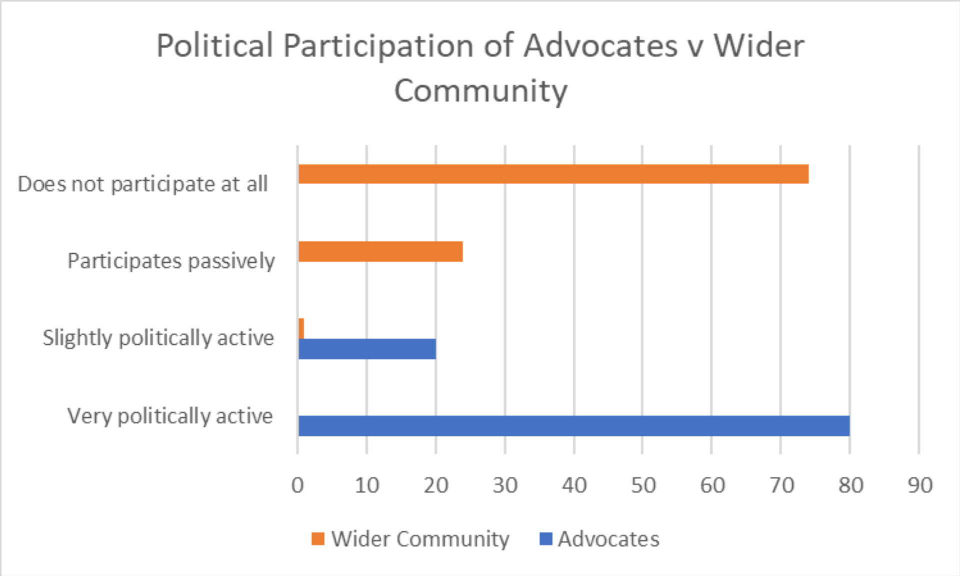

Figure 5: Political Participation of Advocates v Wider Community

The data clearly shows that the majority of the wider community sampled either participate passively, or not at all. Passive participation might include such activities as responding to a consultation/survey or signing a petition – it signals a preference, goal or position but provides amalgamated data for governments rather than contributing specific expertise or being involved in decision-making. Conversely, advocates are much more actively involved. This result is partly to be expected, as advocates by their nature are more likely to be actively involved; however, the degree of difference is striking.

The qualitative data shows, however, a more nuanced picture than the statistics alone would suggest – and this ties into other behaviours which will be discussed later. Where the wider community are aware of a particular means of participation, they are generally willing to participate in it, as shown in Figure 6, which cross-references awareness of different measures of participation with participation in them.

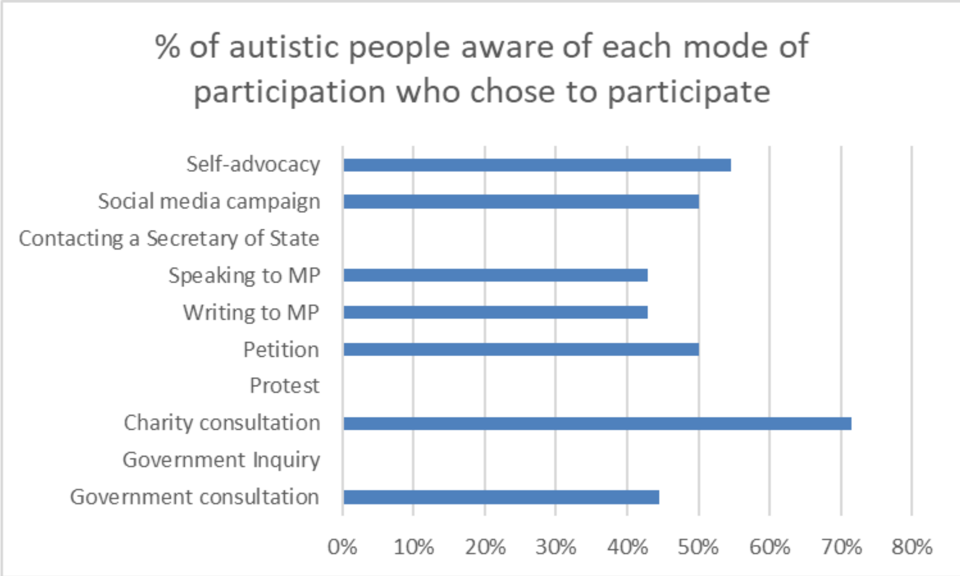

Figure 6: % of autistic people aware of each mode of participation who chose to participate

However, those sampled were, for the most part, unaware of opportunities for active participation. For example, when asked what governments should do to involve autistic people better, suggestions included several things that the government already does, as shown below.

"They should have autistic people involved in making decisions".
[The main decision-making bodies for autism policy are chaired by autistic people and have mandated autistic representation.]
"They should ask us what we think".
[All the previous Autism Strategies have been preceded by consultation exercises.]
"They should write to us and tell us what is going on."
[All information about autism policy is available in accessible format on the government website.]

Therefore, this both shows a correlation of active participation as a behaviour with increased influence, given the framing congruence achieved by advocates, and suggests that more work needs to be done to make autistic people aware of the participation opportunities that are open to them. The revelation of this during the first iteration of analysis led to the creation of additional codes for the second iteration.

Active collaboration

While all autistic advocates are, by definition, actively collaborating with a range of stakeholders, Figure 7 shows that the wider community sampled are much less actively involved.

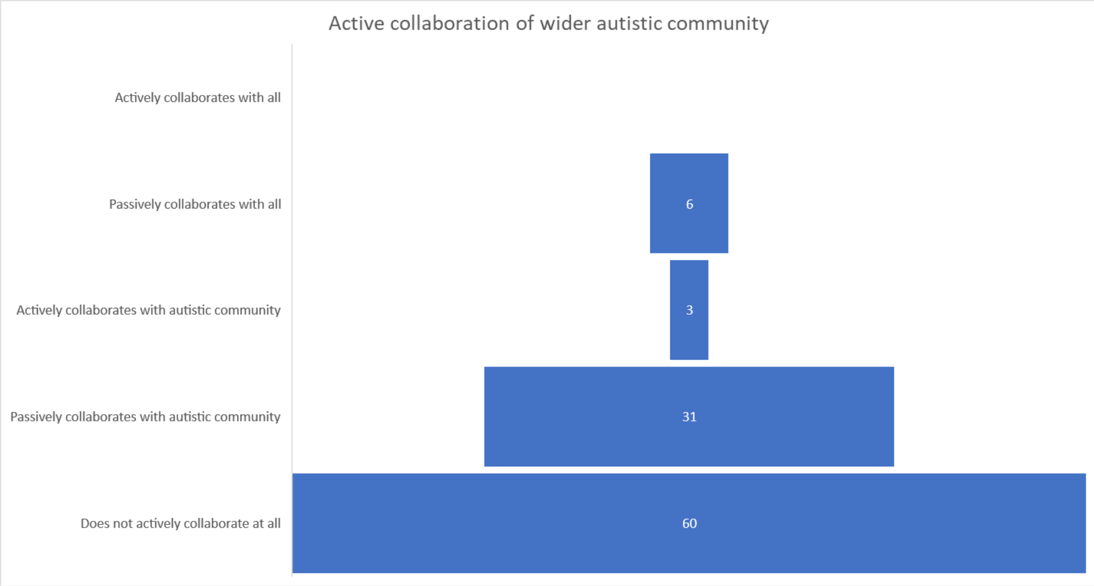

Figure 7: Active collaboration of autistic advocates v wider community

This is further supported by the following quotes from interviews with autistic advocates.

> "It's best to work together. It's not an us and them situation, although I know a lot of people feel like it is. You find the common ground and you build on that."
>
> "I work with other people all the time. It's never just me. Sometimes other autistics, sometimes NTs [neurotypical people], sometimes professionals, sometimes MPs. But you need the power of the collective."

Conversely, the wider community sampled did not seem to see the value in collaborating outside of the autistic community.

> "How would we have the power to influence policy?"
>
> "We don't communicate how others expect so they don't communicate with us"

Once again, then, there is a correlation shown between the behaviour of active collaboration and increased influence.

Positive framing

This has already been touched upon in the section on framing congruence, but Figure 8 shows the difference in the positivity of the language used to describe autism and autistic people between autistic advocates and the wider community sampled.

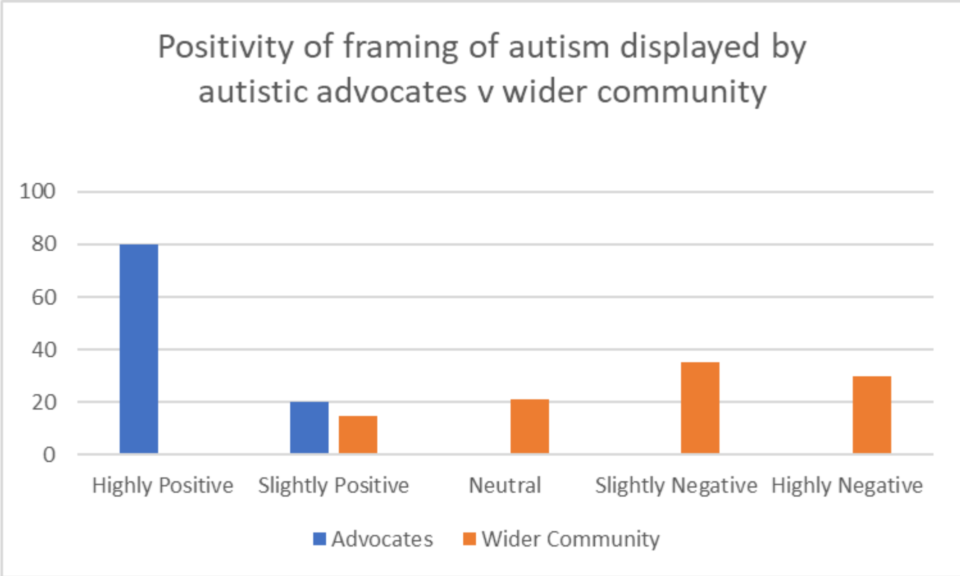

Figure 8: Positivity of framing of autism displayed by advocates v wider community

The data clearly shows that, while the framing of autism by the wider community varies, it is more negative than positive. Conversely, the autistic advocates sampled were universally positive in their portrayal of autism. It is important to remember that this positivity is congruent with the framing adopted by the government – therefore, this framing has been politically successful. The reasons for the difference in framing have already been discussed in the framing congruence section. The remaining behaviours to be analysed are those that were identified inductively as part of the iterative process.

Develops knowledge of self

Figure 9 shows the level of development of knowledge of oneself displayed by autistic advocates and the sampled wider community.

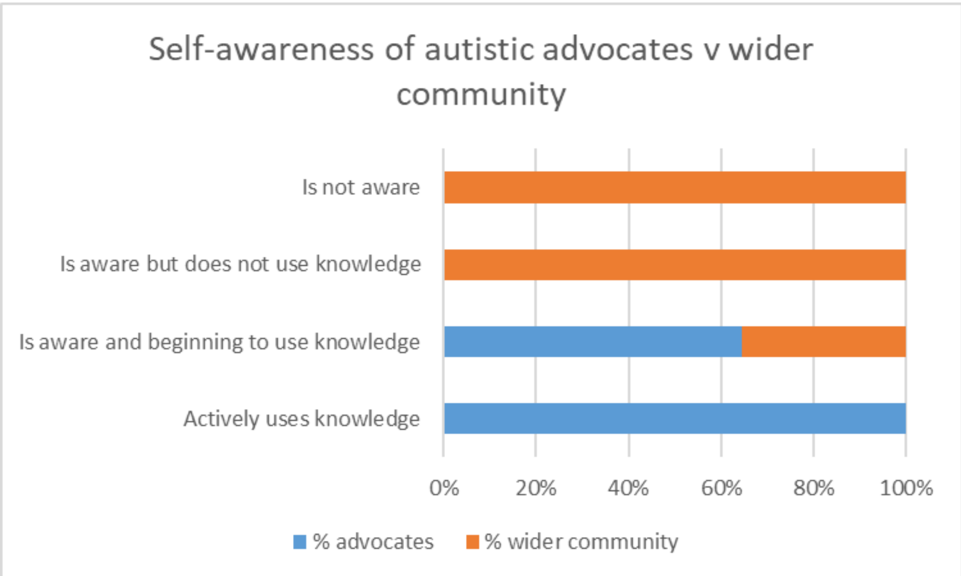

Figure 9: Self-awareness of autistic advocates v wider community

The data shows that the majority of the wider community sampled are either not aware of their own strengths and difficulties in relation to autism policy advocacy or are not using them. Some are beginning to use their self-knowledge, which is encouraging. However, all of the advocates sampled were either actively using their knowledge or at least beginning to do so.

The quotes below taken from interviews with advocates show that they demonstrated awareness of what made them a good advocate.

“I’m really detail-focused and I’m good on stats so I’m able to bring lots of evidence to the table and governments like evidence. I’m not so good at the persuading part but there are other people on board who can do that.”

“I think it’s because I’m so bull-headed! [laughs] Once I have a goal in mind, I keep at it, I don’t let it drop. Eventually people have to address the goal even if they might not do exactly what I want them to do with it. Sometimes I can annoy people though, so I’ve learned to watch for signs I need to give it a rest for a bit.”

Conversely, those from the wider community who did show a self-awareness tended to focus more on the negative than the positive, reflecting the findings from framing discussed earlier.

“Complex PTSD and autism (like most have) is debilitating. It's been caused by engaging in this world and being rejected, rejected humiliated and attacked. […] I work full time as a job coach for NAS, I'm a post grad student, wife mother, friend, but I get a panic attack every time I think about work or leaving the house.”

“'Within reason' is unspoken rule. But what is reasonable to you is not reasonable to me?”

“I'm lucky enough to be employed in an area (academic research) with a disproportionately autistic workforce, but I've tried and failed to get into the private sector for various reasons.”

This suggests that, while self-awareness is important, it is most effectively when paired with a positive framing.

Develops knowledge of autism

Figure 10 shows that while all the advocates sampled actively developed and used their knowledge of autism, the picture among the wider community was much more mixed, with more either unaware or not developing their knowledge.

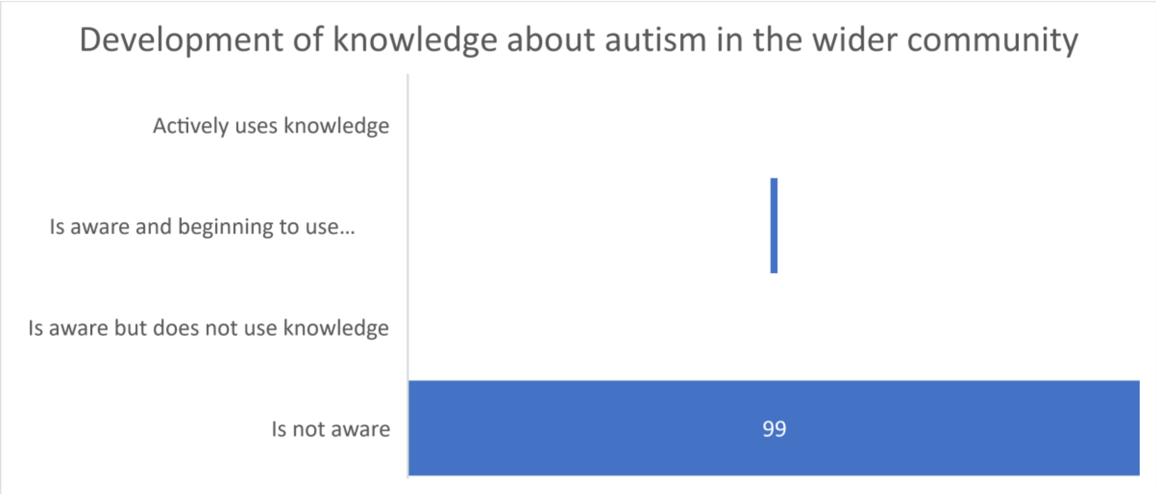

Figure 10: Development of knowledge about the wider community

This is further supported by quotes from interviews with advocates.

> *"I'm learning all the time. I'm autistic but autism doesn't equal me. It's such a diverse spectrum. I try to understand all the diversity and to reflect it."*
>
> *"When I was first diagnosed, I thought I was supposed to be like Rain Man. It felt like a death sentence. Now I know it's just a different perspective and sometimes that's helpful and sometimes it isn't. I try to get other autistic people to see it like that."*

Conversely, these quotes from the wider community surveyed show a lack of understanding as to why developing their knowledge of autism would be helpful.

"Only a minority of autistic people actually have the necessary understanding of our own brains to become self-advocates."   *"Many of the issues covered by autism research can also - certainly in my case - be covered by mental health issues, and poor mental health can be experienced by everyone, whether autistic or not. Many policy issues that are better managed on behalf of autistic people, will benefit society as a whole. Serving autistic people helps all of us."*

Therefore, while understanding of autism is mixed, there is little drive among the majority of the community sampled to try to understand their autism further. Nonetheless, such development of knowledge is strongly correlated with increased influence among the sampled advocates.

Develops knowledge of policy context/environment

Once again, autistic advocates score highly here, with 100% of them actively developing their knowledge of the policy environment. Figure 11 shows that an understanding of how the autism policy system works – or even what autism policy is – is, conversely, almost uniformly lacking among the wider community.

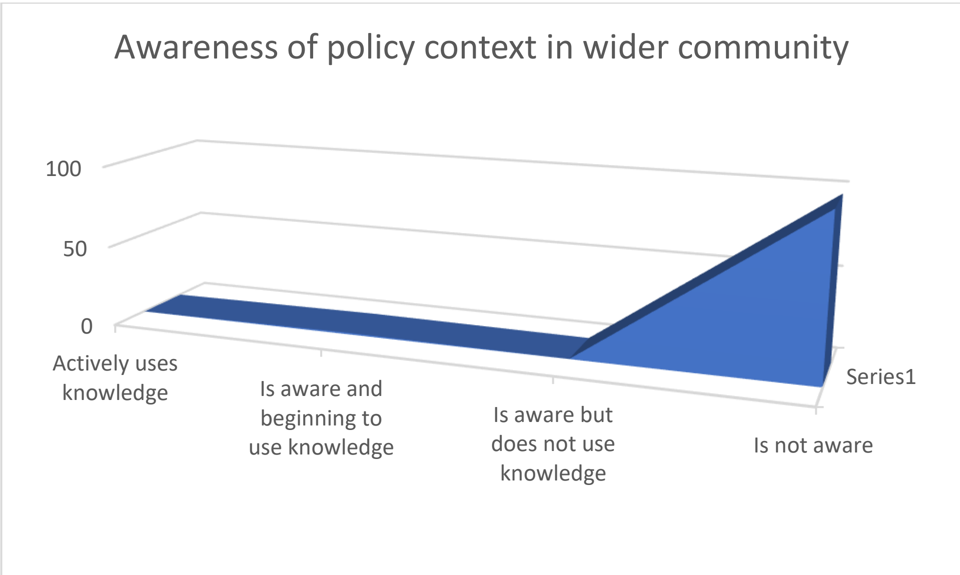

Figure 11: Understanding of policy context/environment in advocates v wider community

As reflected in the discussion on participation, the autistic community surveyed were largely unaware of how the policy system worked and what opportunities there were to get involved. This is clearly an area of knowledge which needs to be developed and addressed.

The quotes below from advocates demonstrate why an understanding of the system is so important.

"You get to know who to go to about what, who will be supportive and who not. How to word something so people will listen. It's all about building knowledge and it takes time and effort."

"I'm quite well-known now so people will approach me, and I'm always surprised how little they know about how to get involved. There are so many ways into the system. You have to learn the system like you learn what an examiner wants or how to complete a level on a computer game. It's no different."

Discussion

Thus, these results suggest key areas of learning around each of the behaviours, which are outlined below. The small n of the sample necessarily limits generalisability of the results but the combination of theoretical grounding and empirical demonstration of the behaviours in a highly targeted sample of demonstrably influential self-advocates generates enough reliability for the information to be of interest to the autistic community.

Developing and applying knowledge

It has long been known that autistic people possess lived experience of interest to policymakers (Cresswell and Hawn, 2011; Werts and Brewer, 2015; McIntosh and Wright, 2019) but the role of other forms of knowledge has received less attention. This research demonstrates the importance of understanding autism, oneself, and the policy context in order to maximise policy influence. Each individual's capacity to develop learning in each of these areas may be different but by developing and applying knowledge to the best of their ability, any gaps in knowledge can be filled through the collaboration outlined below. If each member of the autistic community that wishes to be involved works to the best of their individual ability, the collective will possess the knowledge required and the less able to develop knowledge will be able to benefit from the knowledge gathered by those who find it easier.
Autistic self-advocates are likely to have gathered a large amount of knowledge during their advocacy activity. It is important that this knowledge is disseminated to the

wider community in as accessible a way as possible. Many of those surveyed or spoken to were unaware of what advocates were saying or doing in their name, even though their policy goals and outlook were largely the same. Lack of awareness and knowledge of ways that they can make a difference is a key deficit for the wider community here and one that must be addressed with the same urgency as policy has addressed a lack of awareness of autism in the general population (Dillenburger et al., 2013; Mac Cárthaigh and López, 2020).

Active collaboration within and outside the autistic community

Participation and collaboration have here been combined for ease of reference and to highlight the importance of collaborative participation. The evidence from the sample suggests that the wider autistic community are more likely to participate passively than actively and by promoting collaboration, two goals can be achieved in one. The autistic people in the sample sometimes collaborated with others in the autistic community, but were reluctant to collaborate outside, citing distrust of politicians and scientists and demonstrating an 'us/them' mindset.

Conversely, the autistic self-advocates in the sample actively used other stakeholders, identifying how they might be useful to them and planning a strategy based on that. They reported feeling supported by their peers on the decision-making board and that everyone was 'on the same page'. Thus, autistic self-advocates could play an important role in reassuring the wider community both that they are represented on decision-making bodies and that there are policy actors that they can trust.

Collaboration, like the development of knowledge, is something that may come easier to some autistic people than to others. Some evidence has shown that autistic people communicate more effectively with other autistic people than with neurotypical people (Davidson, 2008; Cummins, Pellicano and Crane, 2020) and this may hamper collaboration outside the autistic community. However, the strength of neurodiversity is that all autistic people are different, and sufficient numbers of autistic people should be able to facilitate wider collaboration for all to benefit.

Positive framing and a strengths-based approach

This is an area which seems to have already seen some progress, perhaps due to the success of the neurodiversity movement (Armstrong, 2010; Kapp et al., 2013; Donaldson, Krejcha and McMillin, 2017). As a state of mind, positive framing is something that is accessible to the majority of autistic people, and it is a way that they can make a difference even if they do not feel able to be politically active. Just by considering the words they use or allow to be used to represent themselves to others in the public sphere, a difference to framing can be achieved. This does not detract from the fact that many of the autistic people in the sample had experienced negative reactions from others which have coloured their view of autism and other autistic people. Once again, by disseminating awareness and knowledge about autism and autistic people, autistic self-advocates can here play a role in altering the collective mindset.

Conclusion

This article has demonstrated that certain behaviours are more in evidence in autistic self-advocates sitting on decision-making bodies in England than in the wider autistic community. These behaviours – developing and applying knowledge, active collaboration, and positive framing - are also theoretically and empirically correlated with higher levels of policy influence. While the ability to demonstrate specific behaviours may vary by individual, the autistic community as a collective can benefit from applying these behaviours where possible.

Autistic self-advocates in particular have the opportunity here to lead in the co-production, with the wider autistic community and others, of a lobbying strategy for autistic people based on these behaviours. By sharing the knowledge they have gained, they can empower the wider autistic community and improve the quality of their representation. Further testing on a wider sample is planned but that does not mean that the process of disseminating information and beginning to build a strategy cannot start now. Knowledge is power, and autistic self-advocates are the gatekeepers to much knowledge.

Evaluation

This is an important article for the expansion of the thesis because it is the first step in moving beyond the policy scholarship to share the ideas with actual professionals and communities.

8. Conclusion

Over the course of this thesis, I have developed my underdog theory of the policy influence of marginalised groups and demonstrated that it can be evidenced through the example of the autistic community in England. I have argued that there are far-reaching impacts of the framing of marginalised groups as disempowered and an excessive focus on who has the upper hand in power relations. This has created a mistaken belief, namely that marginalised groups can rarely influence policy, and this belief has influenced how researchers approach the study of influence and further 'baked in' the mistaken belief.

The case of the autistic community in England stands in opposition to this. The autistic community, ably represented by a small group of self-advocates, even if they haven't always known they were being represented, has succeeded in reframing autism away from being a disability and in improving awareness, understanding and available services. They have done this by demonstrating underdog behaviours: developing their knowledge, actively collaborating, and taking a strengths-based approach.

Nonetheless, there remains much to do to level the playing field for autistic people and to complete the reframing process that needs to happen, and it is here that I hope a lobbying strategy spearheaded by autistic self-advocates will bear fruit.

In this Conclusion, I draw together the threads of the different chapters to summarise the claims and contributions of this thesis, both to the scholarship and to society at large. At the beginning of the thesis, I stated that my main aim was to inform a lobbying strategy for underdogs that would reduce the democratic deficit inherent in social policy. I set about doing so by taking a critical but pragmatic approach, combining threads from different but complementary disciplines and theories to create a rope which would anchor the underdog theory. This was an iterative process, since, like the underdog of popular culture, I did not know whether my expectations were too high or too low. I began with a skeleton framework which was then built upon by an in-depth case study and revised to produce the underdog theory summarised at the end of Chapter 6. In the course of developing the theory, I had to tackle potential limitations such as the spectre of responsibilisation, which led to the widening of the theory to encompass not just underdogs but also governments and researchers.

I begin by summarising the underdog theory. I consider its strengths, its limitations and whether anything can be done to mitigate those limitations. I go on to consider the wider contributions made by this thesis to the scholarship. Finally, I set out my plans for the next stages in developing the underdog theory which is the main product of this thesis.

The underdog theory

The underdog theory which resulted from this iterative process argues that marginalised groups are underestimated: they possess the *potential* for greater policy influence than they or others believe. The word ‘potential’ is important here because this potential can only be realised when the underdog is empowered – a process which requires the co-operation of others combined with the concerted action of the underdog. The disconnect between expectations and potential is a product of a framing of the underdog as a policy target group which assumes that the underdog is weak, in a position of inferiority or subjection and dependent on others. This assumption is false. The framing of the underdog has been built over many decades – centuries, even – by many different actors. The underdog has contributed to it but is not uniquely or mainly responsible for it – all societal actors have contributed to it and share responsibility. All societal actors therefore also have the power to *reframe the underdog*. The underdog is uniquely placed to do so especially effectively because they can literally personify the change they want to make.

Underdogs can empower themselves by *developing their knowledge* and understanding of their environment/policy area and policy system, the wider underdog community of which they are part, and themselves. By understanding how their particular strengths and weaknesses dovetail with those of the wider community and the opportunities available, the underdog can *create a strategy* which enables them to *mobilise strengths* and *mitigate weaknesses*. They can create goals which are achievable in the circumstances and learn how to frame them in a way which is more likely to be acceptable.

Also important is the need for the underdog not to try to do this alone and not to fall into the trap of 'us and them' thinking. Firstly, the underdog will empower themselves more quickly if they form strategic alliances. These alliances could be with other underdogs, with charities, with other societal actors or with non-societal actors, but they must further the overall cause. Secondly, the underdog should be supported by researchers and governments. More detail is given on this later in the chapter but, in brief, researchers can be self-reflexive about what they research, why and how they do it and make a conscious choice to do so in a way which supports the underdog. Governments can create opportunities for participation and choose to *problematise issues not people* and promote a positive framing of the underdog.

This brings us to the final and most important component of the underdog theory. The catalyst for underdog empowerment is a positive framing of the underdog. This framing emphasises their strengths and demonstrates how, rather than *being* the policy problem, the underdog can help *solve it*. As previously stated, the underdog is uniquely placed to embody this positive framing. This positive framing improves the reputation of the underdog, changes how others view them and makes it more likely that they will be listened to.

The underdog theory makes a theoretical and empirical contribution to a range of areas of the scholarship. The theory is still in its early stages but contains empirical evidence from the case study of autism policy. Further details on testing and developing the theory further are given later in this chapter.

Strengths of the underdog theory

The underdog theory supports the empowerment of underdogs by focusing on what they themselves can do to help themselves. The underdog behaviours outlined (deepening knowledge, collaborating with others, taking a pragmatic approach, and projecting a positive framing) are all selected not just because they further the cause of the underdog and make it more likely that they will achieve lobbying success, but also because they build the self-efficacy of the underdog (Dempsey and Foreman, 1997) and therefore boost their resilience and self-esteem (Goodley, 2005).

On an ethical level, it has long been understood that it is better for policy and research to be co-produced by the communities it concerns – that people should be included, rather than 'done to'. The underdog theory is an exemplar of co-production of policy in action since it specifically combines the need for collaboration with targeted behaviours for underdogs. In a similar vein, it promotes the (procedural and substantive) representation of marginalised groups by prioritising the direct involvement of underdogs in the policy process. This goes some way towards plugging the democratic deficit outlined in the opening chapters.

Finally, on a more theoretical level, the underdog theory personifies its collaborative spirit by combining elements of theories from a range of different scholarships (most notably lobbying, policy influence, empowerment, disability studies and autism studies). This results in several strengthening factors: firstly, it means that the underdog theory can be seen as a contribution to a range of different fields. Secondly, it improves the reliability of the theory because the components of the underdog theory are all empirically demonstrated across more than one disciplinary area.

Mitigating the limitations of the underdog theory

While the theoretical construction of the underdog theory is strong, it has thus far only been explored through one case study. Thus, while it does make an empirical contribution, the theory will require further testing before it can be generalised to other underdogs or contexts. At this stage in its development, it is only possible to say that the theory has multidisciplinary theoretical support and has been supported by one case study. Later in this chapter, I will set out how I plan to mitigate this limitation through further research.

Conceptually, there are two further limitations which need consideration and mitigation: the first is responsibilisation and the second is choice of language.

Avoiding responsibilisation

Responsibilisation, in this context, refers to the risk that the message that underdogs have the power/potential to reframe themselves as target groups and policy subjects in a more positive light (Thompson, 2003) will lead to one of two negative scenarios. The first is that underdogs feel responsible for their current marginalised position (and that this creates bad feeling and makes empowerment less likely) and the second is that other actors use the empowerment narrative as an excuse not to be active allies but instead to abandon the underdog to go it alone (Trnka and Trundle, 2014).

The underdog theory expounded in this thesis explicitly seeks to facilitate empowerment without incurring responsibilisation. It conceptualises both disempowerment/marginalisation and empowerment as being framings co-created by a range of societal and political actors over time (Schneider, A. and Ingram, 1993; Thompson, 2003; Nicolet, 2012). Thus, all societal and political actors can contribute to reframing how the underdog is viewed and treated and no actor bears sole or even majority responsibility. Moreover, any attempt to assign a majority 'blame' is likely to be unhelpful, since it negates the ability that every actor holds to reframe the underdog.

However, the underdog has a special advantage in that they can use a strengths-based approach to demonstrate their strengths, rather than just talking about them. The underdog's position is further strengthened by the fact that real empowerment requires them to act, rather than be acted for (Dempsey and Foreman, 1997; Banducci, Donovan and Karp, 2004; Maiorano et al., 2021). Thus, they gain greater benefit from acting than other actors do, because they contribute to their own reconstruction and gain personal power and self-confidence in doing so.

Nonetheless, action by the underdog, on its own, will either be insufficient to result in empowerment or, at the very least, will take much longer than if other actors were to act as allies. Remember that other actors – including governments and researchers – share their portion of the collective 'responsibility' for the marginalisation of the underdog. There is arguably a moral duty to do something about it – however, following rational choice theory, allyship will likely best be achieved by identifying the benefits to each actor inherent in doing so. Suggestions for next steps for governments and researchers are found later in this chapter.

Choice of language

The other potential limitation of the theory comes in its very title: the risk that people will respond negatively to the word 'underdog'. I chose the term 'underdog' specifically because for me, and, I believe, for others from an English-speaking cultural background, and especially from the United Kingdom, the term 'underdog' has positive connotations. It denotes a plucky spirit, a hidden potential, and the ability to come out on top.

However, for other people, and specifically for those who speak another language, or who have a learning difference which affects their receptive communication skills, the term may have more negative connotations, which would be counter-productive. I have carried out three workshops on the underdog theory with self-advocates who have a learning disability, parents of children with a specific language impairment and autistic people. Of these groups, only one, the group with a learning disability, responded negatively to the term ‘underdog’. Nonetheless, they did respond positively to the underdog theory itself, to the ideas and behaviours it put forward. All three groups liked the idea of contributing to a positive reframing and were able to identify ways that they had done this already.

Having identified this as a potential limitation, I propose to mitigate it in two ways. Firstly, I will continue to carry out engagement work to gauge reaction to the term among different interested communities. Secondly, I will focus on the behaviours and strategies rather than the term ‘underdog’ when working directly with such groups.

Beyond the underdog theory: contributions of the thesis

In addition to the theoretical and empirical contribution made by the underdog theory, which straddles the lobbying/collective action, framing (within policy studies) and policy influence, scholarships, this thesis also makes a methodological contribution to the scholarship on policy influence and contributes to the nascent scholarship on autism policy, as shown below.

A contribution to lobbying and collective action

The first area of the scholarship that the underdog theory speaks to is the lobbying and collective action scholarship. Here, it both challenges and builds on existing ideas. It recognises the importance of collective action and collaboration (Baumgartner, F.R. and Leech, 1998; Hardin, 2015; Junk, 2019a) and of maximising political opportunity (Gamson and Meyer, 1996; Koopmans, 1999; Meyer and Minkoff, 2004; McCammon, 2013) but challenges longstanding ideas about resources and about who does and does not have influence.

Focus on resources in the scholarship has mainly remained on external resources such as money (Leech et al., 2007; Binderkrantz and Pedersen, 2019) and access to networks of people (Marsh and Rhodes, 1992; Toke, 2010; Rhodes, 2018). With the possible exception of the analysis of political leaders by political psychologists

(Petersen & Laustsen, 2020), very little attention has been paid to internal resources such as personality traits among civil society actors. This thesis draws attention to these internal resources and the lobbying success that can be associated with them.

In this thesis, I have also demonstrated that scholars' perceptions about who does and does not have influence can be mistaken. Autistic people are unmistakably societally marginalised and do not possess the financial or people resources associated with power – despite this, they have succeeded in exerting policy influence. This is an important challenge to the danger of pre-conceived expectations and how these can become 'baked in' if researchers are not sufficiently self-reflexive in choosing and designing their research.

A contribution to framing in policy studies

The sub-discipline of framing in policy studies is another one which this thesis makes a contribution to. The importance of framing congruence as a lobbying strategy is well documented (Kangas, Niemelä and Varjonen, 2014; Klüver, H and Mahoney, 2015; De Bruycker, 2017; Junk and Rasmussen, 2019), but my work builds on Schneider and Ingram's anticipatory politics and social construction of target groups (Schneider, A. and Ingram, 1993; Schneider, A.L. and Ingram, 2019) and Junk and Rasmussen's work on the framing activities of interest groups (Junk, 2019a) to highlight how framing goes far beyond this in its importance. It doesn't just affect how society sees marginalised groups – or even just how governments see marginalised groups. It also affects how marginalised groups see themselves – and therefore their ability to empower themselves – and it affects how researchers view them, which, as we have seen, has potentially negative repercussions. Thus, the thesis challenges the relatively limited way in which framing is usually treated in the policy scholarship and offers a warning as well.

The concept of reframing is not a new one, in the sense that it could be seen to date back to Foucault's reconstruction of the self (Foucault, 1994; Thompson, 2003; Nicolet, 2012). Persuading the government to 'see it our way', as Börang and Naurin put it (2013), is in itself an act of reframing. However, it is rarely expressed as reframing in the policy scholarship, and this is something I hope that my work will get scholars thinking about: the power of reframing, not just achieving framing congruence.

A contribution to policy influence

The underdog theory also makes a theoretical, empirical, and methodological contribution to studies of policy influence – and this is perhaps its most important contribution. My literature review showed that the scholarship consisted mainly of indicators of influence and methodologies which offered only a partial glimpse of influence, and which were mostly calibrated in such a way as to miss lower levels of influence (March, 1955; Arts and Verschuren, 1999; Dür, 2008; Lowery, 2013). My new template for measuring influence and the evidence that the social policy influence of underdogs appears to be being underestimated and under-measured are important contributions to the policy sciences. They both build on existing knowledge (by combining existing indicators of influence) and add in new indicators from the empowerment scholarship, and they challenge longstanding ideas about who has influence.

From the empowerment scholarship, I introduce the importance of psychological preparation for lobbying influence, by developing skills such as self-awareness and self-efficacy, which is described by Dempsey and Foreman (1993), among others. I also highlight the importance of self-reputed influence, which is often ignored, but which empowerment research shows to be vital to resilience, self-esteem, and empowerment (Balcazar, Keys and Suarez-Balcazar, 2001; Banducci, Donovan and Karp, 2004; Goodley, 2005; Dunn, Clare and Holland, 2008)

These have the potential to cause a shift in how we view both the underdog and social policy influence, which speaks to the issue of power which is so central to both politics and policy studies. By bringing in learning from the empowerment and psychology scholarships, our understanding of the power imbalances in policy can be developed and, importantly, a strategy for reducing the democratic deficit can be put forward.

A contribution to autism policy studies

Equally important is the contribution that this thesis makes to the scholarship on autism policy, which is still in its early stages. While the critical autism studies scholarship is surging in popularity (Milton, D.E., 2014; Gillespie-Lynch et al., 2017; Woods et al., 2018), autism policy itself remains a side-lined topic. With the exception of important work by Dana Lee Baker (Baker and Steuernagel, 2009; Baker, 2011; Baker and Steuernagel, 2013) and Michael Orsini (Orsini and Smith, 2010; Orsini, 2012, 2016), little has been written exclusively or directly about autism policy. Much like influence, when it is referred to, it is usually in a narrowed context, such as education policy

(Della Fina, 2015) or criminal justice policy (King and Murphy, 2014). The impact of this is that there is nothing really in the scholarship to say 'what is autism policy' – and without that understanding, how can the autistic community learn about it?
Thus, it is my hope that by starting a conversation about what autism policy as a collective is, and how it can be influenced, this narrowness of scope can be changed. More importantly, however, the thesis is a call to autistic people to recognise their own potential – and do with it what they will.

Where now for the underdog?

The first step for any underdog seeking to empower themselves in relation to a specific policy area or issue must be an assessment of their starting position. If empowerment is a sliding scale, where is their community on it? Are there specific members of the community, such as autistic self-advocates, who are more empowered and who can take on an informative or didactic role towards other community members? If they cannot learn from members of their own community, can they learn from members of ally, or similar communities? For example, autistic self-advocates might be able to advise other communities with hidden needs.

The key purpose of this first step is to establish where the knowledge and understanding that is going to be built is going to come from. Ideally, it will come from members of the community or an allied community but there may be instances where it has to come from sympathetic researchers or governments. This should not be viewed as automatically a 'bad option' – an 'us' and 'them' attitude to policy change will not help the underdog (Putnam, 2005). This may be a hard mental shift to achieve for some underdog communities – it certainly seems to be embedded in the wider autistic community – but will be an important step on the path to empowerment.

The next step is to develop knowledge and understanding in three areas: the policy area/system, the community's strengths and weaknesses and the individual's strengths and weaknesses. This will enable strategic planning of where specific strengths can be mobilised and which weaknesses may need to be mitigated through alliances with other actors.

Alongside or after this stage, the underdog needs to consider forming alliances for two main reasons. Firstly, alliances provide access to money, knowledge and contacts that the underdog may not possess alone (Matti and Sandström, 2011; Laumann and Pappi, 2013; Hardin, 2015) and, secondly, alliances boost the reputation of the underdog and make it more likely that others will listen to them (Heaney, 2014; Ingold and Leifeld, 2016). Alliances can amplify the message that the underdog wants to transmit so that more people hear it.

The most important step for the underdog, however, and possibly the hardest mental shift, is to promote a positive framing of themselves as a target group. This strengths-based research has been shown in this thesis to be associated with greater levels of influence, even though it may be counterintuitive not to focus on the ‘problem’ to be solved. In fact, it is not counter-intuitive. Social policy may need a ‘problem’ (Rochefort and Cobb, 1993; Jones and Baumgartner, 2005; Edwards, Howard and Miller, 2020), but it does not need the target group to be problematised. If the ‘problem’ focused on is, for example, lack of understanding of autism, or unacceptably long waiting times for diagnosis, this can be highlighted without problematising autistic people at the same time. If the underdog can show how their strengths can be used to help solve the problem, so much the better: they transform themselves from a target group to an implementer.

The detail of any lobbying strategy, however, must be down to the underdog community, who should head the alliance by virtue of their lived experience of the policy problems in question. Goals and framings proposed should be well thought through, form part of a long-term strategy for change and be achievable. The underdog must also recognise that change is likely to be slow. It is also important for the underdog to celebrate and publicise even the small successes as this is all part of altering their public framing.

Finally, the underdog would benefit hugely from being able to bring on board the government and researchers. Therefore, it would be beneficial for them to build relationships with members of these groups and to seek to identify how supporting the underdog may also hold advantages for the government and for researchers. If this can be communicated effectively, it may help create more opportunities for empowerment, as explained below.

Where now for researchers?

Researchers who come across the research in this thesis on measuring influence have the opportunity to reconsider how they measure influence and whether they may inadvertently have been contributing to the marginalisation of underdogs by utilising methods which are less likely to capture underdog influence. Practising reflexivity will allow researchers to consider what pre-conceived ideas may be determining what they choose to research and why, and how they choose to go about it.

Like any other actor, researchers are the product of their environment and their training. The academic arena is heavily predicated on building on previous research, which means that certain areas are more researched than others, and certain methods are more used than others. By questioning specifically whether the research question and methods selected are supportive or unsupportive of the underdog, researchers can do their part to alter the way that marginalised groups are viewed.

If it can become widely accepted that underdog influence is greater than it is currently believed to be – and this will require further research – this could be a game-changer in how underdogs are viewed. Even an act as simple as not shying away from measuring underdog influence because you don't expect to find much can make a small difference. Researchers have a lot of power in this context, because their research often goes straight to governments making policy decisions.

Researchers who actively choose to be allies of the underdog can therefore make a difference to what is researched, how it is researched and what data reaches governments. As well as meeting what is arguably their moral responsibility, this would also increase their own reputation (since the victorious underdog is a well-loved trope) and further our understanding of what influence is and how it is measured and what it means to be an underdog.

Where now for governments?

Governments, after underdogs, are perhaps the most strongly placed to make a real difference to the policy influence of underdogs. This is because they have significant control over the political opportunity structure and can create (or deny) opportunities for underdogs to participate directly in policy decision-making. They also promote a certain framing of the underdog in policy documents and on government-run websites, which trickle through to the dominant framing in the general population.

Existing research suggests that governments are less likely to listen to underdogs because they perceive them to be weak, i.e., to have limited influence. If research about underdog influence continues to support the theory that underdogs are more influential than they expect, this in turn may alter how governments treat underdogs. However, governments do not have to wait for this. They can change the way they act now, by choosing to problematise issues not people/target groups, by viewing marginalised groups in a positive light and, most crucially, by creating opportunities for the active participation of underdogs in policy decision-making spaces.

Governments who actively choose to be allies of the underdog can therefore increase their own reputation while also increasing the empowerment of the underdog through meaningful changes to the political opportunity structure. By rejecting the 'neoliberalist responsibilisation' that is expected of them, governments can reframe how the public views them as well, in a more positive light.

If all three actors can work together in a true alliance, there is strong potential for fast-tracking the empowerment of the underdog. Researchers can produce more research which is beneficial to the underdog, and address misconceptions in the scholarship about the nature of influence. By choosing methods which capture underdog influence, they can alter how the underdog is viewed by the government and the public. They can present the government with the evidence needed to make meaningful changes. Governments can genuinely put underdogs in the driving seat by creating opportunities for participation and by choosing not to problematise the underdog. And the underdog can step into their power and mobilise their strengths with the backing of a powerful alliance behind them.

This is, of course, an ambitious dream. However, the underdog embodies the dismantling of restrictive expectations and the disconnect between expectations and potential. Managing the expectations of the underdog is important – it is not likely that underdogs will achieve sky-high levels of influence, nor is it reasonable to expect that all, or even most, governments and researchers will be willing to form alliances. However, every little increase in influence helps and this is the beginning of a long process of reconstructing the underdog, which I believe to be a worthwhile aim.

Where now for the underdog theory?

So, where next for the underdog theory, which, as previously stated, is still in its early stages? The theory will need to be tested in different policy and country contexts to see if it still holds – and this can be seen as part of an ongoing iterative process. I would like to start by looking at autism policy in Western Europe and North American to see the differences, but also to consider whether the theory holds for other disabled communities, and from there onto other marginalised groups.

I have begun engagement work, including presenting the underdog theory to three groups: the parents of children with a specific language impairment, self-advocates for people with an intellectual disability and autistic people. All of these groups found the underdog theory helpful, but some learning points were drawn out. Firstly, the term ‘underdog’ can be misconstrued, particularly by those with more literal understanding, or those for whom English is not the first language. While the multi-layered meaning to the term underdog is useful to the academic community, it may not be appropriate to use when dealing with underdogs themselves, and an appropriate term should be selected.

Secondly, it should be acknowledged that many groups are already enacting part of the underdog theory without realising it. Naming successes and what is being done right can be an extremely powerful way of reinforcing positive action. Knowing that you have already started doing the right thing, and building on it, is a definite step-up on the path to empowerment. Further engagement work will bring new lessons and is definitely planned. A co-produced piece of research with an underdog community is also an important next step.

Over to the underdog

In conclusion, this thesis has met the aim that it set out with, namely, to inform a lobbying strategy for marginalised groups. It has answered the research question ‘to what extent, how and to what effect do marginalised groups exert social policy influence?’ through a case study of the autistic community in England. The response to the question is that marginalised groups exert more influence than expected through a constellation of behaviours which can result in their empowerment and ability to teach others. At the heart of these behaviours is a willingness to build awareness and knowledge, to collaborate with others and to adopt a positive framing. It has made a theoretical, empirical, and methodological contribution to the lobbying, policy influence, empowerment, autism policy and disability policy scholarships and it has provided autistic people with a skeleton lobbying strategy which they can embellish and develop themselves.

It is my hope that the underdog theory will be further tested and developed in the years to follow and that it can be utilised by a variety of marginalised groups to alter the political landscape in which we live and to reduce the democratic deficit inherent in social policy. The underdog represents untapped potential inside all of us. We can all learn from the underdog, set our expectations high and confound the lower expectations of others. This thesis represents the first foray of the underdog theory into the real world. While my own research will continue, it will, eventually, be over to the underdog to take up the baton and enact meaningful change for themselves.

Appendix 1: Data Repository

The following items are available in the data repository for this thesis, which can be accessed at https://researchdata.bath.ac.uk/id/eprint/1131.

The data repository contains:

- MRes thesis
- Actor mapping data
- Interview questions
- Survey questions
- Focus group questions
- Feedback from autistic consultants
- Anonymised (where requested) transcripts of all interviews and focus groups.
- Survey results in .xls format
- Coding spreadsheet for Article 1
- Coding spreadsheet for Article 3
- NVivo coding file for Article 1
- NVivo coding file for Article 3

Data for Article 2 is available in a separate data repository available at https://doi.org/10.15125/BATH-00867.

Appendix 2 – Data Management Plan

Doctoral Data Management Plan

Overview

Project title
The underdog empowered: a case study of autistic policy influence in England.
Student name and department
Katharine (Kate) Precious, Department of Politics, Languages and International Studies
Supervisor(s)
Dr. Fran Amery*, Senior Lecturer in Politics, Department of Politics, Languages and International Studies, University of Bath. Dr. Katie Maras, Senior Lecturer, Centre for Applied Autism Research, University of Bath.
Project description
This multidisciplinary thesis by publication challenges the characterisation of marginalised groups as politically disempowered. While acknowledging their very real, structural disadvantage, it argues that dominant framings of marginalised groups, the actions of governments and researchers, and the actions of marginalised groups themselves combine to systematically underestimate and under-measure the policy influence of marginalised groups. This in turn impacts how others perceive marginalised groups, how they perceive themselves and how they behave. Through two articles and a case study of the adult autistic community in England, I use process tracing of policy documents, Hansard records, stakeholder interviews and focus groups to track behaviours and outcomes during the lobbying process and to build my 'underdog theory' about the hidden potential of marginalised groups. The underdog theory states firstly that marginalised groups have a potential for a greater level of influence than is usually assumed; and secondly, that marginalised groups can maximise their policy influence by adopting a positive framing, learning about themselves and their policy environment (and using that knowledge strategically) and actively collaborating with others. The term 'underdog' reflects the disconnect between expectations of marginalised groups and what they can actually achieve. This theory has implications for researchers and governments, who are urged to consider changes to the way they measure influence and design institutions and policy, but most importantly for underdogs. Through an article on policy design, it uses fuzzy set Qualitative Comparative Analysis to demonstrate the impact that governmental policy design has on autism policy decisions. This thesis therefore makes a theoretical, methodological, and empirical contribution to the scholarship on empowerment, lobbying and policy processes. More importantly, it represents a first step in providing marginalised groups with the information they need about their policy environment to enable them to start their empowerment journey.

Compliance

University policy requirements
Ethical approval will be obtained for each discrete research project before collecting data. Informed consent will be sought from all participants for data to be retained, shared, and used for new purposes and all participants will have the opportunity to end their involvement at any time. Any data stored on a mobile device will be transferred to University servers the same day and then deleted from the mobile device. All data will be stored securely in password protected files on University servers and with a back-up saved to an external hard drive stored in a locked cabinet in my supervisor's office. Data underpinning publications must be kept for at least ten years.
University policy or guidance
University of Bath Research Data Policy
University of Bath Code of Good Practice in Research Integrity
University of Bath Electronic Information Systems Security Policy
University of Bath Intellectual Property Policy
University of Bath Code of Ethics
University of Bath Mobile Computing Policy
Legal requirements
There are no legislative requirements relating to my project.
Contractual requirements
Published results should include information on how to access the underpinning data. All data sources must be acknowledged.

Name of funder	Data policy URL
ESRC (UKRI)	https://www.ukri.org/files/legacy/documents/rcukcommonprinciplesondatapolicy-pdf/

Gathering data

Description of the data
3.1.1 Types of data
I will be using secondary data in the form of publicly available policy documents and statistics and primary, qualitative data in the form of interviews, surveys and focus groups.
3.1.2 Format and scale of the data
Policy documents will be stored in PDF format, and I expect them to take up less than 100GB of space. Interviews and focus groups will be stored as audio files in MP3 format and transcriptions will be saved in Word in .rtf format for long term preservation. I expect to generate around 50 audio files lasting 1-2 hours each. I expect the audio files and transcriptions to take up less than 100GB of space. Original consent form will be stored in ring binders, and I expect them to take up no more than 1 ring binder. PDF copies will be saved on the server, and I expect them to take up less than 100GB of space.
Data collection methods
I will extract data from policy documents in the public domain. I will record and transcribe interviews and focus groups. Online survey results will be downloaded onto the X:// drive in Word .rtf format. I will take written notes and type them up before shredding the original notes,

Development of original software
I will not develop any original software.

Working with data

Short- and medium-term data storage arrangements
Identifiable participant data will be held in an encrypted folder on my supervisor's area of the X: Drive. The encryption password will be different to my University of Bath login password and access to the folder will be restricted to me and my supervisor. When I am working in the field, all of my study data, including identifiable participant data, will be held securely on an encrypted laptop, and backed up to an encrypted external hard drive. The laptop and external hard drive will be stored securely, in separate locations, whilst not in use. When I have access to a secure internet connection I will transfer the data to the University X: drive using files.bath.ac.uk and will delete the data from the laptop and external hard drive. When I return to the University I will ask Computing Services to ensure that the data have been securely deleted from both devices. The University managed servers are enterprise grade storage that are mirrored across two physical locations and are backed up regularly making them resilient to damage failure and security breaches. Non-digital data will be held in a locked filing cabinet in my supervisor's office.
Control of access to data and sharing with collaborators
Only my supervisors and I will have access to my data during the project. We will have the only copies of the key to the locked filing cabinet containing, and the decryption password to the encrypted folder.
File organisation and version control
I use a folder for each project phase, and within this, sub-folders for the study protocol, data, documentation, literature, and publications.
Documentation that will accompany the data
I keep additional notes about interviews in a Word document with the audio recordings and transcripts. I keep analysis notes for document analysis in Word and Excel documents in the data folder.

Archiving data

Selection of data to be retained and deleted at the end of the project
I will keep anonymised transcripts of all interviews but will destroy the original audio recordings in order to remove the risk of accidental disclosure. I will retain all other data in raw format.
Data preservation strategy and retention period
I will submit data underpinning publications and any other data that would be of value to future research to the University of Bath Research Data Archive where it will be kept for at least 10 years.
Maintenance of original software
Not applicable.

Sharing data

Justification for any restrictions on data sharing
All of my data may be shared openly at the end of the project when my research findings are published.
Arrangements for data sharing
My data will be shared openly via the University of Bath Research Data Archive. I will include the DOI to my dataset in data access statements provided in publications from my project.

Implementation

Review of the Data Management Plan
This Data Management Plan will be reviewed on a 3-monthly basis by Kate Precious. The next review is due in July 2022.
Special resources required for the project
No additional resources required.
Further training needs
No further training required.

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