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ORIGINAL ARTICLE

Marginalised or missed? The curious case of influential autistic self-advocates in England: introducing the 3i instrument

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Abstract

This article argues that the social policy influence of marginalised groups is at risk of being underestimated, in the scholarship, policy communities and wider society. It proposes the 3i instrument: a new, triangulated approach to measuring influence with a broader 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 autistic self-advocates in England. Surprisingly, the results show not just that autistic self-advocates but, through them, the wider autistic community, have more policy influence than they or others expect, but that influence is also being missed in its later stages, indicating that researcher bias may also be a complicating factor. While a single case of 'missed' influence is not sufficient to generalise to other contexts and groups, this research opens the door to a wider methodological discussion and reflexivity on the part of researchers.

Keywords Self-advocacy · Lobbying · Policy influence · Autism policy

Introduction

There is a democratic deficit in social policy: those who need social change the most are the least able to influence social policy (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 disempowered (Schneider and Ingram 2019). This article acknowledges the very real

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constraints placed upon marginalised groups but challenges their characterisation as always and automatically politically disempowered. It theorises, instead, that the policy influence of marginalised groups is at risk of being underestimated and that self-advocates from marginalised groups may be able to exert higher levels of influence than both the scholarship and wider societal perceptions would lead them to expect. In short, it hypothesises that the political influence of certain marginalised groups may be being 'missed' by researchers—and presents evidence that in one example, at least, that of autistic self-advocates in England, this has indeed been the case.

This underestimation is conceptualised principally as a product of the social construction of marginalised groups as disempowered (Schneider and Ingram 1993; Fung and Wright 2003; Maiorano et al. 2021). The impact of this social construction is wide-ranging. It affects how marginalised groups see themselves, and how they behave (Goodley 2005; Dempsey and Foreman 1997). It impacts how society views marginalised groups, and how they vote when it comes to issues which concern them (Schneider and Sidney 2009). It determines how governments view marginalised groups and how they design both policies which concern them and decision-making systems which include or exclude them (Schneider and Ingram 2019; Precious 2021). Finally, it colours how researchers determine indicators for measuring influence and therefore the outcome of such research (Lowery 2013)—which, in turn, impacts how governments design policies and how marginalised groups lobby government. This cycle risks 'baking in' errors about missed influence and perpetuating inequalities further.

Thus, this research has three key aims. Its primary aim, which is normative in nature, is to open a methodological conversation about the measurement of policy influence, in short, to ask whether policy influence is indeed being missed. Its secondary, empirical aim is, through an exploratory case study, to determine whether autistic self-advocates in England have more policy influence than we would expect a marginalised group to have: in other words, is *their* policy influence being 'missed'? Its third and final methodological aim is to introduce and test a novel framework for measuring influence, namely the 3i instrument.

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

Explanations for the policy marginalisation of certain groups are forthcoming from a range of disciplines, most notably the emancipation and collective action scholarships, but also critical studies disciplines (Boltanski 2011; Coole 2015; Masquelier 2017; Wrong 2017; Scott 2012). Despite their differences, these disciplines converge on the importance of the social construction of marginalised groups. 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, take time to show results and rely heavily on social constructions (Hornung et al. 2019; Junk and Rasmussen 2019; Cornwall 2017). Common lobbying strategies emerging from the lobbying literature 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 these assumptions are wrong?

We already know that social constructions impact how governments view marginalised groups. Schneider and Ingram (Schneider and Ingram 1993, 2019) highlight that marginalised groups are frequently constructed as politically weak (disempowered) and therefore ignored by governments. It is not, therefore, a stretch to suppose that social constructions also impact how researchers view marginalised groups. Indeed, researcher bias is a known artefact in social research (Chenail 2011). Influence is an intervening variable (March 1955) and only its effects are observable: therefore, scholars must seek observable indicators of influence and the choice of which indicators to look for is paramount and at risk of researcher bias. Moreover, policy change is often slow and takes time to result in observable effects (Baumgartner et al. 2009; Gardner and Brindis 2017); faced with competition from established policy actors, there is a risk that the influence of marginalised groups is missed even before researcher bias is taken into account.

Indicators of influence

Let us look, then, at the most commonly used indicators of, or perhaps, in light of the inherent difficulties in measuring policy influence, proxies for policy influence. *Goal attainment* (also known as lobbying success or preference 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 et al. 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 (Bernhagen et al. 2014; Lowery 2013). Attempts have been made to

nuance this binarity (Verschuren and Arts 2005; Klüver 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. 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 (De Bruycker and Beyers 2019; Leech 2014).

One way that this emphasis on the later stages can be mitigated is by including *agenda-setting* as an indicator of influence. While agenda-setting as a topic has a broad following in the scholarship (Barbehön et al. 2015), and the link between agenda-setting and political influence is well established (Birkland 2017), it is strangely absent from methodological discussions of measuring policy influence (cf Lowery 2013; Dür 2008). 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 one 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 et al. 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 and thereby their ability to empower themselves (Banducci et al. 2004; Dempsey and Foreman 1997; Goodley 2005). Since reputed influence is closely linked to social constructions, it is unlikely that marginalised groups would score highly using this indicator.

Political participation is one way of achieving representation, and some scholars have argued that participation is a pre-requisite for substantive representation (Luxon 2019; Dür and De Bièvre 2007). 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 (Halvorsen et al. 2017; Kingston 2014; Mabbett 2005; Milner and Kelly 2009; Banducci et al. 2004; Dempsey and Foreman 1997; Goodley 2005), 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 (Milner and Kelly 2009; Miraftab

2004). 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; Kangas et al. 2014)—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 et al. 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; Mahoney 2007). Like other measures of influence, active participation is only really useful if it is paired with other measures.

Framing congruence refers to the extent to which the framing of a policy issue put forward by a specific claim-making group is congruent with the dominant framing chosen by government. This indicator allows the user to measure influence at the agenda-setting and problem definition stages of the policy process, which other measures struggle to do (De Bruycker 2017; Klüver and Mahoney 2015; Boräng and Naurin 2015). Framing ties in with the extensive literature on problem definition (Dery 2000; Rochefort and Cobb 1993; Baumgartner and Jones 2015) for issue framing, and the social construction of target groups and anticipatory policy for target group framing (Schneider and Ingram 2019, 1993).

A shift in framing may not be enough for the policy actor to attain their goals but may nonetheless alter the trajectory (Junk 2019b; Klüver and Mahoney 2015). 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 (Mahoney and Kluver 2012; 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. It is therefore, theoretically at least, at risk of being missed. This risk is heightened by the fact that most researchers select and use only one indicator of influence to measure policy influence, despite the fact that all indicators of influence are, in and of themselves, incomplete and insufficient to carry out a full assessment (Dür 2008; Lowery 2013).

Arts and Verschuren (1999) are the only researchers to date to propose a triangulated measure of influence which combines self-reputed influence, reputed influence and goal attainment. They call this the EAR Instrument, with the E standing for Ego-perception (or self-reputed influence), A standing for Alter-perception (or reputed influence) and R standing for Researcher's Analysis (which includes goal attainment). This acknowledges the importance of perceptions, or 'ascription', while balancing it with the more empirical measure of goal attainment. The heuristic formula

PI = GA × AS × PR is used, where Political Influence = Goal Attainment × Ascription × Political Relevance. Political relevance is a function of how 'high stakes' the policy issue is, both politically and to the stakeholders.

An ordinal method is used to quantify influence, with each element being ascribed a numerical score between 0 and 3, with 0 meaning no influence, 1 meaning some influence, 2 meaning substantial influence and 3 meaning great influence. These scores are combined to give a score out of 27, which is then further categorised as 0 = no influence; 1–3 = some influence; 4–18 = substantial influence; and over 18 as great influence. However, the researcher's own judgement is seen as an important element of assigning numerical value to each component and thereby to the outcome. The researchers acknowledge limitations to this method, such as that it is subject to bias and that it favours a pluralistic approach. While this acknowledges the contribution of more minor players such as marginalised groups, it remains inefficient at capturing their influence, particularly given the heavy focus on ascription and perceptions, which social constructions are likely to shape in a more negative way. The heuristic formula goes some way to countering potential researcher bias, but the researcher plays such a key role in assigning the numerical values that form part of the formula that it would be very easy for societal biases to impact the researcher's judgement.

I propose both a specific definition of policy influence and a new way of assessing indicators which builds on the work of Arts and Verschuren (Arts and Verschuren 1999), while maintaining tried and tested methods for assessing influence. Like Arts and Verschuren (1999), rather than viewing influence as binary success or failure, I define it as a spectrum which determines the trajectory of the policy process. Since some actors may wish to maintain the status quo, I include maintenance of the trajectory within my definition of policy influence:

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. 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, across a range of data sources to include stakeholder interviews and document analysis, according to a sliding scale of low, medium or high. There is therefore a dual triangulation—of sources of evidence and of indicators of influence. In so doing, I hope to promote reflexivity on the part of the researcher (in a way not required or promoted by the heuristic method of the EAR instrument), as they assess influence against all possible indicators: not just reputed/self-reputed influence and goal attainment. The template is shown in Fig. 1 below.

This template covers influence at all stages of the policy process and is novel in the sense that it explicitly triangulates measures of influence across a much wider range of indicators than is normally the case, thereby enabling lower levels of influence which might otherwise be missed to be included. It is cumulative, in the sense that the more indicators that are observed, the higher level of influence. It is also relative; it is of most use when compared with the relative influence of other stakeholders. It reflects the scholarship on emancipation and collective action by

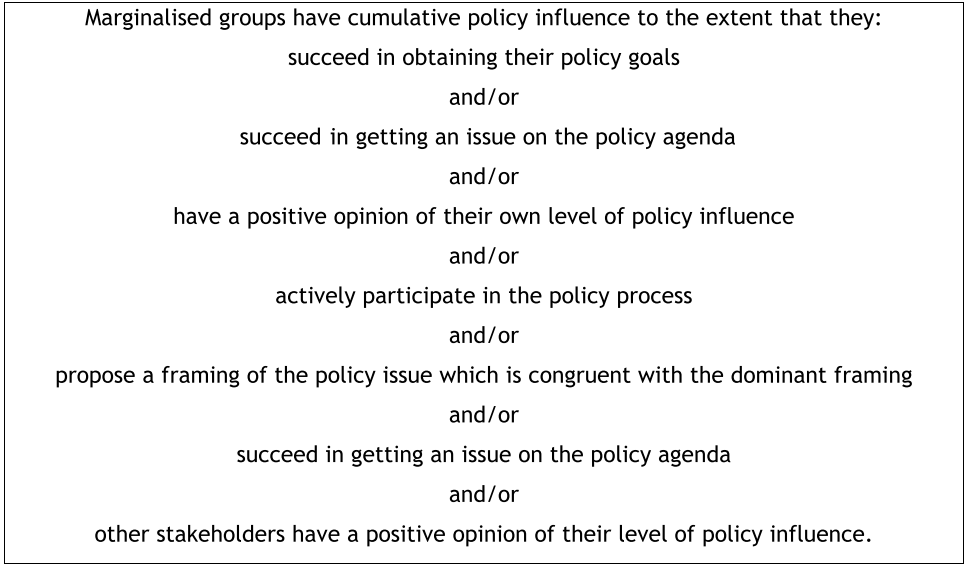

Fig. 1 3i instrument

emphasising active participation, but, in recognition of the risk of missed influence, it also includes those measures that are theoretically less likely to be in evidence. The researcher should classify the influence of each stakeholder in each category as low, medium or high and then assess the overall level of influence based on the spread of scores. The exact criteria for low, medium or high are left to the researcher to determine, since they are context driven.

Bearing in mind the normative aims of this research, it is more likely to encourage researchers to reflect on and ultimately capture the influence of marginalised groups which might otherwise be missed because it (a) requires explicit consideration of all indicators of influence and (b) considers even those indicators of influence which are theorised to be unlikely to be in evidence, minimising the impact of researcher or 'baked-in' bias. I call these indicators the 3i instrument, which stands for Inclusive Indicators of Influence.

Case selection

To test for missed influence, I selected a 'crucial' 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). This selection on the dependent variable limits the generalisability of the results but does allow the theory to be explored and tested on a single case, opening the door to both a methodological conversation and further testing in the future.

Autism itself is clinically defined as a neurodevelopmental disorder (Falkmer et al. 2013; Hayes et al. 2018; NICE 2016), and most autistic people with a clinical diagnosis would meet the legal definition of a disability (Baron–Cohen 2000; Krcek 2013; O'Reilly et al. 2015). Thus, autistic people are constructed as disabled and disempowered; 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 (Donaldson et al. 20172015; Kapp et al. 2013). Strengths commonly associated with autism, such as attention to detail and a strong work ethic, have been empirically demonstrated in the psychology scholarship (Meilleur et al. 2015).

In parallel with a rapid evolution in understanding of autism and the growth of the neurodiversity movement (Chamak and Bonniau 2013; Dillenburger et al. 2013; Donaldson et al. 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 2021). This indicates a possible reframing away from autism as a disability, which can be managed using existing disability policy, into a new policy area (Precious 2022). In many of these countries, the creation of an autism-specific policy was closely linked to advocacy movements (Precious 2018). I focus on England as the first country to pass an autism-specific law, the Autism Act 2009 (Della

Fina 2015; Baranger et al. 2018) and one of few countries to make institutional changes to the political opportunity structure to facilitate autistic participation (Precious 2021), making participation, as an indicator of influence, more likely.

Within this, I differentiate between autistic self-advocates, who emerge from the policy mapping described below as having the most access to the policy process and therefore the greater likelihood of influence (Meijerink 2005; Meyer and Minkoff 2004), and the wider autistic community. It is important to see them as two separate but linked groups because of the difficulty inherent in representing a community as diverse as that of autistic adults in England (McCoy et al. 2020). Autistic self-advocates may possess influence within the sphere of the policy process, but this is only meaningful influence if it also serves to progress the policy goals of the wider community.

Finally, an important reason for selecting autistic self-advocates is that those strengths and skills empirically demonstrated within the autistic community (Meilleur et al. 2015) and described above are precisely those which lend themselves to successful advocacy. This therefore means that there is theoretically more likely to be influence to be captured—or missed.

Methodology

The first methodological challenge is how to determine if autistic self-advocates' policy influence is 'higher than expected', i.e. if low expectations of autistic influence indicate that it has been 'missed'. We already know that societal perceptions of the policy influence of autistic people are low, both from the limited existing scholarship on autism (Feinberg and Vacca 2000; Baker 2011) policy and from the wider disability policy literature (Dempsey and Foreman 1997). Therefore, the starting expectation is that levels of autistic influence will be low. However, it is also important to understand how autistic people perceive their level of influence: I measure this in two ways. Firstly, I use the results of the 3i instrument to compare the wider autistic community's perception of their influence with the perceptions of self-advocates and of other stakeholders and with the overall level of influence for both self-advocates and the wider community. I focus primarily on the perceptions of the wider community since they are the group whose interests should be served by influence. Secondly, I consider that this criterion has been met if there is evidence of goal attainment, or reputed influence for self-advocates or the wider community, since both are shown by the scholarship to be unlikely for marginalised groups.

I use process tracing to assess the presence or absence of 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 (Howlett et al. 2017; Shanahan et al. 2011). 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. However, this shift is a conscious part of the recalibration of the indicators to make it less likely that the influence of marginalised groups will be missed.

Data sources

Data for analysis are 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. Stakeholder interviews allow for interviews to be held with those on the policy frontline, gaining an in-depth understanding of the policy process (Beresford et al. 2020; Fraussen et al. 2020; Stanick et al. 2018). The inclusion of elite interviews with MPs and Lords also allows a glimpse 'behind the scenes' of the process (Aberbach and Rockman 2002; Harvey 2011). Interviews were semi-structured, allowing for questions to be scripted in such a way as to obtain sufficient data to assess the template for influence, but also for flexibility should the conversation develop in an unexpected way (Salmons 2014). 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, 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, 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 were 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 (Berinsky 2017; De Vaus and de Vaus 2013). 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. 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 were anonymised. 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 used the 3i instrument to assess the presence or absence of each indicator of influence at each stage of the policy process according to the evidential markers shown in Fig. 2. These codes were recorded in a master spreadsheet which can be found in the data repository.

I used these data to assess the relative influence of each stakeholder.

Ethical considerations

The main ethical concerns centred around accessibility, given that autistic people can be disadvantaged in communication with non-autistic people (Milton 2017), and minimising power imbalances or perceptions of power imbalances. These were tackled using the AASPIRE guidelines for involving autistic people in research (Nicolaidis et al. 2019): accessible formats for study information; a streamlined online consent process to minimise cognitive load and the offer of different modes of interview. Survey and focus group questions were piloted on three autistic people prior to use; they were paid for this service and full details of the ethical approval can be found in the data repository. All autistic participants noted that they preferred online interviews/focus groups to telephone or face to face. Interviewing online also enabled me to interview against a blurred background, hiding any sign of my own status, and allowed the interviewee to do the same (Salmons 2014).

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.

Fig. 2 Indicators of influence

Results and discussion

The results are supportive of my theory that autistic people possess more policy influence than both their own opinions and the scholarship on policy influence would suggest. Beginning with perceptions of autistic people about their influence, 47% of those surveyed rate the policy influence of the autistic community as 'low', compared to 29% who consider it to be 'medium' and only 25% who consider it to be 'high'. This is supported by NVivo analysis of free text answers in the survey and focus group transcripts which demonstrate that a high percentage of responses indicate an assumption that autistic people are disempowered or excluded by the policy process, as evidenced in the quotations shown below.

Thus, if the level of influence established is higher than 'low', as the majority viewpoint, it can be considered to be higher than expected by the autistic community. As established earlier, the level of influence can also be considered to be higher than expected by the scholarship if goals are fully or mostly attained, or if reputed influence is higher than 'low'. The results of the process tracing are shown in Fig. 3.

These figures differentiate between autistic self-advocates sitting on decision-making boards, who de facto have more access to the policy decision-making process, and the wider autistic community. The first matter of note is that the wider autistic community score high or medium in all areas of influence except self-reputed and framing congruence. This means that the criteria for 'more influence than expected' are met on both counts.

The second matter of note is that autistic people have cumulatively more influence than all stakeholders except for autistic self-advocates, government bodies, government departments and Secretaries of State. This is surprising, and of interest because it indicates that autistic expertise is favoured over professional expertise and the lived experience of families/carers.

The third matter of note is that autistic self-advocates score even more highly than government bodies and are superseded only by government departments and Secretaries of State. This is a strong achievement and indicates that there is an urgency to assessing how far autistic self-advocates represent autistic people.

Drilling down into more detail, using interview and focus group transcripts as well as the survey data, some interesting patterns become visible.

	Goal attainment	Agenda-setting	Reputed influence	Self-reputed influence	Active Participation	Framing Congruence
Autistic self-advocates	High	High	Medium	High	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

Fig. 3 Relative influence of autism policy stakeholders

Autistic self-advocates control the agenda

Firstly, there is strong evidence that autistic self-advocates control the policy agenda. While professional bodies, government bodies and academics are consulted on certain issues, autistic self-advocates have significant sway over the topics which are discussed. Government departments or MPs may table a discussion on a particular topic, but autistic self-advocates are invited to speak in all discussions, whereas professionals are generally invited to speak only on their niche area of expertise. Thus, professionals may exert more influence on an individual policy decision than autistic people, but, across the board, autistic influence is higher.

The wider autistic community, through autistic self-advocates influence the choice of policy goals

In addition to this, there is very strong correlation between the topics that the autistic people surveyed considered to be important, and the areas for change put forward in policy documents. When surveyed about the extent to which the wider autistic community agreed with current governmental policy goals, agreement did not fall below 75% and reached as high as 95%, as shown in Fig. 5. There is therefore very high correlation between autistic goals and the policy agenda (Fig. 4).

Goal attainment is understandably more nuanced, because goals take time to be achieved—and this was acknowledged in all fora: interviews, survey and focus groups. There was largely agreement about what policy goals had and had not been achieved between autistic people, autistic self-advocates and other stakeholders. Despite voicing dissatisfaction with goals which had not yet been attained, autistic people acknowledged that progress had been made in all policy areas, and more than half of autistic people considered that the headline goals on the policy agenda (which, as we know, were autistic driven) had been at least partially met. Speed and ease of diagnosis and autistic employment scored the lowest, which was reflected in interviews, along with mental health provision, as being areas needing further work. This is shown in Fig. 5.

A possible reason why other stakeholders saw more goals attained than autistic people lies in the nature of the goals. Autistic self-advocates and other stakeholders showed an awareness of what was likely to be achievable in the current policy context, whereas autistic people more generally tended to lack that awareness. As a result, those stakeholders with a seat on decision-making boards explicitly adapted their goals to be more achievable ('There are lots of things that I want to change. But I do think the biggest thing I can do is to start focusing on smaller things', James Sinclair, autistic self-advocate), whereas autistic people more generally tended to maintain broader, less measurable goals such as 'make my life easier' or 'the general

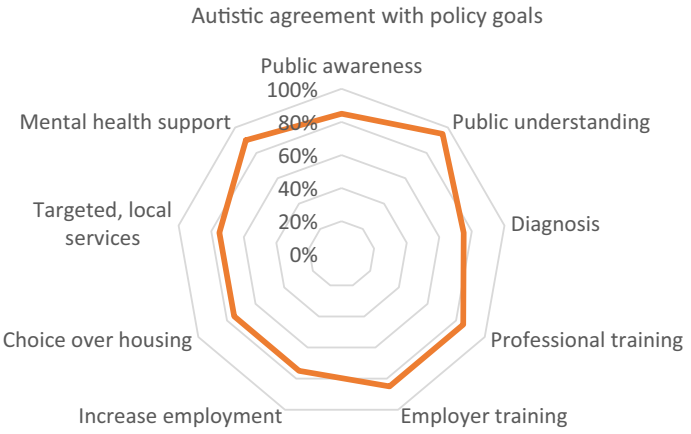

Fig. 4 Autistic agreement with policy goals

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%

Fig. 5 Autistic people's perceptions of goal attainment

public need to change their attitude towards us'. Funding also looms large as a reason why a particular policy goal may not be attained.

Autistic self-advocates are well regarded by other stakeholders

It is also noteworthy that all stakeholders except for autistic people themselves rated the influence of autistic people as medium or high, with a majority choosing high, indicating that reputed influence is significantly higher than self-reputed influence. Autistic people's active participation was low, with 36% of autistic people surveyed not taking part in any political activity. Where political activity was engaged in, it was mostly passive activities, such as responding to consultations (94% of those participating), signing a petition (50%) and sharing posts on social media (50%). This lack of engagement was identified by autistic people as a barrier to influence, and reasons for not participating included 'lack of awareness', 'engaging in this world and being rejected, humiliated and attacked' and 'only a minority of autistic people actually have the necessary understanding of our own brains to become self-advocates'.

Autistic self-advocates promote a more positive framing than the wider community

There was also low congruence between how autistic people framed themselves and their problems and how autistic people and autism policy problems are framed in policy documents. This was largely down to autistic people adopting a much more negative framing of themselves as lacking power. An NVivo analysis of all free text answers from the survey found three times as many quotations that were coded as expressing exclusion or disempowerment, compared to quotations coded as expressing power or strength. In contrast, policy documents correlate highly with a largely positive framing put forward by self-advocates, and congruent with that of other stakeholders. This balancing act is described very well by James Sinclair, in the quotation below.

'The way we should be framed is towards the people who are advantaged, make sure they can make the most of things, they surely can get jobs, make sure systems can be put in place to make them excel. But what happens to the people who are disadvantaged, you know, if you really do say it's not a disability, it's just this great thing that people should embrace, then you can take away things like funding, you can take away research, you can take away a lot of stuff.' (James Sinclair, autistic self-advocate).

Thus, there appears to be a deliberate public framing of autism as being something which is a barrier but not an insurmountable one, while acknowledging that many individual autistic people experience significant struggles. On an individual level, autistic people may focus on their own experience and, if this has been difficult, may find it harder to see the potential positives to their autism.

This research nonetheless has limitations in the sense that its selection on the basis of a likely or crucial case means that it cannot at this stage be generalised to

other groups. It is also not possible to obtain a completely full picture of influence without also considering policy implementation. Finally, the measure of influence used, while broad and designed to minimise inbuilt bias, is subjective in its method. Ultimately, like the EAR instrument, it reflects the researcher's judgement as to the level of influence. However, this is arguably the case for any assessment of influence and these 3i indicators do at least require researchers to be reflective in their approach and consider all the angles.

Conclusion

In conclusion, I have demonstrated in this article that using a triangulated approach to measuring policy influence in the form of the 3i instrument, which incorporates indicators sensitive to influence in its early stage, reveals missing influence in the context of autistic self-advocates in England. Despite having a low opinion of their own influence, and despite being socially constructed as disempowered, autistic people, through skilful self-advocates, actually exert influence at all stages of the policy process and represent the primary form of expertise taken into account by policymakers.

While not generalisable at this stage to other contexts or marginalised groups, this suggests that, in the case of autistic self-advocates in England, researcher bias as a result of social constructions may have a role to play in maintaining a misleading construction of autistic people as disempowered. By providing an empirical example of a case where the influence of a marginalised group has been 'missed' by scholars and society, this article opens a methodological discussion on the way that researchers understand and measure the policy influence of marginalised groups.

Further testing of this theory and the framework for measuring influence is planned on autistic self-advocates in other contexts and will then, if successful, be rolled out to other marginalised groups. In the meantime, the 3i instrument is proposed as a theoretically sound measure which has received at least one satisfactory testing on empirical data. It is the author's hope that this will mark the beginning of a discussion about expectations and measurements of the policy influence of marginalised groups that will lead to a more nuanced and positive understanding of their potential.

Such an understanding would be beneficial to both researchers and governments. It would motivate researchers to look into new ways of empowering marginalised groups to exert the influence they didn't know they had. In particular, the highlighting of the importance of self-reputed influence and the move away from goal attainment will enable a more rounded view of political influence to be taken. Influence that is defined only by full attainment of an 'end game' goal will always favour established and powerful actors and minimise the lesser but incremental and cumulative influence of marginalised groups.

It would also require governments to adjust their framings and make it harder for marginalised groups to be consigned to symbolic or surface-level policy changes usually reserved for groups perceived as politically weak (Schneider and Ingram 1993). The Autism Act 2009 in England marked a key change in the political

opportunity structure for autistic people and opened up new opportunities for influence to be exerted. It was driven by a radical reframing of autism by advocates and their allies.

Most importantly, this new understanding would be beneficial for marginalised groups. The case study described in this research, for example, was used as a springboard for a lobbying strategy for autistic self-advocates in England. The belief that you *can* have influence, even when society tells you that you cannot, is a powerful factor in motivating people from marginalised groups to lobby for their needs and rights (Dempsey and Foreman 1997). Ultimately, the 3i instrument is designed for the use of researchers and to open a discussion. The underlying aim, nonetheless, is for marginalised groups to emerge as the major beneficiaries.

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