**Non-electoral representation and promoting welfare – beyond descriptive representation**

McCoy et al give a finely tuned analysis of the role and responsibilities of non-elected or self-appointed representatives in public policy. They take the example of autism activism to illustrate the debate over who can credibly act as a representative of this population and what responsibilities such a role might entail. Non-elected representation is a growing aspect of policy formulation and politics and is part of a general trend to widen democratic engagement beyond the ballot box. Electoral turnouts are decreasing and mainstream politics is suffering a legitimation crisis (Fishkin & Mansbridge, 2017). Yet, people still want to be involved in policy decisions and new forms of non-electoral representation, such as citizen juries and people’s parliaments (Fung, 2003), are increasingly being used as mechanisms to involve people in policy decisions. Institutional forms of democracy are poor at articulating and bringing to the fore interests of small sub-sets of the population, as Montanaro notes, a vote in elections is, ‘a blunt instrument….with little capacity to convey detailed information.’ (Montanaro, 2017:4) McCoy et al quote Saward in saying, non-electoral representatives can help to, ‘give voice to the affected by opening up new lines and styles of representation, which can be more sensitive to intensity of preference and particular lived experiences.’ (Saward quoted in McCoy p14) Consequently, non-electoral representation can be a potentially productive way of involving more people in policy-making – as a way of hearing other, often marginalized, voices.

However, what counts as adequate representation and in what way marginalized groups should be represented are highly contested issues (Dovi, 2018). The complexities of representation in modern society is increasingly being recognised: ‘there’s a lot ‘going on’ in representation, a constant process of making, receiving, accepting or rejecting representative claims.’ (Saward, 2008: 1004). For non-electoral representation, theoretical debates need to cover representation in all its aspects, and not only focus on the requirements of formalistic representation – assessing formal procedures of authorization and accountability. There is a need to consider what the proper activities of representatives should be (Plotke, 1997) and think about the functions of representatives. Hardin (2004), for example, develops a normative account of what a representative should be doing by tying it to their function. These debates over the more substantive elements of representatives are important, as it is here that bioethicists can contribute to normatively assessing these functions and corresponding activities of representatives. Important questions in this vein are: what are the appropriate functions for a representative in a particular context? Does this lead to activities that produce ethically acceptable outcomes? And whose good outcomes should we be concerned with? Prima facie, non-electoral representation can be a positive force that can provide a mechanism for giving voice to often marginalized or unheard groups. However, it can also create its own power imbalances and this raises important normative questions.

In this commentary, I will consider the issue of partial representation that McCoy et al see as a key problem facing non-electoral representation in the autistic community and question whether partial representation can ever be fully overcome.

McCoy et al are concerned with establishing who can claim to speak legitimately for the autistic community and the problems that can result from inadequate representation. They give a detailed account of recent policy areas debated by this community, drawing attention to the so called ‘the autism wars’. These are disputes between, ‘competing perspectives on Autism Spectrum Disorder (ASD) — one associated with self-advocates and one associated with parents.’ And these, ‘have become bound up with questions about which individuals or organizations can legitimately claim to represent autistic people in the public forum.’ (McCoy, p3) For McCoy et al the key problem facing autistic advocacy is that of partial representation. ‘Partial representation occurs when an actor claims to represent a particular group of people, but appropriately engages with only a subset of that group.’ (McCoy, p5) They draw on Montanaro’s conception of ‘skewed representative outcomes’ to explore this. ‘Skewed outcomes can refer to outcomes that are inconsistent with the interests of the entire constituency or outcomes in which certain “interests are over-represented or under-represented within a claimed constituency.” (Montanaro quoted in McCoy, p23) Partial representation can lead to poor outcomes, symbolic and substantive harms, harms caused by representative not fulfilling their functions properly. This is an important problem given the group that McCoy et al focus on. The autistic community has traditionally been marginalized in the political process. McCoy et al quote Liu who says there is, ‘significant historical precedent for incorporating the insights of parent advocates and other stakeholders in broad initiatives related to autism, whereas voices of self-advocates have traditionally been marginalized.’ (P24-25) It is precisely for this reason that we need to be particularly attentive to how forms of representation do and should fulfil their chief function of furthering the interests of autistic people.

McCoy et al suggest two ways to overcome these problems raised by partial representation. First, the representative should take greater steps to engage the marginalized sub-groups within their claimed constituency, they should have sustained engagement with that constituency. However, if a group is very diverse it may be hard, if not impossible, to identify common interests. Therefore, they propose a second element, in the case of heterogeneous communities, ‘it makes sense to organize representation in a more differentiated manner.’ (p27) The representative has to make more modest claims and, ‘it may be more feasible for representatives to speak on behalf of subgroups within the broader autistic population that share a more substantial set of lived experiences.’ (p29)

One way of ensuring differential representation, is to insist on descriptive representation. There has been extensive debate over the merits and utility of descriptive representation – that marginalized groups should be represented by a member of that group. As it has been noted in other contexts, letting a dominant group look after a marginalized groups’ interests is wrongheaded. For example, when husbands spoke on behalf of their wives politically, before women had the vote, women’s interests were often marginalised (Sapiro, 1981). McCoy et al hint at a form of descriptive representation – autistic people ought to be represented by other autistic people, ‘Because autism is a neurodevelopmental condition that affects cognitive functioning, it is reasonable to believe that only autistic people fully understand ‘what autism is like from the inside.’ (McCoy p16). And, ‘questions about how and by whom autistic people should be represented must be continually renegotiated by all members the autism community.’ (p29-30) Whereas, in other places McCoy et al appear to position the representative as not being member of the group on whose behalf they claim to speak (e.g. ‘representatives (and group members themselves’). (p27)[[1]](#footnote-1)

Mansbridge (1999) has argued that descriptive representation is necessary when a group’s interests have not been heard – this improves the quality of deliberation – their interests are better articulated; and increasing a group’s legitimacy as members of the polity – seeing them as capable of ‘ruling’ themselves – where historically this has been questioned. Phillips (1998) also points to descriptive representation making visible ‘overlooked interests’ and justice arguments that it can compensate for past betrays of the group. Descriptive representation could address the symbolic harm that McCoy et al argue arises from partial representation, ‘a representative organization that does not allow autistic people to engage in deliberation and decision-making on an equal footing with others can exacerbate prejudice and stigma by conveying the message that autistic people’s own viewpoints do not warrant recognition.’ (p26)

Descriptive representation has not been without its critiques (Dovi, 2018) and while the contingent circumstances that make some descriptive representation beneficial for the ASD community obtain now (paraphrasing Mansbridge, 1999), these circumstances might change in the future. There are also problems with diversity within and between groups (Dovi, 2002), what characteristic we pick to organise the group around and how homogenous do these sub-groups have to be for us to be able to say that people within them are adequately represented? In the case of autism, a spectrum condition, people may not share salient characteristics with very many people and if we add to this different social and economic situations people may be in, our differentiated groups could become very small and reduce for the force of their advocacy. As Iris Maron Young points out, ‘suppression of difference is a problem for all representation’ and this is a difficulty inherent in one person claiming to represent many people. Therefore, attempts to speak for all members of a group always have to be tempered and cautious and ‘representation is an ongoing process of making and receiving claims.’ (Saward, 2008:1003). Hence, partial representation is a problem with any form of representation, as Saward notes, ‘None of us is ever fully represented – representation of our interests or identities in politics [or policy] is always partial. Representative claims are redeemed, if at all, only imperfectly.’ (2008:1003) Pitkin argued that representatives always have to act on others behalf and an overt concern with the characteristics of a representative might divert attention from what the representative is actually doing (Pitkin, 1967).

While it is important, all other things being equal, to make sure if possible, that autistic people represent themselves, it might be hard for a number of reasons, those who lack the capacity to participate in engagement and deliberations about their interests,[[2]](#footnote-2) diversity of the community and other practicalities, for this to happen. And while McCoy et al talk of the importance of taking steps to engage with the community, representation will always involve imperfectly speaking for others and therefore always be partial. Therefore, attention also needs to be paid to the functions and consequent activities of representatives and their underpinning normative values. These might be having the groups’ best interests and welfare as the primary goal and paying attention to other groups’ interests and well-being (as McCoy et al discuss on page 27). We might want representatives who are able to adjudicate fairly between competing interests and help formulate more considered responses. There may also be certain skills that are desirable, such as being able to translate individual interests into workable policies or solutions. These types of skills and normative values need further attention, so that representative’s actions are underpinned by additional claims to legitimacy, as arguably, the problem of partial representation can never be completely resolved.

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1. However, situations where an autistic person could not act as a representative due to capacity issues should be distinguished from those where an autistic person could act as a representative but someone else from outside that group has been chosen. [↑](#footnote-ref-1)
2. This issue is discussed in McCoy et al’s paper and they propose a form of surrogate representation to ensure that those who lack capacity have their interests taken into account. [↑](#footnote-ref-2)