



# A seat at the table? Autism advocacy - lessons from the autistic community

KATE PRECIOUS

POSTGRADUATE RESEARCHER

DEPARTMENT OF POLITICS, LANGUAGES AND INTERNATIONAL STUDIES





# Why does autism policy exist?



# Outline of Presentation

- ▶ My background and research
- ▶ What is public policy?
- ▶ How can ordinary people influence public policy?
- ▶ Theories about advocacy
- ▶ Autism advocacy
- ▶ Over to you?



# My Background



- ▶ SEN Officer at Oxfordshire County Council from 2010 to 2015.
- ▶ Assistant SENCo at a diverse secondary school from 2015-2016.
- ▶ Parent supporter since 2016.
- ▶ Sister to a unique, non-verbal but highly communicative young lady with a mitochondrial disorder causing global developmental delay.
- ▶ Mum to a daughter currently on the waiting list for an autism assessment.

# My Research

- ▶ Collaboration between POLIS (Politics, Languages and International Studies) and CAAR (the Centre for Applied Autism Research).
- ▶ Politics of need - how do target groups get their needs met by policy?
- ▶ Impact of autistic self-advocacy on autism policy
- ▶ Three year research project - one year in!
- ▶ Typology of European autism policy with a focus on inclusivity.





# What is public policy?



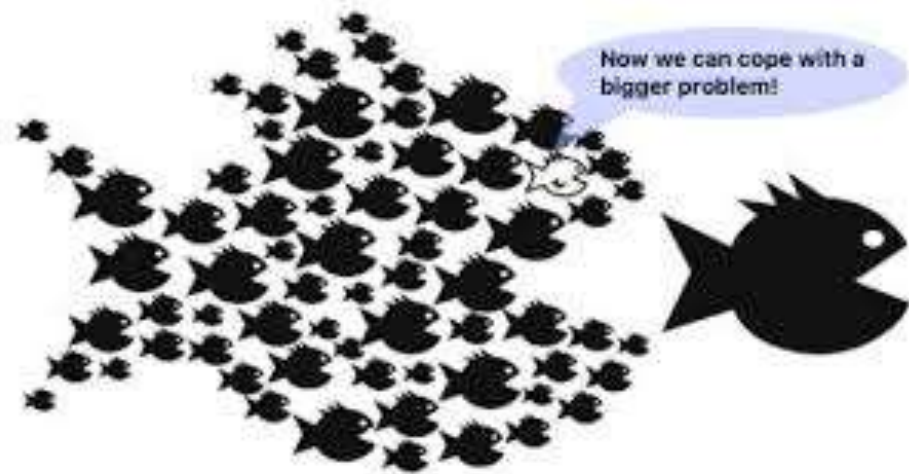
- ▶ The aim of public policy is to solve public problems (Knill & Tosun 2012)
- ▶ Policy is anything a government chooses to do or not to do (Dye 1979; Howlett 2019)
- ▶ Can refer to central, local or supranational government (Rhodes 1997)
- ▶ Policy process is cyclical with a feedback loop (Pierson 1993)
- ▶ Public policy should serve the people (Fischer 2019)

# Public policy and the public

- ▶ There is a democratic deficit in public policy (Fraser 1987; Hamilton 2003)
- ▶ Resources matter: financial, people, expertise (Jones & Baumgartner 2005)
- ▶ Target groups (the people affected by the policy problem) tend to lack resources (Hamilton 2003)
- ▶ Groups with disabilities in particular are often 'fobbed off' with symbolic policy change (Schneider & Ingram 2019)



# How can ordinary people influence policy change?



- ▶ Electoral representation and petitions
- ▶ Protests and social movements
- ▶ Interest groups and advocacy
- ▶ The power of the collective (Marsh & Smith 2001; Klüver 2013)
- ▶ Main area of influence is usually over the narrative around the problem (framing)



# Theories about advocacy

- ▶ Advocacy: definitions and pitfalls
- ▶ Self-advocacy (by parents or people with disabilities)
- ▶ Importance of collective action, positive narrative and a unified goal (Wiebke & Rasmussen 2018)
- ▶ Goodley (2005): self-advocacy improves the resilience of people with intellectual disabilities



# What is autism?



- ▶ A contested area!
- ▶ A diverse community
- ▶ Diagnosed on basis of social communication deficits
- ▶ Estimated to affect around 1% of the population
- ▶ Strategic public policy priority: 13 new autism-specific policies in Western Europe in the past 20 years.

# Autism advocacy and policy

- ▶ Autistic self-advocates and parent self-advocates are mandated policy actors (Feinberg & Vacca 2000; Orsini 2012; Chamak & Bonniau 2013)
- ▶ Autistic self advocacy has been around since the 1980s and founded the neurodiversity movement (Bumiller 2008; Ne'eman 2010)
- ▶ Autistic self-advocates are accepted to have played a part in achieving policy change (Baker 2011)
- ▶ Autism awareness has improved
- ▶ Not a panacea – needs still going unmet
- ▶ Can autistic self-advocates (or parent advocates) represent all autistic people?



# Over to you?



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- ▶ If you want to ... you can advocate not just for your child but for other children and people
- ▶ Join forces – act as a collective
- ▶ Include self-advocates as well as parent advocates
- ▶ Include charities and other organisations
- ▶ Promote a positive view – celebrate the strengths
- ▶ Be clear about your goals
- ▶ Be realistic about what can be achieved



Kate Precious

[k.j.precious@bath.ac.uk](mailto:k.j.precious@bath.ac.uk)

@MsKJP