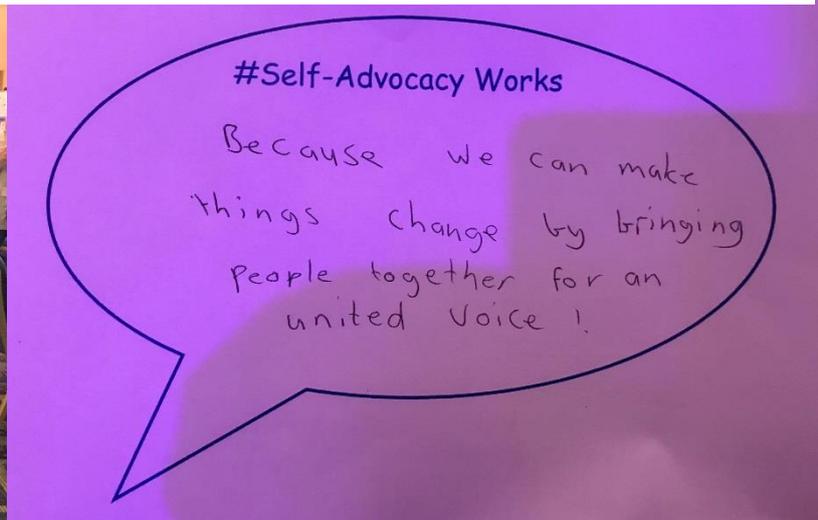




## What are the Barriers for Self-Advocacy Groups?

What are some of the Challenges facing people with a Learning Disability and or Autism?



## National Self Advocacy Convention – Blackpool 2019



## Introduction

Sunderland People First ran a Workshop on 26<sup>th</sup> February called 'Speaking Up for Advocacy – the barriers, benefits and future of self-advocacy' at the National Self Advocacy Convention 26.2.18. Advocates facilitated two group exercises, the first involved attendees talking about the benefits of Self-Advocacy including local examples. The second exercise focused on the barriers to self-advocacy as well as the challenges that people with a learning disability and or autism are facing in 2019.

These are the responses from attendees. An **easy read version** is being developed.

## Barriers to Self-Advocacy

- Having advocacy means that we can talk about anything confidently.
- Lack of money, lack of support, no resources = Inequality.
- Even if you have funding its sometimes going to things that don't work. Hard to grow the group.
- Funding to keep them going.
- Being misunderstood.
  - Getting anxious and nervous.
  - Looks can be deceiving.
  - Lack of support.
  - Problems getting their voice across.
- False promises to lack of money.
- Funding, travel.
- Funding, jobs, speaking up.
- Listening, skills from staff, not heard.
- No money for good people.
- Self-advocacy groups not being supported by Government.

- Lack of communication.
  - Getting the right support.
  - Getting enough support.
  - Not enough self-advocates doing training themselves.
  
- Lack of understanding about reality of people's lives.
  - Poverty.
  
- Funding.
  - People not having the skills.
  - Not being afraid.
  - Lack of support.
  - Peer support.
  - Ask, listen.
  - Speaking up.
  
- Having a learning disability and not being given a chance.
  
- Money.
  
- Lack of understanding and empathy.
  
- Lack of funding.
  - Lack of training.
  - Lack of communications.
  - Being used and abused because of our disabilities.
  - Lack of listening skills.
  - Afraid to challenge.
  - People do not know their rights speaking up for others.
  - Inclusion, respect.
  
- People not being supported to be a self-advocate.
  
- Transport.
  - Low self-confidence.
  - Prejudiced.
  
- We need money to pay for advocacy support: help us set up and run a group. We cannot do it on our own.
  
- Professionals don't always sign so that they cannot communicate with me.

- Being left out of meetings.
- Problems/barriers for self-advocacy groups / challenges for people with autism.
  - General awareness of existence.
  - Funding streams.
  - Difficulty in networking opportunities.
  - Cost of attending – for example this conference many can't afford.
- Northamptonshire are strongly with cuts across the boards. No funding for advocacy groups and the only one still going is Northamptonshire People First.
- New contracts.
  - Fundraising.
  - Speak-up.
- Funding.
  - Lack of understanding of what advocacy is e.g. meaning lack of referrals.
- In Knowsley Disability Concern – we are a charity and have to rely on volunteers. We have a limited budget of money and have had some money cut backs meaning the advocacy group had to go.
- It is the Government funding. I want to get more sessions but too many cuts in the self-advocacy.
- Support for regional areas are in decline i.e Mind, etc and local and funding and charity... Self-advocacy and finding a voice.

## Challenges

- A system that does not care.
- Not enough choices such as relationships and friendships.
  - More support to develop independent relationships and friendships.
- More support for caring roles. I am a carer for my mum who has dementia. We need more information about caring for someone with dementia.
- Learning disabilities and autism in our area not working together. Autism is better funded. We miss our Partnership Board.
- Crowded centres, transport public or private.
- Learning is hard
  - People with autism struggle to understand different accents / unable to communicate reasons for distress.
- Speaking up for ourselves and other's that don't have a voice.
  - Being able to talk about LGBT.
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- We need better transport and more drivers.
- People not listening.
  - People not getting the right support.
  - Not all people having person centred planning.
- Being misunderstood about my disability.
  - Negative attitudes of people towards my disability
  - Lack of respect for people in wheelchairs to get on the bus when the wheelchair area is full.
  - People are unwilling to leave the bus.
- Government not listening.
  - No money.
  - No agenda.
  - People with autism not on agenda.

- Where does funding come from?
  - How do people with learning disabilities and autism get their voices heard when the Government is listening?
- Lack of information and support to access it.
  - Lack of opportunities to make decisions.
- Not having enough money to run courses – we call it cut-backs.
- Lack of employment.
  - Fear about benefit changes.
  - Changes to Mental Capacity Act.
  - Loss of services.
- Criminal justice system.
- Benefits – they cut my money.
- Not everyone can communicate as they aren't able to sign.