



# Your Voice Network Neurodiverse group

Thursday 7th September 2023

## Attended by

Self-advocates from Gloucestershire

Self-advocates from Wiltshire

Self-Advocates from Bristol

Self-advocates From Devon

Self-Advocates from North Somerset

## Represented groups

Dimensions for Autism

Your Voice

## Ice breaker question

### - Do you like fireworks?

People said:

people said they might like organised displays but weren't so keen on ones in individual gardens

## Main Discussion

## PIP and disability benefits

# Feedback given by the group

- It was mentioned how people feel very angry and very frustrated about the process applying for PIP,
- It was mentioned that the assessor made presumptions about the way some one interacted with them. They decided because the person did not tremble, was not restless or agitated, behaved 'normally', not hostile or withdrawn that they had no anxiety. However the person was masking and the assessor did not ask about it so how did they know they were anxious without asking? The assessor also decided because the person had good insight in to their needs and condition that they didn't have any needs. This is their 2nd application, they applied July last year and now it is November
  - It is difficult when people have needs that are not being met. The issue remains with not understanding neurodiversity
  - Somebody else applied for PIP and went through the process and didn't get it. They did the mandatory reconsideration but had no support. They finished that process at one of the worse mental health periods in their life. It means they are too autistic to apply and it is not accessible. The person has to pay for counselling because they cannot get the therapy they need. They can't get any other care or support, so they are fully reliant on their mum. The money would significantly improve their life. However, they have completely disregarded this because it is so inaccessible.
- We have all that research to show how our live experience is affected – yet, why isn't a diagnosis enough? It takes so long to get the right diagnosis
  - It was shared that these discussions echoes that which has been shared in Devon. The processes are very difficult, very frustrating, unethical, designed to prevent people from accessing. It puts so many people off from applying,. You do really need to be an expert in the processes to have any chance of succeeding.
    - People felt there is so much wrong with the system and it is hard to know where to start. Mandatory reconsideration processes etc.
- It was said that once you have been around the system – the process does get easier. The first few rounds of the process are designed to kick you to the curb. Once you get through that process – it is easier.

# Feedback given by the group

- Assessments often require statements from GPs but this causes a barrier because it can be any GP from the practice, they often don't know anything about you or how your autism affects you. The health inequalities that autistic and Neurodiverse people encounter can also mean that GP's have very few notes on people as going to the doctor can cause anxiety and people avoid going.
- It was mentioned that the form is historically biased in favour of other disabilities. And although there have been adjustments over the years. It is still a misunderstood thing. It feels like if you are able to function – you are excluded. We are in a group that often falls through the gap, because we are a group who have autism / neurodiversity, and don't have a learning disability
- We talked about what we can do to make a difference to the process
- It was thought perhaps we can co-produce something that helps to challenge the process. It was asked 'What about using the drama group associated with IG?' as it's important to do something different to make an impact.
- One of the group has already written to MP who is head of the DWP she has shared the letter with the group it will be attached to this email

## Next meeting

- Next meeting is Thursday 7<sup>th</sup> December 2023 – 6:00-7.30
- We will be talking about our online conference