

Obtaining Access to Services: Barriers and Solutions

AnAuternative Project



This autistic-led project is investigating barriers and strategies for full autistic participation and empowerment. It is funded by DRILL (Disability Research for Independent Living and Learning). Research activities will include a questionnaire, interviews and diary exercise.

Results of Questionnaire
223 responses

Participant data	%
Male	57.3
Female	32.6
Other gender	10.1
White	85.6
Black, ethnic minority, mixed race	14.4
Working class	37.4
Middle class	46.6
Other class	16
16-24 years old	19.2
25-40 years old	37.4
41-50 years old	23.3
Other age	2.3

Problems with Benefits	%
Being unsure about entitlements	62.3
Staff not communicating clearly	61.7
The need to sign-on regularly	61.7
Anxiety about being refused benefits	58.1
General anxiety	55.7
The need to complete forms	41.9
The need for face-to-face interaction	40.7
The need to queue	32.9
The presence of other people in the bureau	31.1
Strong or unpleasant smells in the bureau office	30.5
Bright or dim lighting	25.1
No problems	7.0

Strategies for benefits appeal	%
Asking for advice from an organisation	64.4
Asking for advice from an individual	56.8
Getting help to complete the appeal	61.0
Being accompanied to the interview	56.8
Getting an advocate to speak on their behalf in the interview	51.7
Overstressing the difficulties they experienced	37.3
Asking for the interview to take place in a quiet room	38.1
Asking for information on the appeal interview and all questions to be sent to me in advance	44.9
No support needed in this area	5.9

Healthcare strategies	%
Having a prepared list of questions	66.2
Taking another person with me	50.9
Asking someone else to phone for appointments	38.4
Asking the doctor to repeat things	34.7
Asking the doctor to write things down	31.9
Finding a practice you can contact by email	30.1
Using relaxation techniques	27.3
Asking what the doctor knows about autism	21.8
I do not need support in this area	5.1

Comments:-

Many participants prefer to use email and online booking systems as opposed to using the phone.

Only 7% did not have problems accessing benefits. Only 12.7% are (generally) able to get the help they need. 62.6% had problems in getting a diagnosis of Autism.

Benefits staff lack training in supporting disabled people and the system is aggressive. Having issues with phoning and dealing with receptionists are a big barrier to accessing services and the medical system. There was a desire for more proactive health care.

Participants use a wide range of different strategies. The presence of a trusted person is generally the most effective. Masking autistic traits is common, but does not make participants feel good. Avoidance is also a common strategy.

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