Insights from UK Adults with FASD(or Suspected FASD)

22

Total Responses

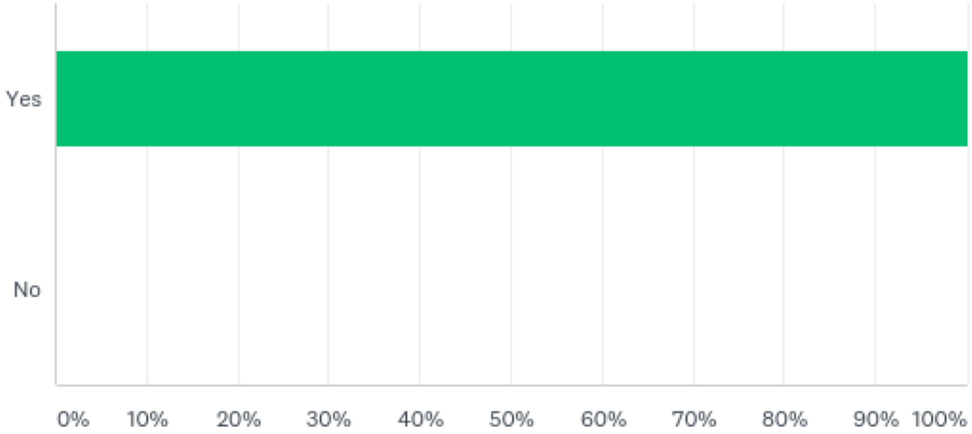
Collected 20 September 20 – 18 October 2018

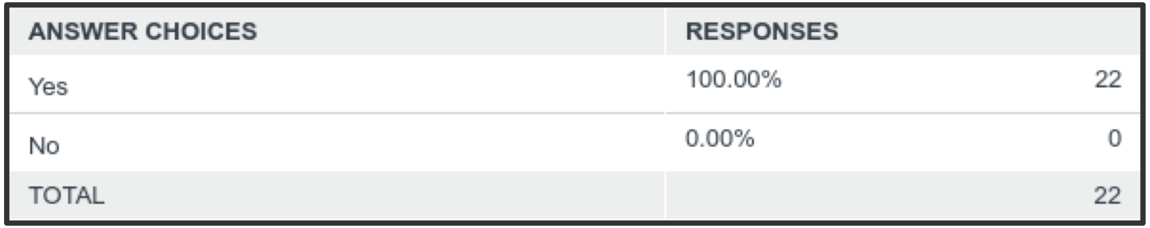
National FASD Advisory Committee

Presented in Meeting 22 October 2018 with
Deputy Chief Medical Officer Prof. Gina Radford

Q1: I am an adult with FASD (or I think I have FASD) and I live in the UK

Answered: 22 Skipped: 0

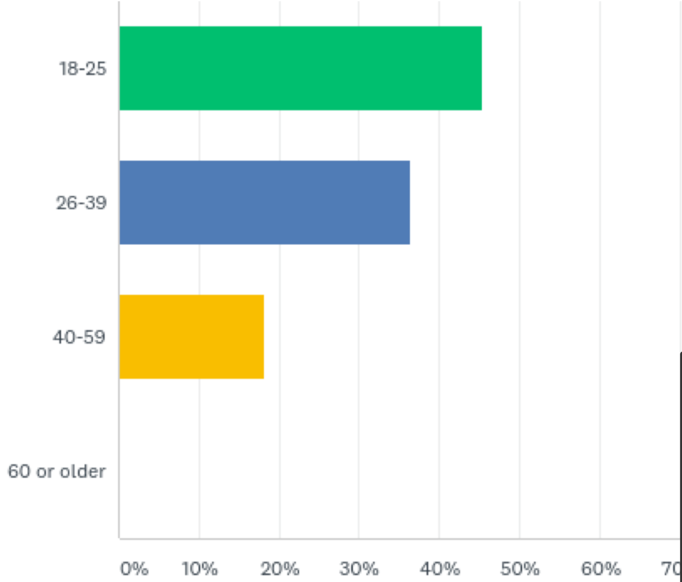


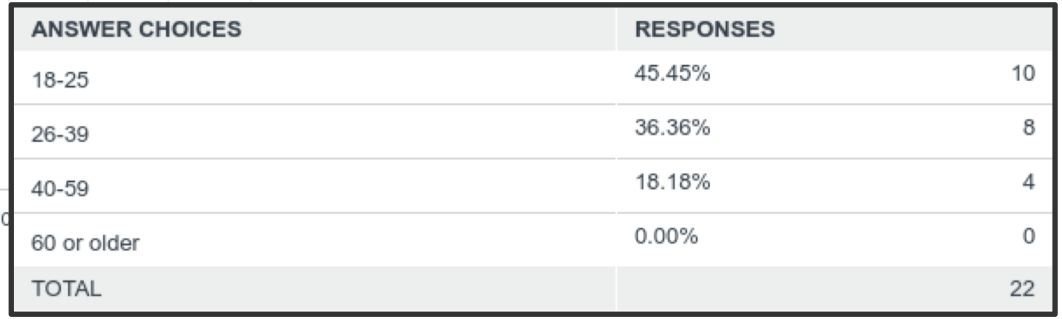


ANSWER CHOICES	RESPONSES	
Yes	100.00%	22
No	0.00%	0
TOTAL		22

Q2: How old are you now?

Answered: 22 Skipped: 0

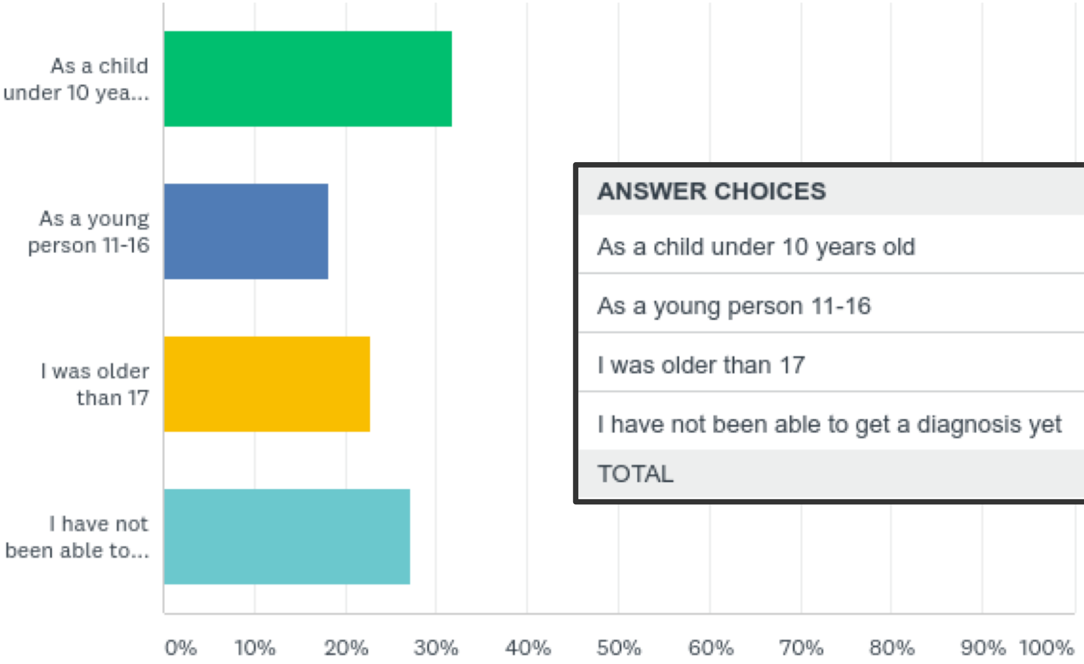




ANSWER CHOICES	RESPONSES	
18-25	45.45%	10
26-39	36.36%	8
40-59	18.18%	4
60 or older	0.00%	0
TOTAL		22

Q3: When were you diagnosed?

Answered: 22 Skipped: 0

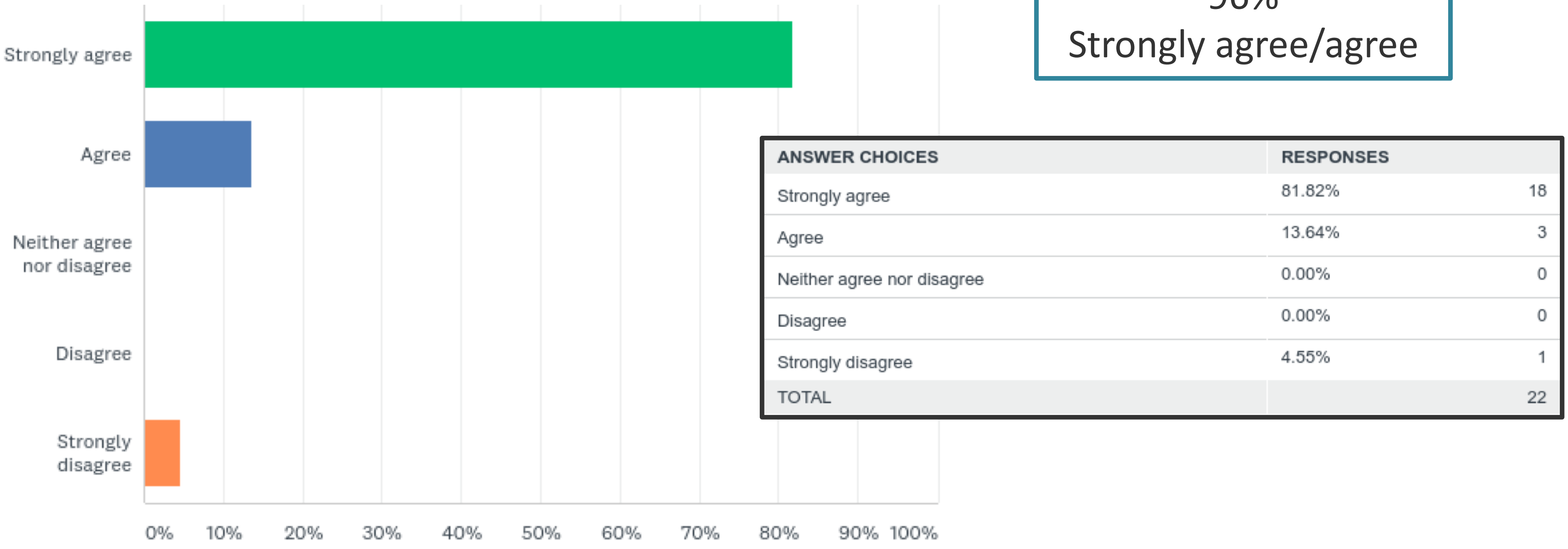


ANSWER CHOICES	RESPONSES	
As a child under 10 years old	31.82%	7
As a young person 11-16	18.18%	4
I was older than 17	22.73%	5
I have not been able to get a diagnosis yet	27.27%	6
TOTAL		22

Q4: "I needed more support in school. My teachers did not understand my needs."

Answered: 22   Skipped: 0

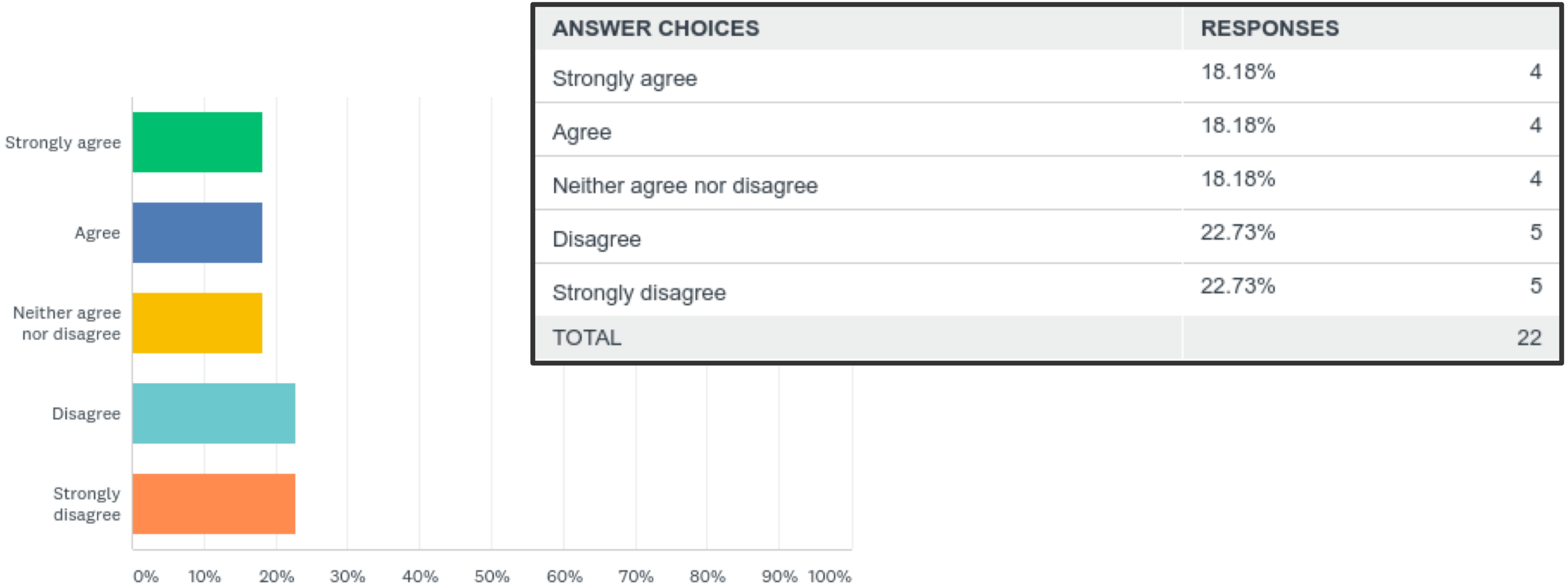
96%
Strongly agree/agree



ANSWER CHOICES	RESPONSES	
Strongly agree	81.82%	18
Agree	13.64%	3
Neither agree nor disagree	0.00%	0
Disagree	0.00%	0
Strongly disagree	4.55%	1
TOTAL		22

Q5: "Growing up, my family understood how to support me"

Answered: 22 Skipped: 0

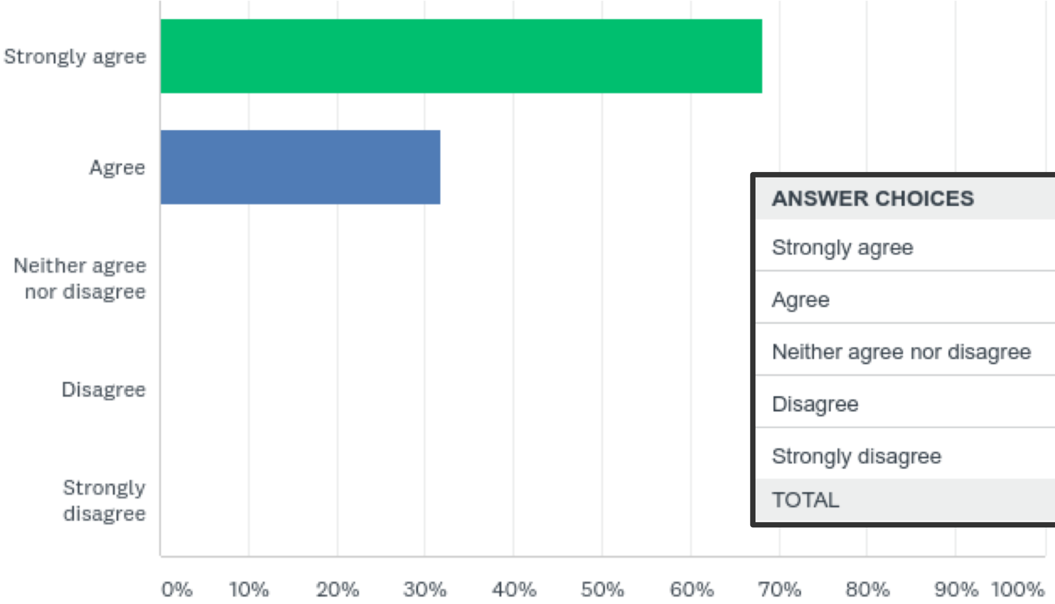


ANSWER CHOICES	RESPONSES	
Strongly agree	18.18%	4
Agree	18.18%	4
Neither agree nor disagree	18.18%	4
Disagree	22.73%	5
Strongly disagree	22.73%	5
TOTAL		22

Q6: "As an adult, I struggle because people don't understand my condition."

Answered: 22 Skipped: 0

100%
Strongly agree/agree

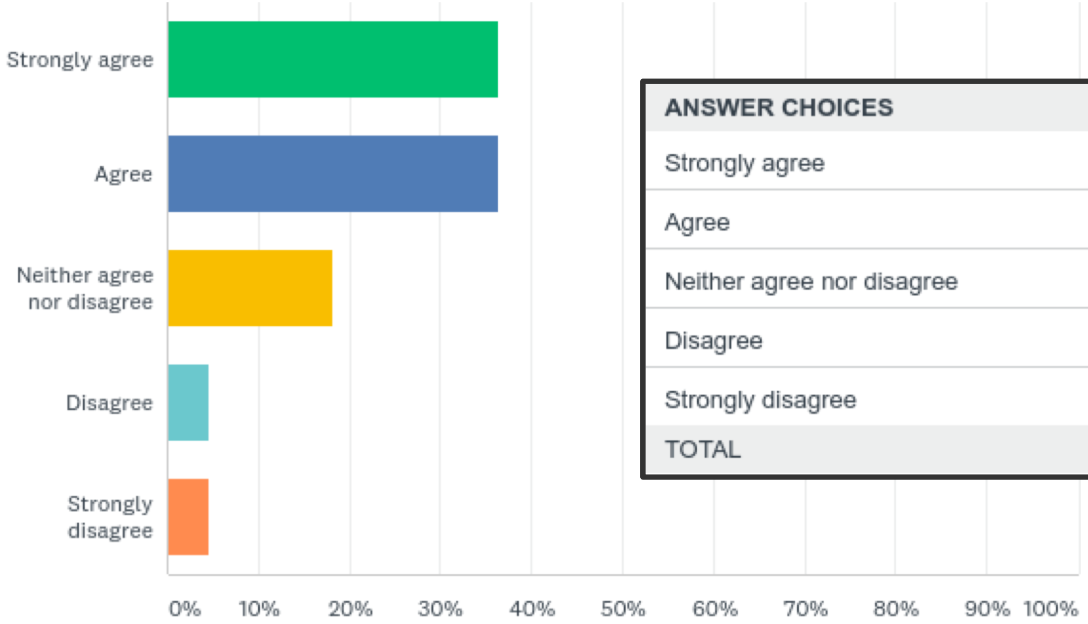


ANSWER CHOICES	RESPONSES	
Strongly agree	68.18%	15
Agree	31.82%	7
Neither agree nor disagree	0.00%	0
Disagree	0.00%	0
Strongly disagree	0.00%	0
TOTAL		22

Q7: "My doctors don't understand FASD."

Answered: 22 Skipped: 0

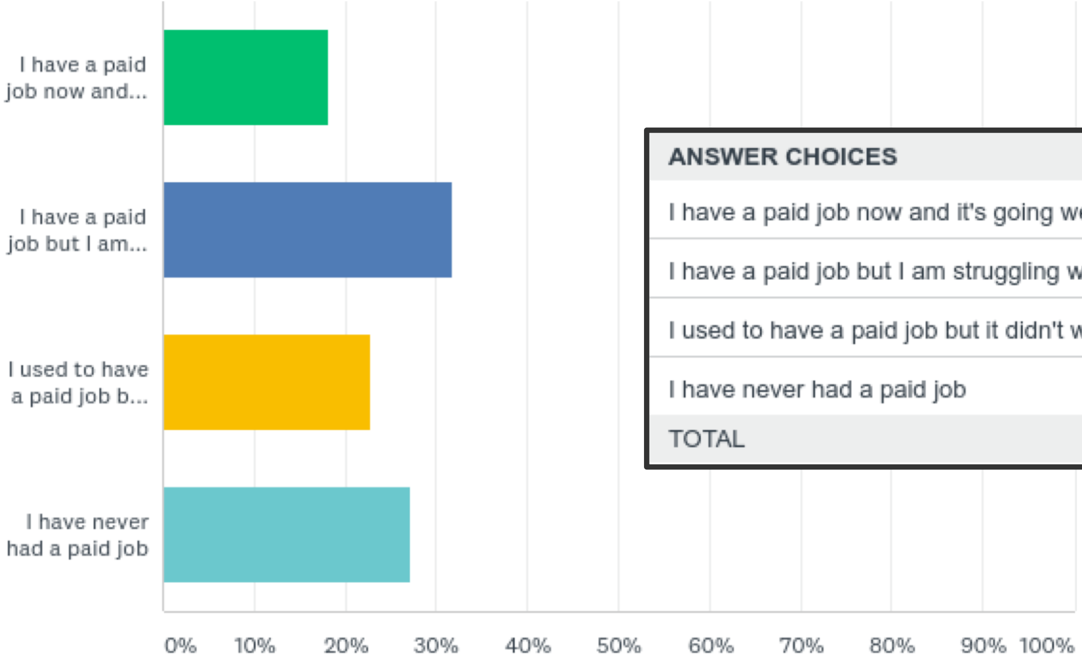
72%
Strongly agree/agree



ANSWER CHOICES	RESPONSES	
Strongly agree	36.36%	8
Agree	36.36%	8
Neither agree nor disagree	18.18%	4
Disagree	4.55%	1
Strongly disagree	4.55%	1
TOTAL		22

Q8: Are you employed?

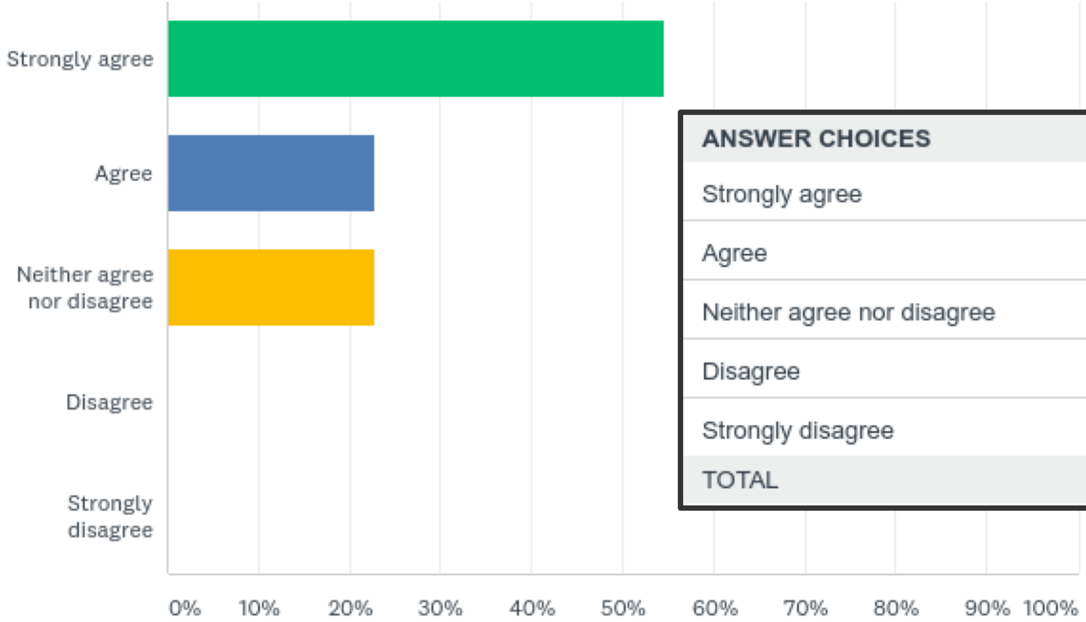
Answered: 22 Skipped: 0



ANSWER CHOICES	RESPONSES	
I have a paid job now and it's going well	18.18%	4
I have a paid job but I am struggling with it	31.82%	7
I used to have a paid job but it didn't work out	22.73%	5
I have never had a paid job	27.27%	6
TOTAL		22

Q9: "I wish employers better understood my needs."

Answered: 22   Skipped: 0



78%
Strongly agree/agree

ANSWER CHOICES	RESPONSES	
Strongly agree	54.55%	12
Agree	22.73%	5
Neither agree nor disagree	22.73%	5
Disagree	0.00%	0
Strongly disagree	0.00%	0
TOTAL		22

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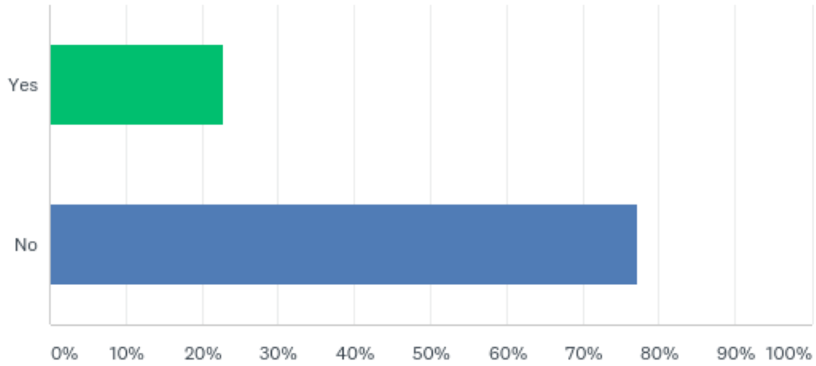
Q10: Do you help as a volunteer with any organisation/charity?

Answered: 22   Skipped: 0

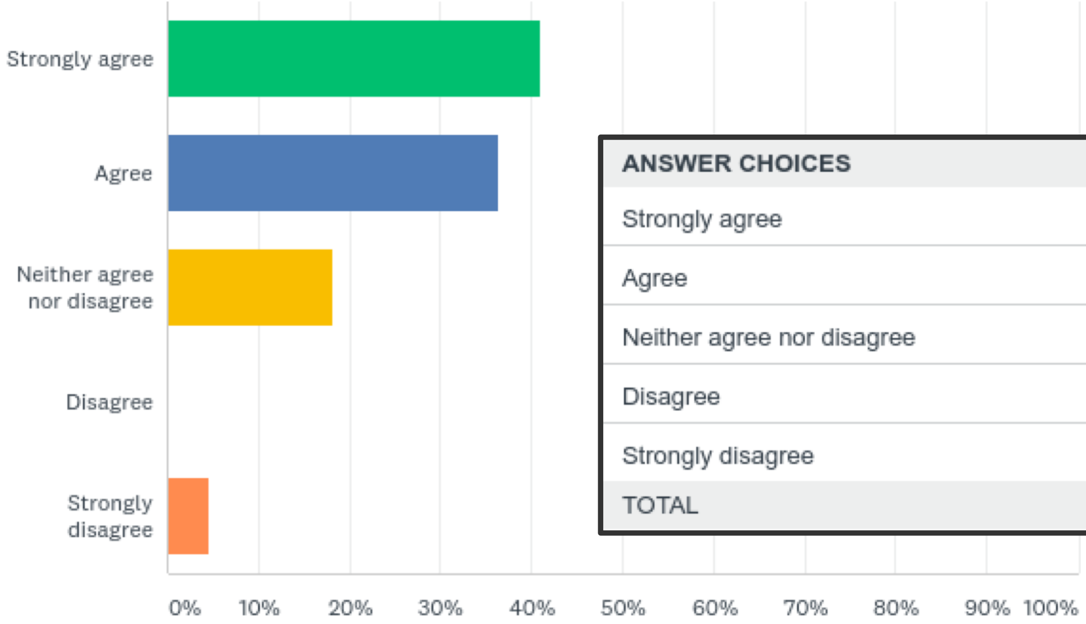


ANSWER CHOICES	RESPONSES	
Yes	22.73%	5
No	77.27%	17
TOTAL		22

Q11: "I struggle to access benefits, people making decisions don't seem to understand my needs."

Answered: 22 Skipped: 0

77%
Strongly agree/agree

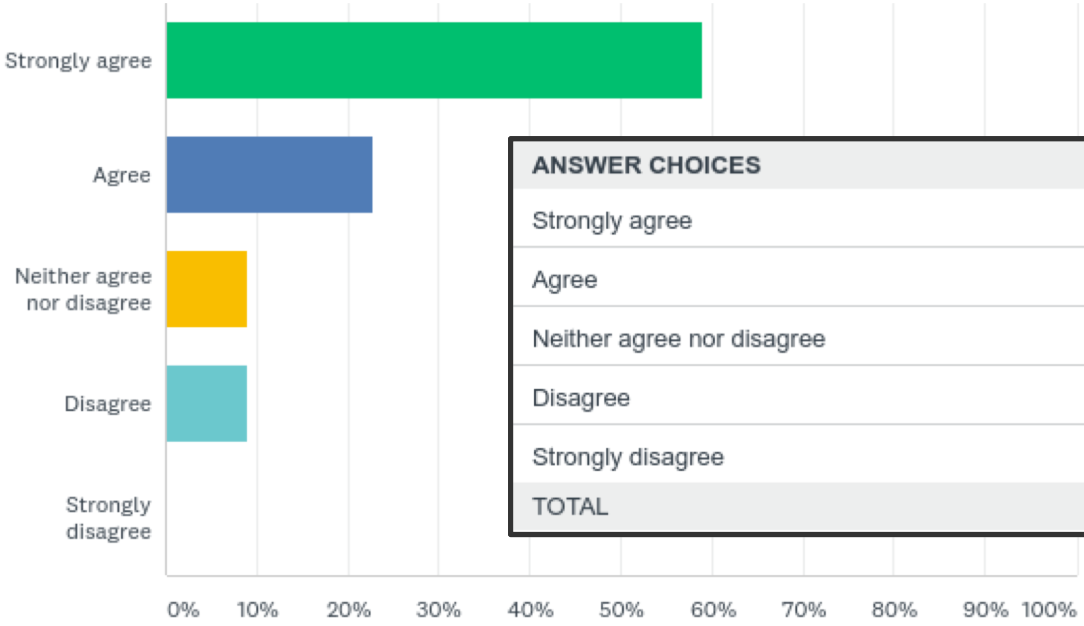


ANSWER CHOICES	RESPONSES	
Strongly agree	40.91%	9
Agree	36.36%	8
Neither agree nor disagree	18.18%	4
Disagree	0.00%	0
Strongly disagree	4.55%	1
TOTAL		22

Q12: "I worry about the future."

Answered: 22 Skipped: 0

82%
Strongly agree/agree



ANSWER CHOICES	RESPONSES	
Strongly agree	59.09%	13
Agree	22.73%	5
Neither agree nor disagree	9.09%	2
Disagree	9.09%	2
Strongly disagree	0.00%	0
TOTAL		22

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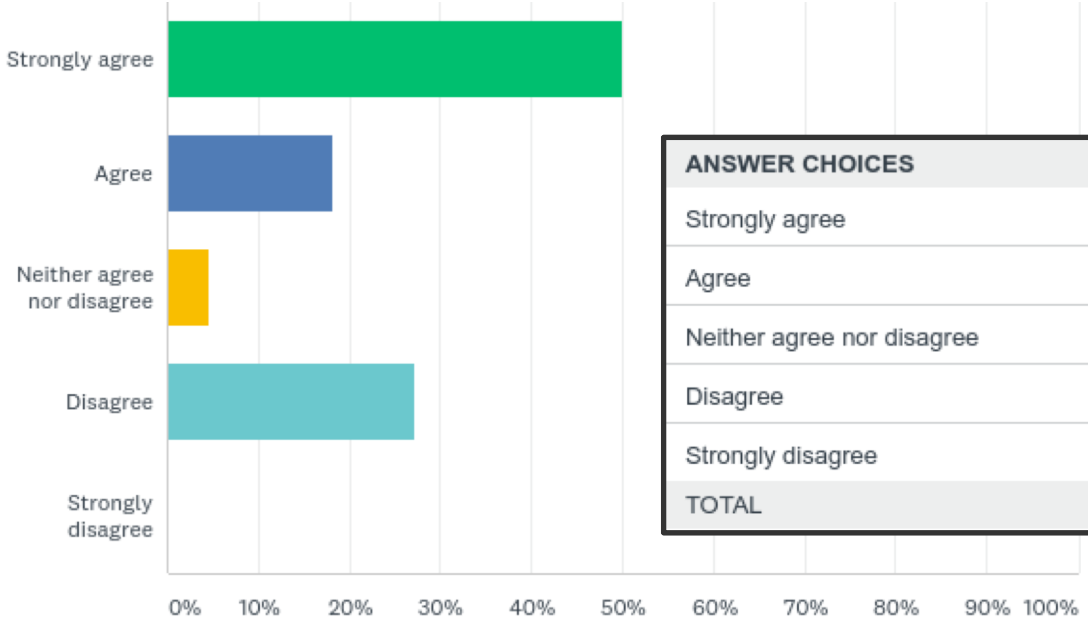
Q13: "I worry about my housing situation."

Answered: 22 Skipped: 0

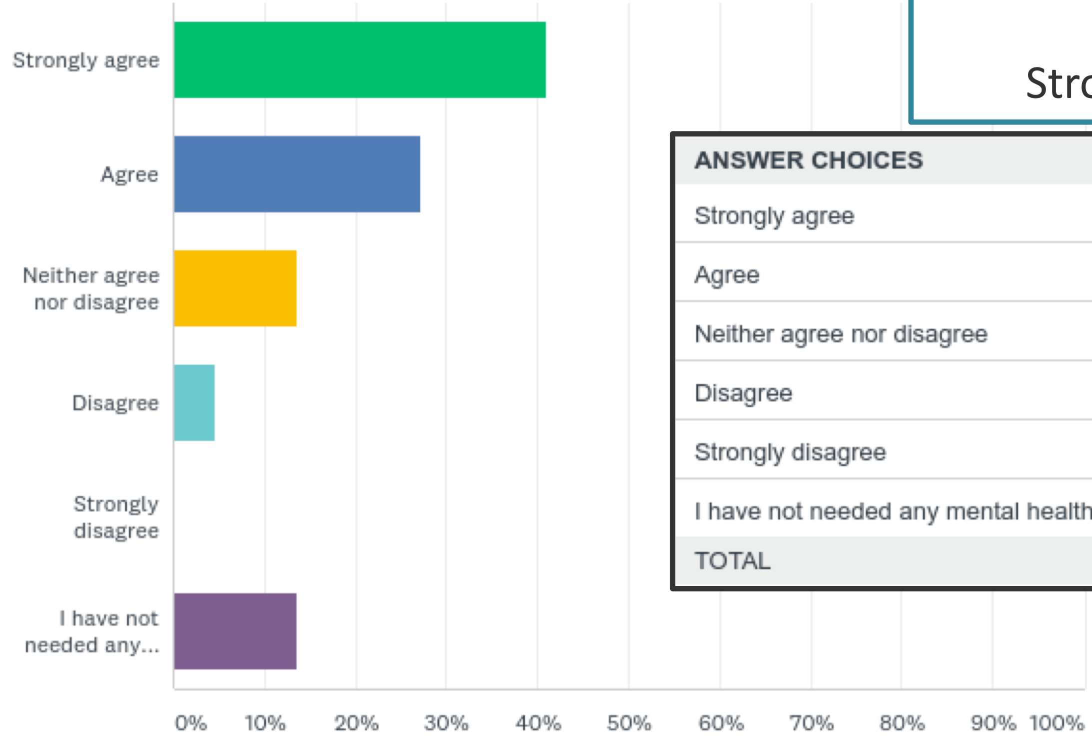
68%
Strongly agree/agree



ANSWER CHOICES	RESPONSES	
Strongly agree	50.00%	11
Agree	18.18%	4
Neither agree nor disagree	4.55%	1
Disagree	27.27%	6
Strongly disagree	0.00%	0
TOTAL		22

Q14: "Professionals in mental health and/or addiction services do not understand my FASD (or suspected FASD)"

Answered: 22 Skipped: 0



Of those who have used these services
79%
Strongly agree/agree (15 of 19)

ANSWER CHOICES	RESPONSES	
Strongly agree	40.91%	9
Agree	27.27%	6
Neither agree nor disagree	13.64%	3
Disagree	4.55%	1
Strongly disagree	0.00%	0
I have not needed any mental health or addiction services	13.64%	3
TOTAL		22

Q15: What other things do you struggle with?

Answered: 20 Skipped: 2

- Working full time so that i can earn enough money to live independently. Also because i do not have the facial features and have been told i am intelligent people do not recognise that i have a learning disability. I also struggle mental tiredness and my immune system and get ill frequently
- Life as a whole
- Tidying up
- Physical condition and my health
- Managing money
- The ignorance and lack of support for sufferers of FASD and their families in medicine, education, social services and judicial system. Diagnosis is difficult to get. There is no educational provision in the U.K. we are very vulnerable members of society.
- Totally struggle with services assessing my needs around FASD they don’t use correct assessment
- I struggle with anxiety, socialising, struggle with empathy and maths
- My mental health and drug addiction I am suicidal all the time I just want to die that's all I've ever wanted. My mum has been doing what she can but every time she tries to help it makes it worse for me because they don't understand that even though I tell people I'm ok I'm not. I'm 34 and I know that the average lifespan is 34 my mum knows I don't want to live but she won't help me die

Q15: What other things do you struggle with? (continued)

Answered: 20 Skipped: 2

- Money, emotions, behaviour, social norm, personal relationships, right and wrong self esteem, regulation, death, you name it its there!
- Time money health depression
- Relationship
- As I adult I still struggle with impulse control and social/communication ques. Thankfully I now have a good support network.
- Peer relationships. Anxiety, me of swings. money
- Everything to do with everyday life.
- My memory, organisation, money, planning, time management,
- Budgeting with money. I find maths difficult.
- Day to day tasks like cooking as I will cook and forget about it or forget to turn the heat off.
- Depression, anxiety, psychosis PTSD
- Eyesight and hearing problems.
- Heart defect - septal ventricular Defect/immediate orthostatic hypotension. "
- Dunno
- Everything

Q16: What do you want people to know about the challenges you face as someone with FASD (or suspected FASD)?

Answered: 19 Skipped: 3

- That we are not lazy. That i want to be like everyone else and do a normal job full time but i struggle because of how exhausted and ill i get when i do.
- Its tougher than you all think
- People don’t realise I always in pain with my body the pain never gets better
- I can only work part time, I can’t work full time as I’m in so much pain so I’m not earning enough money to survive on
- Just need people to recognise it’s a disability
- Then have suitable housing that I can afford
- It is a life long, incurable condition, we need support financially, housing, carers
- Recognise invisible disability
- Timing, I can be late
- It’s similar to ASD with the traits, impulsive, obsessive behaviour, routines, listen to songs on repeat
- No
- Don’t bother we will be removed from society before any changes happen due to lack of reality for people with FASD and there incompetence to accept that they have no choices in the matter of the ''norm''

Q16: What do you want people to know about the challenges you face as someone with FASD (or suspected FASD)? (continued)

Answered: 19 Skipped: 3

- It is hard and I never got help
- Just because you can't see my disability didn't mean I don't have one
- Children with FASD need more support within schools. People need to understand that those with FASD need support in social skills development as well as educational development.
- I want the public and professionals to have increased knowledge and understanding that there is a whole generation of people affected by FASD and the next generation will be worse . misdiagnosis just makes it worse
- I want more awareness out there more workshops
- I want them to know how to support me properly with my struggles in everyday life
- That simple tasks can be difficult to do. Also dealing with bad situations.
- It's hard Having FASD. I wish people would know the challenges people struggle with EG. Hyperactive to the point of not sleeping. problems with money and time management. Also including often being judged for something that you can't see
- I dunno
- I don’t

Q17: If you could ask policy makers to change something that would make your life easier, what would that be? (You can list more than one.)

Answered: 20 Skipped: 2

- Support in school - school was awful for me. No-one understood me and i was labelled a bad kid in primary school
- How fasd affects my mental health and my ability to cope with daily life. "
- "More support
- Guidance
- Knowledge"
- Try to help the condition to be recognised as a disability and have access to more benefits and housing
- Protective housing, proper allowances, proper medical team to support us.
- Treat us with respect , this wasn’t our fault
- Work flexibility
- I don’t know 🤔
- No
- What’s the point? its not going to change anything it will cause just a more resentful attitude towards those who try to help ''oh but you have a choice''
- FAS is real we need you to know it won't go away, it's forever
- To make it quicker for adults to seek help with FASD
- More training for health and education professional on the effects of FASD.
- Raise awareness of FASD it’s causes and it’s diagnosis

Q17: If you could ask policy makers to change something that would make your life easier, what would that be? (You can list more than one.)

Answered: 20 Skipped: 2

- No alcohol no risk
- I want the same measures as smoking gets.
- I’m unsure on this question
- I was not considered eligible for adult care support under a care act assessment. The assessment was completed by a social worker i had never met, he met with me for twenty minutes and the outcome of that assessment has not been shared with me despite it being completed almost four months ago. The assessment document has been sent to the fostering agency that my foster carer is registered with but not to myself or my foster carer. I have made repeated requests for the document and have been infomed everytime that it will be sent out in the post. It has not arrived. The fostering agency that has received it can not share it with me as it would breach GDPR yet GDPR was breached when the document was sent to them in the first place as i was an adult at that point and no longer in the care system.
- More support for those affected.
- More awareness of the affects of drinking during pregnancy.
- Better healthcare professionals
- More awareness. More social care help
- Professionals having more knowledge
- I don’t know

Q18: If you have a diagnosis, how did that help you?

Answered: 19 Skipped: 3

- I was able to get extra time in exams at school but diagnoses isn't always fantastic as so many people don't understand the condition even if they know you have it
- It hasn’t I had mine when I was born but I have never had any help from anyone
- Made me understand why I was the way I was and how to get on with my life now knowing
- It hasn’t helped me at all
- My mum and dad fought to get me the correct help in education. It helped them understand and learn about my needs
- Brining on board medical intervention
- I haven’t had one
- No
- it doesn’t it just harms and causes a destruction trail until suicide, murder or prison
- Because I wasn't a bad child
- I don't
- Unfortunately it is only in the last 5 years that I have started to understand my diagnosis and investigate it further. As a child the only understanding of FASD was that I had a small head and small frame, nothing else was explained to me.

Q18: If you have a diagnosis, how did that help you? (continued)

Answered: 19 Skipped: 3

- I don’t have one
- I’m in the process of getting a possible diagnosis
- It ensured my foster mam knew what my problems might be and she could fight for help for me.
- I think it help me to understand why simple tasks are more difficult for me to do.
- It helped me understand my challenges, it Also helped my family understand more about why i am like this.
- Understand why I am the way I am
- It didn’t really help me

Q19: If you don't have a diagnosis, why not? Why do you think a diagnosis would help?

Answered: 13 Skipped: 9

- There's not a lot of places doing diagnosis. Very expensive privately. My parents paid £3,000. Why?
- Maybe medication trial
- Yeah I think a diagnosis would help me to understand my issues and problems more
- No
- I have been waiting for over 3 years, and it would help with working in how to help me
- I was supported through foster care but as I became independent I really started to struggle. After a particularly difficult time sofa surfing I was prescribed antidepressants and got support from MH team to secure a bedsit. Earlier diagnosis could have helped to sign post me to support and help
- I didn't get tested.
- I'm in the middle of being referred and have got an appointment next week, a diagnosis would not help me as I don't want to be labelled but it would help me and others to help better understand why i am like I am and why I do the things I do, to get more support in areas where I need it,
- I have one
- I have one

Q20: What strengths do you have that you wish people recognised more often? What are you good at?

Answered: 19 Skipped: 3

- Honest
- Loyal
- Treating people fairly
- Good with children
- Working hard
- Determined
- Willing to help people out
- Loving and caring about others I would do anything for anyone
- Good at art
- Horse riding
- Good mum
- I’m good at cleaning, I can drive , looking after animals , I’m good at nature recognising bird song
- I am the same as everyone I just process differently. I can learn with the right help.
- People pleaser

Q20: What strengths do you have that you wish people recognised more often? What are you good at? (continued)

Answered: 19 Skipped: 3

- I’m thorough & precise
- Good at languages, I can sing, good at makeup.
- mine are exsausted out my strents as it dont matter in the real world. when i was a child but it means sh** as an adult
- I am kind I like art
- I try my beat at all I do
- I am good with horses
- Ice hockey sports
- I’m good at caring, and understanding but this does not always come across because of my learning difficulties I struggle to understand sometimes and it’s take me longer to process information
- I work full time now because i have routines in place to enable me to do this.
- I'm good at creative writing, long term memory and imaginative
- None
- Running, horse riding

Q21: Anything else you would like to say?

Answered: 13 Skipped: 9 (didn’t include some answers that were just ‘no’

- Need more housing and more benefits
- Fasd needs to be known and recognised for what it is preventable, unavoidable caused by alcohol. Life long causing great hardship for those that have it. Advise woman to stop drinking in pregnancy. Give legal rights to the unborn child to stop FASD!!!
- I don’t think I have anything else to say! 😊
- theres no poiint being alive as altho were human on the outside were broken insoide and un fixable….thank you for waising my time. if you realy want to help me or others then do it rather than asking no rationable questions. your stupid in thinking that this will help people.
- I need help
- Children, teenagers and adults with FASD need more support within education and more help and support transitioning into adulthood.
- FASD is a time bomb waiting to explode. There must be so many people out there now with wrong diagnosis and without any understanding of what is wrong with them. My foster carers explained my issues but they couldn’t stop my mental decline