Welsh Parliament

Health and Social Care Committee

Inequalities in mental health online advisory group

Summary of engagement findings

November 2022

1. This document has been prepared in Microsoft Word. An explainer document is available [[in Microsoft Word format](https://eur02.safelinks.protection.outlook.com/?url=https%3A%2F%2Fsenedd.wales%2Fmedia%2Fqz5haotp%2Fword-accessibility-options.docx&data=05%7C01%7CRhayna.Mann2%40senedd.wales%7C6dca2be09fd34b7e7c1608dadddef418%7C38dc5129340c45148a044e8ef2771564%7C0%7C0%7C638066246888773471%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=57vx9HAQRv4hP188X3tjqIEY5nnVS7m2GcYry9LIOfQ%3D&reserved=0)] if you need any help to use the ‘Read aloud’ function, or to change the page background colours, text sizes or text colours.

As part of the [Health and Social Care Committee’s](https://senedd.wales/committee/737) inquiry into [mental health inequalities](https://business.senedd.wales/mgIssueHistoryHome.aspx?IId=38553), the Citizen Engagement Team facilitated an online advisory group with people who have experienced mental health inequalities. This paper summarises the online advisory group’s first and second meetings.

## Participants

Ten people (participants hereafter) were selected to take part in the online advisory group. Participants have lived experience of mental health inequalities and have faced barriers in accessing support. Information about the demographic makeup of the online advisory group can be found in [Annex A](#_Annex_A:_Demographic_1).

## Advisory group meetings

During the first online advisory group, participants discussed the key barriers to improving mental health and what they thought could be done to remove the barriers. Participants also suggested several questions for the Committee to consider at its [evidence session](https://business.senedd.wales/ieListDocuments.aspx?CId=737&MID=12966) with the Deputy Minister for Mental Health and Wellbeing and the Deputy Minister for Social Services.

Participants watched the Deputy Ministers’ evidence session. Participants then met for the second online advisory group meeting to discuss their thoughts, in light of what the Deputy Ministers said.

This paper summarises the online advisory group’s first and second meetings.

# Causes of poor mental health

1. Participants agreed with the Deputy Minister for Mental Health and Wellbeing that meeting people’s wider needs is key to addressing the causes of poor mental health.
2. Isolation, poverty, hardship, and loneliness, all of these are associated with deteriorating mental health. Living in poor or unsafe housing, or having no home at all, is another factor in creating poor mental health.
3. Participants felt that the mental health and wellbeing of the population won’t improve unless the basic needs of people suffering from societal inequalities are addressed e.g. poverty, poor housing, discrimination, and loneliness and isolation
4. If we deal with the basics, then the number of people needing mental health intervention will drop dramatically. If we are looking at having a mentally well population we should be looking at it holistically; the whole of society should be supported.
5. However, participants felt that the Deputy Minister does not recognise the complexity of societal poor mental health and did not explain how the Welsh Government’s existing mental health strategy is and will achieve its aims in addressing the range of factors that contribute to poor mental health.

## Stigma and poverty

1. Some participants illustrated how the stigma associated with living in a deprived area can actively reduce a person’s educational opportunities and life aspirations, which can lead to ongoing poor mental health.
2. The assumption was made that because of the area I lived in I wasn't set out to achieve or have a good job…When you've got teachers telling you “You can't do this because you live down there”, that's obviously got an impact on your well-being, your ability to have agency over your own life, belief that you can do whatever you want to do.
3. Participants went on to describe the societal divide, amplified by initiatives such as free school meals for example, and the need to bridge the gap in understanding the causes of poor mental health.
4. We need to bridge the divides between communities to break down that stigma. Stigma often comes from not knowing or understanding people with different experiences from you. E.g. the divides between affluent and non-affluent areas, communities with more people of colour vs communities with predominantly white people. People often fear the opposite or make those assumptions about the 'other'.

## Impact of poor physical health

1. Participants highlighted the connection between long-term poor physical health and poor mental health.
2. People living with long-term physical health conditions can develop mental health problems for a few reasons, such as not being believed, diagnosed, supported, or treated. This can result in patients feeling isolated as they lose work, relationships, and income. Not only that, physical pain in itself causes depression and heightened stress.

## Substance misuse

1. Several participants felt that the Deputy Minister has not fully recognised the connection between drug and alcohol misuse and poor mental health. Participants suggest that not only do people often misuse substances in an attempt to cope with their symptoms of poor mental health but that substance misuse can make it more likely for someone to experience poor mental health. Thereby creating an inescapable trap.
2. Drug abuse can cause psychosis and is a contributor to poor mental health in young people. So many young people don’t know about the way that drugs and alcohol can damage you later in life.

## Women’s health

1. Some participants felt that women are at risk of misdiagnosis because their symptoms are often misunderstood, contributing to the causes and longevity of poor mental health.
2. My neurodivergence was missed because I was dismissed as a woman who was “anxious and hormonal”. Since my diagnosis, I can understand why I do things the way I do and what I can do to help myself. But I could have done this so many years ago, and then I wouldn’t have struggled as I have. I would have had the help that I needed rather than being put on anti-depressants.
3. Peri-natal mental health, premenstrual exacerbation / dysphoric disorder, menopause, and hormone-mediated psychiatric illness don't get anywhere near enough investment in research, support, or treatment. If any of these issues aren't recognised and dealt with promptly, they can cause life-long, intractable mental illness.

### What needs to change to address the causes of poor mental health?

1. Participants suggested the following ideas for change:
2. Mental health services to work together with drug and alcohol services to provide joined-up support to patients.
3. A public awareness campaign to remove the stigma of poor mental health.
4. This starts at school, they need to be teaching children all about different conditions. This provides a solid foundation for children to be more accepting. We should run awareness campaigns for everyone. Maybe a day in the life of someone who has x. Learning about people with different conditions would be incredibly helpful. Especially to people who feel like they might have a condition or parents just finding out their child has a condition.

# Barriers to accessing mental health services

## Self-referral

1. Self-referral is the worst approach ever. I am never going to put my hands up again and say “I need help, please help me”.
2. Participants agreed that the self-referral system was in itself a barrier. Participants illustrated the difficulty they experienced completing self-referral forms and managing the self-referral process whilst suffering from poor mental health.
3. When you can only just get out of bed to ask for help, how are you going to talk on the phone to lots of different people? How are you going to do it online? It's one of those things that you can put off. It almost feels punitive and deliberate to have that barrier there.

## Waiting lists

1. All participants agree that waiting lists are excessively long which is not only a barrier to improving mental health but exacerbates the problem.
2. When you’re put on a waiting list, especially with my children, you're waiting with no support in the meantime. When you finally get to the service they look and they say “oh, look Mum’s stressed, all the family are stressed, there must be issues”. They're looking at the froth on top of the pint! The reason we're so stressed and that things are strained in the house is because we haven't had the services we've been begging for.
3. Three participants told of waiting times of up to a year when trying to access support for suicidal thoughts. One participant, who had previously experienced suicidal thoughts, described reaching the end of a four-month waiting list only to be given cognitive behavioural therapy rather than counselling, the participant was then put on a further eight-month waiting list for counselling.
4. Participants feel that there is a need for support whilst waiting for initial appointments and that the lack of support is a significant barrier to improving mental health.

## Initial appointments

1. All participants agree that initial appointments are devoid of flexibility and are poorly communicated.
2. You’re given an appointment at the end of a nine-month waiting list; you’re waiting all that time for that one-chance appointment, and then something happens and you may not be able to attend. At the end of such a long waiting list, the risk of missing that appointment and going back to square one is quite a pitiful result.
3. I had my first counselling session appointment. They rang me up and said, “this is the appointment”. They gave me no context about the appointment, what it was for, who it was with, or even if it was for me or my son. I have lots of people ringing me to make appointments, so just ringing me and saying “this is the appointment. Do you want it?” It isn't really helpful. That's a basic failure at the very start.

## Jargon-free language

1. Participants agree that current communication and writing styles are a barrier to accessing mental health support. Participants suggested that simple language and explanations are needed, in both Welsh and English.
2. *We struggle with communication, how we understand things, and understanding jargon. We get sent letters or information that’s full of things we don't understand. Simple explanations, simple information, and less jargon, definitely.*

## Getting a diagnosis

Participants feel that there are obstacles within the diagnosis pathway that need to be addressed to make the pathway more accessible.

*The criteria for diagnosing people needs to change because at the moment if you can’t get your family to give a statement about what you were like as a child it is nigh on impossible to get diagnosed as an adult. There is a high number of neurodivergent people who are estranged from their families purely because they didn’t fit in because they had neurodivergent issues that weren’t understood.*

*It’s hard to prove you’re neurodivergent when you’re trying to get benefits. I’m on a massive waiting list for an autism and ADHD diagnosis, which goes against me when I’m applying for benefits. Then I’ll have to go through the appeals process which cripples your anxiety. It’s an extra kick when you’re already vulnerable.*

1. Therefore, participants welcomed the Deputy Minister’s recognition that “it is absolutely crucial that support is put in place without a diagnosis being necessary”, but requested more practical detail.
2. I think the support being available without diagnosis is crucial, so that's something I really do welcome. But I'd like to know how that will work practically. A lot of the agencies that we rely on aren't necessarily run by Wales, for example, there's always the need for a diagnosis when claiming certain benefits.
3. Some participants are concerned that the Deputy Minister has not considered that there are groups within society that are already disadvantaged in accessing a diagnosis and that they might be further marginalised as the barriers to accessing services will not have been addressed.
4. For women, it's harder to get an autism diagnosis and many people are getting it later in life. It's even worse for women of colour because there are assumptions made that their behaviours are some mental illness rather than neurodivergence. It’s the same for people in poverty. There are cultural reasons that will stop people from even being able to seek a diagnosis or think that they may be neurodivergent.

## Crisis support

1. Participants felt strongly that support for people in crisis is such a major barrier that many are frightened to ask for help.
2. We need to take away the fear of being sectioned just because we're autistic. It's not a mental health issue, it is just our neurology and it should never be grounds to have us institutionalized against our will. The fear of being sectioned is probably one of the top reasons why autistic people tend to not seek support when they need it.
3. Participants agreed that Police intervention was not an effective way to support people in crisis. Several participants gave examples where neurodivergent people have been sectioned when in crisis.
4. People are fearful of being sectioned because if they have a meltdown, the police don't know how to deal with them. They get stuck in these places and can't get out. Must be horrendous.
5. Participants agreed that there is a lack of crisis support. Participants identified that support needs to be available 24 hours a day, every day, and that a joined-up approach is necessary rather than relying on helplines.
6. When you’re in crisis, a list of telephone numbers is not the answer. The system only gets that one chance when a person first rings up to ask for help. If you miss that, their next stop could be going to get a bottle of pills.

### What needs to change to remove the barriers to accessing mental health services?

1. Participants suggested the following ideas for change:
2. For all health services to communicate in a jargon-free way, using accessible language.
3. The development of a medic alert accessory for neurodivergent people, to relay essential information to first responders including how to respond to the person’s behaviour and neurodivergence.
4. A nice bracelet or necklace with instructions. Something recognizable to people who need to recognize it, so they know “We need to see what that says”.
5. Interim support for families and service users whilst waiting for a diagnosis.
6. 24-hour a day crisis emergency support service. A face-to-face, joined-up service, trained in working with and supporting neurodivergent people in crisis.

# Joined-up, person-centred care

## Person-centred care

1. Participants agreed that services do not join up effectively and that a holistic and integrated approach is necessary for the whole person to be treated rather than a single issue or diagnosis.
2. *When someone has psychosis, for example, they go to mental health services and quite often those services say, “oh, I'm sorry, but you're also autistic. We can't touch you. That's a complex case. You have to find someone who's trained in autism”. But the people trained in autism might not be trained in OCD or Tourette's, or any of the other neurodevelopmental differences that we might have.*
3. In Swansea, there are no in-patient eating disorder facilities and only one peri-natal mother-and-baby unit. There’s no in-patient intensive treatment for patients with OCD and limited awareness of the implications of self-harm or trauma-informed care. How can that be accessible, person centred care!
4. Participants felt that progress is not being seen “on the ground” with joined-up working.
5. They'll only deal with one problem. If you get a referral to substance misuse services, they’ll only deal with that, they won't look at your mental health. You have to get a separate referral. They've got to be more joined together to support people with co-occurring conditions.
6. Participants also feel that patients should be listened to more by medical professionals. Enabling patients to give their personal preferences and views about their treatment and symptoms, supports the idea of person-centred care.
7. *It's assumed that because I'm a younger person I have no understanding or awareness of my own mental health issues. I probably have more understanding than most of the professionals I've come into contact with because I've done the work.*

## Pathways

1. Participants discussed the barriers to finding the right pathway; several participants agreed that the system is confusing and inaccessible.
2. Finding the right pathway to get the right assistance is impossible. You have to knock on lots and lots and lots of doors to find the right door to get the right help. That’s not helpful!
3. When you finally get on the pathway you have to be able to know where the pathway is leading. What direction it's going to take? How long it's going to take to get you to whatever happens at the end of it? Is there going to be any help for you while you wait for the proper services? People are floundering and people are un-aliving themselves because the pathway is too long and too unknown.

## Access to medical information

1. Participants agreed that joined-up services should enable patients to access their medical records easily and have more autonomy over their pathway and care.
2. Having those joined-up services should also mean that we, as service users, should have access to our notes in a non-complicated way. We should have access to them all the time. It would genuinely stop medical professionals from writing things they shouldn't in our medical notes that influence the way we are treated by medical professionals.
3. Some participants felt that care needs to be taken when sharing a patient’s history and that full disclosure of a patient’s trauma and/or medical history should not be necessary to access support.
4. I've specifically not shared the details of my trauma, which is the reason I've not been given access to services. They won't do it unless I disclose it. I don't want it in my medical records because I don't want people to have access to seeing that without me trusting them enough to tell them.

### What needs to change to improve person-centred services?

1. Participants suggested the following ideas for change:
2. Mental health services in Wales to connect with local providers for ongoing support as part of a specialised network to enable the sharing of good practice, staff development, and ongoing person-centred care.
3. We should look at when a service is performing well. We should elevate them and say this is the standard we want. Just to say “look, this is a service that's doing well. Follow our suit. Look at our ideas and what we're putting forward”.
4. Development of care coordinators, independent advisors and advocates to support people struggling to navigate systems and access appropriate healthcare services.
5. Patients to have ownership over and ongoing access to their medical records and history, and have a say in which medical professionals have access to their history.
6. Patients should be involved in the design of their person-centred support.
7. Development of patient record keeping across services to ensure that people only need to discuss their trauma once.
8. It's a pain to keep telling your story. We don’t want to re-live the trauma we've had. We need a system that remembers you because it wears you down having to explain something over and over again.
9. An All-Wales pathway
10. Services need to be joined up and have a specific pathway. It should be the same across Wales because it's like a post-code lottery. Services are different in different areas of Wales. It should be the same pathway, like an all-Wales pathway, not different pathways for different health boards. This would make it easier for everybody.

# Workforce

## Awareness and understanding.

1. Participants agree that there continues to be a lack of awareness and understanding across the workforce in supporting neurodivergent people with poor mental health and that training should be mandatory for all public-facing roles.
2. When you can't do forms they think you're stupid. If you can do forms, they think you're far too eloquent and intelligent to have mental health issues. If you’re not sitting in a corner crying and rocking, they think you can’t be autistic. People need to learn to park their own conscious bias and look at the person and not the condition around them.
3. You get horrible letters when you've forgotten an appointment. I've got ADHD and autism; my short short-term memory is terrible. I just need a bit of understanding. I don't need to be shamed for missing appointments, for myself or my children, I’m not a bad mother because I've forgotten a dentist appointment. I genuinely have a bad memory and poor time timekeeping and organisational skills.

## Workforce training

1. Participants agreed that a lack of training in key service areas is a significant barrier to providing effective mental health support. Several participants illustrated the argument for further training for Police and teachers.
2. I was having a meltdown. Because I'm dyspraxic I staggered and I fell over. I was sitting in the corner going, “Don't touch me. Don't touch me. Don't touch me” and crying and rocking having fallen over. Obviously, according to the police that was I must have been off my face on drugs. So, training to recognize what's going on is needed.
3. Gatekeepers to services urgently need training. You have to get evidence from teachers and doctors, both of whom you would assume know about neurodivergence. But no, they don't. If you have to rely on gatekeepers like teachers and doctors then they need to know what they’re looking for.
4. One participant spoke of the difficulties she experience in accessing support for her son as he did not display stereotypical symptoms.
5. …even though I'm telling the school about his symptoms, they're like, “Oh no, he's fine. He's not naughty”. It’s so frustrating. All teachers should have basic training to be able to spot neurodivergent conditions and support mental health conditions. In my children’s school, they've got ELSA buddies, which is great. But there's only one in the school. So when you've got a school of 600 plus children, there is no way that that one person can support those children.
6. Some participants described the need for further training for medical staff, with particular reference to GP surgeries, crisis support, and helpline staff.
7. We need medical staff and receptionists who are trained in neurodivergence. We need them to be aware of the double empathy problem, to understand that our communication style is different to neurotypical people, and who can account for our differences.
8. There doesn't seem to be any training in terms of the different factors that can lead to someone having suicidal thoughts. The lack of awareness that there are a variety of issues that can impact someone's suicidal ideation or lead them to harm can come from a different range of things. But quite often the way you’re treated is as if you’re a risk to yourself and probably a risk to others. “So we're going to lock you in this place”. It's almost like safeguarding themselves, like an insurance thing, “we don't want to get in trouble because that person succeeded in killing themselves. So we'll put them in this prison and we can tick the box and say we protected them”.
9. Some helpline operators need further training on how to deal with autistic people. I happen to have experience because I live with autism. That's the only reason. But I’m the only one on the helpline, that I know of, who understands autism.
10. Participants illustrated their concern that people are being misdiagnosed and over-medicated due to a lack of training to address professional bias.
11. A borderline personality disorder diagnosis carries a lot of stigma. And it's massively overdiagnosed in neurodivergent people who are being diagnosed incorrectly. Medical professionals jump to conclusions that aren’t correct. because they're holding so many biases. I won’t go near a mental health service now because it's on my records that I've got traits of BPD and therefore I know I won't be treated like a human.

## Staffing

1. Participants suggest that turnover of staff within the mental health workforce in particular is an issue. Participants feel that there is a high staff turnover due to short-term contracts and limited career opportunities.
2. This is hugely problematic for patients. Half of the battle when supporting people with mental health difficulties is gaining their trust and enabling continuity of care. Constantly expecting patients to re-tell their stories due to high staff turnover is massively traumatising and actually exacerbates and prolongs mental health.

## Lack of representation among the workforce

1. Several participants described how a lack of representation among the workforce acts as a barrier to improving mental health.
2. My counsellor isn’t ND informed. Whilst he does help me, he can’t understand what burnout means, he can't understand what rejection sensitivity is, and he can't help me understand my behaviours. We need neurodivergent people in every role.
3. Participants agree that it is essential to have neurodivergent people within the workforce to support them as a community and to improve services.
4. The only way to do this is to have neurodivergent people teaching others and taking on these roles. Then we access support from people that “get us”. Then we don't have to spell out what burnout is, what a shutdown is, or what sensory overload is.
5. I think the people delivering services must be neurodivergent themselves. All too often we get sent to counselling and the counsellor says “Oh, how do you cope with this autistic behaviour?” and it turns into a lynch mob against the autistic person who's not conforming to neurotypical norms. If we want somewhere where we can go and be better understood, have our families understand, our difficulties and our stresses understood, then I think it has to be neurodivergent people that deliver it.
6. However, participants warn against the idea of expecting a neurodivergent workforce for free.
7. Autistic people are amongst the most unemployed or underemployed in the population. I think it's only 16% of us, last time the NAS looked into it, were in full-time employment. Most of it is because we don't do well at interviews. We don't necessarily shine in those kinds of settings. We struggle with application forms. So we're really at a disadvantage in the workplace.

### What needs to change to support and improve the workforce?

1. Participants suggested the following ideas for change:
2. Awareness training on mental health and equality issues among healthcare professionals and all public-facing roles. Along with training for healthcare professionals in identifying biases and communication.
3. When it comes to which organizations need training, it should be mandatory for all organizations that have a customer-facing side. So whether it's the prison services, the police, the doctors, even receptionists and council workers, everyone whom the public has no choice but to have to interact with should have an understanding of neurodiversity.
4. *“ Nothing for us without us”.* Representation of neurodivergent people in the workforce with effective training and support to get into roles which deliver mental health services, so that the services are truly neurodivergent-aware, friendly, and accessible.
5. Neurodivergent people to be involved in the design and facilitation of the Healthcare Education and Improvement Wales and Social Care Wales’ workforce plan and training framework.
6. An assurance from Welsh Government that it will not use unregulated or untested treatments and conversion therapies, such as Applied Behavioural Analysis, in its training.
7. Behavioural therapies aim to make everyone respond in similar ways to situations, but they do not account for our different communication styles, our different behaviours or our different sensory needs. Behavioural therapies can often lead to reduced well-being for autistic people and worsening mental health as it teaches us that our natural ways of responding to stimuli, communicating with others, and moving our bodies are wrong and we need to change who we are on an integral level.

# Communities

1. Participants agree that more needs to be done to make community facilities and activities more accessible in terms of travel cost, location (particularly in rural areas), advertising and awareness, and timings.
2. For me to access any of that support is impossible without taking time off work, which I shouldn't have to do if work is part of the thing that keeps me well, which it is.
3. Participants are also concerned over the management of community groups, highlighting the difference in provision across Wales. Participants feel that community groups appear to be mainly self-regulated and some are not fit for purpose.
4. I'm part of two community groups, one of which has been absolutely brilliant and a great distraction. And the other has been awful. It's been absolutely terrible. When you first go in they weigh you and take your blood pressure and your height. I asked why they needed to weigh me. And they said they needed my BMI to measure how I’m getting on during the course. My BMI has absolutely nothing to do with my pain levels! For somebody like me who has had an eating disorder since I was 15, going in and being told I'm eating “bad food” and then weighing me is awful.
5. Participants all agree that accountability in delivering community activities and facilities is essential.
6. The Deputy Minister seems to just want to throw some money at it and let those running the community groups do what they like. Where's the accountability? Where's the body that people would need to report to? Where would be the metrics of how successful it is? Where are the risk assessments?

## The importance of connecting with other people

1. Group support shows you're not alone. A lot of people have mental health problems and then they isolate themselves from society. They think, “I can’t have help. I’m alone”. But when you got to groups like pool, football, coffee groups, walking groups, or any activity, you can start a conversation with people and they can say “oh I've got a similar problem to you. You've got psychosis. I’ve got psychosis. How did you get it?” and so forth. It starts a conversation and makes people feel like they can come back into society when they are isolated from it.
2. Participants all agreed that connecting with other people is very important and can provide great support in improving poor mental health. Participants felt that online and face-to-face groups are a lifeline for people and should be supported. Furthermore, participants agreed that an online buddy system would be an effective measure in improving mental health support.

### What needs to change to improve the use and delivery of community facilities and activities?

1. Participants suggested the following ideas for change:
2. A single body to manage, advertise and regulate local community facilities and activities.
3. Welsh Government to provide financial support to set up local community facilities and activities, assist with ongoing costs, and develop an accessible funding application process.
4. I set up a community group during covid specifically for young people 13-25 who were struggling with loneliness. It was really successful in creating a safe online space run by young people for young people. But access to funding was so restricted that we just couldn't sustain it. Big organisations always get the money because they have fundraisers write the applications to apply for funding
5. A wider range of local community facilities and activities to cater for all ages, genders, interests etc.
6. Local community facilities and activities to be run by/with people who have lived experience.
7. If it's a group for neurodivergent people it needs to be run by a neurodivergent person. If it’s a group for chronic pain, it needs to be run by someone who has suffered from chronic pain. They will have genuine empathy and understanding.
8. Financial support for neurodivergent people to learn to drive.
9. How about we fund helping neurodivergent people to drive, by funding driving lessons? Especially in poorer areas. People can get about more easily to support groups, employment, and appointments, and to not have to use public transport which can cause anxiety. It also helps us to get employment. It enables people to get out and about more.

# Welsh Government policy implementation

1. Participants considered the [Deputy Ministers’ comments](http://www.senedd.tv/Meeting/Archive/e37f6f0e-d823-4cc8-9c1f-0f7768dd3aaf?autostart=True) about improving support for neurodivergent people. Participants feel that further detail on policy detail, practicalities, and implementation would be welcome.
2. The Deputy Minister mentioned lots of strategies, schemes, and advisory groups, but I want to see clear and concise information on exactly what services are going to be provided in my community. What hubs? What services for children? What services for families? What support for parents and carers.
3. Participants call for unambiguous communication from the Welsh Government on its policy, to ensure that the neurodivergent community are effectively updated and informed of policy progression and implementation.
4. One thing that neurodivergent people need is clarity. We're not very good with vagueness. We're not very good with sound bites, buzzwords, blue-sky thinking, and out-of-the-box thinking.
5. Participants described the Deputy Minister's language as jargon-heavy and vague, which they said could exclude people from understanding Welsh Government policy and.
6. *The Deputy Minister said, that evaluating the impact of social prescribing across Wales is “challenging”. What does challenging mean? Does it mean it's not doable? Does it mean that we can do it but it's going to cost? What does it mean? If you’re co-designing policy with people who live with the repercussions of that policy, be clear. It feels disingenuous like we're being kept in the dark and I don't want to be kept in the dark*.

## Provision and policy for neurodivergent adults.

1. Participants agree that early and continued support is needed for children, young people, and families. But, some participants feel that the Deputy Minister focused too heavily on the needs of neurodivergent children and young people, and are concerned that this could be to the detriment of neurodivergent adults.
2. There doesn't seem to be any focus on autistic adults, we do exist. Autistic children grow up to be autistic adults. But, support tends to stop at young adults. So we're almost invisible.
3. Participants are concerned that neurodivergent adults are not supported with long-term mental health care resulting in a “revolving door” of services
4. Patients are discharged from secondary care after a short-term intervention. Then they have to go back to the GP or primary care mental health team before waiting many months or years before re-accessing secondary care. This is a revolving door of services which doesn't provide ongoing, lower-level support. The system is beset with barriers.
5. Some participants are concerned that the neurodivergent services Ministerial Advisory Group will not support the timely implementation of support and services needed now. One participant said that the Welsh Government was “kicking the issue into the long grass”, whilst a second participant described the Welsh Government as “having meetings to decide what the next meeting was about”.

### What further changes would support the implementation of the Welsh Government’s strategy?

1. Participants suggested the following ideas for change:
2. For the Welsh Government to communicate its policy and planning in a jargon-free way and using accessible language.
3. A clear roadmap outlining the practicalities of how the Welsh Government will improve mental health among neurodivergent people, at a local and national level.

# Annex A: Demographic makeup of the online advisory group

Below is a list of all diagnoses presented by participants:

* Attention deficit hyperactivity disorder
* Attention deficit disorder
* Anxiety
* Asperger’s
* Autism
* Cerebral Palsy
* Chronic migraines
* Dyscalculia
* Dyslexia
* Dyspraxia
* Ehlers- Danlos Syndrome
* Fibromyalgia
* Grief
* Obsessive compulsive disorder
* Osteopenia
* Postpartum depression
* Psychosis
* Post-traumatic stress disorder

## Local authority

#### South East Wales

|  |  |
| --- | --- |
| Local Authority | Number of participants |
| Caerphilly | 1 |
| Cardiff | 2 |
| Newport | 2 |
| Rhondda Cynon Taff | 1 |

#### South West Wales

|  |  |
| --- | --- |
| Local Authority | Number of participants |
| Carmarthenshire | 1 |

#### Mid-Wales

|  |  |
| --- | --- |
| Local Authority | Number of participants |
| Powys | 1 |

#### North Wales

|  |  |
| --- | --- |
| Local Authority | Number of participants |
| Flintshire | 1 |
| The Isle of Anglesey | 1 |

#### For further information, please contact:

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