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Health and Social Care Committee

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Jayne Bryant MS
Chair, Children, Young People and Education Committee
Jenny Rathbone MS
Chair, Equality and Social Justice Committee
John Griffiths MS
Chair, Local Government and Housing Committee

15 July 2022

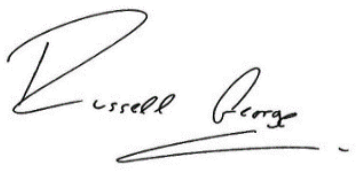
Dear Jayne, Jenny and John

Health and Social Care Committee inquiry into mental health inequalities

Further to my letter of 6 June 2022, I am writing to provide a further update on the Health and Social Care Committee's inquiry into mental health inequalities.

I enclose for your information summaries of the issues emerging from our discussions with people with lived experience of neurodiversity, and our visits to EYST Cymru and Barnardo's Cymru's Beyond the Blue project. These notes have been published on the inquiry webpage. I also enclose in confidence for your information a copy of the Senedd Research briefing prepared for our recent oral evidence session on 6 July.

Yours sincerely



Russell George MS
Chair, Health and Social Care Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg. We welcome correspondence in Welsh or English.

Health and Social Care Committee inquiry into mental health inequalities: update

Background

The Health and Social Care Committee launched an inquiry into mental health inequalities in January 2022. The terms of reference were very broad, seeking to identify which groups were most likely to experience mental health inequalities, what barriers they face, whether Welsh Government policy does enough to recognise and address these groups' needs, and what more needs to be done.

Drawing on the evidence we received in writing, through focus groups and during initial oral evidence sessions, in March 2022 we decided to focus on four emerging themes: mental health and society; community solutions; the impact of mental health inequalities on people with neurodiverse conditions; and the role of the healthcare and wider workforce.

During the summer term we have taken oral evidence from stakeholders (4 May, 19 May, 8 June and 6 July), held a private informal stakeholder event on the experience of mental health inequalities of people with neurodiverse conditions and their families or carers, and visited projects and services working in their communities to support people from ethnic minority communities, and children, young people and their families.

Next steps

During the summer recess, the Citizen Engagement team will hold focus groups with frontline health staff to discuss: how they meet the mental health needs of diverse communities; whether staff feel equipped to recognise and meet diverse needs; what barriers may inhibit more effective working; the role of prevention and the promotion of good mental health; and the mental health and wellbeing needs of the workforce itself. A summary of the findings will be published in the autumn.

We have established an online advisory group, comprising people with a range of different lived experiences. The group will be asked to provide its views on emerging issues at key milestones in the inquiry. We will also be asking members of the Welsh Youth Parliament to share their views on emerging issues.

All of the evidence we gather throughout the inquiry, including the written update we have sought jointly with the CYPE Committee on progress made on key recommendations made by Fifth Senedd committees in respect of mental health, will inform an oral evidence session with the Welsh Government to be held in the autumn term.

Welsh Parliament
Health and Social Care Committee

Mental health inequalities: stakeholder discussion

8 June 2022

Background

1. As part of our inquiry into mental health inequalities, on 8 June 2022 the Health and Social Care Committee held a private informal discussion with people with lived experience of neurodiverse conditions. We are grateful to everyone who took part for sharing their views, experience and expertise with us. We would also like to thank the ADHD Foundation, Autistic UK and Parents' Voices in Wales for working with us to identify and support participants.

2. We asked participants to consider:

1. What factors contribute to poor mental health for people with neurodivergent conditions (and their carers/families)? What are the wider impacts of this (e.g. on education, employment).

2. Whether there needs to be more awareness/understanding of neurodiversity among the healthcare and wider workforce (including e.g. education, social services).

3. What would more effective support for people with neurodivergent conditions (and their families) look like? What are the key changes needed?

4. What is your one key message for the Committee's inquiry?

3. This note summarises issues and themes discussed during the session. Reference to an issue does not necessarily represent endorsement either by all participants or by the Committee.

Barriers and mental health inequalities

4. A significant proportion of people in society are neurodivergent. Individuals' circumstances and experiences will differ, and the extent and way in which they experience barriers and mental health inequalities will vary.

5. People who have neurodivergent conditions have the same rights, and should have the same access to support and services, as neurotypical people. It was noted that organisations like Disability Wales have run campaigns to help disabled people understand their rights, and suggested that similar campaigns targeted at neurodiverse people could be helpful.

6. We heard that society needs to be much more inclusive and accepting of difference. Insufficient awareness and understanding of neurodivergence in society and public services creates barriers that can disproportionately affect neurodivergent people, with corresponding trauma and detrimental implications for their mental health and wellbeing. Such barriers include trying to fit in with neurotypical social norms, bullying, discrimination, and ableism, as well as having to fight continually to be heard, respected and to receive the support they need, or that is needed by their child, family member, or person to whom they provide care. People who are neurodivergent may also experience a range of inequalities, including higher levels of unemployment, lower life expectancies, or increased risk of experiencing addiction, early pregnancy, domestic violence or of suicide.

7. The cumulative impact of these factors can be compounded by a lack of support to meet people's needs. It was suggested that trauma and other mental health issues are a symptom both of the barriers and stigma people have faced, and of inadequate or non-existent support for people who have neurodivergent conditions.

Intersectionality

8. Understanding of neurodivergence and neurodevelopmental conditions and the services that have been developed to support people are largely based on the experience of people who are male, white and middle class. It is important to recognise that people who are neurodivergent are also be diverse in other ways, and these other aspects of their diversity can also carry a risk of discrimination or stigmatisation.

9. Too little is known about the experience or needs of other groups or communities, for example women and girls, people from ethnic minority backgrounds, people living in more socioeconomically-deprived circumstances, people who are LGBTQ+, or people who may not have the skills or resources to navigate different services or pathways. We heard that women

and girls for example, may be more likely to 'mask' their neurodivergent traits and to internalise their distress.

10. There needs to be more understanding of how traits associated with neurodevelopmental conditions, and the social or emotional challenges which may arise from engaging with neurotypical norms, may affect people with different characteristics, including the cumulative impact of intersectional characteristics. This would help to counteract biases and make sure that all 'learners of concern' were identified and treated fairly.

Parents, families and carers

11. Services and professionals need to listen to parents. Parents report that they often feel they're not believed, even though they're the ones who know their child, and their child's difficulties and strengths, best.

12. Families can feel as though they have to become experts in their child or family member's condition. Parents, families and carers who have knowledge and understanding of neurodiversity are more likely to identify whether someone in their family or for whom they provide care may have a neurodivergent condition. Not all families will have this understanding, and it can be difficult to know where to start, but it is important to empower people and communities to find and access the help and support that they may need.

13. Parents who are neurodivergent themselves may have greater understanding of the issues experienced by children who are neurodivergent than parents who are neurotypical. However, neurodivergent parents may also face greater challenges in supporting their children while also managing their own condition.

Diagnosis and thresholds

14. Diagnosis and the resultant 'label' can often be seen as a golden ticket. Diagnosis can help, for example, people to access support in schools, or pharmaceutical interventions or other elements of the medical pathway that can help to meet their needs. We heard calls for an ADHD diagnosing service for adults in Wales, and for pre-diagnosis support for people waiting for a neurodevelopmental diagnosis.

15. Even when people are able to access a diagnosis, they are not always able to access the support that they need. Reasons for this could include:

- A lack of capacity in services or long waiting times.

- A diagnosis for a single condition may fail to take account of other, co-occurring conditions for which the individual may also need support.
- Misdiagnosis, which can then lead to inappropriate support or medication that can fail to meet the individual's needs or cause harm.
- The level at which severity thresholds are set. The result can be the exclusion of some children, young people or adults from receiving support, potentially giving the message that some people's needs do not matter. This can include the 'missing middle' as identified by the Fifth Senedd Children, Young People and Education Committee in its Mind over Matter report.

16. In addition, not everyone who is neurodivergent, who has neurodiverse traits or who exhibits neurodivergent behaviours will want or need to have diagnosis or a 'label'. An alternative is a needs-led approach that focuses on what advice or support an individual may need to self-manage their neurodevelopmental condition and their mental health within the community.

Access to healthcare services

17. Healthcare professionals are not always understanding, particularly if the person has not had a formal diagnosis. Also, people are moved through the system, seeing numerous professionals before they've had a chance to build a rapport, and without that rapport, neurodiverse people find it very difficult to engage.

18. Neurodiverse people often struggle to access primary care services. Most GP surgeries require patients to telephone at a certain time to secure an appointment (e.g at 8.00) but neurodiverse people find phone calls difficult and often struggle with getting up early so many are just put off from trying to get an appointment.

19. A&E departments can be a hostile environment for a neurodiverse person due to the noise, bright lights, number of people, etc.

Access to specialist mental health support

20. When people are able to access services, the people providing services too often have too little knowledge or awareness of how to communicate effectively with neurodivergent people. Services are also too siloed, with a disconnect between neurodevelopmental teams and mental health teams, rather than mental health, social care and education services working together to support people.

21. Services may also fail to see people as individuals rather than as their diagnosis or condition, with the result that, in some cases, the nature of support offered by mental health services, for example group therapies or work, may not be suitable for neurodivergent people. However, instead of offering alternatives or adjusting their approaches, services may describe individuals as challenging or unwilling to engage.

22. While access to services via the internet was welcomed during the pandemic it should not be a substitute for human interaction. It is also important to recognise that not everyone that needs access to services has access to the internet.

23. CAMHS may refuse referrals for children or young people who are neurodivergent and have co-existing mental health difficulties as these can be seen as an inevitable consequence of neurodevelopmental conditions. This can include children and young people who are self-harming or at risk of suicide. Adults can also be denied support. We heard examples of adults being discharged from mental health services as soon as they received a diagnosis of autism.

Complaints

24. It was suggested that there should be a route for parents, families and individuals to raise their experiences of local services directly with Welsh Government when things go wrong, as existing routes for complaints could be slow and difficult to navigate, particularly for people who are neurodiverse, or who are caring for someone who is neurodiverse. This can, itself, have a detrimental effect on people's mental health. We also heard the need for advocates to be available who understand neurodiversity, the experiences of neurodivergent people, and how to communicate effectively.

Training and awareness

25. There were strong calls for mandatory training for people working in education, health and other public services, including the police, to increase their awareness and understanding of neurodiversity and neurodevelopmental conditions. It was suggested that there is a desire among professionals to receive training so that they are able to provide better and more effective services and support.

26. Such training should not just be about specific conditions – it should be focused on how to support and help people, and developing positive, constructive and helpful attitudes and cultures. For example, it could include how to communicate effectively, what language and terminology is appropriate, how to adapt or tailor services and support to meet neurodiverse people's needs, and how to ensure that services and support enable neurodiverse people rather than 'disabling' them. Role-specific training may be needed in addition to general training, for

example specific training for teachers as part of their initial teacher training. Neurodiverse people must be involved in designing and delivering any training, as well as in the design of services.

27. Concerns were also raised about working cultures within public services, including a lack of collective responsibility and accountability, internal antagonism, and longstanding issues relating to pay and conditions, especially for lower paid health and social care workers, including carers, porters and cleaners.

Education and schools

28. It's common for neurodivergent children and young people to find the school environment difficult. Prior to the COVID-19 pandemic, if a child was struggling to attend school, schools weren't often able to provide any resources to help them continue to learn at home. If schools could continue to provide online resources (for example, pre-recorded lessons) for children at times they're not able to be in school, this would help ensure the connection with school and learning wasn't lost.

29. As noted earlier, schools often require a diagnosis of a neurodivergent condition before more formal support can be put in place. There's a need for improved pre-diagnosis support and strategies in schools (and in general), particularly as waiting times for an assessment can be two or more years.

30. There was support for the whole system approach to mental health in schools, and a focus on 'going upstream' to address the causes of poor mental health. There were calls for a similar 'going upstream' approach to be taken to neurodivergence, to help to identify people who may be neurodivergent or have a neurodevelopmental condition at an earlier age and focus on meeting their needs. It was suggested that this could be dovetailed with the NEST/NYTH model, ALN (additional learning needs) reforms and the whole school approach to mental health, and be part of an 'early help' model, supported by therapeutic interventions available in communities.

31. Other approaches suggested to improve support in schools, and reduce the risk of mental health issues developing for children, young people and school staff, included:

- Train and empower families to identify and manage neurodiversity and support children and young people to communicate and build on their strengths, for example through educating children, young people and their families in how to co-regulate emotions and behaviours. A whole family approach can be very effective in reducing the risks of trauma or adverse experiences.

- Drive cultural and attitudinal change by increasing teachers' knowledge and awareness of neurodiversity. In addition to being better able to meet the needs of neurodiverse children and young people (whether or not they have a diagnosis), this would also help them to identify 'learners of concern' and provide the support that may be needed rather than stigmatising or punishing behaviours or traits that may be signals of distress or unmet need.

- Digital assessment using the tool developed by the Together 4 Children and Young People programme of the cognitive profiles of children and young people identified by parents or schools as exhibiting signs of distress in order to put in place therapeutic interventions.

- Adopt neurodiversity sensitive measures, such as allowing children to move around in classrooms, scheduling frequent breaks, providing visual learning materials, positive reinforcement rather than negativity or reprimands, a focus on developing relationships etc.

- Develop a greater appreciation of different learning styles. Not everyone can follow written instructions but learn through using their hands/doing. There is currently an absence of kinesthetic provision and as a result children with autism are missing out.

- Change the inspection approach to ensure that schools are able to take a strengths and skills based approach which helps children and young people harness their strengths and develop their skills.

Employment

32. Neurodivergent people are less likely to be employed or in education or training. They may face barriers in navigating processes or pathways to employment, including job interviews. This can affect individuals' mental health and wellbeing, for example in terms of self-esteem and self-confidence, but also as a result of reduced earning capacity. Tackling biases or structural inequities would reduce the risk of developing mental health problems, and the need to access mental health services.

33. Employers need to offer greater flexibility. The flexible, working from home arrangements which have applied to many people during the pandemic may have been of particular benefit for some people with neurodivergent conditions, who can struggle with the office environment for example.

34. In addition, there would be considerable benefits to society and the economy of harnessing the strengths and talents of people who are neurodiverse. Autistic people may have strong analytical capabilities, people who have ADHD may bring creative energy and drive, and people with dyslexia – who may be more likely to think visually – may bring an alternative perspective compared with people who are neurodiverse in other ways or who are neurotypical.

35. Neurodiverse people can be really good at their job but may struggle with things like getting to work on time, filling out timesheets, forms, etc and a lot of employers are not willing to compromise on those things or offer the support needed to overcome such issues. It was suggested that often HR policies are put in place to protect the employer from litigation rather than support their employees.

School exclusion, youth offending and the criminal justice system

36. People who are neurodivergent and who experience poor mental health may be more likely to experience school exclusion, or to come into contact with the criminal justice system including as a result of youth offending. It was noted that an estimated 1 in 3 people in prisons are neurodivergent. While there is limited research on this, it may be because neurodivergent people are more likely to experience risk factors such as family breakdown or substance misuse that are themselves more prevalent among the prison population.

37. A lack of understanding or awareness of neurodivergence, including how to adapt communication appropriately, can have very real implications, for example if a person is unable to make eye contact, or remember events in a linear way, they may be less likely to be believed when they come into contact with the police or other parts of the criminal justice system. Techniques such as Witness-Aimed First Account[1] can be used to reflect the way in which autistic witnesses process information in memory, but this is not widely used.

Research

38. There were calls for a greater focus on social-based research to understand more about how autistic and neurodivergent people experience the world, rather than focusing primarily on the medical model of neurodiversity.

[1] **The Witness-Aimed First Account (WAFA): A new technique for interviewing autistic witnesses and victims — the University of Bath's research portal**

Legislative and policy approaches

39. The legislative and policy approaches to neurodiversity, for example the Code of Practice on Autism, should take an inclusive approach that takes into account the full range (and frequent overlapping nature) of other neurodivergent conditions. Such approaches should be applied in education settings as well as in communities and primary care to help to identify people as early as possible.

40. There needs to be greater recognition of the impact of successful and effective projects, organisations or services. Where such projects are having a positive impact on their service users' quality of life and wellbeing (and where they are delivered by people who are themselves neurodiverse, on their staff's quality of life and wellbeing) good practice and innovation should be shared. It also needs to be recognised that many of the organisations providing these services are volunteer run and need support themselves to be able to continue to provide these services.

41. There were calls for an all Wales neurodiversity alliance to bring together a diverse range of voices and perspectives from people who are neurodiverse and experts and organisations working in the field. The role of the alliance would be to ensure that neurodiverse people are involved in framing and developing legislation, policies and decision-making from the start. It was suggested that the alliance should be mirrored by structures within the Welsh Government to ensure that issues are considered on a cross-portfolio basis. This could be a single Minister with responsibility for neurodiversity, or an inter-ministerial forum or working group.

42. There was a clear message that politicians from all political parties need to work together to bring about cultural and societal change, as well as ensuring that the right policy and legislation is in place supported by appropriate funding. There were also suggestions that all Members of the Senedd should receive neurodiversity training which focuses on people's lives, not just on different conditions.

Welsh Parliament
Health and Social Care Committee

Mental health inequalities: visit

23 June 2022

Background

1. As part of our inquiry into mental health inequalities, on 23 June 2022 the Health and Social Care Committee visited EYST Cymru in Swansea, and the Barnardo's Cymru Beyond the Blue project in Neath.

2. We are grateful to both organisations for their warm welcome, and to their staff and service users for sharing their views, experience and expertise with us.

3. This note summarises emerging issues and themes. Reference to an issue does not necessarily represent endorsement either by all participants or by the Committee.

EYST Cymru

Issues affecting mental health and wellbeing

4. People from ethnic minority communities can face racism and discrimination in everyday life. This can have a significant impact on their mental health and wellbeing.

5. People contacting EYST often have multiple problems, and it can be challenging for staff to know which issue to address first. Many of the problems people are experiencing – e.g. health, housing, problems with the benefits system, family breakdown – have significant impacts on mental health.

6. Ethnic minority communities may face barriers to education and employment opportunities. There needs to be greater representation of these communities within schools and further/higher education and in the wide range of careers. Young people need role models they can identify with.

Impact of community projects

7. EYST provides a safe space where people feel they belong and can be themselves, without having to answer intrusive questions about, for example, how they look, what they're wearing. This applies to service users and to staff employed by EYST.

8. EYST is a lifeline for the communities it supports, and is often the first point of contact for people needing help. There is great diversity within and among the communities EYST supports. EYST also provides support to other organisations who need their expertise.

Impact on staff and service providers

9. EYST staff often have to work/provide services outside their core role due to lack of other service provision which meets the needs of diverse communities. Two key examples are providing translation for people when accessing healthcare and other public services, and the lack of culturally-aware counselling services. EYST staff find themselves needing to provide counselling to people they support, even though they're not trained to do so. Providing translation or counselling for traumatic events can have an effect on EYST staff, often making them relive their own traumatic experiences with consequences for their own mental health and wellbeing. There is a need to make sure that staff also feel supported, as well as service users.

Engagement with public services

10. There is a lack of cultural awareness/competence among public services' staff (and a lack of diversity). This is a key element of the success EYST has in supporting people from diverse communities – its staff are relatable to the person they support and also have an understanding of that person's culture and what's important to them.

11. EYST's youth support workers can however struggle to get statutory services (e.g. social services) to engage with them in a timely way, and feel they don't always have the credibility/recognition they deserve – and need – in order to secure the help that's needed for the people they're supporting. Early intervention is key, and getting people the help they need before problems escalate. We heard distressing accounts of people ending up in the criminal justice system or dying by suicide because the right support wasn't available at the right time.

12. We also heard positive examples of EYST and other agencies working well together to provide effective, timely support to young people in the Gwent area. It was noted that there can be significant geographic variation in access to support and services.

Translation services

13. The lack of translation services is a significant issue. It's not uncommon for young children to have to translate for their parent at a medical appointment for example. This is particularly distressing and traumatising when having to discuss issues such as rape. Also, medical language can be difficult for people to understand and interpret, and this can have serious consequences if people then don't receive the correct treatment or incorrectly take medication for example. As noted above, despite not being trained translators, EYST staff may find themselves needing to provide translation, sometimes in their own second or third language. There was discussion of the need for a medical translation service. There's a significant language barrier with health triage systems, including GP appointments systems and the NHS 111 system - these can be very difficult for people to navigate.

Mental health: understanding and terminology

14. Different communities may have different understandings of 'mental health' (and different language around this). Mental health is often stigmatised. In some communities for example, a person with mental health problems may be thought to be possessed. 'Possession' may actually carry less stigma than mental illness in these communities.

Impact of the pandemic on mental health

15. There's been a big increase in mental health difficulties among the communities EYST supports as a result of the pandemic. This includes rates of self-harm and suicidal behaviour. Loneliness and isolation has also increased. The support of family and community is really important among ethnic minority groups, and this plays a vital role in protecting people's mental health and wellbeing. The pandemic restrictions significantly reduced that support.

Funding sustainability

16. Demand for EYST's services far outstrips its capacity to provide those services. There's no shortage of people to recruit, but more longer-term funding is needed. The lack of sustainable funding is a key issue. Significant staff resource goes into preparing new funding bids for projects at the end of their funding period, even when those projects have already proved themselves to be successful. Core funding would enable EYST to develop services further, and make more effective use of staff resources.

Asylum seekers and refugees

17. Asylum seekers and refugees may already have experienced significant trauma. The struggles they can face once in the UK compound this. This includes difficulties accessing healthcare and other services (including dentistry and optometry), but also loneliness, having no support networks, and not feeling as though they belong. Asylum seekers face lengthy waits

while their claims are processed, and are left in limbo during this time. As well as the anxiety this causes, it also has wider impacts in terms of people losing skills etc. while not able to work.

18. Having to keep repeating their story to different people/agencies is re-traumatising. Many refugees from other countries (e.g. Afghanistan, Syria) perceive that they are less 'welcome' in the UK or worthy of support as Ukrainian refugees, and this unfairness also has a negative impact on their mental wellbeing. Free public transport should be reinstated for all refugees.

Barnardo's Cymru Beyond the Blue

The role of community services

19. There is a real need for community-based services which provide an alternative to more traditional NHS mental health services in clinical settings or schools-based counselling. Many children and young people may prefer to attend a community service as there's less stigma attached. Such services can sit between the NHS and social services, and help to meet the needs of the 'missing middle' as identified by the Fifth Senedd's Children, Young People and Education Committee.

Whole family approach

20. It is very important that support is focused on the wider family, not just the child in question. Children seem to enjoy visiting the centre and taking part in the activities there. Parents also valued the service.

Access to support

21. The families we met had travelled to Beyond the Blue by bus. If transport links are not available, the people most in need of support services may have the most difficulty accessing them, further exacerbating existing inequalities.

22. An alternative to families travelling to the centre could be 'outreach' i.e. the service going to people's homes.

Service availability

23. There doesn't seem to be a clear 'map' of this sort of service provision across Wales. It isn't clear whether there is a strategic approach (for example across or within regional partnership boards) to developing such services. The NEST/NYTH framework developed by the Together for Children and Young People Programme may be helpful in this.