

## **Consultation on draft Code of Practice on the Delivery of Autism Services and accompanying guidance**

Learning Disability Wales has responded to the Welsh Government consultation on *the Code of Practice on the Delivery of Autism Service*. We responded together with other members of the Learning Disability Consortium (All Wales People First and Cymorth Cymru) and the Engage to Change project: (All Wales People First, Agoriad Cyf, ELITE Supported Employment Agency and the National Centre for Mental Health at Cardiff University).

### **Key points of our response are:**

- We welcome guidelines making mainstream services more accessible to autistic people
- Much of the Code seems based on the medical model of disability. In order to give real support to autistic people the Code needs to be informed by the social model of disability
- We would like to see more focus on disabled people's rights and the role of advocacy to support them fighting for their rights
- Self-advocacy should be more explicitly mentioned and give more emphasis
- Preventative services should have as their main purposes to improve quality of life, not merely reduction of cost
- We are glad to see flexibility endorsed in order to make transitions into adult services smoother and would like to see even more flexibility than currently mentioned
- The strong focus on awareness raising is promising. We would like to see a commitment to self-advocacy here
- It is promising that Welsh Government has looked at intersectional issues and how autism and having other protected characteristics overlap. However, it is not clear how the acknowledgement of these issues translates into practical changes

**Q 1 Is the proposed definition accurate for service providers and acceptable to autistic people?**

The definition of autism in this Code is one based on the medical model of disability that is focused predominately on deficits.

We strongly suggest this definition is replaced by one that is based on the social model of disability where an understanding of disability that takes into account the structural conditions that lead to neurodivergent people struggling with their environment.

**Q 2 Do you agree that the Code should focus on autism services or could be expanded to cover other neurodevelopmental conditions?**

There is significant overlap between autism and other neurodivergences. It therefore makes sense to have a Code of Practice that allows for this overlap.

**Q 4.2 Arrangements for Accessing Health and Social Care Services**

**General notes:**

- We would have liked to see WG endorse a person-centred approach that puts the needs and choices of autistic people first; makes it clear that autistic people should receive flexible support; and that the support that autistic people receive should not be dictated by what happens to be available.
- While it is important that autistic people can easily access all the social care services they need, it is also vitally important that life for disabled people should be about more than just services. We would like to see a stronger focus in this Code on services that will support autistic people to become part of communities and to live in the real world. This is a point that applies to all the different sections in this category. In each instance service providers need to make sure that their services empower people to make their own decisions according to their own definition of what having a good life means.

**Advocacy:**

- We have concerns about the understanding of advocacy in this proposal. The Code defines the purpose of advocates as “to help them [autistic

people] express their views, wishes and feelings, to support them to weigh up options and to make decisions about their well-being outcomes.” What is missing from this definition is an acknowledgement that advocates should support autistic people in fighting for their rights when those have been violated, for example through local authorities or service providers. If Welsh Government truly cares about the well-being and autonomy of autistic people that means enabling them to challenge service providers and local authorities. The Code should not only make a mention of conflict arising between service users and providers but actively encourage supporting autistic people in fighting for their rights.

- We would also like the relationship between an autistic person and their advocates to be more clearly defined in that autistic people should be empowered to speak for themselves whenever possible. An advocate should be supporting this, not speak for the autistic person unless that person wishes them to.
- Most importantly we are missing any mention of self-advocacy in this context. In fact there doesn't seem to be a significant mention of self-advocacy in the whole Code of Practice. It is vitally important that autistic people are not only listened to but given real power in shaping the way they are given support. The only reference to self-advocacy we could find was a link in the further information section to the People First website (PeopleFirstLDT.Com). While we do not in any way wish to diminish the work of People First we would like to point out that this is a group operating in and focusing their efforts on people with a learning disability in England, not Wales. There are plenty of self-advocacy groups within Wales, most notably All Wales People First (AWPF). The fact that the biggest and most important self-advocacy group in Wales was omitted from this list implies a disinterest in substantially engaging with people with a learning disability in Wales that we find concerning.

### **Preventative Services**

- The Code defines the purpose of preventative services as “include[ing] contributing towards preventing or delaying the development of people's needs for care and support and reducing the needs for care and support of people who have such needs. One of the other purposes is the promotion of the upbringing of children by their families, where this is consistent with the well-being of children.” We disagree that this should be the main points

of preventative services. Instead, the purpose of preventative services should be to enable autistic people to live a good life however they may define that.

- It is true that very often giving appropriate support early will lead to a decrease in support needs later and dramatically reduce the cost of the care provided. However, this should not be the primary motivation for offering preventative services. Instead the wellbeing, rights and autonomy of autistic people should be in the foreground here.
- It is here too where an acknowledgement of the social model of disability would have been important. The first criteria in the prevention section that refers to wellbeing states that prevention should: “minimise the effect on disabled people of their disabilities”. According to the social model of disability in which a person with an impairment or, as in the case of autism a neurological difference, becomes disabled through not having an environment that is accessible to them. Saying that prevention should reduce the impact of a disability on a disabled person implies that it is the disability itself that is the problem. Instead it would have been better to say that prevention should reduce the amount to which autistic people are disabled by their environment. A happy and mentally healthy autistic person is not “less affected” by their autism. To imply that it is harmful in itself.
- We do welcome the guidelines in the Code that are supposed to make services more accessible. It is a vital function of prevention that services themselves were not disabling and traumatising people, and many of the steps within them will indeed make things more accessible for autistic people. It would also be helpful to acknowledge that some autistic people have made traumatic experiences with services in the past and that this might significantly add to distress.

### **Educational establishments**

- There are some welcome suggestions within the guidance for educational establishments that should make schools more accessible to autistic children. We are very happy to see the guidance explicitly acknowledge that behavioural issues in autistic children will usually be caused by their accessibility needs not being met.
- We suggest however that some ableist phrasing within the Code is removed. For example, on page 60 of the Code it states “All children with an ASC have impairments in social communication, social

interaction, social imagination and a preference for routines.”. This is incorrect. Autistic children will have communication and social interaction styles that differ from those of their neurotypical peers. This does not mean that these are impairments. To write that neurodivergent ways of being are “impaired” implies that there is one right way to think, feel and interact and that not behaving in a neurotypical way means there is something wrong with someone.

- Similarly, we would suggest you remove the term “high functioning ASD” (p.60). The high functioning label is controversial since the degree to which someone “functions” will often depend on their environment and in how far this environment allows them to prosper.

## Transition

- We agree that it is important to coordinate transitions well and that it is very important that age boundaries are more flexible, although we would like to see more flexibility here than just accepting referrals to adult services from 17, and a half years.
- We would like to point out that transitions cannot just be about moving from one kind of service to another. Instead, autistic people need to be given real opportunities to live independent lives. Autistic people should also have the freedom to decide what they are transitioning towards. Again, it is important that services are decided on the basis of what a person wants and needs, not on the basis of what happens to be available.
- Where young autistic people want to work they should be given support to do so. We know from our own work that supported employment can be an excellent method to support autistic people and people with a learning disability into long-term paid employment. These programmes should be offered to everyone who might benefit from them. Participation in the labour market for many disabled people opens up doors to participation in society. More on this can be found in an evaluation of the Engage to Change Project here

Steve Beyer (2019): What needs to change to allow people with a learning disability and/or ASD equal access to employment?:

<http://www.engagetochange.org.uk/article/what-needs-to-change-to-allow-people-with-a-learning-disability-and-or-asd-equal-access-to-employment/>

### **Q5– SECTION 3: Arrangements for Awareness Raising and Training on Autism**

#### **Please explain:**

We welcome the strong focus on raising awareness in this Code of Practice.

We would like to urge you to make a commitment to make sure awareness raising is led by self-advocates.

### **Q8 – SECTION 4: Arrangements for Stakeholder Engagement**

We are very glad to see stakeholder involvement from autistic people mentioned in this part. It would have been nice to better show what powers these stakeholders will have in holding local authorities and service providers to account. There is also no mention in the Code about the exact nature of these roles, in particular if participants will be paid for their work.

**Q10 - The Welsh Government is interested in understanding whether the proposals in this consultation document will have an impact on groups with protected characteristics. Protected characteristics are: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex, and sexual orientation.**

**Q10.1 - Do you think that the proposals in this consultation will have any positive impacts on groups with protected characteristics? If so, which and why?**

We welcome Welsh Government's interest in exploring intersectional issues and explicitly in the beginning of this Code of Practice. However, it is not clear how far the insights in these sections have had any impact on the rest of the Code. Acknowledging an injustice is not the same thing as correcting it and it would have been good to show how autistic people with the protected characteristic specifically are being supported.

There is also no mention of how people with some protected characteristics also tend to be economically disadvantaged. Being poorer and subject to

significant health inequalities will impact on autistic people's ability to access diagnosis and support, something the Code of Practice should acknowledge and aim to mitigate

Finally, it would have been good to name racism as the main issue affecting black and minority ethnic people with autism.

For more information please contact Grace Krause at Learning Disability Wales

[Grace.Krause@LDW.org.uk](mailto:Grace.Krause@LDW.org.uk)