

**EMBARGOED FOR RELEASE**

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**People with brain-based condition caused by alcohol exposure in pregnancy call for the same respect as others**



At a time when government is focusing efforts on improving the quality of life for people with autism and learning difficulties, people with FASD (Fetal Alcohol Spectrum Disorder) are calling in a new [UK FASD Manifesto](#) for health professionals, educators, policy makers and their communities to treat them “with the same respect as others.” Research shows that FASD affects between 1.2 and 2.4 million people in the UK but is widely under-recognised and under-diagnosed.

“At a time when [mandatory training](#) for autism and learning disabilities is being rolled out as a result of the [Health and Care Act](#), and when the Department for Education has launched its new [Special Educational Needs and Disabilities \(SEND\) and Alternative Provision \(AP\) Improvement Plan](#), we are pleased Government are taking some steps to meet the needs of some of society’s most vulnerable,” said Sandra Butcher, Chief Executive of the National Organisation for FASD. “But they are limiting their impact and wasting funds by gatekeeping these services and schools only for those with autism and learning disabilities. This definition excludes other neurodevelopmental conditions and too often leaves out those with lifelong brain damage caused by alcohol-exposed pregnancies but who don’t meet typical definitions of learning disabilities.”

The Local Government and Social Care Ombudsman has already [ruled](#) that a local area could not exclude someone with FASD from those services for autism and severe learning disabilities. According to Butcher, “National FASD is calling for FASD to be prominently included and recognised in all such designated services and training. The rest of the UK could take the Scottish approach, where they have included FASD within their planning for all those with neurodiversity.”

The [UK FASD Manifesto](#) was created by people with FASD from across the UK. It is being unveiled by a panel of young people with FASD today in front of the UK’s leading FASD experts, charities and policy makers at a major “FASD in the UK” conference at the University of Salford. The manifesto is part of The National Organisation for FASD’s “Me and My FASD” project that was originally funded by the Department of Health and Social Care in partnership with Seashell.

A group of young leaders with FASD is presenting the Manifesto at the conference. They are hoping to change the way society treats people with FASD.

Claire McFadden said, “As an adult with FASD, I wish people would understand me and treat me with the same respect as they do for people with other conditions.” Georgia Roberts said, “People with FASD have a right to support from medics and teachers who take the time to understand us and our disability.” Paula McPhail said, “People with FASD should be treated equally. Remember that it’s a brain-based condition and not wilful behaviours, it’s symptoms of our condition.” Bailie Jordan-Collins says, “People with FASD are like everyone else. We want people to be kind to us and to be patient. Understanding and believing that FASD is a life time disability is most important. Educators need to arm themselves with lots of knowledge about it in order to understand us.” Rachel Jackson said, “It’s so important that doctors and teachers listen to people with FASD. This manifesto is how we’d like them to support us. When we say we need help, even if it’s not verbal, just ask and talk to us, then we will tell you when we are ready. Medication and therapy aren’t always the answer.”

The manifesto calls on a wide range of professionals to “remember, just because you can’t see our disability doesn’t mean we don’t have one” and to “understand why things are harder for us.” It says, “We are sick of people saying they understand, or that they are trying to help, but they do nothing.” A poster summarising the manifesto, intended for display throughout the NHS, features key themes such as, “listen to us,” “speak slowly and calmly,” “remember our difficulties are lifelong,” “know our brains are different and sometimes we don’t get it,” and “never give up on us.”

Professor Raja Mukherjee, a leading researcher with 20 years clinical experience working with FASD says, “It’s critical that we listen to the voices and experiences of people with FASD as we begin to ramp up services across the UK following on from the NICE Quality Standard on FASD. This manifesto should be a great starting point for every discussion any professional has when supporting a person with FASD.”

Dr Patricia Jackson, a leading paediatrician who with colleagues successfully produced the first UK diagnostic guidelines for children and young people with FASD that are now in effect across Scotland, England and Wales said, “This FASD Manifesto is the first of its kind in the UK, and we hope to see it shared as widely as possible, particularly amongst those who work with people with FASD and other additional needs. People with FASD and indeed other conditions tell us they are often spoken down to or do not have their communication needs addressed properly. This can cause an array of issues. By asking people with FASD directly how they would like to be treated, we can establish the best possible basis for effective and supportive communication.”

The [FASD in the UK conference](#), being held today at the University of Salford, is co-sponsored by National FASD, the University of Salford, FASD Greater Manchester, and NHS Greater Manchester. FASD experts and those with lived experience are gathering from all over the country to celebrate 20 years of progress in FASD in the UK and to look ahead.

Butcher said, “Research from the University of Salford, host of today’s conference, has shown that there are more people with FASD than autism in the UK. If we don’t support people with FASD too, already overburdened services will continue to use funds on ineffective interventions with devastating impact on those with FASD and their families. People with FASD today are rightly standing up and saying they deserve recognition and informed support too.”

The last two years alone saw the release of ground-breaking FASD healthcare policy, in the form of the DHSC FASD Health Needs Assessment, the NICE Quality Standard on FASD, as well as National FASD’s report, [The Time is Now](#), which offers actionable routes to progress.

The conference features talks throughout the day from both a research, and lived experience perspective, to help reflect on the progress that has been made, but most importantly to help chart a way forward to increase education and support around FASD in the UK.

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# UK FASD MANIFESTO

**HOW WE WANT YOU TO TREAT US BY PEOPLE WITH FASD**

**LISTEN TO US**

**Slow & calm**  
SPEAK SLOWLY AND CALMLY

**BE KIND**

**KEEP THINGS SIMPLE**

**BE PATIENT**

**GIVE US TIME TO RELAX**

**KNOW OUR BRAINS ARE DIFFERENT AND SOMETIMES WE DON'T GET IT**

**UNDERSTAND WHY THINGS ARE HARDER FOR US**

**TREAT US WITH THE SAME RESPECT AS OTHERS**

**HELP US TO SHINE BRIGHTER**

**KEEP THINGS UPBEAT**

**REMEMBER OUR DIFFICULTIES ARE LIFELONG**

**DO!**  
DON'T TRY - DO

**LEARN MORE ABOUT FASD**

## **NEVER** GIVE UP ON US

**#HearOurVoices**  
@nationalfasd