

Thinking Differently:

Autistic and ADHD Women and Girls

Women and girls presenting with autistic spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) are going undiagnosed. The NFWI calls on the government and funding bodies to fund research into the female presentation of ASD and ADHD, and for action to be taken to improve the diagnosis process for women and girls, to ensure that they are equipped to better manage these conditions and do not suffer in silence. The NFWI further calls on WI members to raise awareness within their WIs of the issues facing women and girls with ASD and ADHD.

Honor Oak WI, West Kent Federation

What we want to achieve from the campaign

This campaign is an opportunity to understand one another better and to celebrate our differences. The campaign gives us a chance to ensure all women are welcomed into the WI and to think about what we can do as individuals and within our WIs to ensure new and existing members with autism and ADHD feel understood, accepted and welcome. This toolkit will help encourage one another to learn more and become better support networks for our loved ones.

We know that for too long, women and girls have been excluded from the conversation and their experiences of autism and ADHD overlooked and missed. Girls in the UK are still being diagnosed autistic on average 2-3 years later than boys and ADHD is almost three times more likely to be diagnosed in boys than girls. This has to change, and as part of the campaign the WI will be pushing for better access to diagnosis and support for all who need it.

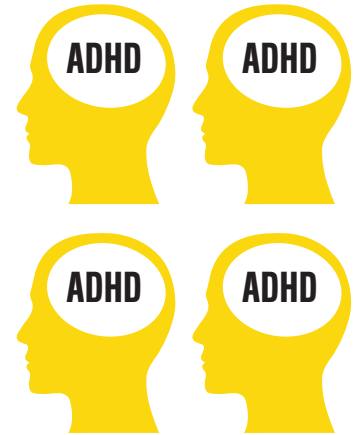
This toolkit aims to shed light on what autism and ADHD in women and girls can look and feel like, as well as to help bring awareness to the ways in which we can support them. It sets out how you can learn more in your WI, take action to raise awareness and call for change from decision makers.

A special thank you to all those who have helped contribute towards building this toolkit and for sharing your views and experiences with us.

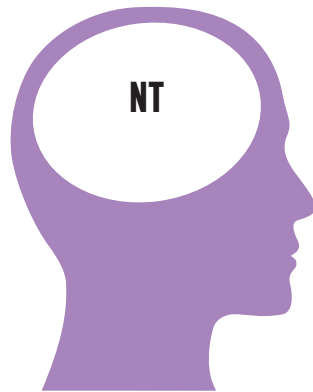
Note on language: The use of 'Autistic Spectrum Disorder' in the resolution has been highlighted as problematic, and the term 'Autistic Spectrum Condition' is now more widely accepted.



Each of these people are
NEURODIVERGENT



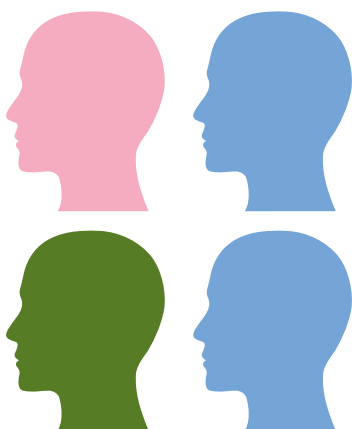
These people are **NEURODIVERGENT**
but the group itself is
NOT NEURODIVERSE



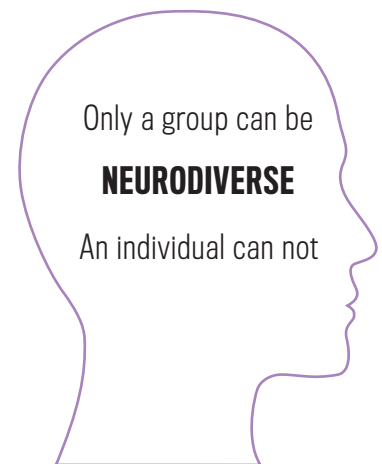
This person is
NEUROTYPICAL



This person is
MULTIPLY NEURODIVERGENT



This is a
NEURODIVERSE group



Only a group can be
NEURODIVERSE
An individual can not

What is Autism?

Autism or Autism Spectrum Condition (ASC) is a lifelong developmental condition which affects how people socialise, behave and communicate with others.

Autism is often missed, in part because there are no 'typical' female autism traits. Often autistic women and girls may present differently to autistic men and boys, or mask their autism, meaning that it can be missed.

Autistic people can share common traits with respect to social communication and social interaction, behavioural patterns, and repetitive and restrictive behaviours. Autistic people may also have sensory differences and special interests. Autism is a spectrum condition and affects people in different ways. These pages outline some of the traits that autistic people may share



Behavioural Patterns

The world is filled with unwritten rules, which can make things unpredictable and confusing to autistic people. As a result, autistic people tend to have traits that include having routines and engaging in repetitive or restrictive behaviour.

Repetitive behaviour could include wearing the same clothes, eating the same thing or travelling the same way each day. They may also stim (repeat noises or movements such as rocking and hand flapping) or repeat the use of an object such as opening and closing a door. These behaviours may be enjoyable to autistic people or they could help calm them in stressful situations.

People with autism can find changes to their routine very distressing and cause them to be anxious. This could include big events such as Christmas or changing schools, facing uncertainty at work, or more subtle things like a bus detour or a wastepaper basket being in a different place. It is important to note that neurodivergent people are different to one another, just as neurotypical people are. Being supportive can often mean trying to understand and being adaptable to an autistic person.



Special Interests

Autistic people tend to have intense, highly focused special interests that may change over time or be lifelong. Autistic people can become experts in their special interests and often like to share their knowledge. Autistic people may be able to focus on an interest for a long period of time and often with great attention to detail, which can be useful for tasks such as detailed crafts, checking accounts and proofreading.



Social Communication and Interaction

Social Communication: Autistic people may struggle interpreting verbal and nonverbal language (e.g. tone of voice or body language). Whilst some autistic people are unable to speak or have limited speech, others may have very good language skills but may not understand sarcasm or gestures.

They may also:

- Need additional time to process information or answer questions
- Take things literally and not understand abstract concepts
- Repeat what others say to them (known as echolalia)

Social communication differences in autistic women and girls may look like:

- Difficulties with speech and language may be more subtle, with no language delay
- Speaking in a scripted manner to try and fit in
- Struggling with social niceties and mimic rather than naturally respond
- Appearing awkward during conversations

Social Interaction: Autistic people may struggle to 'read' or understand other people. This could include recognising others' feelings and intentions and expressing their own emotions. This can make navigating the social world difficult.

Social interaction differences in autistic women and girls can look like:

- Appearing shy or avoiding interaction with others.
- Struggling to make the first move socially, but also keen to have friends.
- May have 1 or 2 close friends but try to hide their traits in an attempt to fit in.
- May make eye contact but it is fleeting and superficial.
- Can show empathy and compassion but may be confused by non-verbal social signs.
- May give an inappropriate response which appears blunt or indifferent.



Sensory Differences

Autistic people may have sensory differences that could include over or under-sensitivity to sensory stimuli such as sounds, tastes, smells, texture, touch, light, colours, temperature or pain. For example, they may find the noise of traffic outside an office window, which other people ignore or block out, unbearably loud or distracting. This could also include examples like a ticking clock being too loud, being touched or feeling too near to somebody else. Sensory differences can cause them sensory overload, anxiety or even physical pain, and they may avoid everyday situations because of these sensitivities. Sensory overload could cause autistic people to have a meltdown or the urgent need to leave a room.

What is ADHD?

Attention deficit hyperactivity disorder (ADHD) is a condition that affects people's behaviour. It is known as a neurodevelopmental condition which means parts of the brain that control emotions, learning, self-control and memory can be affected. The core symptoms of ADHD are hyperactivity, impulsivity and inattention.

There are 3 subtypes of ADHD depending on which symptoms a person displays:

- Inattentive- difficulty regulating attention
- Hyperactive and impulsive- can appear restless or driven
- The combined type which is both inattentive and hyperactive

Many people with ADHD have difficulties that fall into the combined type, but this is not always the case. People with ADHD can concentrate but have difficulty regulating this. They have an 'interest based nervous system', meaning that when their interest is engaged they can concentrate well, even to the point of 'hyper focus' and getting lost in the subject. When not interested it can be impossible, regardless of ability, to sustain attention. This can be very frustrating.

Those with ADHD have impaired executive function, which can mean difficulty starting tasks, organisation and time management, managing instructions, sustaining focus and completing tasks, coping with stress, feeling restless or impatient, and impulsiveness and risk taking. They may also have difficulties with relationships, social interaction or sensory sensitivity.

ADHD in Women and Girls

ADHD is almost three times more likely to be diagnosed in boys than girls as typically girls internalise symptoms, meaning their challenges are less easy to see than their male counterparts. Girls are more likely to have inattentive ADHD, and are less likely to show the disruptive behaviour that makes ADHD symptoms more obvious. As a result, women and girls with ADHD may not always be diagnosed.

A girl with inattentive ADHD may be known as a 'day-dreamer', often in her own world, distracted by her own thoughts. Typically girls will achieve in line with or exceed expectations so it will appear that she is 'fine'. It will likely 'cost' her more to maintain this in the time and energy needed, but this is likely to be hidden. A girl with combined or hyperactive ADHD can be impulsive, chatty, driven, busy, leading others and easily distracted.

Gender bias plays a key role in the misdiagnosis and under diagnosis of ADHD in women and girls. Some of the characteristics of inattentive ADHD, such as being shy or impulsive, or being 'chatty' in the case of combined/impulsive ADHD are often viewed as personality traits rather than symptoms when they appear in women and girls.

Women and Girls with ADHD may:

- Have a short attention span and be easily distracted by their own thoughts or environment when not interested
- Appear careless and lack attention to detail when not interested
- Appear forgetful or continually lose or misplace things
- Appear to be unable to listen to or carry out instructions
- Be unable to stick to tasks that are tedious or time-consuming
- Be unable to sit still for any length of time, especially in calm or quiet surroundings
- Act or speak without thinking
- Continually start new tasks before finishing old ones
- Have the inability to focus or prioritise
- Blur out responses and often interrupt others
- Have mood swings, irritability and a quick temper
- Be unable to deal with stress and be extremely impatient
- Be highly sensitive; having strong emotional responses that do not appear to be in line with the situation
- Ruminates and develop anxiety about performance or their relationships
- Struggle with criticism/ rejection more considerably than peers

ADHD can present differently in women and girls. Please note, the list above is not exhaustive.

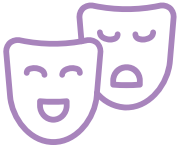


Relationships and Social Interaction

Women with ADHD may feel inadequate in relationships. They may wish they were a better friend, partner, mum etc. and that they could do things that society expects women to do such as remembering birthdays, arriving on time.

Girls with ADHD may often be described as 'driven' because they have lots of energy and like to be busy. As an adult, friendships can be difficult to navigate because social rules seem complicated, especially in group situations.

Women and girls may also be described as talkative. However, they may dislike social gatherings because it may make them feel overwhelmed and shy. Keeping attentive during a conversation may be difficult for people with ADHD unless they are the ones talking, or it's a topic they find interesting.



Masking and Mental Health

Masking, otherwise known as camouflaging, occurs when autistic people and people with ADHD hide their symptoms or 'mask' their feelings until they are in a safe environment before they release their emotions. Masking may be a way for some people to fit in socially, avoid being stigmatised, or feel more accepted.

Masking in women and girls with autism and ADHD is more common than in men and boys, with women and girls spending a lot of time and effort to fit in with peers.

Types of masking include hiding hyperactivity with calmness, sitting quietly at a desk without squirming in their seat but making small repetitive movements like fiddling with fingers, playing with hair or tapping/bouncing their leg. Women and girls often mimic peers and can appear to respond as expected even though their mind feels chaotic. Women and girls often over compensate to hide symptoms by employing perfectionist strategies such as over-focusing on a teacher, task, or activity to avoid distractions and impulsivity.

Masking is mentally exhausting and isolating, and has been shown to be linked to a heightened risk of depression, anxiety and suicidality in women with autism and ADHD. Several research studies have demonstrated the link between masking in women and mental health issues – rather than being related to the severity of autistic or ADHD traits, mental health issues appeared to be most strongly related to the degree to which a women masks.

Women with autism can find it difficult to moderate and manage their feelings when frustrated, which can lead to meltdowns that appear to be disproportionate to the situation. Anxiety can be both a cause and consequence of these meltdowns. Furthermore, autistic women and girls can often lack confidence in their abilities, can be afraid of failing and making mistakes and generally lack self-belief, which can also have an affect on their mental health.

Women with ADHD may experience psychological distress, feelings of inadequacy, low self-esteem and chronic stress. They may also feel that their lives are out of control or in chaos, and daily tasks may seem impossibly huge. Societal expectations of women to fill the caretaker role may also greatly increase a woman's feelings of inadequacy. When things feel out of control, and it's difficult to organise and plan because of ADHD, taking care of others can feel nearly impossible.

Women and girls may also experience mental health conditions in addition to their ADHD and autism, such as anxiety, eating disorders, depression, obsessive compulsive disorder (OCD), bipolar disorder, sleep disorders and substance abuse disorders. The symptoms may look similar to autism and ADHD, making diagnosis more complex.

Do's and Don'ts

Many autistic people see their autism as a fundamental part of who they are, so using positive language is very important.

DO:

- If you are referring to a particular person or group, ask them how they would prefer to be described. E.g. autistic woman or woman with autism, and woman/person with ADHD. The NFWI will be using the terms 'autism', 'autistic woman/girl' and, 'adhd woman/girl' and 'women with ADHD' in written materials.
- Talk about the autistic spectrum and the varying challenges and strengths people have (e.g. some autistic people have an accompanying learning disability and need support to do everyday things like clean, cook or exercise. Other autistic people are in full time work, with just a little extra support).
- Educate yourself using this toolkit, books and other educational resources and try to be flexible in your understanding. 'How things were always done' is not an reason not to adapt to new information on these topics.
- Use the accompanying guide to consider ways your WI can be more inclusive for autistic women and women with ADHD, and take our pledge action to show your commitment.

DON'T:

- Say 'suffers from or is a victim of autism'. This gives the impression that being autistic is negative.
- Use the terms high functioning or low functioning, or 'severe/mild'. Autism is now diagnosed using levels. You can instead say 'autism/autistic'.
- Use the terms 'severe' or 'mild'
- Ask autistic people what 'caused' their autism or ADHD
- Say 'we're all on the spectrum' or 'we're all a little bit autistic'. This can be belittling to autistic people and is inaccurate.
- Talk about 'curing' autism or ADHD
- Use terms like 'normal' or 'abnormal'
- Judge someone else's diagnosis e.g. 'you don't look autistic' or 'I don't think she is autistic'
- Suggest someone should be diagnosed or label them e.g. 'You seem autistic' or 'I think she's on the spectrum'.



What the WI's Thinking Differently campaign is calling for

National level: The NFWI will work with expert stakeholders to raise awareness of autism and ADHD in women and girls, to call for action to improve the diagnosis process and to increase the provision of support available to them. The NFWI will also seek to address and challenge stereotypes about autistic women and women with ADHD.

Regional level: WIs and federations will be supported to learn more and campaign locally to improve the diagnosis process for women and girls with autism and ADHD.

Local level: WIs will be encouraged to learn more and take steps to make sure their WI is open and accessible to all women, including autistic women and those with ADHD.

Get involved- things you can do

1 Read through the internal guidance document 'How to make your WI more inclusive for autistic and ADHD women' and pledge to take action to make your WI more inclusive.

We are calling on all WIs and federations to pledge action as part of the campaign:

- Once you have read the document and identified what you will do, please print out the enclosed pledge, and add your WI or federation name.
- We are asking WIs and federations to show their commitment by taking a group photo holding the pledge and send it back to us at pa@nfwf.org.uk. Please do also share your photo on social media to show your support.
- You will also find a poster available on My WI to download and display at your WI.



2 Hold a WI meeting using the resources at the end of this toolkit to learn more about autism and ADHD.

- The resources list provides a list of books you can read and feature at your book club and a list of videos and podcasts you could feature at your WI meeting.
- Contact your MP on behalf of your WI to tell them about the campaign and ask them to work with your WI to push for action. See below to find out how.
- You can find a template letter on My WI that you can use to write to your MP about the campaign.



3 Write to your MP to tell them about the campaign

Making contact with your MP is a great way to make sure that decisionmakers know about the WI campaign. We are encouraging members and WIs to make contact with their MP using our draft letter. You can download this from My WI and personalise it to adapt it to any concerns or personal experiences. Members in Wales can also find a template letter they can use to write to their Member of the Senedd. Once you receive a reply, please send a copy to pa@nfwf.org.uk

4 Hold an awareness day in your local community

We are encouraging federations and WIs to hold awareness days in their local communities to promote the campaign. This will encourage members and the public to think more about how they can understand the experiences of women and girls with autism and ADHD.

As part of the day you could:

- Ask a local organisation to come and speak about autism and ADHD in women and girls
- Invite representatives from health services to tell your group about the local situation regarding diagnosis and support for autistic women and those with ADHD.
- Display posters on the day and on community noticeboards

5 Watch the webinars on My WI

There are 2 webinars available on My WI for you to watch individually or as a group:

ADHD Women and Girls: Dr Samantha Hiew & Dr Diane Wass

Autistic Women and Girls: Cathy Wassell, Professor Gina Rippon and Sara Gibbs

6 Share your experiences

Share your experiences of autism and/or ADHD, including late diagnosis with the NFWI Public Affairs team. If any member would like to be contacted by us so they can share their experience, please email us and we can provide further details about what is involved. No information about your experiences will be shared further or stored without your consent and you can also remain anonymous if you wish to.



7 Celebrate Awareness Days

ADHD Awareness month takes place in October every year and World Autism Awareness Week takes place from March 29th – April 4th 2023.

Why not host a day of action around these dates to raise awareness of the campaign.

8 Take part in our data gathering action by writing to your local NHS Integrated Care Board (ICB) or Local Health Board (LHB).

As part of the campaign we want to find out about the situation across England, Wales and the Islands.

Integrated Care Boards (ICBs) are responsible for planning and funding most NHS services. In Wales, these are Local Health Boards (LHBs). Use our template letter, available on My WI, to write to your local NHS ICB or LHB in Wales to find out about what support services they arrange in your area for autistic women and those with ADHD, and to ask about how long waiting time are for assessment where you live.

9 Get involved in our craft actions in spring 2023

Members will have the chance to take part in an array of craft projects related to this campaign which will be launched in spring 2023. In the 2023 NFWI March Mailing WIs will receive a craft project booklet, which outlines a series of craft-related campaign activities. The booklet will also be made available on My WI.

Busting the myths and getting the facts: Autism

1 *Myth: Autism is a childhood condition*

Fact: Autism is lifelong. In the UK there are more autistic adults than children. Whilst autistic adults have often been overlooked in research, studies suggest that if people get the right support, for example with language and communication and anxiety, outcomes for people can change over time.

2 *Myth: Autistic people have learning difficulties*

Fact: Approximately 1 in 4 autistic people speak few or no words. Some autistic people take longer to process information, but it doesn't mean they don't understand. With the right support and a suitable environment, many autistic people are very able and independent.

3 *Myth: Autistic people are anti-social*

Fact: Autistic people may need support with social skills or interact differently with the world around them, but most autistic people enjoy having relationships. People show their social difficulties in different ways. Some may be quiet or shy or avoid social situations, others speak too much and struggle to have two-way conversations.

4 *Myth: Autism can be cured*

Fact: Autism is a complex condition that affects everyone differently. Many autistic people feel that autism is a big part of their life and who they are, and not something they would take away.

5 *Myth: Autism is caused by vaccines*

Fact: One of the biggest myths of all is that vaccines, specifically the MMR vaccine, cause autism. The safety of vaccinations has been repeatedly tested across large groups of people. High quality research studies involving hundreds of thousands of people have consistently shown that vaccinations do not cause autism.

6 *Myth: Autistic people have a special talent*

Fact: Many autistic people get asked about this and it can be frustrating. We all have strengths and weaknesses and autistic people are no different. Being autistic doesn't necessarily mean you have an exceptionally high IQ. Research has shown that 28% of autistic people have special talents but the reasons for this are unknown.

7 *Myth: Autism is caused by bad parenting*

Fact: Research has showed that autism is not caused by bad parenting. Whilst parenting style can help an autistic child to cope with the world, it is not the root cause of autistic behaviour.

8 *Myth: People on the autistic spectrum don't feel or express emotions*

Fact: Whilst many people with autism struggle to recognise and communicate emotions, this does not mean that they don't experience emotions.

Busting the myths and getting the facts: ADHD

1 *Myth: People with ADHD are just lazy and lacking willpower*

Fact: People with ADHD can focus on things that they are very interested in or things that are new and exciting. Sometimes they describe 'hyperfocus' where they can lose themselves in a task they are absorbed in. ADHD causes an inability to focus and get down to work on tasks that are mundane, repetitive, boring or require a greater degree of mental effort.

2 *Myth: ADHD is something you grow out of as you reach adulthood*

Fact: ADHD is a 'lifespan' condition meaning it can continue throughout life and symptoms may reduce or increase across the years. ADHD symptoms may get worse as a person reaches adulthood and it can be the first time that the symptoms have been noticed as a problem.

3 *Myth: ADHD isn't a serious condition that can really damage your life*

Fact: Untreated or inadequately treated ADHD can severely affect learning, working life, domestic life, relationships and social life. Many people with ADHD function extremely well, but there are many people with ADHD who struggle to cope with life. People with unsupported/ untreated ADHD are more vulnerable to eating disorders, addiction, unplanned pregnancy, self-harm and suicide.

4 *Myth: ADHD is the result of poor parenting*

Fact: ADHD is not caused by poor parenting, it is a neurological condition. ADHD is believed to be genetic, but it can be influenced by environmental factors such as home life, school, and trauma in early childhood.

Glossary

ADHD: Attention deficit hyperactivity disorder is a condition that affects people's behaviour.

ADD: Attention deficit disorder is a term used for people who have excessive difficulties with concentration without the presence of other ADHD symptoms such as excessive impulsiveness or hyperactivity.

Asperger's Syndrome: Asperger's Syndrome is a form of autism, which is a lifelong condition that affects how a person makes sense of the world, processes information and relates to other people. Please note, this term is no longer used in diagnosis.

Autism/ Autism Spectrum Condition (ASC): Autism is a lifelong condition that affects how a person makes sense of the world, processes information and relates to other people.

Echolalia: Echolalia is the repetition of phrases and words. People with echolalia repeat what they hear, whether this is the spoken language of people around them or things they hear on the TV.

Masking/Camouflaging: Masking refers to the conscious or unconscious suppression or hiding of elements of a person's ADHD or autistic identity. This is often referred to as a social survival strategy - used to conform to expected 'norms', cope with situations or environments, or avoid expressing anxiety.

Neurodivergent: Neurodivergent means that the brain functions, learns and processes information differently.

Neurodiverse/ Neurodiversity: Neurodiversity refers to the different ways the brain can work and interpret information and is the concept that brain differences are natural variations - not deficits, disorders or impairments.

Neurotypical: Most people are neurotypical, meaning that the brain functions and processes information in the way society expects.



Resources

Books

Below you will find a list of fiction and nonfiction book suggestions that you may wish to use in your WI's book group. These are a mix of books aimed at adults and those aimed at young people. You will also be able to find further suggestions on the Autistic Girls Network website and the ADHD Girls website.

- Geek Girl by Holly Smale
- Drama Queen by Sara Gibbs
- A Kind of Spark by Elle McNicoll
- Safeguarding Autistic Girls: Strategies for Professionals by Carly Jones
- The Secret Life of Rose: Inside an Autistic Head by Rose Smitten
- Supporting Spectacular Girls by Helen Clarke
- A Radical Guide for Women with ADHD by Michelle Frank and Sari Solden
- Understanding Girls with ADHD by Kathleen G. Nadeau, Ellen Littman & Patricia O.Quinn

Videos and podcasts

Below you will find a list of short and long video and podcast suggestions that you may wish to use in your WI meeting- you can find them by putting the full title in your internet search engine. You will also be able to find further suggestions on the Autistic Girls Network website and the ADHD Girls website.

- Jac den Houting – TEDxMacquarieUniversity – Why everything you know about autism is wrong
- BBC Newsround – My Autism and Me
- Podcast: Radical Self Acceptance for Women with ADHD with Sari Solden
- Podcast: Understanding ADHD in Girls and the Importance of Encouraging Strengths with Dr Joanne Steer

You can also find a range of other recommended books, videos, podcasts and links at www.autisticgirlsnetwork.org/resources/ and www.adhdgirls.co.uk/books-podcasts-and-workshops-for-understanding-adhd/

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November 2022



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WI

has pledged action to include and support
autistic women and women with ADHD



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INSPIRING WOMEN

visit www.thewi.org.uk/thinking_differently