

# What does being neurodiversity affirming really mean?

A resource to support the webinar hosted by Nicola Reekie (The PDA Space) & delivered by Jess Garner (GROVE Neurodivergent Mentoring & Education)

March 2024
The PDA Space Portal
(www.thepdaspace.com)





## What is 'neurodiversity affirming'?

There is much discussion about **neurodiversity affirming** language and being '**neuro-affirmative**' (used interchangeably). It can be difficult to know what to say, the 'right' words to use and to spot the potential red flags when trying to get support for your neurodivergent child. This booklet is based on the webinar delivered by <u>GROVE Neurodivergent Mentoring & Education</u>. It aims to clarify some of the main points around what it means to be neurodiversity-affirming.

Listed below are some key words and concepts to look up if you want to dive into this a bit further, some of which will be covered in this short guide. <u>GROVE</u> also has a detailed list of all the references from this webinar on their website.

Medical model & Pathology Paradigm
Behaviourism
Neurodiversity Paradigm
Neurodiversity Movement
Neurodiversity Lite
Models of Disabilty
Disorder vs. Disability
Neuro-affirming?
Neuro-affirming education?
Neuro-affirming parenting?
Neuro-affirming services?
Good enough?







## What is neurodiversity?

**Neurodiversity:** "Neurodiversity itself is just biological fact!" (Walker, 2021).

**Neurodivergent**: "An individual is 'neurodivergent' if they diverge from the dominant societal standards of 'normal" (Asasumasu, 2000s; Walker, 2021).

Neurodiverse: The world is 'neurodiverse'; an individual cannot be.

**Neurotypical**: often used to describe people who are not neurodivergent. However, the idea that a 'typical' brain even exists is debated. Beardon (2012) uses the term "predominant neurotype" which some people prefer.

**Identity first language**: Many people in the neurodivergent community prefer identity-first language. For example, they say 'Autistic person' instead of 'person *with* autism'. It is always best to ask people how they prefer to be identified and respect their own choice. (Kenny et al., 2016) & (Fletcher-Watson, 2016).







## What does neurodiversity affirming mean?





Neurodiversity

&

Neurodivergent

"to state something as true" &

"to publicly show your support for an opinion or idea"

https://dictionary.cambridge.org/dictionary/english/affirm

Being neuro-affirming means rejecting a behaviourist approaches including 'Positive Behaviour Support Programmes'

## Why are behaviourist approaches harmful for neurodivergent people?

- Implies behaviour is wilful and chosen so there for it can be changed and coerced;
- Does not take into enough consideration the nervous and sensory system which is really important to bear in mind when supporting neurodivergent people;
- Leads to compliance based approaches / rewards and punishments which can cause feelings of shame and fear for young people;
- Focuses on changing the young person instead of changing the environment. This could make young people think there is something 'wrong' with them that needs fixing and lead to mental health problems and poor self image;
- Can lead to high levels of masking which could have a serious and negative impact on a person's mental health (inspired by Jess Garner's webinar for The PDA Space, March 2024).





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## What is the Neurodiversity Paradigm?

Neurodiversity is natural and valuable.

There is no right/normal type of brain, mind or body.

"The Neurodiversity Paradigm is a perspective that understands, accepts and embraces the differences of everyone. Within this theory it is believed there is no sing 'right' or 'normal' neurotype, just as there is no single right or normal gender or race. It rejects the medical model of seeing differences as deficits."

(Edgar, (2023). The Neurodiversity Affirming Glossary of Key Vocabulary - PDA Summit 2023)

Nick Walker, (2014) expands this definition in more detail by saying:

"The social dynamics that manifest in regard to neurodiversity are similar to the social dynamics that manifest in regard to other forms of human diversity (e.g., diversity of ethnicity. gender, or culture). These dynamics include the dynamics of social power inequalities, and also the dynamics by which diversity, when embraced, acts as a source of creative potential."

The Neurodiversity Paradigm does not deny disability. There are many ways to conceptualise disability, such as the social model, social-relational model, bio-social model, human rights model, predicament model and so on. As Jess highlighted in her webinar for The PDA Space by drawing on the work of Wise (2023), we need to "stop assuming that it's the differences that are the root of any challenges or difficulties... and that individuals who require support [are] abnormal or wrong" (Wise, 2023).

Importantly, the Neurodiversity Paradigm does not deny support (even medical). The Neurodiversity Paradigm highlights the very specific support needs some people may have and also celebrates their strengths.

Based on the work of Nick Walker (2014): "**The Neurodiversity Movement** is a social justice movement driving forward the ethos of the neurodiversity paradigm, working for equality and inclusion for everyone".

(Edgar, (2023). The Neurodiversity Affirming Glossary of Key Vocabulary - PDA Summit 2023)

Check out the new paper: Botha, M., Chapman, R., Giwa Onaiwu, M., Kapp, S. K., Stannard Ashley, A., & Walker, N. (2024). The neurodiversity concept was developed collectively: An overdue correction on the origins of neurodiversity theory. For more information about the how the neurodiversity concept was developed collectively within the neurodivergent community. It is not attributed to any single author.







## **NEURODIVERSITY-LITE**

#### **DEFINING NEURODIVERSITY-LITE:**

Neurodivserity-lite means that people and organisations may appear to be neurodiversity affirming on the surface. If you look at a website for example, it may appear they are using all the right 'buzzwords' (Roberts, 2021). However,once you dig a bit deeper this is often just performative (den Houting, 2019) and shows "no understanding of crucial neurodiversity concepts and thus must be resisted and challenged" (Chapman, 2021).

### Red flags to look out for.....

There are a few red flags to look out for that are likely to signify that a person or organisation is not genuinely embracing the neurodiversity paradigm.

Some of these red flags include:

- Using language such as "ASD (autism spectrum disorder)' or referring to someone as 'neurodiverse" and using person-first rather than identity first language
- Referring to research on deficit based theories of autism e.g.
   Theory of Mind (Baron-Cohen et al, 1985)
- Promoting neurotypical social communication e.g. 'social skills training' (taken from Jess Garner's webinar for The PDA Space, March 2024)

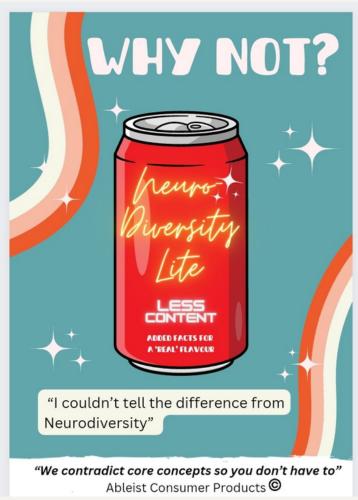


Image from Lisa Chapman Speech and Language Therapist

@CommonSenseSLT







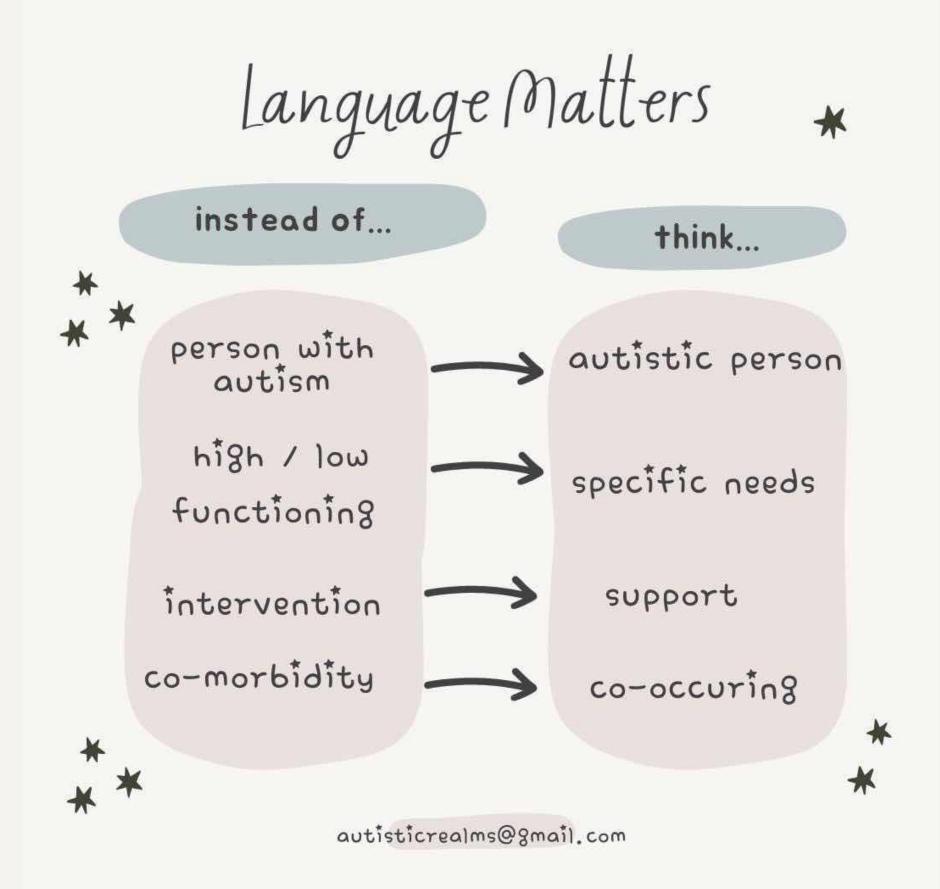
## Neurodiversity Affirming Language

Being neurodiversity-affirming is more than changing your language. It is about shifting your mindset away from deficit-based approaches that try to change or 'fix' a person instead of looking at how we can change the environment to meet needs, as advocated for by Beardon (2017).

### "autism + environment = outcomes"

Dr. Luke Beardon, (2017)

It can be really hard to break old habits but we feel thinking about this is really important to foster a positive sense of neurodivergent identity for our young people. Making shifts in the way we talk and write about our own children and those we support can help this journey as highlighted below.







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## The Roots of Being Neuro-Affirming

INTERSECTIONALITY

PROMOTE SELF-ADVOCACY

ADAPT ENVIRONMENTS/SYSTEMS RESPECT & VALUE AUTISTIC CULTURE

SUPPORT NEEDS/CHALLENGES BUT NOT AUTISTIC WAYS OF BEING

RESPECT AUTONOMY

STRENGTH-BASED

NURTURE POSITIVE IDENTITY

VALUE & VALIDATE DIVERSITY & DIFFERENCE

LQBTQIA+ AFFIRMATIVE

PRESUME COMPETENCE

REJECT PATHOLOGY Paradigm & Neuro-Normativity

ANTI-RACIST

HONOUR ALL FORMS
OF COMMUNICATION

UNDERPINNED BY THE NEURODIVERSITY PARADIGM & MOVEMENT

Barlman et al. 7024 bilas://www.lass.org.uk/asschologist/wisd-dess-il-maan-be-neurodiversite-effirmative

GRAPHIC TAKEN FROM JESS GARNER'S WEBINAR FOR THE PDA SPACE, MARCH 2024

### **Check Out These Resources...**

Adkin, T., and Gray-Hammond, D., (2023) Creating Autistic Suffering: Autistic safety and neurodivergence competency, www.emergentdivergence.com

Roberts, J (2022) Therapist Neurodiversity Collective: www.therapistndc.org/wp-content/uploads/2022/10/10-Neurodiversity-Affirming-Principles-for-Therapists

www.learnplaythrive.com/podcasts

Hartman et al., 2024 www.bps.org.uk/psychologist/what-does-it-meanbe-neurodiversity-affirmative

Thriving Autistic (2023): www.neurodivergentpractitioners.org/about-verified-practitioners/

Wise, S: www.livedexperienceeducator.com/neurodiversityaffirmingpractice

Anna Freud: www.annafreud.org/resources/under-fives-wellbeing /a-guide-to-neurodiversity-in-the-early-years



Do your research and chat to other families and professionals in the neurodivergent community. A good practitioner will be happy to answer any questions you may have.





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## What might being neurodiversity affirming look like?



Being neurodiversity affirming will look different for everyone depending on a person's interests, sensory, social, communication and physical needs.

(inspired by Jess Garner's webinar for The PDA Space, March 2024)





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## **Neuro-Affirming Family**

#### **POSITIVE SELF IDENTITY = PRIDE**

- Pride combats shame, may develop collective self-esteem, solidarity and agency;
- Pride and celebration has been effective in promoting acceptance and positivity about a stigmatised identity;
- Community together able to overcome previously obscured aspects of understanding (Barnes, 2015);
- A better understanding of positive Autistic identity has been suggested as a potential protective factor against poor mental health (Cooper et al., 2022; Heselton et al., 2022).

(taken from Jess Garner's webinar for The PDA Space, March 2024)







with The PDA Space March 2024



## Further Reading & References

### WANT TO LEARN MORE ABOUT BEHAVIOURISM?

- Greg Santucci
- Mona Delahook:
- Spectrum Gaming (see their anti-behaviourism policy)
- Alfie Kohn

- Dr Ross Greene
- Sarah Ockwell-Smith
- Dr Naomi Fisher
- https://amase.org.uk/pbs/
- https://stimpunks.org/2024/01/02/high-school-anti-behaviourism-behaviour-management-policy/
- https://endseclusion.org/articles/the-problem-with-behaviorism/
- https://therapistndc.org/positive-behavior-support-pbs-positive-behavioral-interventions-and-supports-pbis-or-positive-reinforcement/
- https://www.ted.com/talks/amy\_laurent\_compliance\_is\_not\_the\_goal\_letting\_go\_of\_c ontrol\_and\_rethinking\_support\_for\_autistic\_individuals?
   fbclid=IwAROwGMtzWA4KEhsS\_bCYMeYVioZvEdrNiOTl\_3Bya4majobOuBckao-869Q

#### WANT TO LEARN MORE ABOUT NEURODIVERSITY?

- Houting, J: https://www.youtube.com/watch?v=A1AUdaH-EPM&t=3s
- https://aucademy.co.uk/2021/11/25/resources-supporting-preference-but-importantly-wellbeing-properties-of-identity-first-language-we-are-autistic/?
  - fbclid=IwAR0reLly\_OVwgGUnfTzVty39S10n6fjPUyipIvoRp7LVPJ7NZjjIa9O4m98
- https://neuroqueer.com/
- https://thinkingautismguide.com/neurodiversity-faq
- https://therapistndc.org/wp-content/uploads/2021/04/We-dont-treat-Autism.pdf
- https://journals.sagepub.com/doi/full/10.1177/1362361318820762
- https://aucademy.co.uk/2021/11/25/resources-supporting-preference-but-importantly-wellbeing-properties-of-identity-first-language-we-are-autistic/?
   fbclid=IwAROreLly\_OVwgGUnfTzVty39S10n6fjPUyipIvoRp7LVPJ7NZjjIa9O4m98
- https://link.springer.com/book/10.1007/978-981-13-8437-0#about

#### WANT TO LEARN MORE ABOUT NEURODIVERSITY LITE?

- https://therapistndc.org/performative-neurodiversity-the-appropriation-and-watering-down-of-a-human-rights-movement-for-profit/
- https://therapistndc.org/wp-content/uploads/2022/03/1ND-AFFirming.pdf
- https://rewirenewsgroup.com/2018/02/09/siri-love-problem-neurodiversity-lite/
- https://journals.sagepub.com/doi/full/10.1177/1362361318820762
- https://criticalneurodiversity.com/2021/09/05/why-are-cambridge-menso-great-simon-baron-cohen-neurodiversity-lite-and-the-history-ofeugenic-thought/
- https://therapistndc.org/wpcontent/uploads/2023/10/Look-out-for-these-Buzz-Phrases.pdf
- https://therapistndc.org/wpcontent/uploads/2020/09/Terms-therapistsshould-know.pdf
- https://therapistndc.org/wpcontent/uploads/2022/03/1ND-AFFirming.pdf

#### WANT TO LEARN MORE ABOUT SOCIAL VS DISABLITY MODEL?

- https://stimpunks.org/glossary/biopsychosocial-model/
- den Houting, J. (2019). Neurodiversity: An insider's perspective. Autism, 23(2), 271-273. https://doi.org/10.1177/1362361318820762
- https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Barnes-implementing-the-social-model-chapter-3.pdf?fbclid=IwAR2ytlLYnjnXuqKVDy2fwJSqzZIYA0pwhaALgoKMFVBRGX3nNkaFXNUPp3I
- https://dsq-sds.org/index.php/dsq/article/view/4448/4212?fbclid=IwAR0kZ-E2efnU-B1bDMPC51DGHK\_quKK4zjHzc9L5GpQV2vZ0as7CivraBmE
- https://autistictic.com/2020/02/14/the-holistic-model-of-disability/?fbclid=IwAR1E\_jzrbr7KggWm\_aGwZNK009i9-5DV1qhw1bG3hypPfl4p\_ohjJCAdvCQ
- Murphy, K. (2023b) A guide to neurodiversity in the early years, Anna Freud Centre, https://dluwldikibnh8j.cloudfront.net/media/18298/anna-freud-neurodiversity-booklet-early-years-110423.pdf - see section on Models of Disability

#### WANT TO LEARN MORE ABOUT NEURODIVERSITY AFFIRMING WORK?

https://www.bps.org.uk/psychologist/what-does-it-mean-be-neurodiversity-affirmative?

fbclid=IwAROHeUkLvalAl1YgqQxFABj8DlNmjfJUm3V3EUoklrMlYwnjad3eGKsj6F4

Roberts, J (2020) Therapist Neurodiversity Collective: https://therapistndc.org/wp-content/uploads/2020/08/8-Signs.pdf

Roberts, J (2022) Therapist Neurodiversity Collective: https://therapistndc.org/wp-content/uploads/2022/10/10-Neurodiversity-Affirming-Principles-for-Therapists.pdf

https://learnplaythrive.com/podcasts/81-strengths-based-ot-and-self-determination-in-action-with-kelsie-olds-the-occuplaytional-therapist/ https://learnplaythrive.com/podcasts/73-a-therapists-guide-to-supporting-authentic-autistic-social-communication-with-rachel-dorsey-and-v-tisi/ (see list of other episodes - so many amazing ones!

https://www.davidsdivergentdiscussions.co.uk/p/creating-autistic-suffering-autistic-safety-and-neurodivergence-competency

https://autisticadvocacy.org/policy/briefs/intervention-ethics/?fbclid=IwAR20VKl6GE5-FhfZwjp2sUsmK8D5HqWIvk\_uuBiCqcHflHYgQkBNtmWRdnY https://www.annafreud.org/resources/under-fives-wellbeing/a-guide-to-neurodiversity-in-the-early-years/?

fbclid=IwAR3NksmXzyUvh6vNcbAKkaVsUJVTpjPm7tko93IM1U5IKtxG\_2fZqn2K8l8

https://www.verywellmind.com/what-does-it-mean-for-a-therapist-to-be-neurodiversity-affirming-6829954

 $https://reframing autism.org. au/neuro diversity- affirming-language-a-letter-to-your-childs-support-network/\ (also \ relevant \ for \ services)$ 







## Signposting

1

### www.thepdaspace.com

Family support workshops, webinars, coaching and online peer support groups. (Founder: Nicola Reekie)

2

### www.gr0ve.org

Support for neurodivergent young people - individual mentoring, social and interest-based groups, bespoke 'Autistic Identity' programmes.

(Founder: Jess Garner)

3

## www.autismunderstood.co.uk Website designed by autistic young people, for autistic people

4

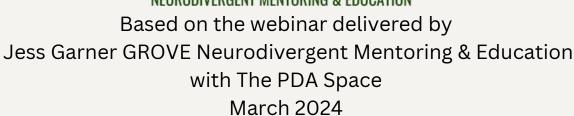
# www.autisticrealms.com Autism/ education/ mental health articles and resources (Founder Helen Edgar)

(Founder: Spectrum Gaming)

Please seek professional advice if needed.











A free community resource to support the webinar hosted by Nicola Reekie & delivered by Jess Garner (GROVE Neurodivergent Mentoring & Education) for The PDA Space

Created By
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Autistic Realms

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