



**UNIVERSITY
OF WARWICK**

Carer support: parents and parent carers

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<https://mindfulmedicine.co.uk/>



A pause

'The invitation is always to set the intention to be present, prioritise self-care, and bring attitudes of:

- ▶ *kindness*
- ▶ *curiosity*
- ▶ *and non-judgment*

to your experience

with core instincts or 'gut feeling' as your guide.'

Karen E. Neil



WALVERTON OAK
TWENTY THOUSAND YEARS AGO
ALLEYTON DID NOT POSSESS
A COURT HOUSE AND IT IS
SO OLD THAT THE ST. JAMES
WELLS WERE BUILT BY
REMOVING BRANCHES
AND LEAVES FROM
THE TREE



INSTITUTE OF
HEALTH PROMOTION
AND EDUCATION

Health Promotion Principles

- ▶ Fundamental conditions, rather than just medical care, to improve and sustain population health:
 - ▶ peace,
 - ▶ shelter,
 - ▶ **education,**
 - ▶ food,
 - ▶ income,
 - ▶ a stable ecosystem,
 - ▶ sustainable resources,
 - ▶ social justice,
 - ▶ and **equity.**



[Ottawa Charter for Health Promotion](#)

Statutory framework is already in place:

- ▶ Children Act 2004
- ▶ The Care Act 2014
- ▶ The Children and Families Act 2014
- ▶ The Health and Care Act 2022
- ▶ Carers Leave Act 2024

A whole-family, multi-agency approach across health, education and social care is **already required**.

The Equality Act 2010 includes support, accommodations, and protection from discrimination for people with disabilities.

Laws to Support Families

Parent

From the Latin *parentem* 'father or mother, ancestor,' noun use of *parire* 'bring forth, give birth to, produce.'



Mammalian Care-Giving



Parent or Parent Carer?

Carer

A carer is anyone who cares, unpaid, for a friend or family member due to illness, disability, a mental health problem or an addiction. *Carers Trust*

Disability

A physical or mental impairment with substantial and long-term adverse effect on ability to carry out normal day-to-day activities. *Equality Act 2010*

Parent Carer

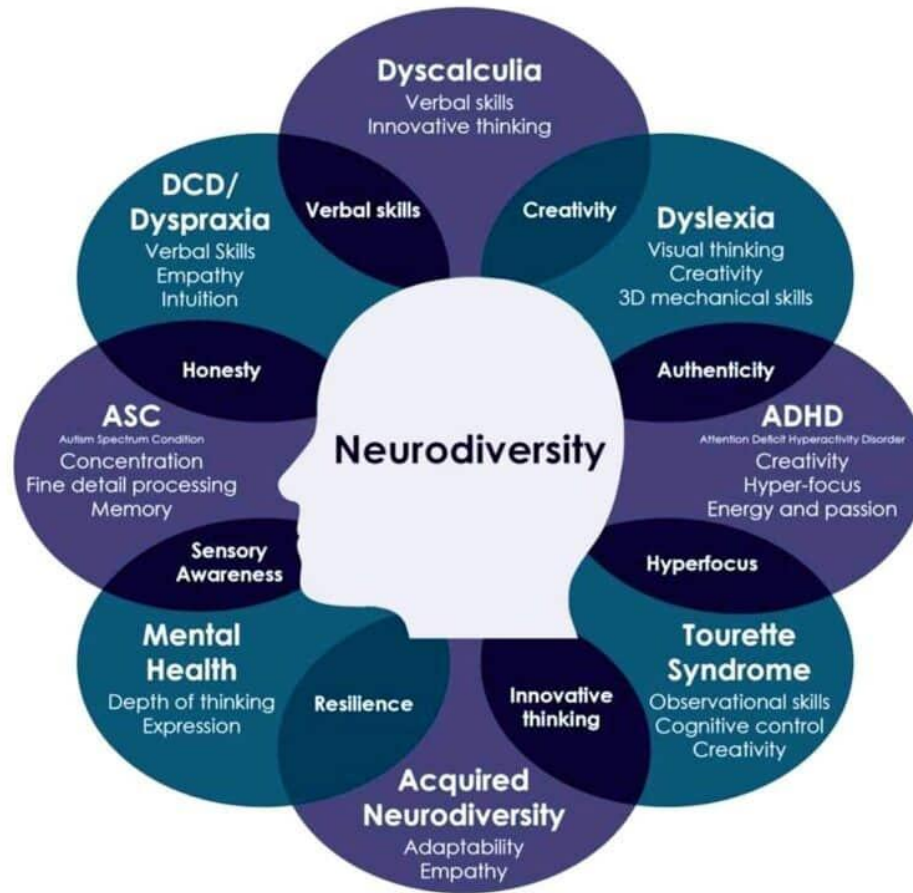
A parent becomes a carer when a child has additional needs mentioned in the definitions above.

The Human Spectrum



- ▶ Human beings are neurodiverse.
- ▶ Additional needs not always visible or meet thresholds for diagnoses.
- ▶ Traits can vary considerably from one person to another, one situation to another, and different stages of development.

Hopkins GT (2025), "The human spectrum: a position paper". *Journal of Applied Research in Higher Education*, Vol. 17 No. 1 pp. 6-22, doi: <https://doi.org/10.1108/JARHE-05-2023-0176>



Individual Variation

With permission of Dr Blandine French

Nurturing Parents

‘a society that values its children
should cherish their parents’

Bowlby, 1951

‘supporting the child starts with
supporting the adult’

State of the Nation Survey, UK, 2020

Parental Wellbeing: Blame and Trauma

- ▶ Significant evidence of system-generated trauma:
 - ▶ ‘the severe harm that disabled children and their families experience through their interactions with public services.’
- ▶ ‘Urgent need for a fundamental shift in institutional culture and a move beyond superficial policy adjustments to address these systemic issues.’
- ▶ BPS calls for a trauma-informed approach.

[Systems Generated Trauma - Cerebra](#)

[Trauma and parent carers | BPS](#)

Emotions are Contagious

‘You are only as happy as your unhappiest child.’

- ▶ We naturally “catch” the emotions of people we are close to.
- ▶ Parents are especially sensitive to their children’s feelings.
- ▶ Parents often mirror their child’s stress or sadness almost automatically.
 - ▶ When a child struggles, the parent’s mood drops too.

Stress is the 'off-switch' to connection



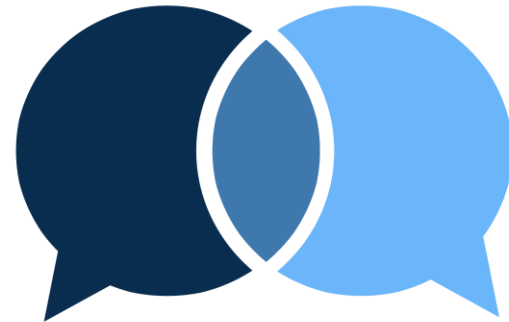
- ▶ States of threat and 'self-defense' compete with caring systems, getting in the way of connection with our children

Dan Hughes, Brain-based Parenting

Co-Production- Lived Experience

Helpful:

- ▶ Peer support (18-25 yrs)
- ▶ Peer support (parents)
- ▶ Psychoeducation
- ▶ Supportive GPs



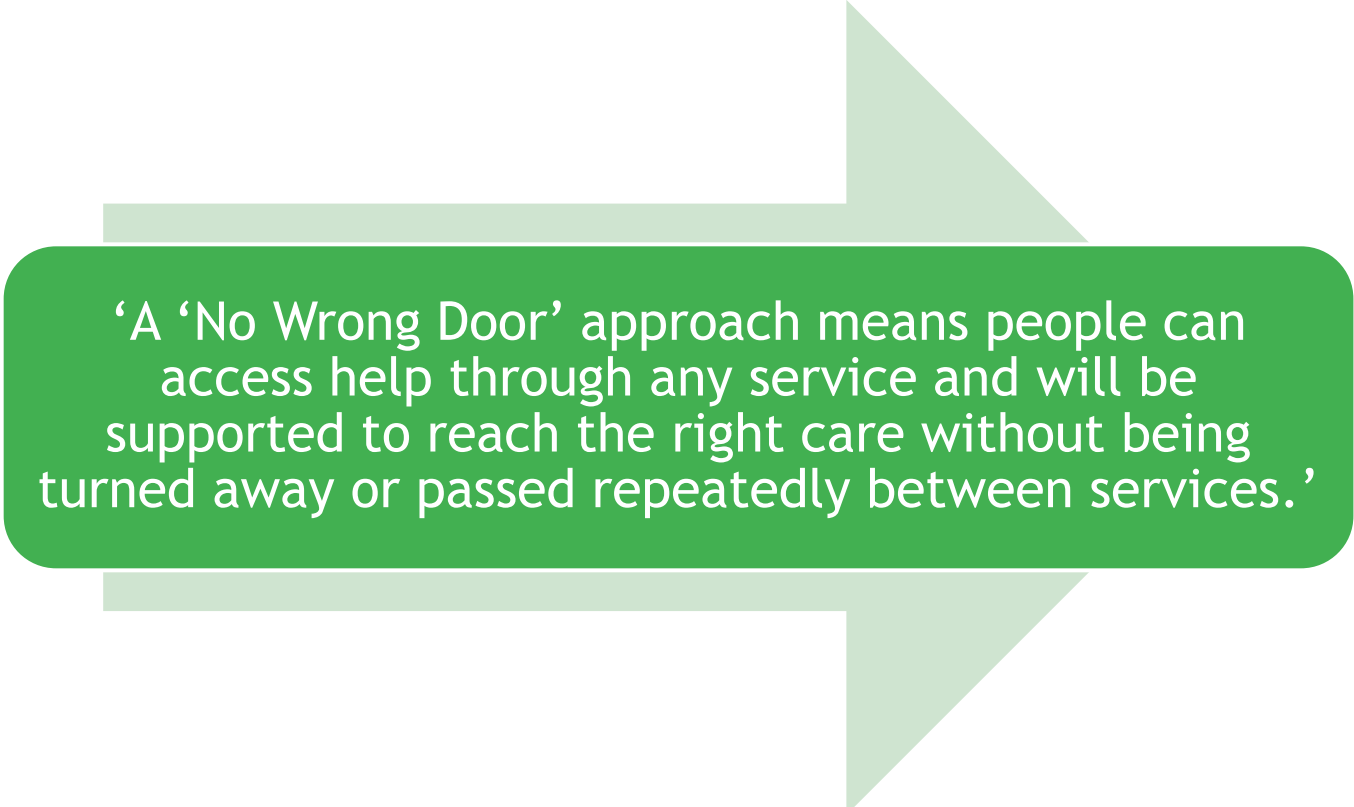
**PARTNERS
IN MIND**

Partners in Mind Lived Experience, Co-Production Group

Challenges:

- ▶ Children and young people with complex needs and those considered 'not severe enough' for CAMHS
- ▶ Transitions- post 18 (adolescent brain ages 9-32)
- ▶ Parents seen as a safeguarding risk
- ▶ Parent blame
- ▶ 'Bounced' between services
- ▶ Crisis service

No Wrong Door



‘A ‘No Wrong Door’ approach means people can access help through any service and will be supported to reach the right care without being turned away or passed repeatedly between services.’

Bell, A. and Pollard, A. (2022) No wrong door: A vision for mental health, autism and learning disability services in 2032. London: Centre for Mental Health for the NHS Confederation.

Case Study



Signs of difficulty poorly understood/ missed. Most prominent was hyperacusis from very young.



Average test scores interpreted as 'no problem'



Poor understanding at school. Accused of trying to advantage child. Bullying by peers.



Late diagnosis of autism led to autistic burnout and home education as last resort.



GP surgery added as a carer and texted link to carer support but not accessed.

Needs Not Met

- ▶ **Mental Health Crisis line**
 - ▶ Partners in Mind work identified training needs.
- ▶ **CAMHS**
 - ▶ Gaps identified: extremes of children not bad enough or too complex.
- ▶ **NHS**
 - ▶ Long waiting list for autism assessment. Late diagnosis.
 - ▶ No OT services for sensory processing difficulties.
 - ▶ Transitions at age 18: e.g. no further OT support.
- ▶ **School**
 - ▶ Poor understanding in schools.
 - ▶ Insufficient support in schools, lack of resources.

What Helped?

- ▶ Child's voice
- ▶ Strengths and assets focus
- ▶ Music and creative writing
- ▶ 'The Village'
- ▶ Small group learning and 1 to 1 support
- ▶ Supportive GP and practice staff
- ▶ Paediatrician, OT, clinical psychologist
- ▶ Pets
- ▶ Humour
- ▶ Mindfulness
- ▶ Counselling
- ▶ Time





Helpful Reflections

Bring awareness, or mindfulness to your experience:

- ▶ What is here and What does this need?
- ▶ This too will pass
- ▶ It is what it is- acceptance of what can't be changed

Practice:

What do I need to best take care of myself?

4 Ds to lighten the load: Do, Decide, Delegate, Delete



**WHAT DO YOU NEED
TO DO?**



**PRIORITISE: WHAT
CAN YOU DELAY?**



**ASK FOR HELP:
WHAT CAN YOU
DELEGATE?**



**IS NECESSARY:
WHAT CAN YOU
DITCH?**

Eisenhower Matrix (the Urgent-Important Matrix)

Pauline McGowan OBE

Health and Care Act 2022 statutory requirement for staff to receive learning disability and autism training.

- ▶ Oliver McGowan Training:
 - ▶ ‘Nothing about us, without us’
 - ▶ ‘Culture where everyone is listened to, respected and cared for in a way that works for them’
 - ▶ And No Wrong Doors is what that prevention looks like in practice.

[About us | Oliver McGowan](#)

[Mandatory training on learning disability and autism - GOV.UK](#)

Parent Advocates

Roots causes?



Widespread myths and misunderstanding.



Resources for schools reduced over time.



Curriculum and assessment changes over time.

Increased academic focus

Reduce time for arts and physical activity

Attendance pressures



Wider societal pressures.

Support for Parent Carers

- ▶ Provision of accessible, accurate information at an early stage.
- ▶ Support timing of diagnosis and understanding of positives and negatives.
- ▶ Social media e.g. Facebook local networks
- ▶ Peer support- local community groups
- ▶ Charities and expert groups e.g. APPG, National Autistic Society, Nottingham Neurodiversity Network

[Emotional Support for Parent Carers of Seriously Ill and Disabled Children](#)
[APPG](#)

French B, Cassidy S. “Going Through Life on Hard Mode”—The Experience of Late Diagnosis of Autism and/or ADHD: A Qualitative Study. *Autism in Adulthood*. 2026;8(1):127-136. doi:[10.1089/aut.2024.0085](https://doi.org/10.1089/aut.2024.0085)

Institute of Health Promotion and Education: Policy Recommendations

- ▶ **A National Carers' Strategy is needed** to ensure implementation of existing legal frameworks.
- ▶ Provision of needs-based, cross-sector, health-promoting approach to individualised care within a whole-family and wider community setting.
- ▶ Identification of carers and signposting to support via settings e.g.:
 - ▶ schools, medical centres, pharmacies, voluntary sector, community groups.

Summary Points



Parents supporting children with additional needs are, by definition, parent carers.



Parents of neurodivergent children are at increased risk of mental health difficulties and PTSD.



People with 'lived experience' are often best placed to advise on what support and services will make a positive difference to their lives.



If prevention is our national direction, then parent carers must be part of that conversation.



A needs-based, '**no-wrong door**' approach is required, providing individualised care within a whole-family and wider community setting.

Links

[Resources | IHPE](#)

[Partners in Mind – Improving Lives in Nottingham](#)

[Home - Nottingham Neurodiversity Network](#)

[Home | Minds of All Kinds - Notts](#)

[National Network of Parent Carer Forums C.I.C - Company Number: 12362344](#)

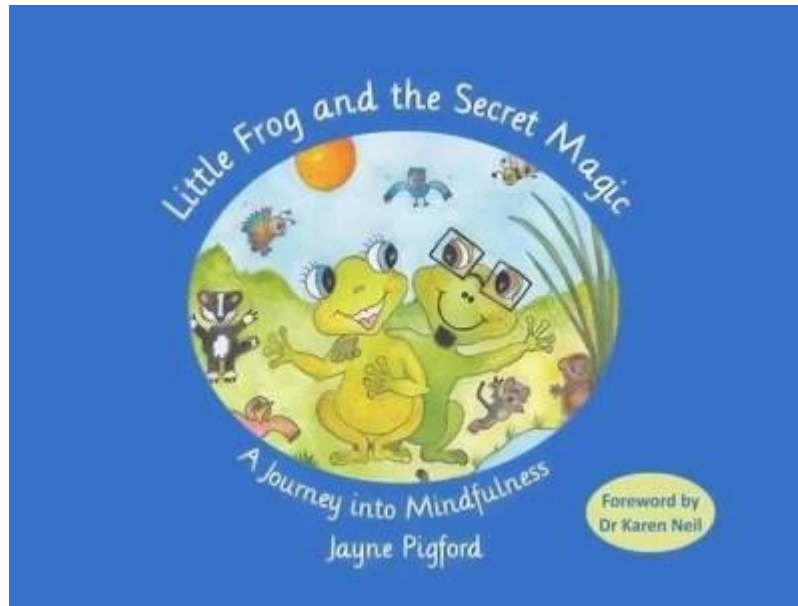
[Carers Trust | Transforming the lives of carers](#)

[NHS England » Co-production](#)

[The World of Co-Production and QI](#)

[NHS England » Supported self-management: peer support guide](#)

Little Frog and the Secret Magic - a children's journey into mindfulness



[Remembering Jayne Pigford - Mindful Medicine](#)



Thank You :)

May you feel heard,
connected and supported.