Supporting children and young people with PANS and PANDAS

South East SEND FORUM

Aims

- Understanding PANS or PANDAS

- Progress to Date

- Opportunities for Action

Our vision is a brighter future for people affected by PANS and PANDAS.

Our mission is to raise awareness, to support and empower individuals and their families, to engage and inform health, social care, and education professionals and to accelerate UK-led PANS and PANDAS research.

No child or family should face PANS and PANDAS alone.
PANS PANDAS UK strives to ensure they do not have to.

Registered in England and Wales: 1178484
Registered in Scotland: SC053206

What are PANS and PANDAS?

PANS
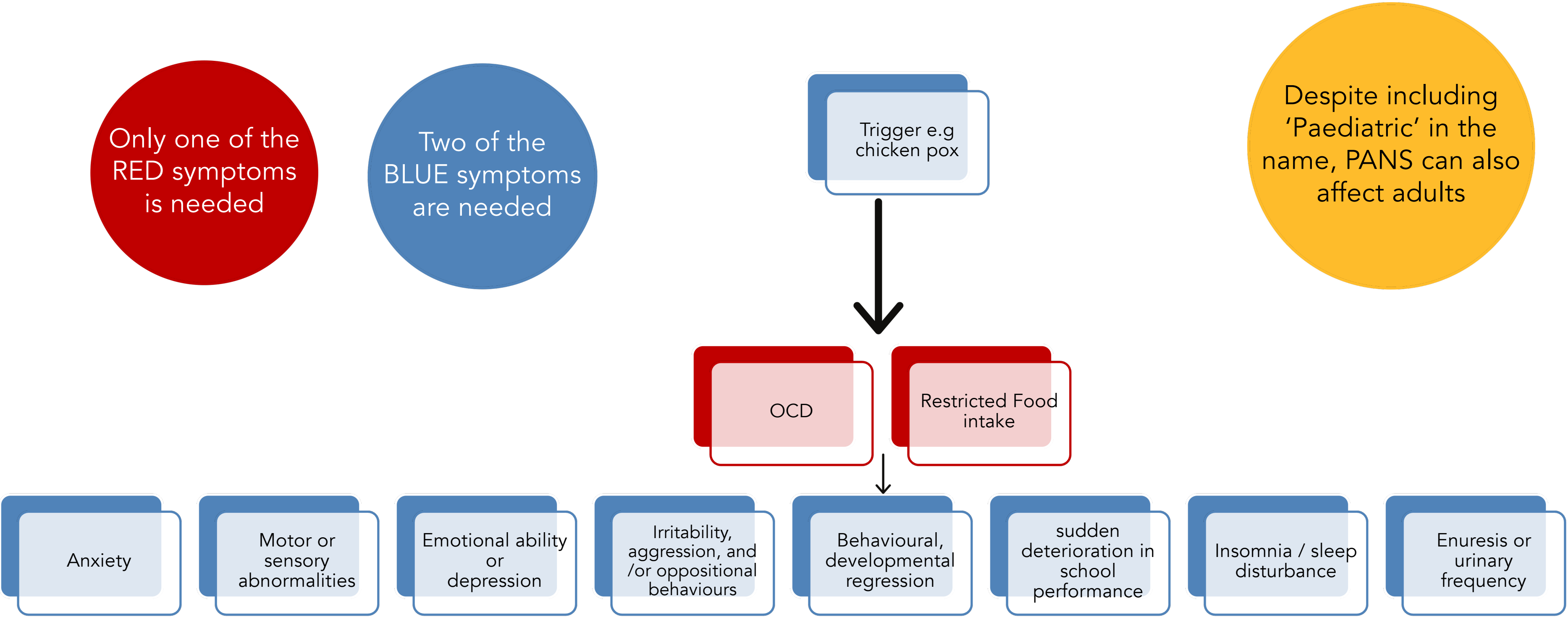Paediatric Acute-onset Neuropsychiatric Syndrome

PANDAS
Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

As with medical conditions which affect both physical and mental health, a post infectious and/or immune cause targeting the brain may be implicated.

Triggered by common infections (for example, strep throat, chickenpox, or influenza) and can only be diagnosed by a medical professional.

PANDAS is a paediatric condition (onset usually happens between 3 and 12 years) Symptoms do not suddenly remit at 16.

PANS however can also affect adults. Conditions are usually relapsing and remitting, (symptoms go up and down) and an exacerbation of symptoms is known informally as a flare.

Diagnostic Criteria : PANS

Only one of the RED symptoms is needed

Two of the BLUE symptoms are needed

Trigger e.g chicken pox

Despite including 'Paediatric' in the name, PANS can also affect adults

OCD

Restricted Food intake

Anxiety	Motor or sensory abnormalities	Emotional ability or depression	Irritability, aggression, and /or oppositional behaviours	Behavioural, developmental regression	sudden deterioration in school performance	Insomnia / sleep disturbance

Enuresis or urinary frequency

Diagnostic Criteria : PANDAS

Only one of the RED symptoms is needed

Some of the other symptoms may be experienced, but are NOT required for a diagnosis

Trigger: Streptococcus infection
e.g. tonsillitis, scarlet fever, strep throat

A paediatric diagnosis, but symptoms do not suddenly resolve at 16

OCD

Motor / vocal Tics

Anxiety

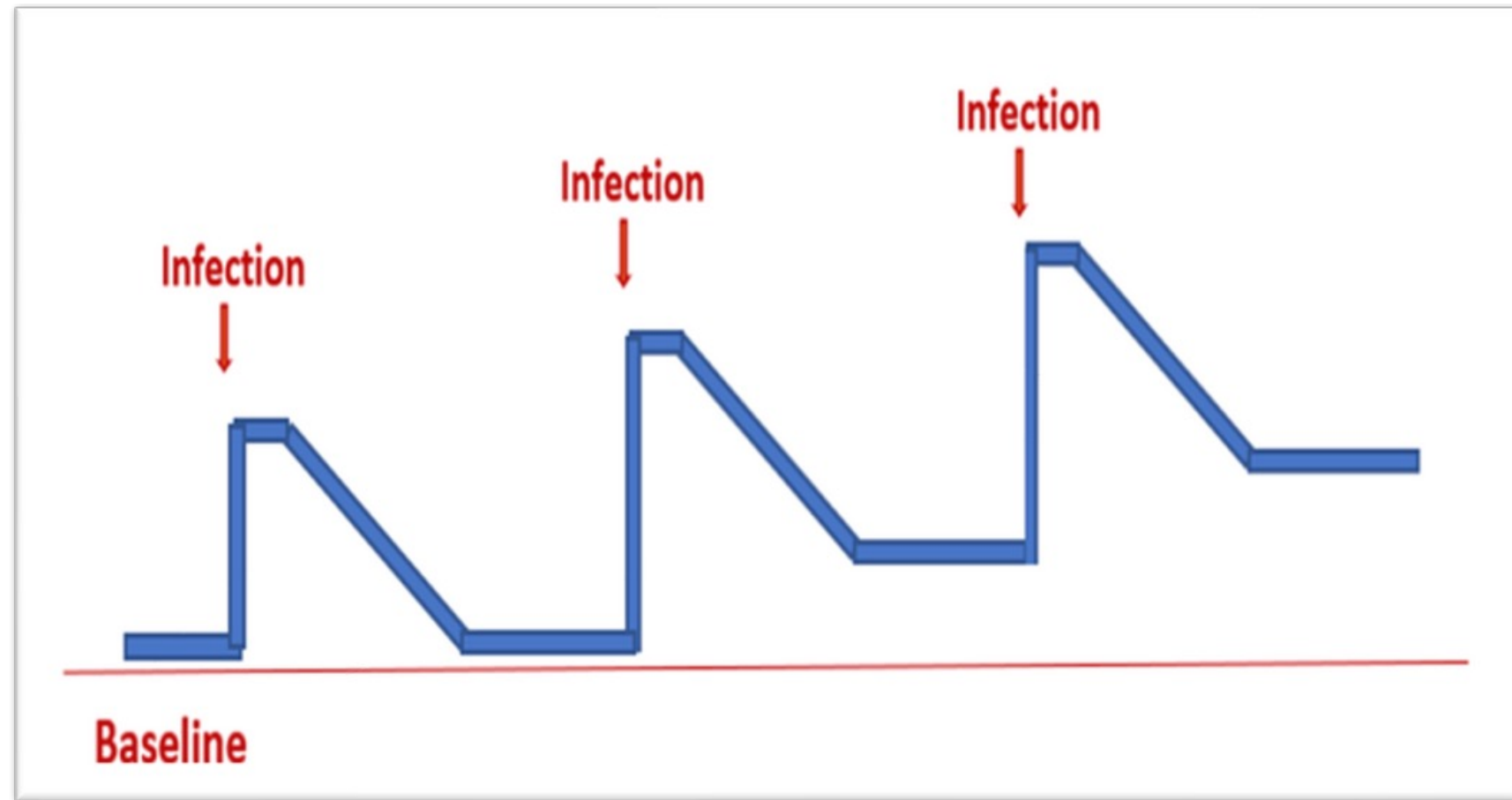Motor or sensory abnormalities

Emotional ability or depression

Irritability, aggression, and /or oppositional behaviours

Behavioural, developmental regression

sudden deterioration in school performance

Insomnia / sleep disturbance
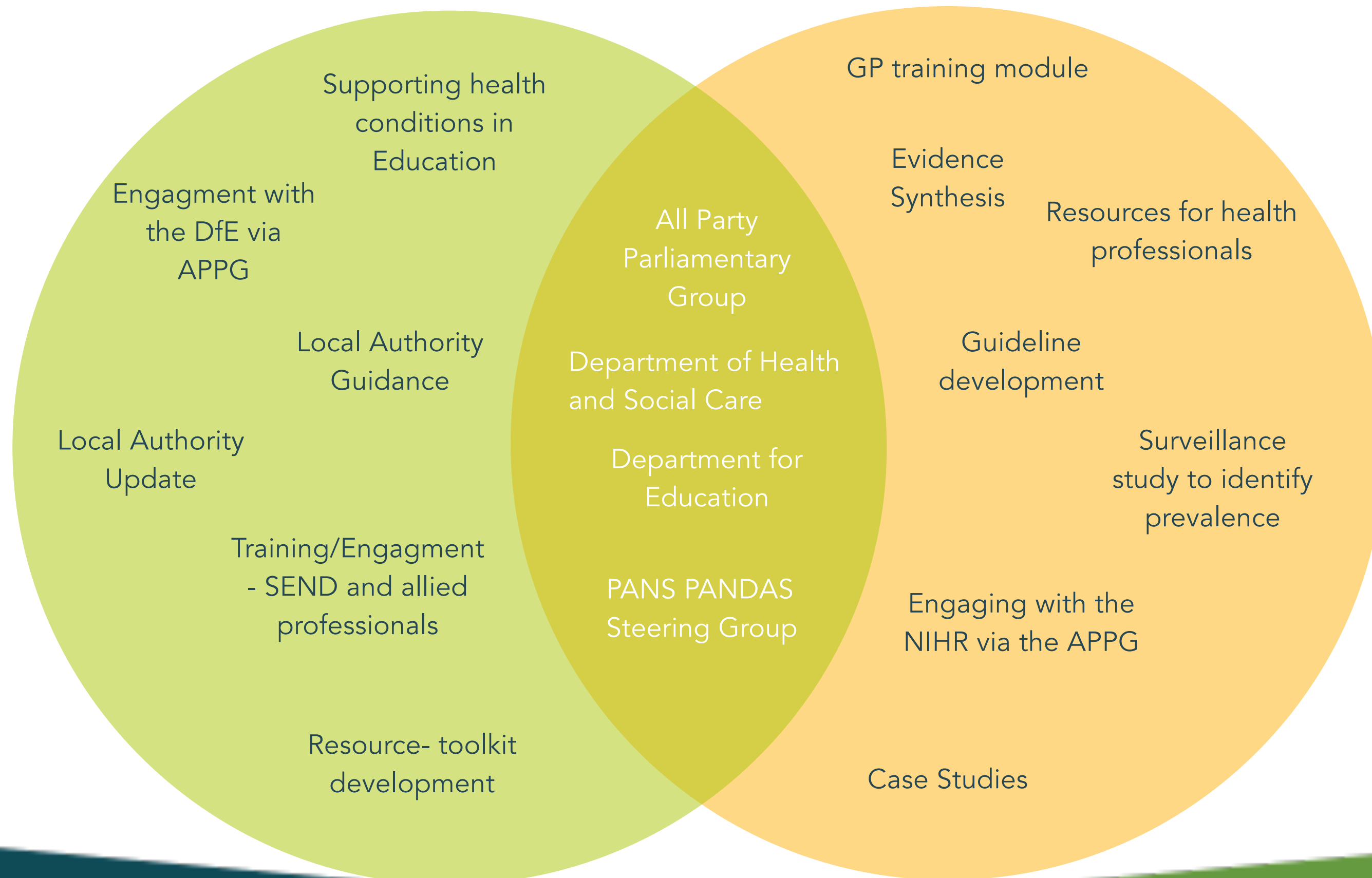
Food restriction

Early identification and treatment leads to the best outcomes

Some children and young people recover

Some children and young people do not return to their baseline

Others develop a chronic static or chronic progressive course

Work underway

Supporting health conditions in Education

GP training module

Engagment with the DfE via APPG

Evidence Synthesis

Resources for health professionals

All Party Parliamentary Group

Local Authority Guidance

Department of Health and Social Care

Guideline development

Local Authority Update

Department for Education

Surveillance study to identify prevalence

Training/Engagment - SEND and allied professionals

PANS PANDAS Steering Group

Engaging with the NIHR via the APPG

Resource- toolkit development

Case Studies

- Share the updated GP leaflet with first line testing
- Signpost GP/Paediatrician to the PANS PANDAS UK website for updated health information
- Regional/tertiary services can be contacted for discussion
- MIMS online training module
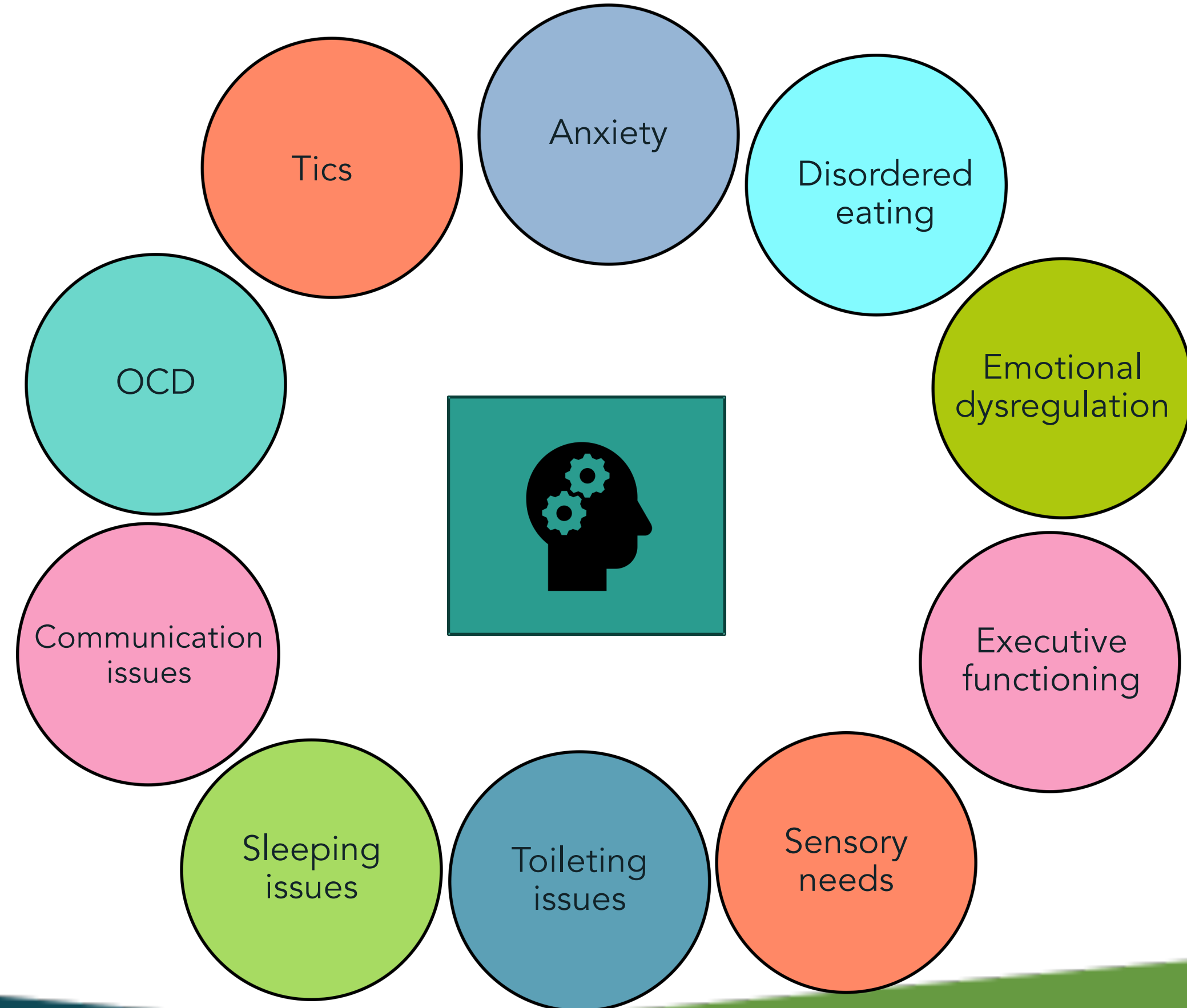
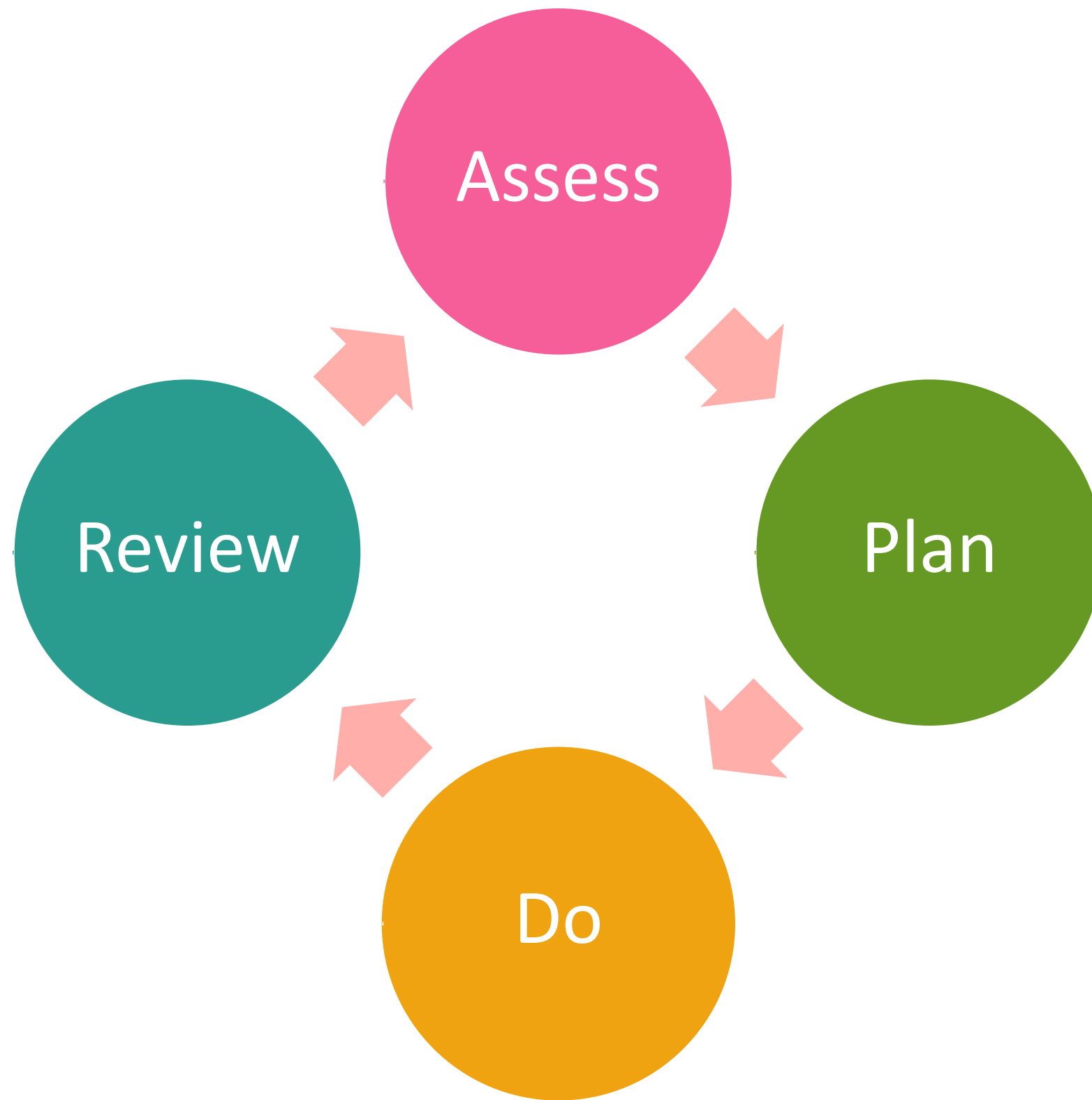# Symptoms in the classroom

Sudden drop in school performance

New onset of SEND needs

Fluctuating and confusing pattern

May resemble typical challenges but with a different cause

Symptoms often misinterpreted as behavioural or mental health issues

Tics

Anxiety

Disordered eating

Emotional dysregulation

Executive functioning

Sensory needs

Toileting issues

Sleeping issues

Communication issues

OCD

SEN support :The Graduated Approach

Assess

Plan

Do

Review

Four-Part Cycle:
Assess, Plan, Do, Review
May be insufficient for acute or fluctuating presentations.

Tailored Support
Standard cycles may not keep pace with medical flares

Limitations in Severe Cases
May need immediate and significant intervention, rather than gradual escalation.

- **Fluctuating and Complex Needs**
  - Symptoms can vary dramatically and unpredictably
  - EHCPs must be flexible and responsive to episodic flare-ups.

- **Misconceptions**
  - Symptoms often misinterpreted as behavioural, parenting issues, neurodivergence or purely mental health
  - Lack of awareness and training

- **Assessment Challenges**
  - Standard educational assessments may not capture the full impact of PANS or PANDAS
  - CYP may mask symptoms or present differently in school vs. home.

- **Medical input** - essential but often missing
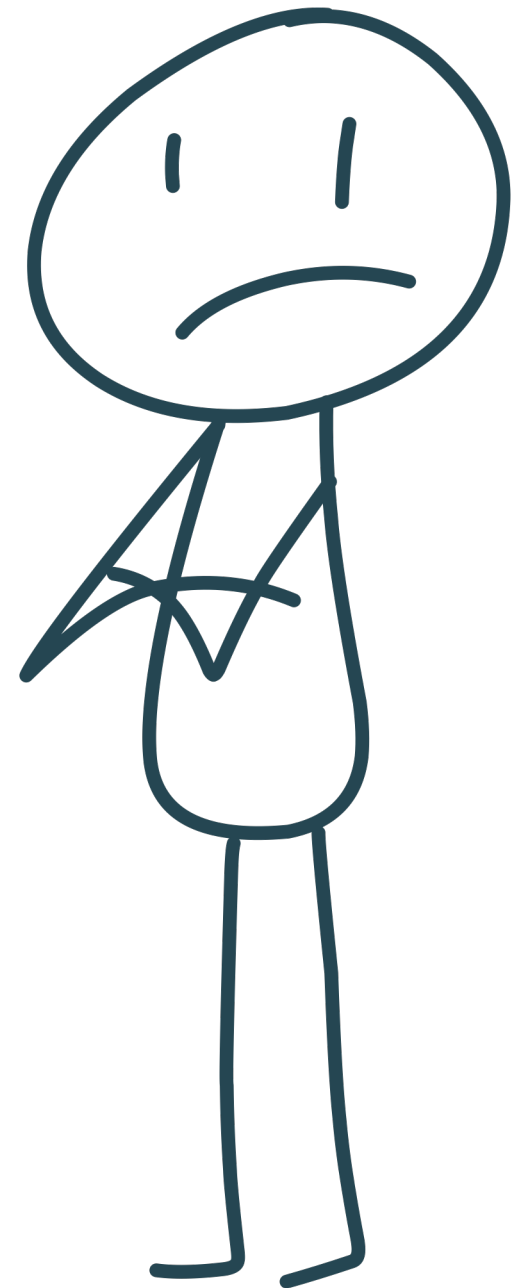
Child and young person's voice

Call to Action

- Embed understanding of PANS and PANDAS as medical conditions

- Promote early identification and multi-disciplinary collaboration

- Ensure access to appropriate educational support

- Champion awareness and training for school staff

- Collect data to build a clearer picture

Aspire (2021a) Pans Pandas Symptoms, Available at: https://aspire.care/symptoms-diagnosis/symptoms/ (Accessed 3 April 2024)

Aspire (2021b) Pans Pandas at School, Available at: https://aspire.care/treating-pans/pans-at-school/ (Accessed 3 April 2024)

Child Mind Institute (2021) Parents Guide to PANS and PANDAS. Available at: https://childmind.org/guide/parents-guide-to-pans-and-pandas/ (Accessed 3 April 2024)

Miglioretti, M. (2019). School-Based Services for Children with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS) (Doctoral dissertation, Duquesne University). Available at https://dsc.duq.edu/etd/1808 (Accessed 3 April 2024)

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Swedo, S. (2018) PANDAS/PANS – Moving Past the "Controversy" To Recognition and Diagnosis. 4 October. Available at: https://www.youtube.com/watch?v=CqjTIyW-xYg&ab_channel=ChristineKapetanakis (Accessed 3 April 2024)

UK PANDAS and PANS Physicians Network (2018) PANS and PANDAS Treatment Guidelines (v1.6). Available at: https://www.e-hospital.co.uk/wp-content/uploads/2019/04/PANDAS-Protocol-V1.6.pdf (Accessed 3 April 2021)

Ward K. and Edelstein J. (2015) Effects of PANDAS/PANS on Communication: What SLPs Need to Know; Poster Presentation at the American Speech-Language Hearing Association's National Convention. 14 November. Available at: https://www.mnsu.edu/comdis/kuster/related/pandas/pandashandout.pdf (Accessed 3 April 2024)