

# Kent Health and Wellbeing Board

## Neuro Developmental Disorders Deep Dive

26<sup>th</sup> February 2020

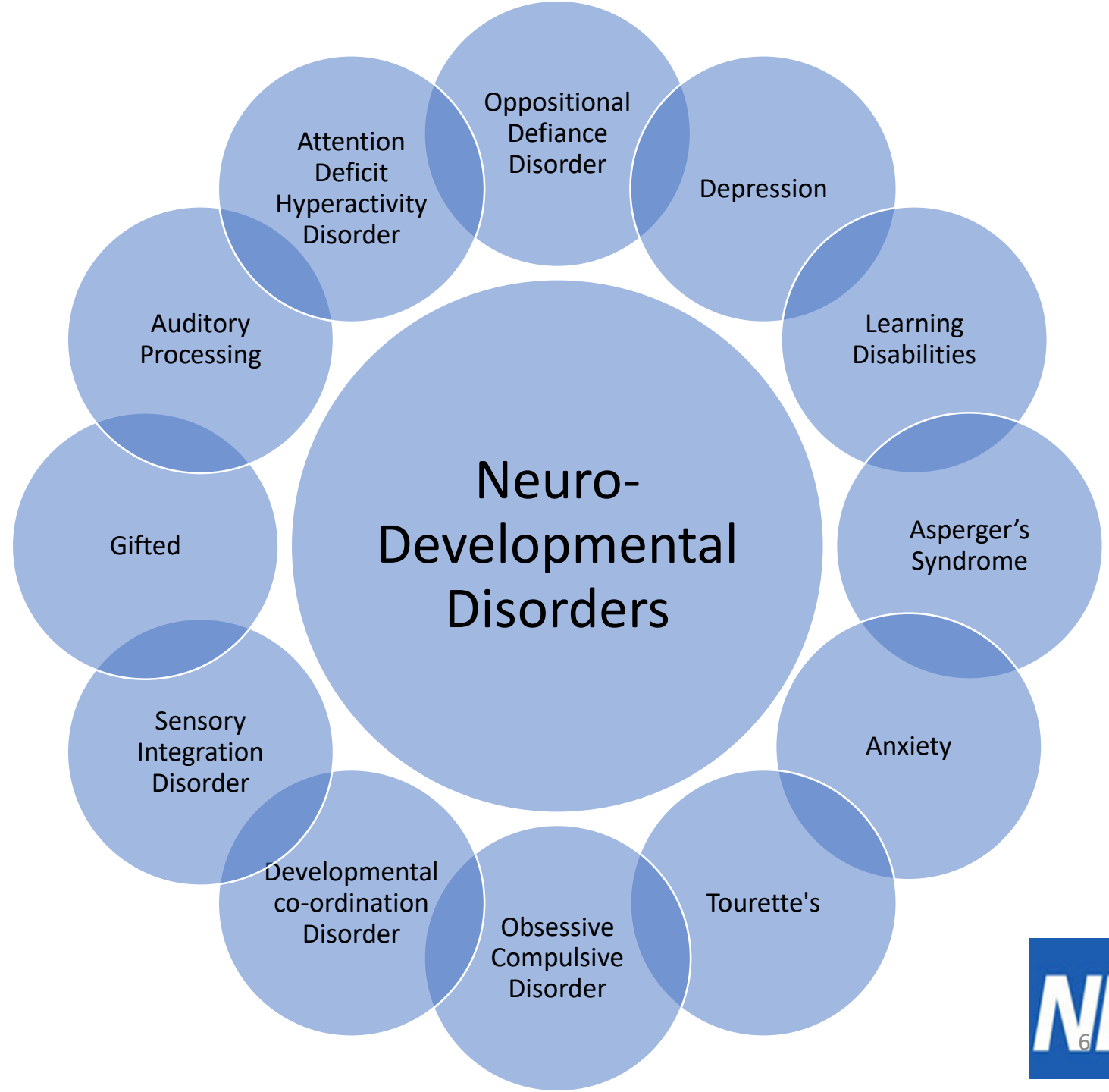
Rachel Jones/Emma Hanson/Sue Mullin



- Complex whole system issue
- Fragmented pathways
- High levels of demand
- Postcode lottery of support
- Little investment in pre and post diagnostic support
- Poor outcomes



Co-morbidities and clustering of conditions add to complexity of an individuals profile and therefore the various levels of support required



# Autistic Spectrum Disorders

Autism is described as a 'Spectrum' because of the way in which the condition affects individuals varies greatly.

On one end of the spectrum people with autism may have an additional learning disability and be more severely impaired



On the other end individuals may have an average or above average intellect and may function at a higher level

Of course there are many shades in between which require a joined up whole system approach that can be personalised for individuals needs

# Written Statement of Action

Lifted the lid on what we need to do better, the ASC pathway issues were clearly articulated as a major theme throughout and resulted in following actions;

- Review and strengthen the leadership within the children's commissioning function and agree a future model for integrated commissioning
- To co-design and implement a CYP neuro-developmental pathway, including ASC and Attention Deficit Hyperactivity Disorder (ADHD)
- Parents and YP have a clearly defined integral role in reviewing and designing services
- Develop more targeted and specialist training options for teaching staff to improve skills and knowledge to meet ASC needs

# System Challenges

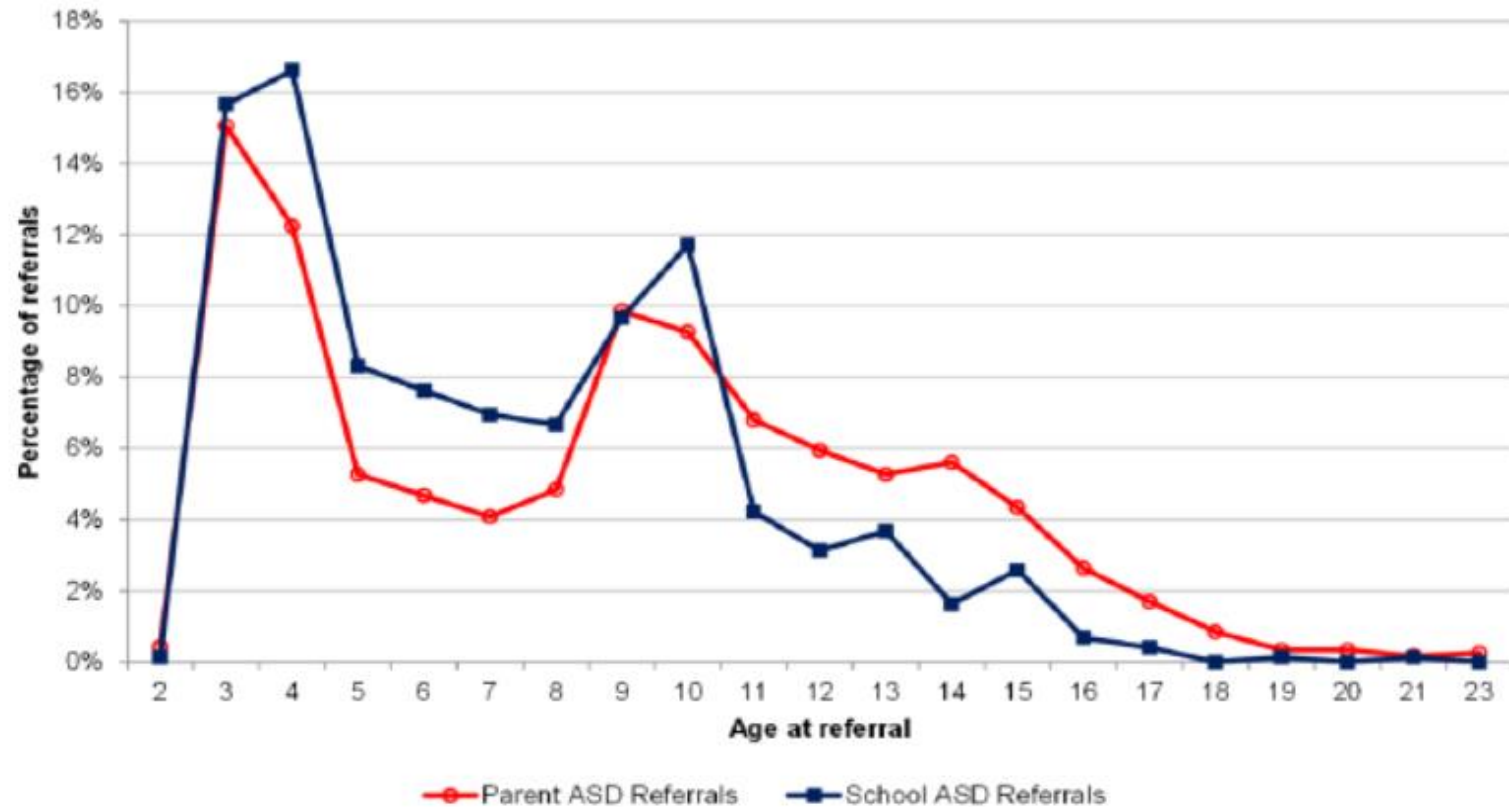
- Demand issues
  - Huge rise in ECHPs
  - Incorrect referral process for diagnosis i.e. Single Point of Access
  - Long waiting lists for diagnosis – NHS diverting £2.1m to meet demand
  - Increase prescribing budget
  - Increase in school exclusions
  - Increase in Independent School's budget
  - Other LA's placing CYP with ASC in Kent
- Over reliance on crisis / emergency support
  - Tier 4
  - Residential schools
  - Residential homes
- Fragmented and postcode lottery of pre/post diagnostic

# Medical and Social Models

- Current pathways and systems drive need for diagnosis
- Diagnosis is important for some, but so are interventions to support:
  - awareness,
  - understanding and
  - support
- System not coping because of medicalised diagnosis led pathway which is often unnecessary
- Very little funding for pre & post diagnosis all of which comes from social care

# ASC Referrals by Age & Referral Source

This chart shows that there are two spikes in referrals one at pre school and a second before transfer to secondary school



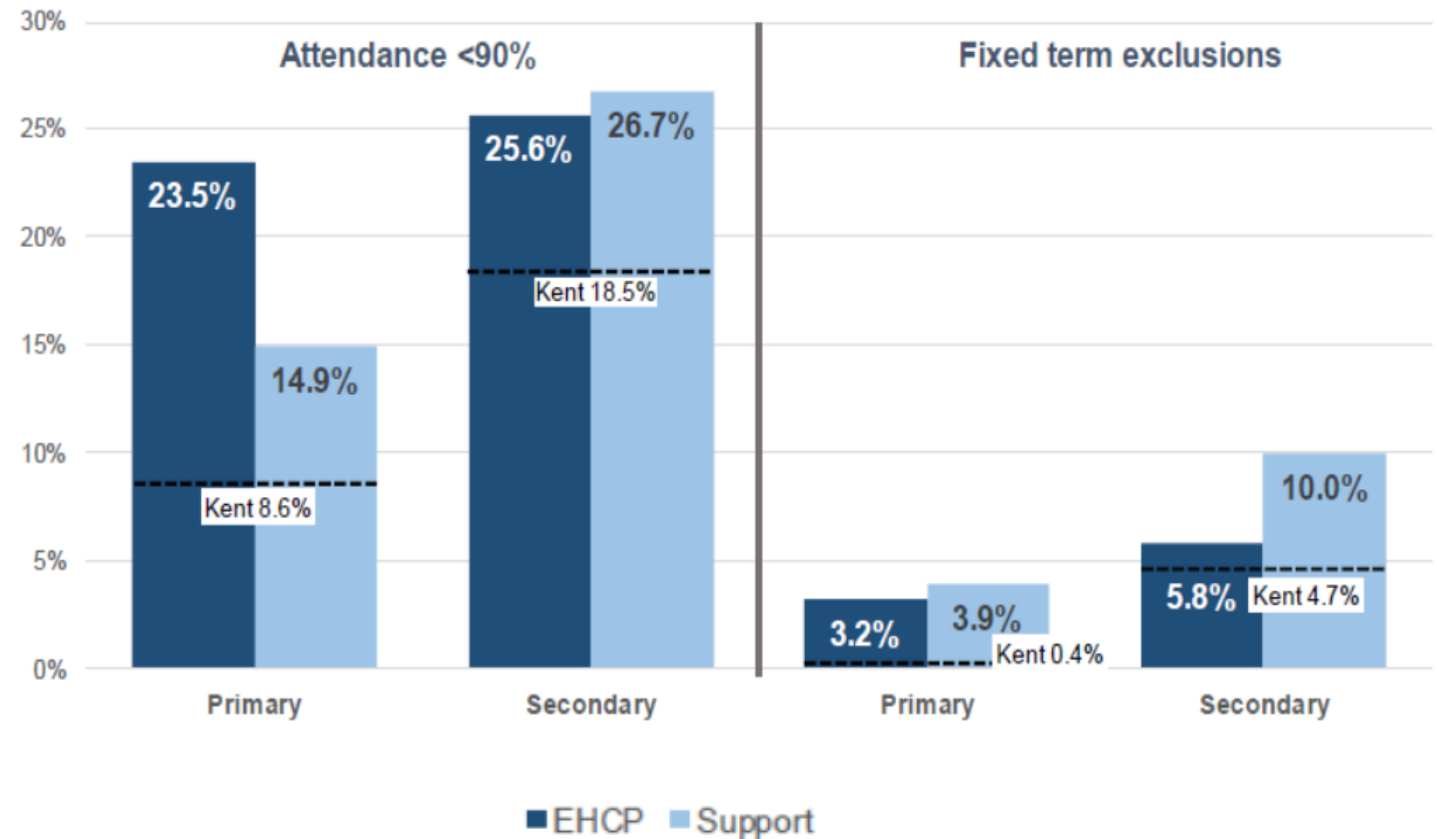


# CYP with ASC - Attendance and Exclusions

Almost a quarter or 24% of primary pupils with EHCP/ASC had poor attendance, the figure for all Kent children of 8.6%

Over a quarter of all secondary pupils with SEN/EHCP/ASC had poor attendance, much higher than the Kent figure of 18.5%

Fixed term exclusions, a higher proportion of pupils with ASC are excluded



# Diagnostic Pathway Caseloads and Waiting List

- The providers of Neuro-Developmental Assessments are the North East London Foundation Trust (NELFT) and Kent Community Health Foundation Trust (KCHFT) for under 12's in West Kent Only
- There are currently (8/19) 6,230 children and young people waiting for an ASC diagnosis with NELFT
- Plus, an additional 1,440 in west Kent who are under 12 awaiting a KCHFT assessment
- The Neurodevelopmental Diagnostic wait is currently approx. two years
- As of August 2019 NELFT's caseload was 13,800.
  - The combined locality team caseload account for 4,700 of the total and
  - ND/LD holding a significant volume of 9,100

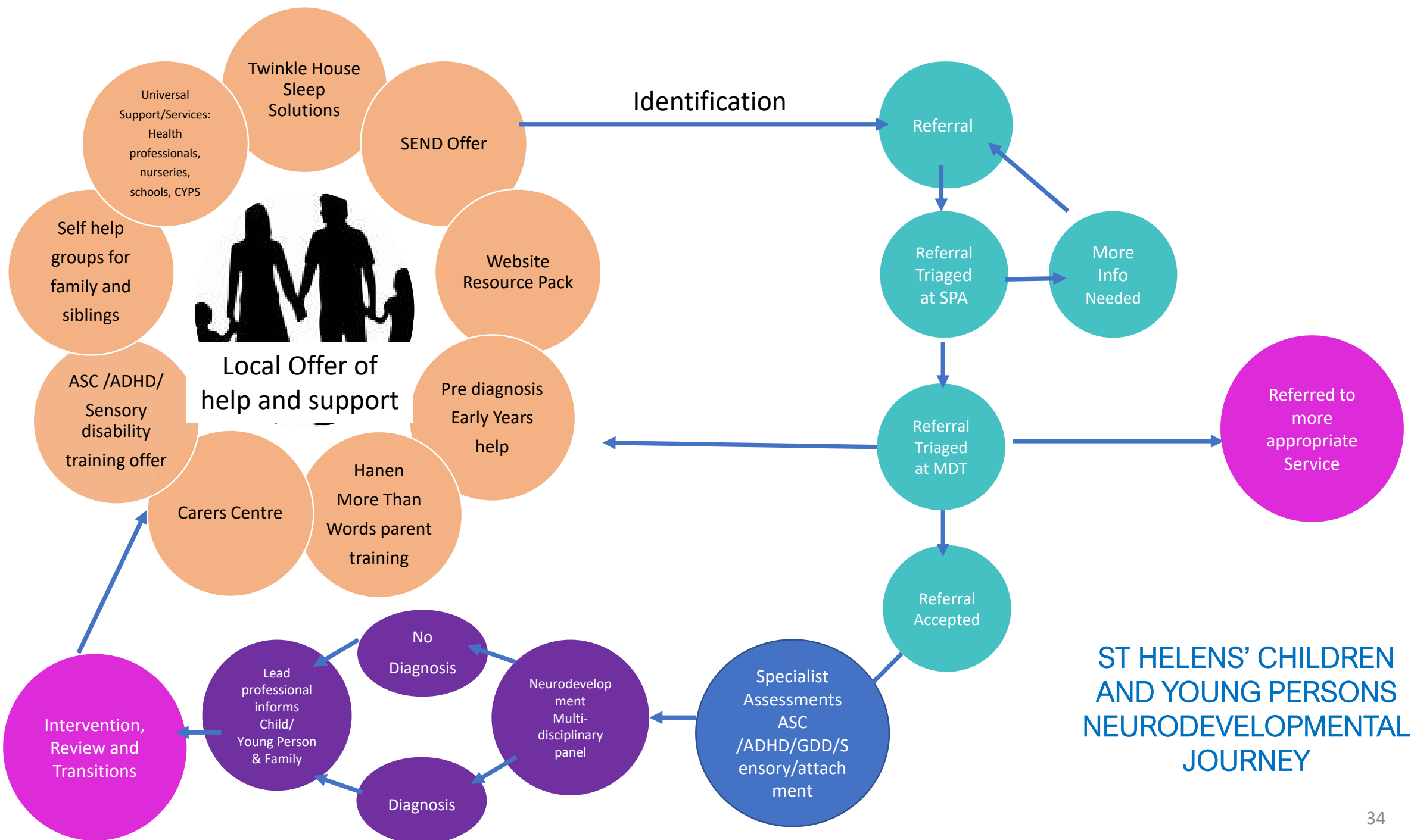
# Impact of Delayed Diagnosis

- Denies the child or young person the opportunity to understand their condition and why they respond in specific ways – they cannot develop appropriate self care strategies
- Creates undue stress in families, with their child's response to the world often misinterpreted as poor behavioural issues
- Delays accessing the right educational offer – slows academic progress
- Means co-morbid mental health conditions are undiagnosed too and potential trauma left untreated
- Limits access to early intervention or prevention services
- Perpetuates a crisis driven model – which is more costly for the whole system and leads to poor outcomes for our young people

# Communication and Access to Information

- Lack of clear accessible information
- People don't know where to go, what to do or what help is out there
- Parents talk to each other – which in most cases is really helpful but also can fuel myths and demand in system
- Myths drive behaviour – e.g. need an ASC Diagnosis to get a ECHP





**ST HELENS' CHILDREN AND YOUNG PERSONS NEURODEVELOPMENTAL JOURNEY**

# Joint Commissioning

Effective joint commissioning arrangements have been recognised throughout the local area SEND inspections as enabling better coordination of services and improved outcomes for children and young people.

## **Kent's Joint Commissioning Test Pilots:**

- Neurodevelopmental (ASC ) Pathway Redesign
- Speech and Language
- Independent Specialist School Provision
- Joint Resource Allocation Panel

# Hypotheses – Conclusion

- There are a group of children whose needs are such that they would benefit from a clinical diagnosis
- There are also a group of children whose needs in the past would have been met in mainstream settings but who are now seeking assessments and diagnoses
- This is motivated by a belief that a diagnosis that is required to access to educational support, EHCPs, special school and resourced places
- Our system's (Education, KCC, Health, Housing , Welfare) behaviour has resulted in parents seeking SEN support and EHCPs as the only way to get help
- The open self referral in health SPA facilitating EHCP increase in numbers and requirements

# Hypotheses – Conclusion

- The system (at all stages) has been under resourced and uncoordinated
- The early years offer for children is also uncoordinated.
- We have changed and further fragmented the pre diagnosis pathway over the years. This includes education, LIFT , Cygnet, Early Bird, Speech Language and Communication
- The introduction of the new code of practice has resulted in diagnosis being the first point of action for many parents
- Seeking additional funding - schools may be recording (and are not being challenged) ASC SEN type rather than LD mild/moderate
- We may be better than other authorities at identifying ASC in children but don't have the resources to diagnose and provide the support that people need



# Since September 2019:

- System deep dive to understand the current situation has been undertaken and widely socialised and accepted as our current position
- Clinical Reference Group (CRG) has been established to support the programme of transformation
- Neurodevelopment pathway has been drafted by the CRG and is being tested for implementation
- Audit of referrals, screening and diagnosis and an audit of data across providers has been undertaken and findings fed into the waiting list initiative proposal. The proposal seeks to drastically reduce the number of children currently waiting over the next 16 months.
- Canterbury Pilot has delivered 2 family events, undertaken family survey, created resources and supported a number of families currently waiting for assessment
- NHS investment in increased assessments

# Since September 2019:

- KCC is delivering a programme of improvement for children with neurodevelopmental needs across a range of services:
  - Creation of new directorates bringing together disabled children, SEND and educational psychology
  - Improvement to Early Help and Adolescent offer
  - Extension of KEPS into Early Help
  - Investing in training
- Consistent delivery of parenting programmes across Kent
- Co-production model of parent and family engagement being developed and parents have been engaged in the work stream (based on the Canterbury Pilot model)
- Information, advice and support is being cascaded to 7,000 families waiting for assessments in Kent (based on the Canterbury Pilot) including resources for schools and primary care. Information, advice and support events are being planned in every CCG area for 2020/21
- Aligning the Adult Assessment pathway and considering emerging potential for development of an all age pathway

# Questions & Discussion?