

DIAGNOSTIC PATHWAY BEST-PRACTICE

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POINTS TO COVER

- Things to consider when developing the pathway:
 - National context
 - Local context
- Designing the pathway; step by step guide
- Delivering the pathway:
 - Challenges
 - Solutions
- Evaluating and developing the pathway





THINGS TO CONSIDER WHEN DEVELOPING THE PATHWAY

Understanding context

NATIONAL CONTEXT

- Clinical features identified by Elizabeth Newson.
- Screening questionnaire – Extreme Demand Avoidance Questionnaire by Liz O’Nions.
- PDA Society; campaigning and increasing knowledge of the profile of differences nationally.
- Services across the UK starting to diagnose PDA/Extreme Demand Avoidance/autism diagnosis with features of demand avoidance.
- DSM 5 – PDA not recognised as a diagnosis.
- Recognition of insufficient research in the area.
- Agreement nationally to refer to demand avoidance as an additional dimension.

LOCAL CONTEXT - SOLIHULL



- No Educational Psychology Service.
- Education support services had become traded, except for the ASD specialist teaching service.
- Increasing number of children were having a breakdown in education placements.
- Changes to Social Care and Child and Adolescent Mental Health Service (CAMHS).
- Demand to recognise the PDA subtype was increasing.
- Unmet need for PDA assessment was resulting in private assessment and 'false positive' diagnosis of PDA.
- Highest demand for people already diagnosed with an ASD.

DESIGNING THE PATHWAY

Step by step guide

STEPS TAKEN

1. Meetings; drafting of pathway.
2. Audit of demand.
3. Briefing document for commissioners.
4. Pilot phase; trial of consultation meeting.
5. Development of paperwork:
 - a. Referral pack.
 - b. Report template and referral response letter.



STEPS TAKEN

6. Training to enable schools and families to implement the PDA strategies, as well as skill up the assessment team to be able to identify the key features of PDA.
7. Dissemination of the pathway:
 - a. SENCo conferences and ASD Lead Meeting.
 - b. Paediatrician conferences.
 - c. CAMHS department meeting.
 - d. Parents support network in Solihull.



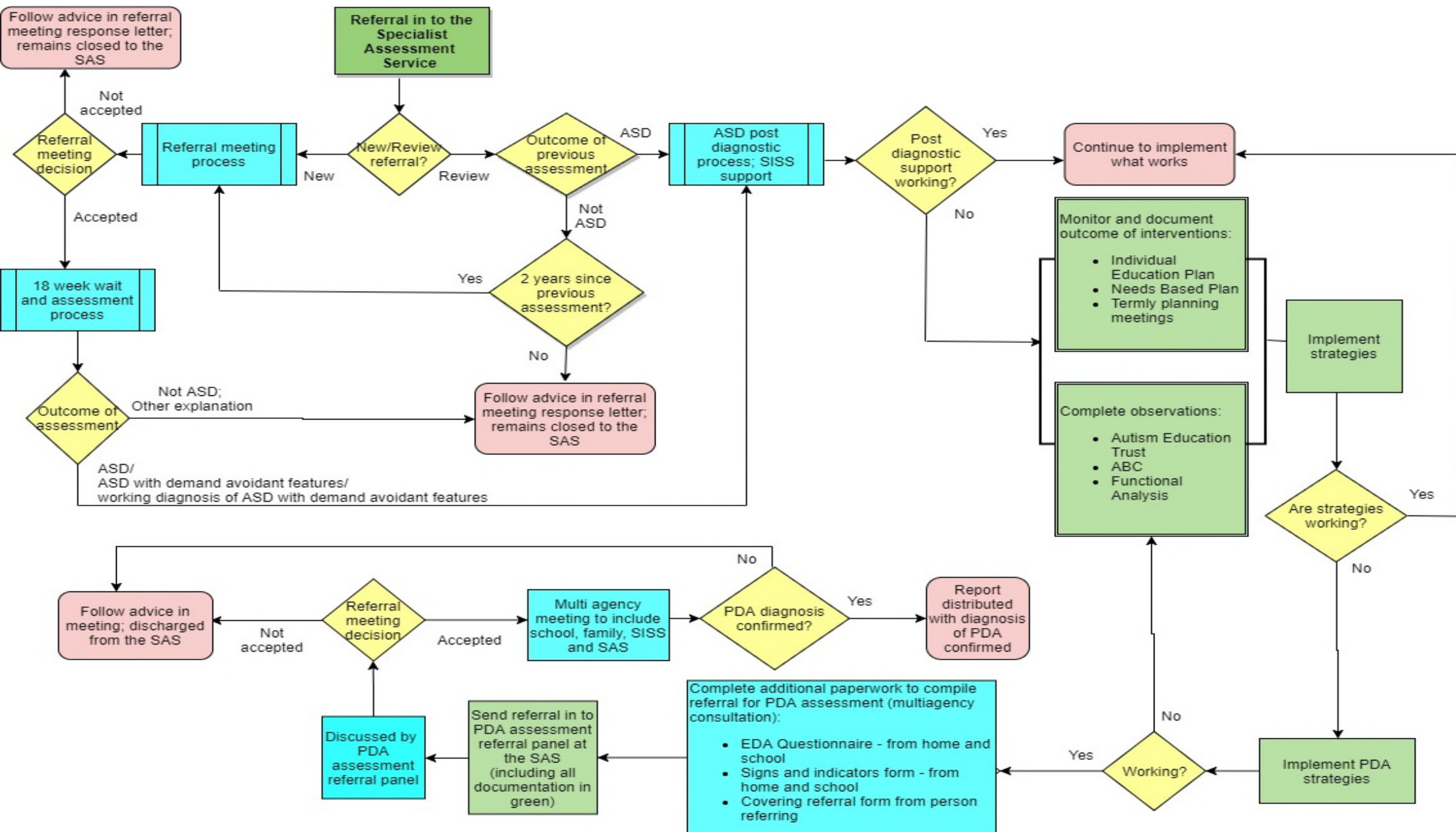
ONGOING STEPS

- Agree 'post diagnostic' actions if PDA is given as a diagnosis for young people.
- Outcomes to be reviewed and adjustments made over time.
- Audit longitudinal demands.
- Fact sheets/advice sheets.
- Service evaluation.



STEP 1

Drafting branches in the
pathway



SERVICE PATHWAYS PRIOR TO THIS NEW PATHWAY

Specialist Assessment Service (SAS):

- 0-18.
- Solihull GP.
- Open referral system.
- Assessment and diagnosis only.
- Multidisciplinary, Case Lead model of assessment.
- Evidence of difficulties across social interaction, social communication and flexibility of thought and behaviour.
- 'Graduated response'; appropriate services have been put in place for a child for a minimum of 6 months (2 terms) and evidence of impact provided.
- Review assessments can be completed for those not diagnosed 2 years after previous assessment has been completed.

Post assessment referral to the Specialist Inclusion Support Service ASD (SISS ASD) Team:

- SISS ASD team develop a needs based plan and offer family support as well as support to teachers.

KEY PATHWAY PRINCIPLES



- Use pre-existing processes and procedures and try to make the approach efficient and effective; assess, make diagnostic decision*.
- Agreement with education about 'assessment over time':
 - On-going observations.
 - Implementation of strategies over time.
 - Assessments and interventions by other services; meet need and rule out differential and co-occurring difficulties.
- If all other strategies unsuccessful, implementation of PDA strategies**:
 - Gather evidence of the benefit of confirming this as a clinical description.
 - Empower people to use the strategies without the need for the label.
- Referral in to SAS for multi professional and family meeting for consultation to consider clinical description of PDA; **not a referral for direct assessment.**

*DIAGNOSTIC/CLINICAL DESCRIPTION OUTCOMES ON THE NEW PATHWAY

Does not meet diagnostic criteria for an ASD but has a lot of PDA features

- Give a ***working diagnosis of ASD/atypical ASD*** and comment on the demand avoidant features present
- Get access to post diagnostic ASD specialist teaching service
- 'Assessment over time' commences

Meets diagnostic criteria for an ASD and has features of PDA

- Diagnose **ASD**
- Comment on the demand avoidant features present
- 'Assessment over time' commences

** PDA HANDLING STRATEGIES

PDA Society:

- [Booklet.](#)
- [Contact directly.](#)
- [Mind map.](#)
- [What PDA means to me.](#)



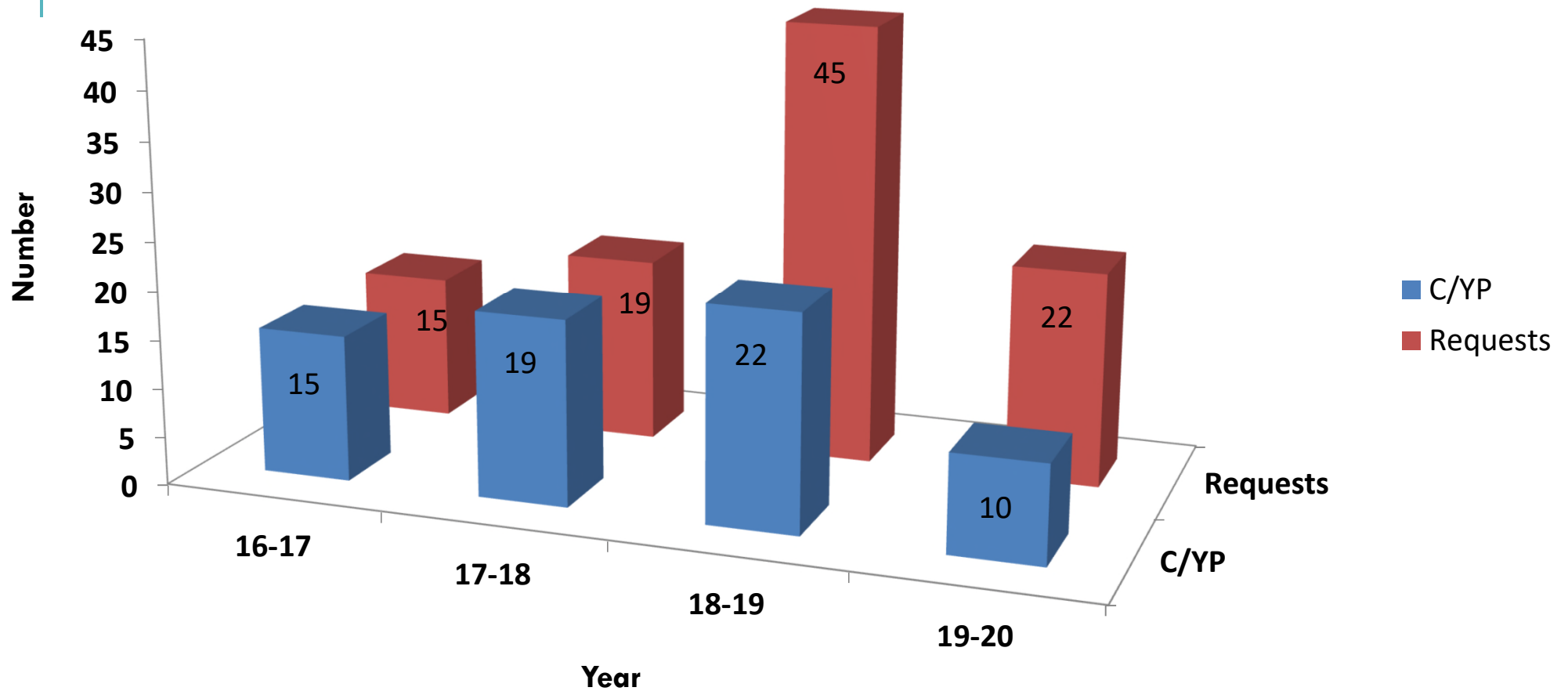
Autism Education Trust handling strategies:

- Relationship.
- Flexibility and creativity.
- Environment.

STEP 2

Audit of demand

NUMBER OF REQUESTS



TRENDS

- 30% females.
- 55% aged over 11 years.
- 30% were out of school/specialist provision/placement breaking down.
- 1/4 of total annual referrals to the service.
- Biggest demand for those CYP already assessed and diagnosed with an ASD.
- Small number of children now on the pathway who have been identified as having features; we are yet to know the outcome of the 'assessment over time'.
- 3 C/YP have received a confirmation of PDA as part of the clinical description of their profile of needs.

STEP 3

Briefing commissioners

BRIEFING DOCUMENT FOR COMMISSIONERS

- Executive summary.
- Purpose.
- Current situation:
 - National context.
 - Local demand.
- Audit data.
- Outline of proposed pathway.
- Benefits and costs.
- References.
- Appendices with draft proposed documents to use in delivery of the pathway.



STEP 4

Pilot phase

PILOT

MDT MEETING

- SISS unavailable.
- Complex dynamic in room between family and professionals from school; what was unspoken.
- When school representative left, information shared by family about adaptations made at home that could account for why the difficulties were not being seen at home.
- Experiment set for parents to challenge assumptions about school and increase awareness of adaptations made.

PAPERWORK

- Draft signs and indicators form for SISS.
- Parents and school asked for a version to complete; need to adapt form to gather information from various stakeholders.
- Additional information provided by family; could conduct an ABC analysis on it.
- Report.

UNEXPECTED ACTIONS;DEMAND

- Occupational Therapy assessment.
- Possible need to request that the information be presented to the Dyslexia board; to address unmet need.
- Feedback on hold due to changes in setting being considered.

STEP 5

Development
of paperwork

DOCUMENTATION REQUIRED FOR ANY REFERRAL TO THE PDA PANEL AT THE SAS

- Observation paperwork:
 - [AET observation sheet.](#)
 - [ABC observation.](#)
 - Functional Analysis observation.
- Review meetings and documentation:
 - Individual Education Plan (IEP).
 - Needs Based Plan (NBP).
 - Termly planning meetings.
 - Education Health and Care Plan (EHCP) planning meetings.
 - Other.
- PDA referral booklet and signs and indicators form:
 - Home.
 - School/SISS ASD Team.
 - Other professional/service.
- [EDA questionnaire.](#)

STEP 6

Training

TRAINING PACKAGE OFFERED

- Health and Education joint training.
- 2 days.
- Audit of need prior to delivery.
- Evaluation of training at end of day 1 and day 2.
- Training in PDA:
 - Features.
 - Differentials.
 - Functional Analysis.
 - PDA handling guidelines; for home and education services.



DELIVERING THE PATHWAY

Challenges and solutions

CHALLENGES TO OVERCOME IN SERVICE DELIVERY

- Referrals kept coming back to the SAS.
- Lack of understanding about the role of the SAS.
- Lack of understanding about PDA.
- Changes to services and staff.
 - SISS ASD Team Lead left.
 - Access to SISS ASD Team stopped.
 - Staff changes; staff mix not skilled in identifying and supporting people with a PDA profile.
 - Lack of joint working; single clinician with responsibility to make decisions and to review all referral information.



SOLUTIONS

- Further direct assessment.
- Presenting at a local parents forum.
- Delivering more training.
- Take key learnings from each case to inform developments to the pathway.
- Linking with Psychology in Solar (CAMHS) and the Educational Psychology Service.
- Involving service users and carers in pathway development work, starting with service evaluation.



EVALUATING AND DEVELOPING THE PATHWAY



KEY MESSAGES THAT HAVE COME BACK SO FAR

- Neighbouring service against consideration of PDA because it is not recognised in the diagnostic manuals.
- Young persons' voice in a recent parent forum about 'diagnosing' earlier not making children/young people wait.
- Parents report that PDA would help change the systemic script around their parenting and approaches to their child; took 18 months to reach a point of realisation that a different approach was needed for this family.
- Parents report concerns about length of time taken to access the consultation stage in the pathway.

PLAN FOR EVALUATING THE PATHWAY

- Audit of demand and diagnostic/clinical description outcomes.
- Service evaluation in January 2020.
 - Analysis of cases where referrals have been made requesting consideration of PDA.
 - Analysis of cases who have been described as having demand avoidant features as part of their primary assessment by the SAS.
 - Feedback from stakeholders.
 - Review impact for cases where PDA has been confirmed.
- Results to be used to implement changes to the model.

FURTHER INFORMATION



Journal Article:

Summerhill, L and Collett, K. (2018) Developing a multi-agency assessment pathway for children and young people thought to have the PDA profile. *Good Autism Practice* 19 (2) 25-32.

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