

ASD Case vignette #1 Liam

Background:

Liam is a 5 year old boy, referred for an Assessment of Need by his parent due to the following concerns:

- Difficulties with attention
- Delays in speech
- Behavioural difficulties e.g. hitting out
- Repetitive motor mannerisms e.g. hand flapping

An AON prior to 2020 was likely to consist of:

- SLT & OT assessments involving parental interview, use of parent rating scales, and direct assessment of Liam using standardised measures
- Psychology assessment including:
 - parental interview;
 - standardised measures / rating scales completed by parent and teacher;
 - cognitive assessment of Liam;
 - preschool observation;
 - ADOS (play based assessment) and ADI-R (specific interview schedule with parent) both of which aid in an assessment of ASD
- Team discussion to pull together assessment conclusions and recommendations
- Feedback session with parent(s) to explain the results of the assessment and recommendations

Findings of assessment:

- SLT assessment identifies severe receptive and expressive language delay and severe phonological disorder
- OT assessment identifies difficulties with fine motor skills, self-care skills and sensory processing skills
- Cognitive assessment indicates his nonverbal ability falls in the borderline range of ability. Adaptive behaviour fell in the extremely low range of functioning.
- Observations and ASD specific assessments supported a diagnosis of ASD

Outcome of assessment:

- Parents receive feedback on assessment results and recommendations so that they have a clear understanding of Liam's difficulties and the nature of his disability and are signposted regarding a range of supports, entitlements and benefits including the DCA
- Recommendations made regarding the clinical supports that Liam and his family require e.g. ASD specific parent skills training; SLT,OT, and other team supports from a HSE child disability team (referral made).
- Recommendations also made regarding optimal educational supports for Liam. In this case an ASD class was identified as the optimal setting; parents provided with information on how to research local options.

An AON using the PTA model:

- Two disciplines,90 minute session comprising:
 - Parent interview
 - Observation
 - Informal play based assessment
 - Screening questionnaires completed by parent

Outcome of PTA:

- Assessment may suggest a disability, however there is insufficient information to confirm the nature or extent of this, or to identify the needs arising from same
- Liam would be referred to a disability team for an assessment for ASD and further team assessment to identify his level of intellectual ability, communication ability etc. Waiting times to access disability teams are currently often running to 2-3 years or longer.
- In the meantime, Liam would be unable to apply or enroll in an ASD class in school because he does not have a diagnosis of ASD. He would likely start in a mainstream primary school, without SNA support, and find this extremely challenging.
- Parents would also be unable to avail of other targeted supports (e.g. parent support groups, financial assistance etc.). Parents now have to wait several years before a comprehensive assessment can take place, Liam can be diagnosed with ASD, and appropriate health and educational supports can commence. By this time Liam is likely 8 years old and he has had no ASD-specific intervention from the state.

Case vignette #2 – Sarah

Background:

Sarah is an 11 year-old girl, referred for an Assessment of Need by her mum Helen following encouragement from school. Concerns identified in the referral were:

- Disruptive behaviour in class, having temper tantrums and lashing out
- Speech difficult to understand, poor pronunciation, often appears not to understand what is said to her
- Behind academically
- Interpersonal difficulties. Difficulty following / understanding the rules of games. Sarah showing a preference to go into her own world, speaking to herself
- Poor handwriting
- Constantly on the go, difficulty concentrating and staying in her seat
- Occasional spinning in circles
- Overreacting to loud noises, preference for wearing the same clothes

An Assessment of Need prior to introduction of the new SOP might comprise:

- SLT & OT assessments involving interview with Helen, use of questionnaires, direct assessment of Sarah using a range of standardised measures
- Psychology assessment involving interviews with Helen / interview with birth father Phil (parents separated and unwilling to meet together) / school observation & teacher interview / use of a range of standardised questionnaires with Helen and school / obtaining information on the concerns and past input of a wide range of agencies previously involved with the family, including TUSLA / cognitive assessment of Sarah / short series of 1:1 sessions with Sarah to assess emotional wellbeing / ADOS with Sarah to explore possibility of ASD
- Finally liaison between above clinicians in order to arrive at conclusions and recommendations DCD, and borderline or mild ID

Key findings of above assessments:

- SLT assessment identifies that Sarah meets criteria for Developmental Language Disorder. Referral made for community SLT intervention.
- OT assessment identifies that Sarah also meets criteria for Developmental Coordination Disorder. Referral made for community OT intervention. Assistive technology options to be explored as a reasonable accommodation in school.
- Information obtained identifies that Sarah has experienced a number of adverse situations and traumatic events in her life including physical and emotional abuse. In the present there are substantial concerns regarding the extent to which Sarah's psychological needs are being met in the home. Much of Sarah's emotional and behavioural difficulties may be understood as sequelae of same. Sarah does not meet criteria for ASD. Detailed feedback on report provided to Helen over two sessions, given complexity and sensitivity of the situation. Recommendations include that Sarah is referred for 1:1 therapeutic input. Referrals to TUSLA (on grounds of emotional abuse) and a range of other supports are made, including counselling for Helen. TUSLA specifically asked to assess suitability of current access arrangements between Sarah and Phil given emerging concerns.

Alternatively, if a PTA took place rather than a comprehensive assessment, as per the new SOP:

Two staff, of different but no specific disciplines, carry out the single session screening. Whilst one clinician interviews Helen for approximately an hour, the other attempts to engage Sarah in age-appropriate play and informal conversation. There is insufficient time to liaise with other professionals who may have further information. Feedback at the end of the session to Helen is that whilst several aspects of Sarah's presentation appear atypical, it is not possible to determine the nature and extent of same. ASD, ID cannot be ruled out.

Given complexity of case a referral is made to the SADT for assessment (waiting time was approximately 3 years pre-PTA in Sarah's CHO; this will increase given how many PTAs reach the same conclusion and thus also refer on to SADT for comprehensive assessment). Helen is encouraged to attend a parenting course in the meantime. Generic parenting advice given.

No other interventions recommended or referrals made due to limited information obtained during the screening.

ASD & ID Case vignette # 3: Sean

Background:

Sean is a 4 year old boy, referred for an Assessment of Need by his parents and supported by his Public Health Nurse, due to the following concerns:

- Delays in speech, not responding to name
- Sensitive to loud noises, hair being brushed and cut
- Not toilet trained and requires parental assistance to dress/undress and to feed him
- Has been unable to enrol in local preschool due to his care needs
- Has an older sibling who has ASD and ID

An AON prior to 2020 was likely to consist of:

- SLT & OT assessments involving parental interview, use of parent rating scales, and direct assessment of Sean using standardised measures
- Psychology assessment including:
 - parental interview
 - standardised measures / rating scales completed by parent and teacher
 - cognitive assessment of Sean
 - ADOS and ADI-R (both of which aid in an assessment of ASD)
- Team discussion to pull together assessment conclusions and recommendations

Findings of assessment:

- SLT assessment identifies severe receptive and expressive language delay in the presence of delayed social and play skills
- OT assessment identifies difficulties across the areas of self-care, gross motor and fine motor skills, and sensory processing
- Cognitive assessment indicates an Intellectual Disability estimated in the moderate range
- Sean receives a diagnosis of ASD

Outcome of assessment:

- Parents receive feedback on assessment results and recommendations so that they have a clear understanding of Sean's difficulties and the nature of his disability and are signposted regarding a range of supports, entitlements and benefits (including the DCA)
- Recommendations made regarding the clinical supports that Sean and his family require. Referral made to the HSE child disability team
- Recommendations also made regarding optimal educational supports for Sean. In this case a special school is identified as the optimal setting; parents provided with information on how to research local options
- This family subsequently became homeless. They were able to apply for housing under medical grounds on the basis of Sean's assessment and diagnosis

An AON using the PTA model:

- Two disciplines, 90 minute session comprising:
 - Parent interview
 - Informal play based assessment
 - Screening questionnaires completed by parent

Outcome of PTA:

- Screening carried out suggests a disability, however there is insufficient information to confirm the nature or extent of this, or to identify the specific needs arising from same
- Sean is referred to a disability team for a comprehensive assessment for possible ASD and of his intellectual ability, communication ability etc. Waiting times to access disability teams are currently often running to 2-3 years or longer
- In the meantime Sean is unable to access the optimal school supports (in this case a special school). In the eventuality that he commences in mainstream school he would be highly likely to struggle in this setting and end up on reduced hours
- In the absence of clarity regarding Sean's disability, parents are unable to avail of other targeted supports (e.g. parent support groups, financial assistance etc.). Parents now have to wait several years before a comprehensive assessment can take place which would diagnose ASD and ID, and appropriate health and educational supports can then commence. By this time Sean is likely 7 years old and he has had no targeted intervention or support from the state.

Case vignette #4 – Elizabeth

Background:

Elizabeth is a 9-year-old girl, referred for AON by her parents. Their concerns are

- They feel she is bright, but she is struggling in school, particularly with handwriting
- Elizabeth is sociable but finds it difficult to make friends in school.
- She dislikes participating in afterschool activities and prefers to play alone.
- Elizabeth appears to have an advanced vocabulary but struggles with understanding sometimes.
- Lately she has become very anxious and tearful.

An AON prior to 2020 was likely to consist of:

- **SLT Assessment:** parental interview (with team), use of parent and teacher rating scales / questionnaires, and direct assessment using standardised measures.
- **OT Assessment:** including parental interview (with team), use of parent and teacher questionnaires, and direct assessment using standardised measures as indicated by results of interview and questionnaires.
- **Psychology assessment:** parental interview (with team), standardised measures / rating scales completed by parent and teacher; cognitive assessment.
- **Team** would discuss and need for and carry out ADOS (play based assessment) and ADI-R (specific interview schedule with parent) both of which aid in an assessment of ASD.
- School observation if appropriate.
- **Team** discussion to pull together assessment conclusions and recommendations
- **Feedback** session with parent(s) to explain the results of the assessment and recommendations

Findings of assessment:

- SLT assessment identifies semantic / pragmatic language and social skills difficulties.
- OT assessment identifies difficulties with gross and fine motor skills, self-care skills indicative of Developmental Coordination Disorder and sensory processing difficulties.
- Cognitive assessment indicates average ability.
- Observations and ASD specific assessments supported a diagnosis of ASD

Outcome of assessment:

- Parents receive feedback on assessment results and recommendations so that they have a clear understanding of Elizabeth's difficulties and the nature of her disability and are signposted regarding a range of supports
- Recommendations made regarding the supports Elizabeth will require for school to ensure that she can reach her academic potential.
- ASD specific parent skills training.
- Team supports identified and referral made to appropriate disability team.
- Recommendation for support for anxiety and monitoring of same to ensure that this does not become a primary concern.

An AON using the PTA model:

Two disciplines, 90-minute session comprising:

- Parent interview
- Observation
- Informal play-based assessment
- Screening questionnaires completed by parent

Outcome of PTA:

- Depending on the expertise of the clinicians involved, assessment may or may not suggest a disability. Statistically girls are less likely to be diagnosed with DCD and ASD than boys as they appear to be better able to mask their difficulties.
- Elizabeth may be recommended for further assessment in which case she will be added to a waitlist but may never be prioritised as her difficulties are subtle.

We know that children with mild ASD and DCD who are of average ability will find school and social situations increasingly difficult and are likely to develop mental health difficulties as they age. These children, if their difficulties are recognised, understood, and supported at an early stage can do really well.