



# Navigating the first conversation about autism with parents

Presented by Holly Puckering & Robyn Stephen

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# Summary

## About Robyn Stephen

Robyn has been a Speech Pathologist for 40 years and was one of the pioneers of private practice Speech Pathology in Australia. She has a strong belief in supporting families with a family-centred approach and vigorous in the provision of a psychologically empowering workplace emphasising continual professional development.

- Member of the steering committee for the first National Guideline for the Assessment and Diagnosis of Autism in Australia 2018
- Member of Speech Pathology Australia working group for the Autism Practice Guide update 2022
- Founding member of the Developmental and Autism Assessment Team at Melbourne Paediatric Specialists Royal Children's Hospital Melbourne

## Touchpoints parents may ask about autism:



New client call



Initial parent interview



During assessment sessions



Feedback sessions



Education visit



During therapy sessions

“If you seek peace, be still. If you seek wisdom, be silent. If you seek love, be yourself.” - Becca Lee

## Listen to parents and acknowledge their stories

### “I’m worried my child might have autism”

Ask probing questions but also listen and give parents an opportunity to tell you about their child.

#### 1. Prompt with affirming questions

“How would you describe your child?”

What potential barriers are impacting the child at home, day care, kinder or school?

What supports are in place to help the child?

#### 2. Acknowledge and listen

It's important that your clients have a safe space to talk, acknowledge without judgement. In some sessions you will be speaking the least.

You may say, “I can understand that you might be worried and this is difficult to manage.”



## The Assessment & Diagnostic Process

### Explaining the differential diagnostic process

For example a parent to a child with speech delay, you could say: "There are several reasons why your child might have delayed speech and communication. During our assessments we will look at each aspect of your child's development to see if we can uncover the underlying reasons for this delay."

Delayed speech and communication may be related to hearing difficulties, therefore a hearing assessment will be part of the process. It's important to communicate clearly with parents about the diagnostic process.

### The Holistic Assessment

Clearly describe each component of the assessment. The point of a holistic assessment is to get a whole individual picture of the child.

- Holistic assessments need to focus on the child's strengths
- Assessments should be helpful for the parents

Practitioners should collect information in the Assessment of Functioning that provides an understanding of the child's characteristics, functioning and their context, including their strengths and support needs, across activities.

### Evidence-based Assessment

Assessment frameworks for diagnosis must be evidence-based. Either use the Diagnostic and Statistical Manual of Mental Disorders, 5th edition text revision 2022 (DSM-5-TR) or the International Classification of Diseases (ICD-11). The DSM-5 criteria are the most used in Australia.

#### Essential features of Autism Spectrum Disorder the DSM-5-TR

##### Criteria A

Impairment in reciprocal social communication and social interaction.

##### Criteria B

Restricted, repetitive patterns of behavior, interests, or activities.

##### Criteria C & D

These symptoms are present from early childhood and limit or impair everyday functioning.

The stage at which functional impairment becomes obvious will vary according to characteristics of the individual and their environment.

Core diagnostic features are evident in the developmental period, but intervention, compensation, and current supports may mask difficulties in at least some contexts.



## How does the assessment fit with the National Guideline?

The Comprehensive Needs Assessment is a core component of all assessments for autism and seeks to understand all relevant aspects of the client's characteristics, functioning, context, strengths, and support needs.

### Objectives of Comprehensive Needs Assessment:

- connect client to relevant supports as early as possible
- determine if diagnostic evaluation is required
- to inform practitioner in diagnostic evaluation

**Assessment of Functioning:** Focused on understanding the client's characteristics, functioning, context, strengths and support needs.

**Medical evaluation:** focuses on client health, functioning and wellbeing, including medical history, physical examination and further clinical examinations.

### Consensus Team Diagnostic Evaluation:

multiple practitioners with specific qualifications, contributing to a consensus-based diagnostic decision.

### Lead Practitioner Diagnostic Evaluation:

A practitioner with medical or allied health qualifications, making a considered diagnostic decision. It's recommended to have at least one other relevant practitioner consulted.

## National Guideline Recommendations

### Recommendation 46

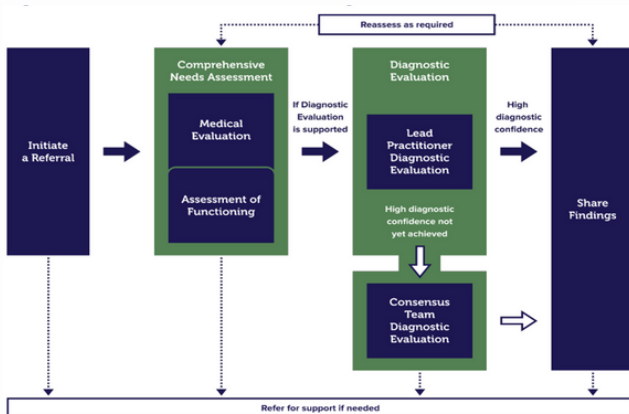
Where support needs have been identified, practitioners should inform the client of their support options and provide a referral if appropriate.

Support is the most important element in looking after the child and their family.

### Recommendation 46

Where the findings of the Assessment of Functioning are consistent with a possible diagnosis of autism, the next step/s in the assessment and diagnostic process should be initiated.

[Click here](#) to read the full PDF on the National Guideline Update.





## Feedback to parents & getting it right

### 1. Set up a formal feedback meeting

Where possible with both parents. If findings are consistent with diagnosis, explain **why** using the DSM-5 criteria.

Tip: Telehealth is a great tool for when parents are reluctant to commit to formal meetings in-person.

### 2. Formulate a clear summary of the report & recommendations

**Example clinical case report summary:**

*E's individual developmental profile shows strengths with counting, letters, and patterns. He has delayed verbal and non-verbal communication in both Cantonese and English, and in peer interaction. He enjoys playing by himself particularly in repetitive play with counting, sorting, stacking, and lining up and he develops routines in his play and interaction.*

*E has strong sensory preferences involving movement, taste, sound, and pressure. He often sought movement-based activities to calm his emotion often prior to activities with other children.*

*This presentation is consistent with the DSM-5-TR criteria for autism spectrum disorder. It is recommended that E complete a medical and diagnostic evaluation. It is also recommended that E receive Speech Pathology and Occupational Therapy early intervention and his parents and educators learn strategies to develop E's strengths and to support his development.*

### Supporting parents in next steps

Be prepared for various emotional responses and remember not to take their reaction personally. It is about what they are going through and everyone behaves and copes in stressful situations differently.

### Prepare for parent emotional reactions

- Fight, flight or freeze
- Anger, blame, shock, denial, fear
- Relief

### Client choice & control

- Processing time
- Next step is to support parents with however they choose to proceed with the information

### Keep up the great work including:

**Listening** to and acknowledging parent celebrations and fears

**Hypothesizing** & differentially diagnosing as you assess

**Gathering** qualitative and quantitative evidence for criteria

**Providing** clear feedback and referral pathways to parents for support and diagnosis

# About us

**Early Start Australia is a national organisation committed to delivering evidence-based early intervention and therapy services to children, young adults and families**



Everyone has different needs and abilities, so everyone's therapy journey is their own. We know it's not always easy. It can be confusing, frustrating and challenging. That's why we are here.

We help people realise their full potential, no matter where they are in their therapy journey, and no matter when they choose start it.

## Careers with Early Start Australia

As part of a national allied health organisation, there are opportunities to work around the country. We offer flexible working arrangements because we respect that people have varying needs and want you to be the best version of yourself at work. We provide comprehensive professional development to help you reach your full potential and be able to provide the best possible outcomes for our clients.

**To find out about our open roles visit the APM Careers website by clicking the button below or email our recruitment team about our job opportunities at [recruitment@earlystartaustralia.com.au](mailto:recruitment@earlystartaustralia.com.au)**

[Browse open roles](#)

## Get in touch with our speakers

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