Early Detection for Better Outcomes

Building capacity to identify and support children with early signs of autism in early childhood education and care settings

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To improve early identification of autism and other social and communication delays/disabilities so children and their families can get the services and support they need.

Research Aim



The Challenges



22% developmentally vulnerable (AEDC, 2013,2015, 2018)

2% incidence of ASD

12 months- diagnosis possible (Veness et al, 2012)

18 months- diagnosis reliable (Lord, 2006; Webb & Jones, 2009)

75-95% who receive **EARLY** intervention make excellent progress (Lord, 2014)

5.7 years median age of ID- worldwide

4-6 years in Australia (Bent et al , 2014)

Research evidence shows that *inclusive* and *family-centred* early intervention supports can:

- ✓ Prevent secondary complications (Dawson, 2008; Webb, Jones, Kelly, & Dawson, 2014)
- ✓ Improve communication, cognitive and adaptive skills (Clark, Vinen, Barbaro & Dissanayke, 2018)
- ✓ Receive more inclusive education placements (<u>Charman & Baron-Cohen, 2006</u>; Clark, Vinen, Barbaro & Dissanayke, 2018).
- ✓ Reduce stress for families (Zwaigenbaum et al., 2009; Charman, 2003)
- ✓ Increase opportunities for learning (Lord, 2014)
- ✓ Maximize early brain plasticity (<u>Dawson et al., 2010</u>; Edwards and Silva, 2017)





Inadequate monitoring of children's development in community settings prevents recognition of social, emotional, and behavioral challenges

- Less than one percent of young children with emotional behavioral problems are identified
- Nearly 55 percent of family practitioners and pediatricians report that they did not use a standardized tool to screen for developmental delays during routine well-child visits for two-year olds.
- Early childhood challenges can affect adolescent behavior and mental health

From Social-emotional Development in Early Childhood What Every Policymaker Should Know (Cooper, Masi and Vick, 2009)



"When educators have a deep understanding of children's social and emotional development, they are able to scaffold experiences that assist children in becoming confident learners" (Kids Matter Australian Early Childhood Mental Health Initiative, 2014)



Mental health= social, emotional and behavioural wellbeing

Best Practice Guidelines for Early Childhood

1. Family – the centre of all services and supports

Your family works together with early childhood intervention practitioners as active and equal partners where planning and interventions for your child are based on your family life and your priorities and choices.

2. All families are different and unique

Early childhood intervention practitioners provide services and supports in ways that are sensitive and respectful of your family's cultural, language and social backgrounds and your family's values and beliefs.

3. Your child at home and in the community

Your child is fully included and participates meaningfully in home and community life, with additional supports as needed, creating a real sense of belonging.

4. Your child practises and learns new skills everyday

Your child engages, learns and practises skills through participation in the activities and daily routines of their everyday life.

5. Team around your child

Your family works together with practitioners as a team around your child communicating and sharing information, knowledge and skills, with one main person, called a key worker, working with your family.

6. Building everyone's knowledge and skills

Building the knowledge, skills and confidence of your family and the important people in your child's life will have the biggest impact on your child's learning and development.

7. What you want for your child and family

Early childhood intervention practitioners will focus on what you want for your child and family and will work closely with you to achieve the best outcomes for your child.

8. Quality services and supports

Ensures that practitioners working with your child have appropriate qualifications and experience and base their intervention on sound clinical evidence and research.

endorsed by the NDIA and can be accessed on the <u>NDIA website</u>. https://reimagine.org.au/practitioner/what-is-best-practice/

Identification of developmental challenges enabling access to Early Intervention support requires:

1.Developmental Screening and/or Surveillance using *reliable* and *valid* methods by <u>frontline</u> professionals (GPs, maternal child health nurses or <u>early childhood education professionals</u>)

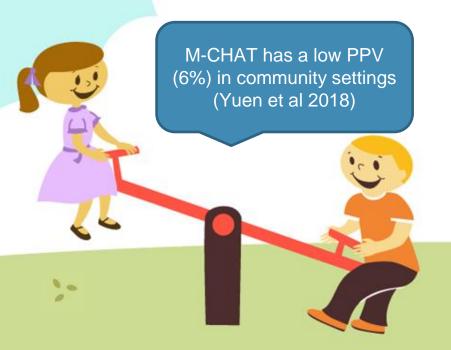
2. Comprehensive Diagnostic Evaluation by multidisciplinary team of specialists

^{*}See https://www.autismcrc.com.au/access/national-guideline for recently updated National Guidelines

Current Practice

PEDS alone may be 25% less sensitive when used without an autism-specific screening tool (Eapen et al 2014)

Over-referral rates up to 73- 80% have been reported for M-CHAT and PEDs in population screening contexts



Acme Pediatrics PEDS RESPONSE FORM Provider Child's Name Roger J. Parent's Name Malinda J. __ Child's Age ____ 2 ___ Today's Date ___ 8/10/07 Child's Birthday 8/8/05 Please list any concerns about your child's learning, development, and behavior. I'm worried about how my child talks and relates to us. He says things that don't have anything to do with what's going on. He's oblivious to anything but what he is doing. He's not doing as well as other kids in Do you have any concerns about how your child talks and makes speech sounds? Circle one: No (Yes) A little COMMENTS: He repeats odd things like "Wheel of Fortune" Do you have any concerns about how your child understands what you say? Circle one: No Yes A little COMMENTS: I can't tell if he doesn't understand, doesn't hear well or just ignores us Do you have any concerns about how your child uses his or her hands and fingers to do things? Circle one: (No) Yes A little COMMENTS: He's good with manipulatives but does a lot of the same things over and over: spinning wheels on cars, flicking light switches, flipping pages Do you have any concerns about how your child uses his or her arms and legs? Circle one: (No) Yes A little COMMENTS: He's very coordinated and very fast! Do you have any concerns about how your child behaves? Circle one: No Yes A little COMMENTS: still lots of tantrums but headbanging is almost gone. Behavior therapy has been helpful and his tantrums are less severe and shorter Do you have any concerns about how your child gets along with others? Circle one: No Yes (A little) COMMENTS: He doesn't seem interested in watching other kids, let alone playing with Do you have any concerns about how your child is learning to do things for himself/herself? Circle one: No Yes A little COMMENTS: He's very independent Do you have any concerns about how your child is learning preschool or school skills? Circle one: No Yes A little COMMENTS: He's too young for any of that!

Please list any other concerns.

We spend lots of time playing with Roger and talking to him. This seems to be helping him be more engaged. I still wonder about his hearing.

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Permission is granted to photocopy these scored forms for training purposes.

Translation and implementation of current/recent evidence

Social Attention and Communication Surveillance (SACS-R)- Olga Tennison Autism Research Centre

- Developed recently in Australia
- Over 30,000 children monitored in Victoria
- SACS method is now used in a variety of services in Poland, Korea, Japan, Nepal, and China.
- Play-based items for 12, 18, 24 and 42 months (4 x brief checklists)
- Best psychometric properties of any autism identification tool- 96% sensitivity; 99.6% specificity; 83% PPV (M-CHAT only 6% PPV without follow up interview) (Yuen et al, 2018; Petrocchi et al, 2020; Sánchez-García et al., 2019)
 - Now available as a mobile App, ASDetect



Local Partners













Over 20 Early Childhood Education and Care Centres and families





Translating research evidence into practice

Study 1: To establish interrater reliably of early childhood education professionals administration of SACS-R (Mozolic-Staunton, Donelly et al. 2017)

Study 2: To compare the effectiveness of current practice of developmental surveillance (PEDS-pathASD) with SACS when implemented across health and early childhood education settings

(Mozolic-Staunton, Donelly et al. 2020)



Study 3: To reduce the 2.5 to 5 year delay in access to EI BY PROVIDING early childhood professionals with reliable and valid tools and training to implement early detection (Mozolic-Staunton et al, 2021)

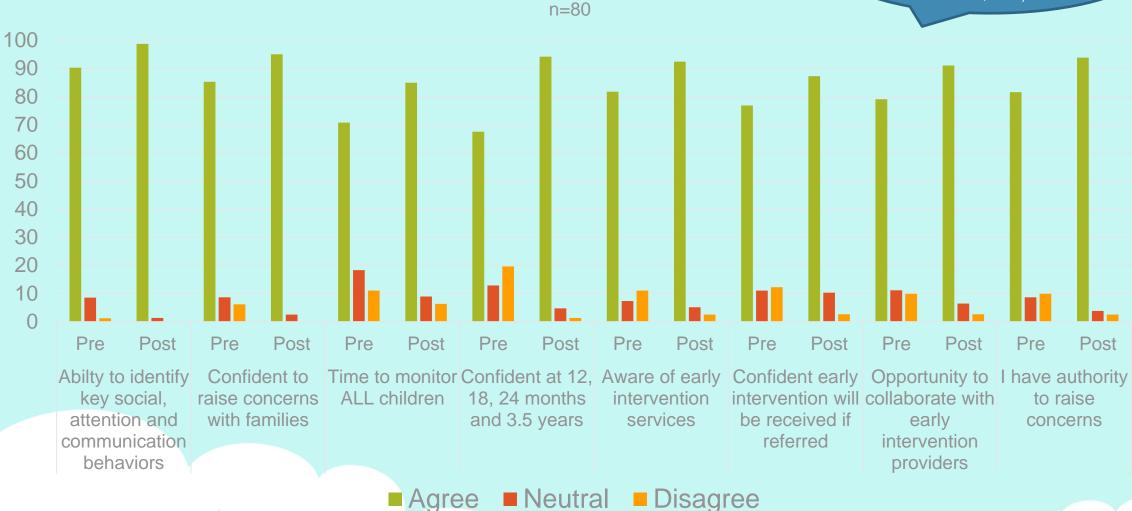
Data Collection and Key Findings

Context	Maternal Child Health	Early Childhood Education
Participants	184 Health Centre 241 Nurses 14,113 Children	20 Long Day Care 60 Early Childhood Educators 623 Children
Surveillance Method	Trained to id key markers for ASD Implement SACS-R and PEDS at 12, 18, 24 and 42 months Children with 3 key concerns on SACS-R or PEDS (Path ASD) referred for comprehensive developmental assessment	
Follow-up assessment	ADOS-2; M-CHAT; cognitive, motor, language + clinical judgement Referral to local early intervention supports	

	RESULTS	
Agreement	54.84%; k = 0.161, 95 % CI (0.81 to 0.241, p<.0005).	
Sensitivity	SACS= 82%	PEDS (Path ASD)= 6.7%
IRR	very high (k = 0.909). Between MCH nurses and Early Childhood Educators	

What do educators think?

85% of early childhood educators work with a child with a disability (NSW DET, 2019)



It seems children need a diagnosis before being able to access services

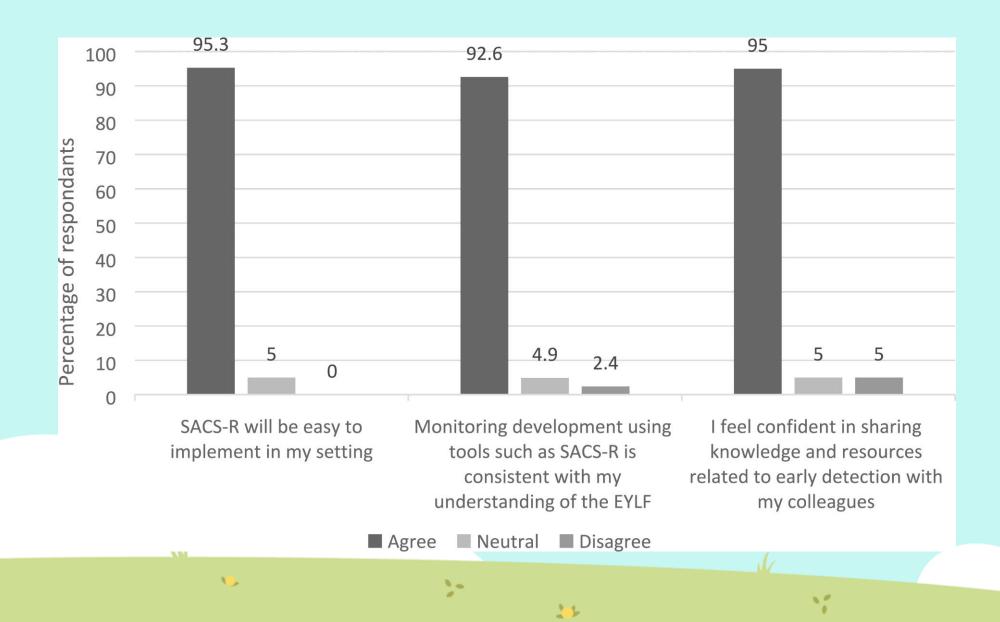
...long wait times for NDIS approval and the system is complex for families...[there have been] reduced community services due to NDIS, thus there are limited services for those children who do not qualify for NDIS.

I feel new graduates are very unequipped in the monitoring process and lack skills to discuss concerns with families...

I appreciate having more formal tools rather than relying on my anecdotal professional judgement



Post-workshop perspectives of early childhood education professionals



Conclusions

- Early Childhood Education Professionals are effective and reliable in implementing developmental surveillance at multiple points in a children's development (12, 18, 24 and 42 months) using SACS-R.
- Reliance on parent report alone via PEDS (as is current practice in many communities) has the potential to:
 - Miss 30% undergoing developmental monitoring due to poor rate of return on parent PEDS (completed by parents) vs. <1 % SACS-R (completed by professionals)
 - Miss highly likely cases of ASD or significant developmental challenges in this study if SACS was not used due to very low sensitivity rate of 6.7 % for PEDS (path ASD) vs. SACS-R (82%)



Through specific early detection practices, families of young children who are showing signs of autism or other developmental challenges may be able to access specialised support, intervention and resources in a timely manner to maximize developmental potential.





What's going on with the NDIS?

And how can community-based early childhood professionals can leverage these resources to promote better outcomes for individuals with autism?

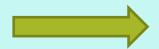
Core Principles
Holistic assessment
Individual and family-centred
Lifespan perspective
Evidence-based

Early Childhood Approach



Through early childhood intervention, infants and young children as well as their families, can get specialised supports and services

- Children < 7 yrs with developmental delay or disability
- Children who do not fully meet the <u>definition of developmental delay</u>, but <u>developmental concerns</u> have been identified will also be supported through ECA



- Early Connections
- Connections with mainstream and community services
- Connections to practical information that's relevant to your child's development
- Connections with other families for peer support
- Connections with early supports
- Connections to apply to the NDIS



To get early connections, you can <u>contact an early childhood partner</u> but it is often best to first make contact with your GP, child health nurse, health service or <u>early childhood educator</u>.



NDIS supports for Developmental Delay- Early Childhood Approach

Diagnosis is NOT necessary

Report: Increase Early Childhood partner capacity to identify and help young children and families from hard-to-reach communities or those experiencing disadvantage or vulnerability, so they can connect to – and benefit from – early intervention supports.

NDIS defines developmental delay:

- is <u>due to mental or physical impairments</u>
- <u>substantially reduces the child's functional capacity</u> compared with other children the same age.
- means the child needs specialist services from more than one professional working as a team to support the child and for longer than 12 months.

Evidence from a health, allied health or **early childhood professional**, who uses multiple sources of information about the child's ability to do everyday activities.

This will include information that parents or carers report about their child. It will also include a mix of standardised assessments of developmental and functional capacity, both in everyday activities and natural settings.

It should also include observations in everyday play, learning, activities or routines to better understand how the child participates in these everyday activities.

Independent Assessment- watch this space- ongoing policy changes are underway

- The assessment tools included for children aged 1-6 years are:
 - Ages & Stages Questionnaire (ASQ-3) OR Ages & Stages
 Questionnaire -Talking About Raising Aboriginal Kids (ASQ-TRAK)*
 - PEDI-CAT (Speedy) OR PEDI-CAT ASD (Speedy)
 - Vineland-3 Comprehensive (Interview Form)
 - Young Children's Participation and Environment Measure (YC-PEM) for children under 6 years
 - Participation and Environment Measure Children and Youth
 (PEM-CY) for children 5+ years
 - See NDIA- Tools paper Appendix

Read all 23 Recommendations

https://www.ndis.gov.au/community/welistened/you-said-we-heard-postconsultation-reports/supporting-youngchildren-and-their-families-early-reachtheir-full-potential

No autism-specific assessment tools have been included in the proposed NDIS IA plan

Links and Resources

- Barbaro J, Sadka N, Gilbert M, et al. Diagnostic Accuracy of the Social Attention and Communication Surveillance—Revised With Preschool Tool for Early Autism Detection in Very Young Children. *JAMA Netw Open.* 2022;5(3):e2146415. doi:10.1001/jamanetworkopen.2021.46415
- Link to full text: https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2789926
- https://www.latrobe.edu.au/otarc/asdetect
- https://www.aota.org/Practice/Children-Youth/Autism.aspx
- https://www.inclusioned.edu.au/
- https://www.autismcrc.com.au/knowledge-centre
- https://ourguidelines.ndis.gov.au/early-childhood/early-childhood-approach
- https://www.ndis.gov.au/community/research-and-evaluation/early-childhood-interventions-our-research/autism-crc-early-intervention-report#report-summaries
- https://www.ndis.gov.au/community/we-listened/you-said-we-heard-post-consultation-reports/supporting-young-children-and-their-families-early-reach-their-full-potential
- https://www.ndis.gov.au/participants/independent-assessments/independent-assessment-toolkit
- https://www.autismcrc.com.au/interventions-evidence
- Recommended- Early Childhood provider report form

References

Australian Government. (2019). Australian Early Development Census. Retrieved from https://www.aedc.gov.au/resources: https://www.aedc.gov.au/data/data-explorer?id=62249

Australian Government Department of Health, Beyond. Blue., Australian Psychological Association and Early Childhood Australia. (2014). KidsMatter Early Childhood Mental Health Initiative. Commonwealth of Australia Retrieved from https://www.kidsmatter.edu.au/.

Barbaro, J., & Dissanayake, C. (2009). Autism spectrum disorders in infancy and toddlerhood: A review of the evidence on early signs, early identification tools, and early diagnosis. *Journal of Developmental and Behavioral Pediatrics*, 30(5), 447-459.

Barbaro, J., & Dissanayake, C. (2009). Autism spectrum disorders in infancy and toddlerhood: A review of the evidence on early signs, early identification tools, and early diagnosis. *Journal of Developmental and Behavioral Pediatrics*, 30(5), 447-459.

Barbaro, J., & Dissanayake, C. (2010). Prospective identification of autism spectrum disorders in infancy and toddlerhood using developmental surveillance: The social attention and communication study. *Journal of Developmental and Behavioral Pediatrics*, 31(5), 376–385. https://doi.org/10.1097/DBP.0b013e3181df7f3c

Bent, C. A., Dissanayake, C., & Barbaro, J. (2015). Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010–2012. *Medical Journal of Australia*, 202(6), 317–321. doi:10.5694/mja14.00328

Barbaro, J., Sadka, N., Gilbert, M., Beattie, E., Li, X., Ridgway, L., Lawson, L. P., & Dissanayake, C. (2022). Diagnostic Accuracy of the Social Attention and Communication Surveillance–Revised With Preschool Tool for Early Autism Detection in Very Young Children. *JAMA Network Open*, *5*(3), e2146415. https://doi.org/10.1001/jamanetworkopen.2021.46415

Clark, M. L. E., Vinen, Z., Barbaro, J., & Dissanayake, C. (2018). School Age Outcomes of Children Diagnosed Early and Later with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 48(1), 92-102. doi:10.1007/s10803-017-3279-x

Chawarska, K., Klin, A., Paul, R., & Volkmar, F. (2007). Autism Spectrum Disorder in the second year: Stability and change in syndrome expression. *Journal of Child Psychology and Psychiatry*, 48(2), 128–138.

Cooper, Masi, R, Vick, J., 2009, Social-emotional Development in Early Childhood: What Every Policymaker Should Know, Columbia University Academic Commons, https://doi.org/10.7916/D83B67VS.

Dawson, G. (2008). Early behavioral intervention, brain plasticity, and the prevention of autism spectrum disorder. *Development and Psychopathology*, 20(3), 775–803. Retrieved from http://www.scopus.com/inward/record.url?eid=2-s2.0-48949116395&partnerID=40&md5=84bfd62762638b344feb2c146faa0642

Early Childhood Intervention Australia. (2016). National guidelines for best practice in early childhood intervention. https://www.ecia.org.au/documents/item/186

Garg, P., Lillystone, D., Dossetor, D., Kefford, C., & Chong, S. (2014). An exploratory survey for understanding perceptions, knowledge and educational needs of general practitioners regarding autistic disorders in NSW, Australia. *Journal of Clinical and Diagnostic Research*, 8(7), PC01–PC09. Retrieved from http://www.scopus.com/inward/record.url?eid=2-s2.0-84904809746&partnerID=40&md5=8656ae3ac429dba000ada4a62ccc92d9

Glascoe, F. P., Macias, M. M., Wegner, L. M., & Robertshaw, N. S. (2007). Can a broadband developmental-behavioral screening test identify children likely to have autism spectrum disorder? Clinical Pediatrics, 46(9), 801–805. Retrieved from http://www.scopus.com/inward/record.url?eid=2-s2.0-35048827344&partnerID=40&md5=40a638b9da0804fb06d2608ccb6dafd1

Lord, C., Petkova, E., Hus, V., Gan, W., Lu, F., Martin, D. M., . . . Risi, S. (2012). A multisite study of the clinical diagnosis of different autism spectrum disorders. *Archives of General Psychiatry*, 69(3), 306–313. Retrieved from http://www.scopus.com/inward/record.url?eid=2-s2.0-84857943542&partnerID=40&md5=2ec2369dcf2ef3c013844c2cd0a1755c

Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. L. (2012). *Autism Diagnostic Observation Schedule (ADOS-2)* (Second Edition ed.). Torrence, CA: Western Psychological Services.

Maenner, M. J., Shaw, K. A., Bakian, A. V., Bilder, D. A., Durkin, M. S., Esler, A., Furnier, S. M., Hallas, L., Hall-Lande, J., Hudson, A., Hughes, M. M., Patrick, M., Pierce, K., Poynter, J. N., Salinas, A., Shenouda, J., Vehorn, A., Warren, Z., Constantino, J. N., . . . Cogswell, M. E. (2021). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. Morbidity and mortality weekly report. Surveillance summaries (Washington, D.C.: 2002), 70(11), 1-16. https://doi.org/10.15585/mmwr.ss7011a1

McLean, K., Goldfeld, S., Molloy, C., & Wake, M. (2014). Screening and surveillance in early childhood health: Rapid review of evidence for effectiveness and efficiency of models. Retrieved from Melbourne Victoria: www.health.nsw.gov.au/kidsfamilies/MCFhealth/Documents/screening-and-surveillance-in-early-childhood.pdf Not mentioned in text. Please add in text or remove from here.

Mozolic-Staunton, B., Donelly, M., Yoxall, J., & Barbaro, J. (2017). Interrater reliability of early childhood education professionals involved in developmental surveillance for autism spectrum disorder and related conditions. *Australasian Journal of Early Childhood, 42*(2), 61–68. http://dx.doi.org/ 10.23965/ajec.42.2.08

Mozolic-Staunton, B., Donelly, M., Yoxall, J., & Barbaro, J. (2020, 2020/03/01/). Early detection for better outcomes: Universal developmental surveillance for autism across health and early childhood education settings. Research in Autism Spectrum Disorders, 71, 101496. https://doi.org/10.1016/j.rasd.2019.101496

Myers, C. L., Gross, A. D., & McReynolds, B. M. (2013). Broadband Behavior Rating Scales as Screeners for Autism? *Journal of Autism and Developmental Disorders*, 1–11. Retrieved from http://www.scopus.com/inward/record.url?eid=2-s2.0-84888218615&partnerID=40&md5=5de151570549d4cb62eb03f37031457e

National Disability Insurance Agency. (2019). *Autism Advisory Group August 2019 communique*. Canberra, Australia Retrieved from https://www.ndis.gov.au/about-us/reference-group-updates/autism-advisory-group-august-2019-communique.

National Disability Insurance Agency (2022). Developmental delay for children under 6 years. Retrieved 29 July 2022 from https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/what-about-children-younger-6-developmental-delay

Olga Tennison Autism Research Centre (2022). Advances in early detection of Autism. Retrieved 29 July 2022 from www.latrobe.edu.au/otarc/researchers/early-detection-research

Petrocchi, S., Levante, A., & Lecciso, F. (2020). Systematic Review of Level 1 and Level 2 Screening Tools for Autism Spectrum Disorders in Toddlers. Brain Sciences, 10(3), 180. https://www.mdpi.com/2076-3425/10/3/180

Robins, D. L. (2008). Screening for autism spectrum disorders in primary care settings. Autism: *The International Journal of Research & Practice*, 12(5), 537–556. Retrieved from 10.1177/1362361308094502

http://ezproxy.scu.edu.au/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=ehh&AN=34354291&site=ehost-live

Sánchez-García, A. B., Galindo-Villardón, P., Nieto-Librero, A. B., Martín-Rodero, H., & Robins, D. L. (2019, January 08). Toddler screening for autism spectrum disorder: A meta-analysis of diagnostic accuracy [journal article]. Journal of Autism and Developmental Disorders. https://doi.org/10.1007/s10803-018-03865-2

Shattuck, P. T., Durkin, M., Maenner, M., Newschaffer, C., Mandell, D. S., Wiggins, L., . . . Cuniff, C. (2009). Timing of identification among children with an autism spectrum disorder: findings from a population-based surveillance study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 48(5), 474–483. doi:10.1097/CHI.0b013e31819b3848

Veness, C., Prior, M., Bavin, E., Eadie, P., Cini, E., & Reilly, S. (2012). Early indicators of autism spectrum disorders at 12 and 24 months of age: A prospective, longitudinal comparative study. *Autism*, 16(2), 163–177. doi:10.1177/1362361311399936

Webb, S. J., Jones, E. J. H., Kelly, J., & Dawson, G. (2014). The motivation for very early intervention for infants at high risk for autism spectrum disorders. *International Journal of Speech-Language Pathology*, 16(1), 36–42. Retrieved from http://www.scopus.com/inward/record.url?eid=2-s2.0-84892575644&partnerlD=40&md5=a02a08753a405f570a58b7de497c0ad6

Vivanti, G., & Dissanayake, C. (2016). Outcome for Children Receiving the Early Start Denver Model Before and After 48 Months. *Journal of Autism and Developmental Disorders*, 46(7), 2441-2449. doi:10.1007/s10803-016-2777-6

Yuen, T., Penner, M., Carter, M. T., Szatmari, P., & Ungar, W. J. (2018). Assessing the accuracy of the Modified Checklist for Autism in Toddlers: a systematic review and meta-analysis. Developmental Medicine and Child Neurology, 60(11), 1093-1100. https://doi.org/10.1111/dmcn.13964