Washington State Autism Center of Excellence (COE)

Increasing Access to Quality Autism Evaluations and Support:

COE Quick Start Guide

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Note: This PDF guide has internal and external links to direct you to additional information. Click on the table of contents below to skip to a particular section or click embedded cross-references to jump to a section of the guide as well. If you notice a broken link, errors, or have suggestions for content, please email us at autismcoe@uw.edu.

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INTRODUCTION

Welcome, Washington State Autism Center of Excellence (COE) provider. Thank you for beginning your learning adventure and showing an interest in improving access to quality care for autistic individuals and their families, especially autism diagnostic evaluations. You are choosing to be part of a thoughtful and impactful group of clinicians, primary care providers (PCPs), and other partners who are working together to decrease the long, inequitable waits for autism diagnostic services for children and youth with Medicaid insurance in our state. This is an essential service. Families are grateful and appreciative of your work and help in providing these services.

Some COE providers choose to limit evaluations to current patients. Others decide to see patients in their clinic or healthcare system or beyond. Whatever role you choose, the knowledge you gain in working with autistic patients will also help you as a primary care medical home or specialist. With 1 in 36 children having autism (CDC, 2023), you are already serving this population. Congratulations on seeking out additional training and support so you can provide efficient and mutually satisfying family-centered care to your autistic patients.

This guide is designed to help you jump start your autism evaluation practice. It has a variety of sections for your reference, and we hope that it will be a helpful resource. It is not designed to be comprehensive in nature or to replace continuing education or other supports such as participating in ECHO Autism Washington. The goal is to give you what you need to get started in a systematic way without being overwhelming (hopefully!). Throughout, there are embedded links to other resources so you can explore certain sections or topics in more depth if you desire.

As you get started, use this manual to help you plan your practice and take it a step at a time. Build your practice slowly and gain experience and confidence as you go. You can do this and there are lots of people and resources out there beyond this manual to set you up for success.

Thanks again for your willingness to help!

"COE work has been some of the most rewarding work I've done in a long time in terms of people appreciating what you are doing for them." – Jim Troutman, MD, Snohomish County



GETTING STARTED

Obtaining Buy-in from your Administration

Participating in diagnostic evaluations and meeting the individualized needs of youth with autism and their families can be time-consuming and costly. **However, you are already serving these patients**. At 1 in 36 children diagnosed with ASD (<u>CDC, 2023</u>), your practice sees autistic youth, many of whom are struggling to access appropriate care and/or are on long waitlists for diagnostic evaluations. It can be difficult to get approval and support from your administration to do this work in a sustainable way, but it is an important first step in getting started as a COE.

When advocating with your administration to better serve these families or grow your practice to accommodate these families, some talking points to emphasize are:

- **Positive impact**. Families who can see providers that already know their family and can work with them long term experience greater continuity of care. This work is an important part of serving as a medical home and providing comprehensive care to your patients.
- Reducing waitlists. There are long wait times for evaluation at tertiary care centers like
 Children's Village, Multicare Mary Bridge Children's Hospital, Seattle Children's Autism
 Center, or the Washington State University Autism and Neurodevelopmental Program. These
 waitlists can be over two years. Delayed diagnosis leads to delayed access to appropriate
 supports, resulting in significant stress and reduced opportunities for intervention. Early
 diagnosis leads to better outcomes for individuals and their families.
- Increasing equity. Primary care is often the location with the best connection to underserved populations. Many families are unable to travel to tertiary care centers or cannot afford private evaluations. They rely on primary care to serve as a medical home.

Before you approach your administration:

- **Be prepared**. Think about what the process would look like. You may want to bring examples of appointment templates, billing codes, and reimbursement rates. You also want to consider your staffing needs. Consider writing a formal proposal with this information (*Appendix A*).
- **Share successes**. Share that other community clinics have been successful in implementing this work in their setting. Clinics can set boundaries around referrals to keep the work manageable. For example, many practices start with current patients or internal referrals only and focus on younger children. Clinics can also control the number of appointments per week or month, so that providers are not overwhelmed by the work (*Appendix B*).
- **Be persistent**. Multiple conversations are often needed to get the ball rolling. If necessary, identify allies who can help with advocacy, such as members of the <u>Washington INCLUDE</u> Collaborative or other COEs and their administrations who have made it work.

See <u>Appendix A. Primary Care Autism Clinic Proposal</u> for an example of a comprehensive proposal to begin a primary care autism diagnostic clinic with goals, logistics, costs, and process built in.

See <u>Appendix B. COE Provider Presentations at Autism COE Trainings</u> for presentations given by other Washington State Autism COE providers on various topics. These topics are often relevant to those starting a new practice or addressing common barriers in practice settings.

See the <u>American Academy of Pediatrics' tip sheet on Autism Diagnosis in Primary Care</u> for additional ideas on setting up your practice for autism diagnostic work.

Identifying Community Partners and Resources

Remember, you do not need to do this alone! Identifying providers from other disciplines to collaborate with around patient care can lead to multi-disciplinary evaluations that many feel are best practice. It is also important to be aware of the resources available to support families and individuals both locally and across the state. To get started, ask yourself:

What is your scope of practice? You do not need to evaluate every child with autism concerns, especially those who may require more specialized diagnostic evaluation due to complicating factors. By doing evaluations that feel within your scope of practice, such as with younger children or those with more clear presentations, you are freeing space for more complex children to be seen at tertiary care sites in your region. See Referral and Triage section for more information.

Are there local providers who can complete an additional assessment? If your review of history, review of documents/outside testing, and observational assessment leave you unsure of the diagnosis, see if there is someone you can partner with in the process. Consider local psychologists, speech-language pathologists, occupational therapists, behavior analysts, Birth-Three Centers, and local school districts. These providers may have training in administering and interpreting diagnostic tools, like the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), or can provide you with additional information to report using tools like the Child Autism Rating Scale, 2nd Edition (CARS-2) or Monteiro Interview Guidelines for Diagnosing the Autism Spectrum, 2nd Edition (MIGDAS-2). See <u>Diagnostic Evaluation</u> section for more information on components of a comprehensive evaluation and possible tools to use.

Is there a local School Medical Autism Review Team (SMART) or coalition to support you? Many communities already have COEs working with community partners (early intervention, schools, public health, family support etc.) to provide interdisciplinary evaluations and/or improve communication and coordination from screening to diagnosis to support services. Connect with work already happening locally or get help bringing in new partners to support autism evaluations in your clinic or community. To learn more visit the <u>SMART webpage</u> or email <u>Kate Orville, MPH</u>.

Who can I go to when I have questions? It is helpful to know who else in your community is doing this work, so that you can ask them questions when they come up. This might be another provider in your organization, such as a developmental behavioral pediatrician, or a colleague from another agency with more experience doing this work, such as another <u>COE provider</u>. You can get connected to others through participation in <u>ECHO programs with the Washington INCLUDE Collaborative</u> or joining a <u>SMART team community</u>, or you can also reach out to the <u>Partnership Access Line (PAL)</u> for consultation as needed. Some providers also create regional consult groups.

What are my local community resources? Consider what types of services and supports are available to families in your area. It is important to gain more information about what is available to share with families following the evaluation process. Resources can cover a range of topics such as evidence-based interventions, educational navigation, financial supports, parent education, or social and recreational opportunities. We recommend having your region's Arc Parent-to-Parent coordinator contact information (scroll down to see list by region) easily accessible to share with families as a first step. See Appendix C. Washington State Resources for other resources.

Designing your Workflow

There are many options for how to structure the evaluation process, which need to take into account your specific context. Consider what is realistic and sustainable to your situation. If you try to be a one-stop-shop and do it all, you will likely not have enough time and burn out. It is vital to have ancillary staff to support the process. And while there is no one best model for an evaluation, there are some best practices to keep in mind as you think about what is going to work for your clinic. And remember, you can always adjust your model after you have begun.

To get you started, here are some questions you should ask yourself and your team:

What age group do we start with? Sometimes, beginning evaluations with younger children can be helpful before you see older and possibly more complex patients. For those working with older children, consider starting with more straightforward cases, and find opportunities for shadowing or more hands on training. See <u>Referral and Triage</u> for more information.

How many evaluations are realistic? Many providers already have a full schedule. How much time are you able dedicate to conducting evaluations and how spread out do those visits need to be? How often can you do that? It is important to start slowly so you can learn the process, but remember that the best way to become confident doing autism evaluations is to do autism evaluations. Try to schedule regularly enough to gain experience, knowing with time it gets easier.

Who is a part of your team? Autism evaluations have a lot of moving parts, from processing and triaging referrals, scheduling appointments, conducting intakes, doing the evaluation interviews and observations, documenting, billing, and providing follow-up to individuals and their families. Determine who is part of the process. For example, who will be calling families, scheduling visits, and collecting records? If families have questions, who should they speak to? Who is following up with families about accessing resources? Have regular meetings with this team to check in.

How can we make our space accessible? Many primary care spaces are not designed for autism diagnostic practice. Consider how to make your space welcoming and accessible for evaluations. For example, you may have a room set up differently with age-appropriate toys for play-based observations (see <u>Appendix D. Evaluation set up tips, toys, and observation examples</u>). You might also have a sensory friendly waiting area or a toolkit available (see <u>Autism Sensory Strategies</u>, <u>Information, and Toolkit (ASSIST)</u> for information about sensory differences and strategies).

What model of evaluation is best for our practice? Again, there is no one size fits all evaluation model. Some clinics do a day long visit, while others have multiple shorter visits for each stage of the evaluation and allow for time to collect outside information. Additionally, some use a single discipline model (e.g., private practice psychologists), multidisciplinary approach (common in primary care with referrals to community providers as needed to gather more information), or an interdisciplinary team (common at tertiary care centers). Consider whether you are able to do multi-disciplinary team assessments (e.g., collaborating with 0-3 Early Support for Infant and Toddlers (ESIT) providers, school staff, SLPs) or whether there is staff to assist families completing forms (e.g., community health workers, medical assistants, or other administrative staff).

See Appendix E. Overview of Evaluation Workflow for ideas about how to set up and structure your workflow.

COMPONENTS OF A COMPREHENSIVE EVALUATION PROCESS

Referral and Triage

One of the first barriers to overcome when getting started with COE work is understanding which cases are within your current scope of practice, and which fall outside of it. You also want to consider whether you will focus only on current patients, internal referrals, or referrals from outside your practice. There is always room for growth, but it helps to identify a place to start!

Many PCPs feel most prepared to evaluate younger children already in their practice and choose to start here. In fact, <u>research shows</u> that PCPs who receive additional training in autism can be just as accurate as specialists when making a diagnosis of autism for young children. There are many factors that contribute to this success. Younger children often have an existing relationship with a service or school system (e.g., ESIT or developmental preschool program), and there is easily accessible information on developmental concerns and current behaviors. These providers can also be given questionnaires to gather additional information. They can also help families complete any paperwork or prepare for their evaluation, and following a diagnosis, they can help guide families toward local resources. Lastly, there are a greater variety of accessible diagnostic tools and questionnaires that can support primary care autism evaluations with younger children.

There <u>has not yet been research</u> looking into accuracy of non-specialist autism evaluations for older or more complex patients. Available research suggests that non-specialists struggle with accurate rule-outs for a diagnosis of autism. When evaluating these individuals, there is often a greater variability in autism symptomology, increased numbers of differential diagnoses, and additional domains of functioning to consider. A <u>review article</u> of various guidelines, policies, and pathways for autism evaluations highlights the complexities of serving such a diverse population, and offers suggestions for timely, quality, and person- and family-centered care to those in need of autism diagnostic services and supports. The National Institute for Health and Clinical Excellence (NICE) in the UK provides <u>guidelines for diagnosing children up to age 19</u>, and has specific examples of signs and symptoms of possible autism listed by age group (for a summary of their recommendations on what to look for and when to refer, click <u>here</u>). <u>Holland Bloorview</u> has similar age-based guidance for structuring your diagnostic evaluations and decision making.

Even with this information alongside appropriate training and continuing education, it can be hard to decide where to start. Heather Buzbee, a Pediatric Psych NP and COE provider at Sea Mar Community Health Center, recognized this confusion regarding which patients primary care COE evaluations are appropriate for. In response, she worked closely with her team to develop the Autism Primary Care Complexity Triage (APCCT) tool (see Appendix F. Autism Primary Care Complexity Triage (APCCT) tool for full tool). This tool provides a framework you can use to determine your readiness to evaluate patients based on several facilitating or complicating factors, such as age, gender identity, language of care, records access, medical or psychiatric cooccurring conditions, and psychosocial vulnerabilities.

Intake Process

Having a clear intake process, typically consisting of a packet of paperwork for families to review and complete prior to their first appointment, significantly reduces the amount of time required for administrative staff and providers to complete evaluations. An intake packet can include information about what to expect, questionnaires to complete prior to the visit, release of information (ROI) forms, etc. You can also create different packets by age. This ensures that when a family is scheduled for their first visit, you have everything you need to complete the visit.

If you use an electronic medical record (EMR) system, consider having an electronic version of the intake that individuals can return via a HIPAA-compliant system; this makes information immediately accessible and reduces the need for managing paper records. If you do this, you may want to include instructions in your message, such as how to open the attachment, how to return it via the EMR, and how to respond to the original message so it goes directly to the team. You may also want to make your electronic form "fillable." This means that the document does not have to be printed, written on, and scanned, but can be typed into directly by families. If you do this, make a form that families can fill out without needing to worry about formatting issues.

An intake packet could include:

Clinic Information. Provide families and individuals with information about what to expect during their visit, such as how long the process will take (e.g., how many visits, how long they are, and how far apart they tend to be scheduled) and what team members are involved (e.g., first meeting to collect background information with one provider before meeting with another provider for an observational assessment). You can also provide information about clinic policies and procedures, insurance coverage and billing, and payment expectations.

Screening Questionnaire. Decide whether families will complete a screening questionnaire as part of their intake process. Screening tools can help while triaging appointments to different team members. For example, a very high-risk patient may move directly into a visit with an experienced provider, while a lower-risk individual is scheduled for a developmental interview with a less specialized provider. You may also find a screener has already been completed with ESIT or through another provider, which is why they were referred to you.

History Questionnaire. Having families complete a medical, developmental, and psychosocial history form in advance can help the team expedite the screening, interview, and evaluation process. Having this information prior to a visit can help the team plan for the evaluation, such as what additional questions to ask, what records to collect, and what tools to use.

Release of Information (ROI). If this child is being served by other agencies, it can help to have the family complete an ROI as part of the intake process, so that your team can start to request records or open communication with those providers. Have two forms pre-populated – one to get information back and one to send information afterward – and include both in the packet. Consider having additional pre-filled ROIs ready for the feedback appointment so that the family can request sharing the document directly with whomever the family wants.

Outside information. It can be helpful to include forms you want a family to have completed by other providers in this packet (with the accompanying ROI for any follow-up as described above). For example, the <u>Teacher Information Form (TIF) and Provider Information Form (PIF)</u> are two short questionnaires that can be shared with a child's school or outside therapist. Make sure there are clear steps for how forms can be returned to your team (e.g., a fax number or HIPAA-compliant online process). Since you cannot guarantee a family will share the forms or whether they will be returned, you may want to stick with general information forms like the TIF or PIF that can be printed as many times as needed, rather than forms that require you to purchase each copy. You can always follow-up with another questionnaire afterward.

See <u>Appendix G. Intake packet example</u> for an example of what you might choose to include, such as clinical information and a history questionnaire for parents to complete. Additional intake packet materials, such as screening questionnaires and outside information forms like the TIF and PIF can be found in the <u>COE resources folder</u>.

Diagnostic Evaluation

Scheduling your Visits

Scheduling visits in a way that fits with your workflow is key. Get control over your own schedule if you can, or work with your scheduling team so that you have oversight of how scheduling is unfolding. Consider pre-screening potential appointments to make sure it is appropriate for an evaluation before scheduling fills your slots. In addition to a pre-screening process, consider how you will have ongoing communication with your scheduling team. It is much easier (and less stressful for both staff and families) to delay initial scheduling than to correct the problem when a patient is incorrectly put onto the schedule.

If you cannot control your own schedule or access the scheduling process, you may be able to build pre-screening criteria (e.g., age, language of care, whether there are multiple diagnoses, whether certain paperwork is completed first, etc.) and state that all appointments must be scheduled for a certain amount of time out so you can review. You may also choose to give schedulers a list of patients, but this may only work if you are scheduling fewer appointments.

Here are some additional considerations for scheduling:

Contact information. The Washington State Health Care Authority (HCA) maintains a list of <u>Autism COE provider</u>. It is important to make sure that the contact person and phone number on that list are accurate and have the information needed to field calls or questions. This contact information should be checked regularly and can be easily updated with a simple email to the HCA ABA/COE program manager (ABA@hca.wa.gov).

Clinic model. Consider your overall model and workflow. Are you doing dedicated evaluations that often have longer appointment times or are you fitting visits into a more traditional primary care model with shorter appointments happening over several weeks? Are you doing single discipline evaluations, referring to additional providers, or working with a team? More appointments with multiple providers require more complex scheduling practices but may fit better into your current workflow and availability.

Administration and documentation time. Evaluations require a lot of behind the scenes work that are not a part of the face-to-face visit. Depending on how you are billing the visits, you may need to block time on the same day as your appointment in order to be reimbursed for that documentation time, or you may be able to bill that time separately in specific circumstances.

Support families and schedulers. Your scheduling team is the group that likely has the most contact with families before a visit. Make sure to support your schedulers by providing them with the information that families may ask about, such as what to expect from a visit, how long it will take, what they need to do in advance, etc. Ideally, this information was included in your intake packet, but many families get overwhelmed by paperwork and may prefer to ask a scheduler.

Ask about unmet needs. Many families have additional unmet needs and may require extra support to attend or participate in their appointments. For example, do you have an easy way to determine whether a family will need an interpreter present for the visit? And have you accounted for the additional time it would take to conduct your visit with an interpreter? Additionally, consider transportation barriers and needs, or families who may need additional reminder calls for their appointment. You may choose to provide an overview of the supports you offer to all families to let them know you are wanting to work with them around their needs.

Conducting your Evaluation

There are a number of best practice guidelines and recommendations for diagnosing autism (e.g., American Academic of Pediatrics, National Research Council, National Institute for Health and Clinical Excellence [NICE]), which emphasize the need for comprehensive evaluation of multiple domains of development. While specific diagnostic tools provide reliable, quality information for your assessment, PCPs may not have access to the same tools as tertiary care or research clinics. Remember that best practice also includes timely access to care in local communities and there is evidence that PCPs can diagnose autism as accurately as specialists for younger populations. In addition, your ability as a PCP to follow patients and build relationships over time surpasses what can be accomplished at tertiary care centers in regard to care planning following the diagnosis.

Another important step in conducting your evaluation is identifying and assigning roles to each member of your evaluation team. Patients, families, and caregivers should be considered the central members of your team, working alongside others such as medical providers (e.g., primary care providers, doctors, nurses, psychiatrists, developmental pediatricians, neurologists, etc.), behavioral health providers (e.g., occupational, speech, physical therapists), psychologists, and administrative staff (e.g., front desk staff, schedulers, clinic director, etc.).

When conducting your evaluation and making decisions about which tools to use, you also need to consider how to collect information around three components of a comprehensive process: 1) requesting records and reviewing information from those familiar with the patient outside the family where possible (e.g., teachers, therapists, childcare providers); 2) interviewing on medical, psychosocial, and developmental history as well as autism symptomology; and 3) completing a structured observation to directly assess autism symptomology.

- 1) Record Review. Ask for records related to previous evaluations and services, such as the early intervention Individualized Family Service Plan (IFSP) or school Individualized Education Plan (IEP) or 504 documentation. Outside therapy records (e.g., speech or occupational therapy) are also helpful when available. These records often contain information on developmental, cognitive, language, and/pr adaptive functioning, which are important pieces of information to include in your decision making. You can also use a brief questionnaire, such as the Teacher/ Provider Interview Form, to collect information from school, daycare, or therapists. For older individuals, consider gathering employment and occupational information as well.
- **2) Detailed Interview**. In addition to general interviewing focused on medical, developmental and psychosocial history, a structured autism diagnostic interview will help you ask questions related to symptoms associated with ASD and identify strengths and weaknesses. This interview is also an opportunity to explore family readiness for a diagnosis and perspective on their child's strengths and challenges. Keep in mind that a formal DSM-5 checklist is require by most payors, so your interview needs to touch on all parts of the diagnostic criteria. This is one reason why using a structured and validated interview guide (e.g., TASI, MIDGAS-2, ADI-R) can be beneficial.
- 3) Structured Observation. There are many validated observation tools, which provide reliable, quality information for your decision-making process, so consider how to access them whenever possible. You may choose to partner with another provider to complete a formal observation like an ADOS-2, TELE-ASD-PEDS, or Autism Mental Status Exam (AMSE), or develop strategies you can use in the office for an observation of social interaction and behavior associated with ASD (see Appendix D for ideas of activities to elicit behaviors for younger children; see NICE guidelines or Holland Bloorview for activities for school-age or older children) that you can report on a validated tool like the CARS-2 or MIGDAS-2. There are training opportunities on some of these tools in Washington State. WA INCLUDE often can provide information regarding these trainings. When you are deciding what tools to use, you may also consider what is needed by the payor. For example, some may require a specific tool in order to authorize services based on your diagnosis.

It is important to remember that a diagnostic tool is more than just a score! And, importantly, it is not appropriate to diagnose or not diagnose autism based solely on a specific tool or score. If you partner with another provider to complete a formal observation, such as an ADOS-2, ensure that you hold a brief team consultation to review the findings, ask about what was observed, and understand why a specific score was obtained. (Note: Even an ADOS-2 score is not a diagnosis. It is a piece of information that should be included alongside other information in your clinical decision making and reporting the specific ADOS-2 score is not recommended for this reason).

In addition to the above areas which are necessary for an autism diagnostic evaluation, many families benefit from additional testing related to cognitive and adaptive functioning (especially since a measure of adaptive functioning is required for the <u>DDA application and eligibility process</u>). Cognitive assessments are often done as part of special education evaluation, though this is not always the case. And while you may not be able to administer a cognitive evaluation, you can easily include a measure of adaptive development in your evaluation process.

See <u>Appendix H. COE Evaluation Requirements</u> to ensure you are completing all aspects that are required. See <u>Appendix I. Screening and diagnostic tools</u> for information on evaluation tools for different age groups.

Documenting your Evaluation

After you complete your evaluation, you will need to document your findings. Having the appropriate documentation ensures that a family can use their evaluation report to obtain recommended services. Using a template to document your evaluation can also help increase documentation speed, ensure that all the appropriate information is included in the final report, and improve consistency between staff members if multiple people are involved.

If you use an EMR like EPIC, consider using SmartPhrases (also known as dot phrases) to speed up the process. You can also use SmartLists to pre-populate a list of resources and other go-to information (e.g., local Parent to Parent coordinator or ESIT agency by regions, parent advocacy organizations, school resources, common community resources, referral scripts for Speech Therapy or ABA, etc.). The American College of Emergency Physicians has a great tutorial on how.

As part of your report (which should review all relevant information collected through record review, clinical interviewing, and observation), you *must* include a description of how the individual met DSM-5 criteria for autism. Many providers use a checklist at the end of their report template to make this information easily accessible for payors to locate within the document.

Remember, COE requirements are related specifically to families seeking autism services through Medicaid. Private insurance companies may have different requirements such as the use of a specific validated diagnostic tool (see <u>Appendix I. Screening and diagnostic tools</u> for a list of validated screening and diagnostic tools). If you are working with a private insurance company that requires a validated tool and you are not able to complete something such as the ADOS-2, you may want to consider other tools like the CARS-2 or MIGDAS-2, which is an organized way of documenting and scoring information collected through your record review, interviews, and other observations.

See <u>Appendix J. Documentation and report templates</u> for documentation examples (including a template you can copy/paste into your notes as well as an example of an EPIC template with embedded SmartPhrases and SmartLists)

Billing your time

Billing is a critical component of creating sustainable COE work. Autism evaluations involve a significant amount of work outside of face-to-face encounters, such as record review, evaluation prep, and report writing. Learning how to bill for these elements allows you to maximize your reimbursements and bill for as much of your time as possible. The autism clinic proposal in Appendix A offers one framework for a billing structure. However, billing practices vary based on several factors (e.g., provider type, workflow, payor, clinic), so it is important to explore the various billing practices and codes that may be accessible to you; there is also a potential to get reimbursement for the support work of a community health worker. Consider reaching out to ECHO Autism Washington and other ECE Providers to ask about their billing practices or set up a meeting with the billing representative in your organization to get details about what is possible.

See Appendix K. Reimbursement and billing guides for information about how other COEs bill for their time.

Feedback

Communicating the Diagnosis

Once you have completed your evaluation, schedule a time to review and communicate your findings, which often results in giving a specific diagnosis such as Autism, ADHD, or Global Developmental Delay. Effectively communicating the diagnosis can be one of the most challenging aspects of the evaluation; however, it is important not to wait to discuss a diagnosis of autism or the need for further monitoring and screening as early identification creates more opportunities for individuals to receive the supports and services that can help them thrive!

The Autism Treatment Network (ATN) and the Autism Intervention Research Network on Physical health (AIR-P) have developed a <u>toolkit</u> with guidelines and video examples to help prepare providers to communicate a diagnosis of autism and support families on their next steps.

Individuals can arrive at the feedback visit with varying levels in their understanding of the process and their readiness to accept the diagnosis. Before you begin the feedback, ask yourself:

What do they already know about autism? Throughout the evaluation process, you should gather information related to the caregiver's understanding of autism and expectations about the evaluation process. Knowing who referred the family for the evaluation can be a hint. For example, families referred by the school or a provider may have less knowledge of evaluation process or a diagnosis of autism, while those who self-refer may have done more research on it.

What is their readiness for a diagnosis? Understand whether the family feels that the diagnosis of autism is a possibility, or if there are other diagnoses they are expecting to receive such as ADHD or anxiety. Families often share their thoughts during the interview process. This can guide how you approach feedback and help prepare for potential challenges or areas of disagreement.

What else might influence their understanding and readiness? Understanding and readiness for a diagnosis can be influenced by many factors. One of the largest factors is a family's culture and language background (especially if it differs from your own). Other factors that can impact a family's understanding of autism and readiness can be whether this is their first or only child, socio-economic status, presence of disability or mental health issues in the family, and their profession (e.g., teacher, paraprofessional, therapist, nurse, doctor).

During the feedback, consider *how* you are communicating information with families and whether they are understanding the points you are communicating. For example, it can help families if you prepare a few take-aways or next steps, and consider using the repeat back strategy (asking families to repeat back those points throughout). You also want to make space for families to problem solve around any potential obstacles that may come up. Throughout, make sure you are listening, acknowledging, and validated the family's concerns and wishes. The feedback session is not just about communicating a diagnosis, but building a relationship of trust so that a family feels confident and empowered to continue their journey.

It is also important to use a strengths-based and neurodiversity affirming approach as part of empowering families and autistic people. Often, evaluations and feedback heavily focus on the

deficits and medical criteria that go along with a diagnosis. While it is important to understand the skills gaps and challenges an individual experiences, it is also important to highlight strengths, build an understanding of neurodiversity, and support hope. One activity that may encourage this mindset is to review a handout like this one and discuss which areas of strength an individual or family resonates with. You might also choose to discuss diagnostic criteria using visuals like this one that highlight the individual differences and unique presentation that every person with autism has. The UW Autism Center has some great free webinars for families and autistic people on understanding and supporting a strengths-based and disability affirming approach to autism. The Autistic Self Advocacy Network (ASAN) also has a neurodiversity affirming toolkit for newly diagnostic autistic people that is a great resource.

What to Do When You Don't Diagnose or You're Not Sure

There will be times where you are not confident giving a specific diagnosis or need to gather more information before you can make a decision. It is important to clearly communicate those needs and next steps with the family, so they understand the plan going forward. It is okay to say you don't know. It is also okay to say you are not able to make a diagnosis at the time, and that you can re-evaluate in the future. This is an advantage of being a primary care provider. You can follow that family over time to continue gathering information, address their concerns, make referrals for services that may support the individual in the meantime, and revisit the diagnostic question in the future.

Autism is a complex disorder that manifests in many ways. While research shows that non-specialists are quite accurate in making autism diagnoses in young children, it also shows that non-specialists often rule out autism where a specialist would not. This is especially true for patients with complex or atypical presentations. For example, those who speak another language or have different cultural norms, have cognitive or language delays, have medical or psychiatric co-morbidities, or were assigned female at birth are often under-diagnosed with autism and/or misdiagnosed with other conditions. When unsure, it is recommended that referrals be made to tertiary care centers or other specialists that have experience evaluating complex cases and can provide multi-disciplinary assessments before ruling out the diagnosis of autism.

Avoid falling into the "wait and see" trap, which does not provide a plan for addressing their concerns and can feel invalidating to families. Identify what are primary obstacles to learning (e.g. communication, sensory, behavior, motivation, etc.) which can direct to what supports to put into place e.g. (speech, OT, early intervention) and get family on a path for support. Early family concerns are a significant and consistent indicator of later developmental diagnosis like autism; families know when something is wrong even if they are not sure what it is. Be humble and aware that even with additional training, we are still human and can make mistakes. Families are the expert on their own experience, and you will want to consider providing an option for a second opinion or a more comprehensive or multidisciplinary neurodevelopmental assessment.

Here are some different pathways to consider:

Consider alternate diagnoses. When you know that there are developmental milestones that are not being met, a diagnosis of Global Developmental Delay (GDD) can help them get qualified for

services that are not ASD-specific (note: GDD only applies to children under age 5). Previously, providers could use a provisional diagnosis of ASD, but as COVID-related emergency restrictions have ended, insurance companies are often no longer reimbursing for services under that label. Again, a GDD diagnosis is helpful as domains affected include things like language, social skills, and adaptive development. For older children, many individuals presenting for an ASD diagnosis also experience challenges related to language, cognition, inattention, hyperactivity, and anxiety. Consider additional testing or referrals to explore those diagnoses.

Gather more information. If you did not already, make sure to reach out to others who work with this child, such as childcare providers, school staff, or other therapists, to get their input. You may want to gather informal observations, before giving more detailed or formal questionnaires. This is so you can make sure to get information from someone who knows the child and family well.

Refer for additional evaluation or observation. You may want to refer the child for additional testing with a speech language pathologist or occupational therapist to learn more. You might also have the family pursue an IEP evaluation, where they can get more information about cognitive, academic, and social-emotional functioning if that child is struggling in school.

Refer to a tertiary care specialist. In certain cases, you will still need to refer to a tertiary care center for an inter-disciplinary evaluation due to the complexity of the case. When you send a referral, it is helpful to include all the information that has already been gathered which may allow the specialist to streamline their evaluation process.

REFERRALS AND FOLLOW-UP

After completing an evaluation, the next step is to provide recommendations, make referrals and develop a follow-up plan for this individual and their family. If they are a patient in your practice, this could mean scheduling a follow-up with you or another provider in your practice about one or two months out for answering any questions that have come up or support them with service navigation if they are struggling. If this youth has a different primary care provider, you may want to encourage the family to follow up with that provider and have them complete an ROI so you can send the report and your recommendations directly to that provider.

Family Education, Support, and Advocacy

Receiving a diagnosis of autism or another neurodevelopmental disability can be challenging for many families. It changes the way they may understand their child's strengths and challenges and introduces the need for navigating different systems and building a new set of skills that they would not otherwise need. Part of your recommendations and referrals should include connecting that family to an organization that can help them process this information, learn about their child's diagnosis, and guide them in accessing community supports. Your local <u>Parent-to-Parent coordinator</u> is a great first step for getting a family connected. There are also many other resources for parent education, support, and advocacy.

See <u>Appendix C. Washington State Resources</u> for a list of common organizations and informational resources you can share with families, as well as resources specific to culturally and linguistically diverse families.

Educational Supports

Support through the public school system is often the primary support for a child and their family. In some areas with limited community-based therapies and resources, schools may be the *only* support for your patient and their family. Special education includes Birth-to-Three services for children under three years of age and support through local school districts from age 3 –21 when appropriate. Remember that **a diagnosis of autism is NOT required** to initiate early intervention or school services; services are based on needs. This also means that having a diagnosis *does not* automatically qualify children with autism for special education, as there are three requirements for special education: 1) the student must have a disability, 2) the disability adversely affects educational performance, and 3) the student's needs cannot be met through general education.

Families can <u>request an evaluation in writing</u> through their local Birth-Three or school district. Providers can also place a referral for special education <u>using the same process</u>. It is important to note that the school is required to respond to the request within a specific number of days, but that a request does not guarantee an evaluation or services. Families may find it helpful to contact the <u>OSPI Special Education Parent & Community Liaison</u> or the <u>Office of the Educational Ombuds (OEO)</u> for support or more information about this process and what to expect.

When evaluations are conducted, they should be comprehensive and include cognitive, communication, motor/sensory, adaptive behavior, and social development when there are concerns across areas of development. Not all children with autism qualify for special education services. You can provide support for your families by writing a letter that describes the areas of concern that have been identified and recommend an evaluation to determine eligibility for services. However, keep in mind that the school determines eligibility, and that special education is only required to help meet educational expectations rather than general developmental needs.

Many children with autism and other disabilities can (and should!) be supported in the general education environment. Schools can also provide support to students outside of special education. These informal supports can be developed through communication and collaboration with the educational team. Tips for establishing a positive and collaborative partnership with schools can be found here. Potential academic supports that can be offered can be found here.

Community-based Therapies

Depending on the child's identified obstacles to learning and what is available in your community, referrals may be available for community-based therapies. These can include speech, occupational and physical therapies, therapy using principles of applied behavior analysis (ABA), mental health therapy or counseling, social skills groups, and parent education and training. Another common referral is for medication consultation and/or management. The National Professional Development Center on ASD has information about evidence-based practices for providers. The Autism Society is another resource that has neurodiversity affirming and family focused information on therapies, as well as a toolkit for having conversations with providers (you can find the toolkit under ABA services, but this toolkit can help with any service).

Identify what is available in your community so you can inform the families you work with. One option is to explore the county public health department's Children and Youth with Special Health Care Needs (CYSHCN) program webpage. Most counties also have a public health CYSHCN coordinator who is knowledgeable about autism and the local resources available; if you are not sure how to find what you are looking for, reach out to the coordinator. You can also have the family call their insurance company and get a list of providers on their plan. The Washington Mental Health Referral Service can also support families in identifying mental health providers (and ABA providers!) who take their insurance and are currently accepting new clients.

Applied Behavior Analysis (ABA)

There are many misconceptions and misunderstandings about ABA. Simply put, ABA is a behavioral therapy approach informed by regular data collection and data review that combines a variety of evidence-based strategies with the goal of teaching new skills and reducing challenging behaviors. Less simply put, provision of ABA by a Board-Certified Behavior Analyst (BCBA) and their associated team use evidence-based behavioral strategies and interventions, while taking systematic data to determine effectiveness of treatment, seeking to make informed data-based decisions to alter and adapt treatment as needed to meet the needs of each individual learner. ABA aims to decrease challenging, disruptive behavior through consistent implementation of intervention, while also teaching positive, adaptive behaviors.

Making a decision to access ABA intervention can be complicated for families as this intervention has demonstrated moderate to strong effects across research, but more and more information is circulating within the autistic community identifying potential concerns with intervention. The Arc of King County has a series called <u>Unpacking the ABA Debate</u>, that is helpful to both parents and providers. The Autism Society also designed an <u>ABA Resource</u> toolkit to help equip families with the knowledge and information they need to make informed decisions for their family. The INCLUDE Collaborative's also has a position statement regarding ABA treatment.

Referrals for ABA are based upon medical necessity. As identified by the Washington State Health Care Authority (HCA), ABA services are considered medically necessary when other less intrusive interventions and treatment has been unsuccessful, and the child's condition is known to be responsive to ABA based on current research. Medicaid requires very specific language and information in an order for ABA. This information is what guides the COE evaluation process. You can also consult the Washington Administrative Code (WAC) guidelines around ABA.

Navigating private insurance. Private insurance companies have varied requirements and needs to cover ABA services. For example, some companies require specific evaluation tools to be reported in the order. You may want to confirm with your most common private payors what their requirements are. For families, the Seattle Children's Mental Health Referral Service is a great tool they can use when pursuing ABA services in the community through private insurance. The Washington Autism Alliance (https://washingtonautismalliance.org/) has helped many families advocate for insurance coverage for diagnostic evaluations and ABA-based therapies.

Navigating Medicaid. Families with Medicaid should follow the ABA Medicaid Coverage Checklist (additional languages available on the Seattle Children's Autism Center Patient and Family Education Page, under Applied Behavior Analysis) to request an ABA case manager. There is a script that families can follow when making the request, as well as a place to keep track of any phone calls and follow-up steps needed.

See <u>Appendix L. Medicaid ABA order template</u> for autism and non-autism templates you can use. Additional ABA templates, such as those for private insurance, are in the <u>Autism Resources Google Drive</u>.

Availability and accessibility of ABA services across the state are variable and simply not available in some locations. In areas where ABA is not accessible, one option may be telehealth services where a family can receive consultation and coaching from a BCBA remotely. Providers such as speech-language pathologists and occupational therapists can provide supports in some areas of development (communication, sensory/motor, social, adaptive behavior) and often more accessible through school districts and local hospitals. Other providers, such as child psychologists, are also often trained to integrate behavioral methods similar to those in ABA in their approach to working with parents and individuals with autism (for example, through a program like RUBI). If there is a treatment team in place, consider having a BCBA consult with the team on their treatment plan. There are even free online, self-directed programs like the UC Davis Autism Distance Education Parent Training (ADEPT) that a family and their provider can work through together.

THANK YOU!

Thank you for beginning your journey to better support individuals with autism and their families. With autism now present in an estimated 3% of the population, it is necessary for all primary care providers to have knowledge and skills in supporting their patients with autism and their families. The more COE providers we have in our state, the more knowledge and expertise is shared so that families are able to get the care they need at the right time and in the right place. This is best done when close to home and with people who have knowledge of the local resources and community.

Please continue to learn with us and your peers across Washington. We invite you to join a Project ECHO learning cohort through the WA INCLUDE Collaborative or University of Washington On Time Autism Intervention Project (0-3) to help you connect with those active in your community. There are also many Other ECHO Autism communities across the country that can provide more continuing education. You may also be interested in connecting with your communities' SMART team or other regional COEs. It is easier (and more fun) to grow together.

Thank you for joining the community of providers and professionals who are taking on COE work. You are certainly making a difference! Please reach out to us via email at autismcoe@uw.edu if you need additional support or have questions about this work.

APPENDICES

Appendix A. Primary Care Autism Clinic Proposal

Intent: Develop and implement a dedicated Autism Clinic within **COMPANY NAME** to support families in need of autism diagnostic and support services and facilitate a referral mechanism for primary care providers in the Pacific NW region.

Goal: Pilot a model that provides consistent care between **COMPANY NAME** autism providers that is efficient and cost effective and scalable, thus allowing implementation on more regional or national level over time. This model will satisfy **COMPANY NAME** goal of expanding Biopsychosocial services in Primary Care.

Background:

- In 2023, the CDC reported that approximately 1 in 36 children in the U.S has autism spectrum disorder (ASD).
- Most children are still being diagnosed after age 4, though autism can be reliably diagnosed as early as 18-24 months.
- Autism affects all ethnic and socioeconomic groups.
- Minority groups tend to be diagnosed later and less often.
- Average wait list at Seattle Childrens Autism Clinic is 2-3 years and 9-24 months at Providence Childrens Center in Everett. (UPDATE WAIT TIMES AND CHOOSE TERTIARY CENTERS IN YOUR REGION)
- Early intervention affords the best opportunity to support healthy development and deliver benefits across the lifespan.
- Early diagnosis of autism helps patients to access vital developmental services at an early critical age of learning, diagnosis also guides families so they are able to provide best care for their children.
- Autism diagnostic options are disappearing at an alarming rate making outside referrals more and more difficult and further expanding wait times.

Providers:

DISCUSS YOUR CREDENTIALS HERE – TRAINING, BOARD CERTIFICATION, INVOLVEMENT IN AUTISM WORK

Care Model:

Plan is to serve pediatric patients from DISCUSS SERVICE AREA. We can provide this service for patients with an estimated wait time of CHOOSE BEST ESTIMATE, which is much less than the current situation in the community.

Based on community and best-practice standards, the evaluation for autism is a 6–8-hour process (including both face-to-face and administrative work) that takes place over 2-3 visits. Due to the time commitment for these visits, it is difficult to do this work within the template of a regular schedule of pediatric primary care.

Our providers have agreed to a standard for autism evaluation visits which aligns with what is provided in the community.

 1^{st} visit 3 hours – collecting information, interviewing parent(s), reviewing clinical records, writing the first report 2^{nd} visit 3 hours – standardized testing and observation, evaluation of testing, and writing second report 3^{rd} visit 1 hour – visit with the family to discuss report and treatment plan

Clinic Expenses:

Paid clinic coordinator 4 hours/week

Office space FILL IN ESTIMATE HOURS OF IN OFFICE USE

Provider reimbursement as noted below- averaging FILL IN BEST FIGURE per full 7-hour work-up

Supplies - \$1000/year for new kits or evaluation tools CUSTOMIZE FOR YOUR NEEDS

Marketing MOST PRACTICES WILL LIKELY NOT NEED TO ADVERTISE DUE TO DEMAND BUT INCLUDE A DOLLAR FIGURE IF YOU PLAN OUTSIDE MARKETING

Standard Work/Medicaid Reimbursement:

NUMBERS BELOW BASED ON 2023 RATES- UPDATE ACCORDINGLY. ALSO, IT IS APPROPRIATE TO CHOOSE A DIFFERENT MODEL OF CARE DELIVERY TO MEET YOUR SPECIFIC CLINIC NEEDS SO ADJUST MODEL AND NUMBERS BELOW ACCORDINGLY. MOST IMPORTANT THOUGH, YOU WILL LIKELY NEED TO MAKE THE MODEL RETURN SOME POSITIVE CASH FLOW TO CONVINCE YOUR CLINIC TO ADOPT THE PROGRAM

1st Visit: 3-hour clinic appointment - first visit comprised of collecting historical information, detailed parent interview impressions, reviewing clinical records, and writing the first report.

- Billing reimbursement
- 99215 50 minutes Medicaid pays \$166.45
- Bill G2212 15-minute incremental codes total 8 codes for the next 2 hours to finish the interview and write the report the same day. \$24.96 each increment x 8 = \$199.68
 - TOTAL COLLECTED = \$366.13

<u>2nd Visit</u>: 3-hour clinic appointment - do standardized testing and observation (either virtual or in person), write final report.

- Billing reimbursement
- 99215 50 minutes \$166.45
- G2212 x 8 to finish observation and write report = \$199.68 same as noted above
 - TOTAL COLLECTED = \$366.13

3rd Visit: 50 minute clinic appointment - parent debrief about impressions and report. Then discuss a treatment plan.

99215 - \$166.45

TOTAL FOR ALL 3 VISITS AND COMPLETE WORK UP = \$366.13 + \$366.13 + \$166.45 = \$898.71

Provider Reimbursement Proposal:

- Provider reimbursement proposed at \$100/hr, costing \$700 (7 hours) per patient evaluation, which includes all 3 visits.
- As per Medicaid reimbursement, will make \$898.71.
- Positive variance of \$198.71 per patient evaluation or better (for commercial patients)

Note:

- Commercial patients may have higher reimbursements
- This would be a service for COMPANY NAME; this can potentially increase patients within our clinic who will establish with PCP for this service.
- 245 outgoing referrals in 2022 (Approximately 20/month) EXAMPLE ONLY- USE YOUR DATA HERE
- Develop scripting for pricing for commercial patients in the future

Compensation:

Hourly rates, providers will submit hours biweekly or monthly to the compensation department for pay

- Per Diem Rate \$100/hour, total \$700 per each complete evaluation consisting of 3 visits (NOT ALL CLINICS WILL OFFER A PER DIEM OPTION BUT IF SO, CHOOSE APPROPRIATE HOURLY RATE TO FIT YOUR BUDGET)
- Providers on productivity
 - Clinicians who are paid on productivity can do autism evaluations as part of their work schedule
 - o They will be paid based on WRVUs per the routine provider compensation model

Provider Schedule:

Provider schedule will vary and will depend on the visit they are booked for, but a typical 8-hour day can look like this:

- AM Schedule
 - One 3-hour visit (this can be either 1st or 2nd visit)
 - One 1-hour visit (this will be the 3rd visit)

- PM Schedule
 - One 3-hour visit (this can be either 1st or 2nd visit)
 - One 1-hour visit (this will be the 3rd visit)
- Total visits per day: 2-4
- Total hours per day: 4-8

Notes on Interested Providers: INCLUDE INFO HERE ON PREFERRED SCHEDULE AND HOURS OF WORK AND WHETHER IN OFFICE OR ONLINE EVALUATIONS OR BOTH AND LANGUAGES SPOKEN BY PROVIDERS

Referral Process: Patients would be internally referred to the autism clinic through Epic **EXAMPLE DISCUSS YOUR REFERRAL PROCESS IF DIFFERENT**

The autism clinic requests a dedicated administrative support person (clinic coordinator) budgeted initially for 4 hours per week to handle incoming referrals, send out needed intake paperwork, collect additional reports from school or other appropriate providers, answer questions from families and schedule appointments. It is imperative this work NOT be handled through a resource center as it is too complex and will not fit under their standard work.

The dedicated autism providers will manage the referral list, follow up with families as deemed necessary and work with the administrative coordinator to facilitate and expedite appointments. Once paperwork is returned in full, the clinic coordinator will call and schedule the evaluation.

For commercial patients, the clinic coordinator will be letting the patients know in advance to check with their insurance company if the services are covered – YOU NEED TO DEVELOP YOUR OWN SCRIPTING WITH YOUR FINANCE/BILLING DEPT FOR HOW COMMERICIAL PATIENTS ARE BILLED AND HANDLED AND OUTLINE HERE

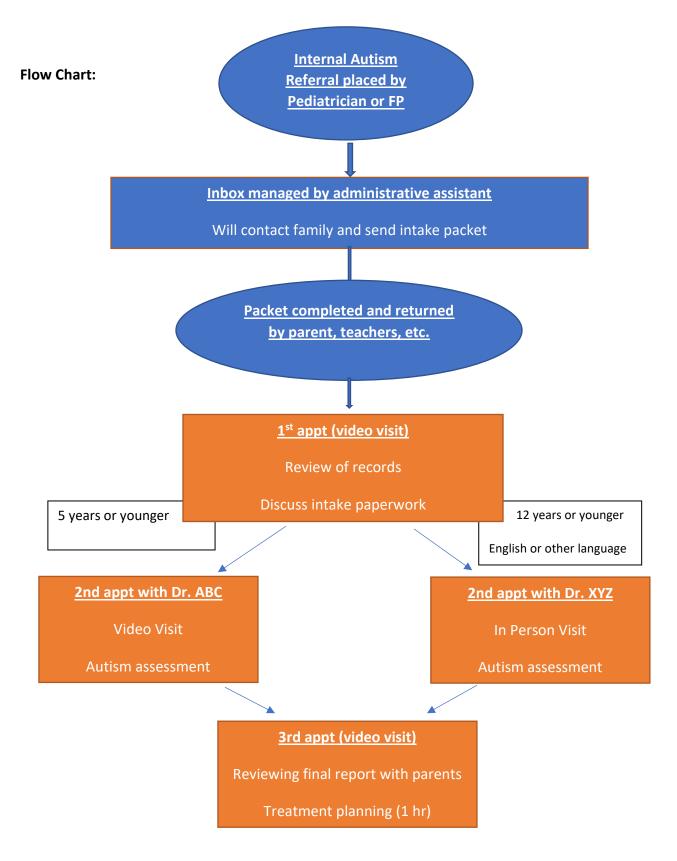
Coding/standard workflow and compensation are the same for all providers interested in this work as well as for state and privately insured patients. FLOW DIAGRAM- SEE NEXT PAGE – THIS IS AN EXAMPLE ONLY THAT YOU CAN CUSTOMIZE TO FIT YOUR CLINIC PLANS

Summary:

Implementation of a COMPANY NAME based Autism Clinic is a vital service to the community at large and would open up care to a highly under-served group of families and patients who routinely wait up to 2 years to be seen for initial evaluations. Early diagnosis and treatment of children with autism is imperative and greatly affects long term outcomes.

The above model provides consistent care across Optum providers, is cost effective and scalable for future expansion. We have experienced ASD providers already trained and ready to continue this work with the support of COMPANY NAME.

We urge COMPANY NAME to support this proposal, expedite the review of this project, and approve it so this important work can start again as soon as possible. LIST PROVIDER NAMES HERE are passionate about this work, are committed to seeing it succeed and eager to help other COMPANY NAME providers expand into this work in the future. Let's do the right thing! Thank you.



Appendix B. COE Provider Presentations at Autism COE Trainings

(revised 1/30/2024; materials here: https://drive.google.com/drive/folders/1UW8lcaAQdYnDU91fbnjpf6w-FxeGKFmv?usp=sharing)

Date	COE Name & Affiliation	Clinic type	County	Other Handouts
2/2/2023	Daniel Delgado, MD, HealthPoint Community Center - Auburn PPT: What I Wish I Knew When I Started My ASD COE Journey	Community Health Center (CHC) / Federally Qualified Health Center FQHC)	King	None
9/29/2023	Patricia Scott, MD and Thanh Kirkpatrick, MD, HopeCentral and Vietnamese Family Advisory Board PPT: Supporting Autism in the Community: A Collaborative Approach	Pediatric Primary Care & Behavioral Health	King	None
3/3/2023	Kathleen Johnson, DNP, FNP-BC, C-PMHS, PMHNP-BE Yellow Brick Clinic PPT: Yellow Brick Clinic: Following Our Yellow Brick Road Integrating the Autism COE with Specialty Community Practice	Specialty Community Practice	King- telehealth to whole state	None
12/9/2022	Emily Bianconi, ARNP, Skagit Pediatrics PPT: Developing a COE Practice in Primary Care Pediatrics	Mid-size Private Pediatric practice	Skagit	 EMR Full Autism template Sample Autism Visit Note
9/23/2022	Vanessa Frank, DNP, ARNP Columbia Basin Health Association (CBHA) PPT: "Incorporating COE Work Into a Federally Qualified Health Center with Migrant Farmworkers"	Federally Qualified Health Center (FQHC)	Adams	 CBHA Autism Intake Form Visit Template 2020 CBHA CBHA Autism Toolkit CBHA Autism Toolkit in Spanish
1/28/2022	Kristi Rice, MD, FAAP Providence Pediatrics - Northpointe PPT: How to Incorporate Autism Evaluations in a Busy Pediatric Practice	Large private practice	Spokane	Autism Intake Questionnaire
12/10/2021	Christina Pease, MD, FAAP Sea Mar Community Health Centers PPT: Addressing Health Inequities with an Autism Diagnosis	Federally Qualified Health Center (FQHC)	King	 El Autismo- words and pictures from the SCH 101 Autism in Spanish video done by Dr. Pease and partners Entrevista con los Padres acerca del Autismo- Version Clinica en Espanol (2002 translation by Stone et al)

9/24/2021	Jim Troutman, MD, FAAP Everett Clinic PPT: What I wish I had Known and What I Have Learned on My Journey So Far	Large private practice	Snohomish	 Welcome letter Everett Clinic Autism Center The Everett Clinic- Autism Eval- Teacher Interview Form Social Communication Observation Tool e form 2017 Preparing for your child's telehealth visit_ Clinician- VUMC New patient intake packet 2020 Everett Clinic Autism Evaluation form DSM-5 Diagnostic Checklist Dr. Cheek 5 y.o. ASD Report example Dr. Cheek 2 y.o. ASD Report example Child Cambridge University Behavior and Personality Questionnaire 2-Tele-ASD-PEDS Administration guidelines
5/14/2021	Heather Buzbee, MSN, CPNP- PC, PMHNP-BC Psych and Ped ARNP Sea Mar Federal Way PPT: Applying the Autism COE to the Community Health Primary Care Setting	FQHC	King	No handouts
2/12/2021	Liz Vossenkemper, MSN, RN, CPNP-PC, Tri-Cities Community Health PPT: Building an Autism COE in Primary Care: Choose Your Own Adventure	FQHC	Benton	 Note- as of 2023, Liz is now serving as a COE at United Family Health Behavioral Health and Family Services in the Tri-Cities

0/10/2020	Iulia Chaok MD TAAD Daarattaalit	Larga militata	NA/II.	
9/18/2020	Julie Cheek, MD, FAAP PeaceHealth	Large private practice	Whatcom	Cheek Handouts:
	PPT: Neurodevelopmental and			Visit Template
	Autism Evaluations in Primary Care			New Patient intake
	Practice (Cheek)			packet 2020 Cheek
				Neurodev and Autism
				Screening in Primary
				Care
	(cont. on next page)	Parent		NDClinic appointment
	Monica Burke, PhD, Arc of Whatcom	Support and		checklist
	and SMART team lead	Advocacy		NDC new patient history form
		1.0.0000,		
	PPT: Collaborating to Support a			Letter apt reminder Developmental
	County Center of Excellence for			Developmental Olivia
	Autism Evaluation and Diagnosis			Clinic
	(Burke)			Appointment
	(Barne)			process
				Dev CI FOLLOWUP Appt Characteristics
				Check list
				Burke Handouts:
				DDA Overview + How to
				Apply 2020
				Community Services for
				CSHCN 2020
				Communication – to
				School from Provider e
				form
				Communication – to
				School from Family e-
				form
				Communication- to PCP e-
				form
				Autism Services 2019
				Autism – Could it Be – 1019
				ABA Provider Matrix 2020
				ABA Intake Form Fillable
				2020
7/31/2020	Bill Cheney, M.Ed	School	Skagit	Skagit COE Process Flowchart
		District		COE Evaluation: Early
				Intervention Provider
	Rick Levine, MD, FAAP Skagit	Mid-Sized		Summary Evaluation
	Pediatrics	Private		Information
		Pediatric		
	(no PPT) "A Community COE	Practice		
	Perspective: Skagit County"			
		1	1	

Appendix C. Washington State Resources

Here are commonly referenced resources following an autism evaluation (Last updated 6/12/2024; items listed by topic and alphabetically). You can find more resources on the <u>COE Autism Resources google drive</u>. You may also want to refer to the <u>Seattle Children's Autism Center's Patient and Family Education website for more in-depth and up to date info!</u>

General autism information

- Autism Self Advocacy Network Welcome to the autism community book
 (https://autisticadvocacy.org/book/welcome-to-the-autistic-community/): was written by autistic people to provide general information to those with a new diagnosis of autism, or for those wanting to learn more.
- Autism Speaks First 100 Days Kit (https://www.autismspeaks.org/tool-kit/100-day-kit-young-children): provides support and information to families who have children with Autism Spectrum Disorder, including 100 Day Kit who have just received a diagnosis of Autism Spectrum Disorder.
- Centers for Disease Control and Prevention (CDC; www.cdc.gov/ncbddd/autism/index.html) information and videos about what autism is and how it is treated (in English and Spanish.)
- **People First of Washington** (https://www.peoplefirstofwashington.org/): a self-advocacy organization for individuals with disabilities working together to support the community.
- Seattle Children's Autism Center (https://www.seattlechildrens.org/clinics/autism-center/patient-family-resources/) has a range of topics to help understand child development, access resources, locate services, and to participate in treatment.
- **UW Autism Center** (https://depts.washington.edu/uwautism/) provides information on resources and free webinars for parents on a variety of topics such as neurodiversity and ABA.
- People First of Washington (https://www.peoplefirstofwashington.org/): a self-advocacy organization for individuals with disabilities.
- AS360 (https://www.as360.org/) is a platform designed for individuals in Washington state to share access to ASD providers, resources, information, and community.

State resources and information:

- Ben's Fund (<u>www.featwa.org/bens-fund.html</u>) provides families with grants for therapeutic services, support, or
 equipment. Visit their website for more information about requirements including a family story, tax return,
 provider letter and your child's autism diagnosis.
- **Department of Vocational Rehab** (DVR; <u>www.dshs.wa.gov/dvr</u>) assists individuals with disabilities in obtaining and maintaining employment, as well as high school transition support.
- Developmental Disability Administration (DDA; https://www.dshs.wa.gov/dda) assists individuals with developmental disabilities and their families to obtain services and supports (e.g., case management, respite, caregiver support, assistive technology, employment and day program services, etc.).
- Developmental Disability Council (DDC; https://www.ddc.wa.gov/) collaborates and coordinates with other agencies and organizations, trains leaders and advocates, and advocates for better policies, programs, and practices.
- Help Me Grow Washington (https://helpmegrowwa.org/; for children 5 and younger) and/or ParentHelp123 (https://www.parenthelp123.org/; for children 6 to 18) provides supports to families in Washington accessing state services, such as Early Support for Infants and Toddlers (ESIT), food stamps, parenting classes, transportation, health insurance, etc.. Families can call 1(800) 322-2588 to be directed to the correct resource and support options for their region. Staff speak English and Spanish and have access to interpreters for many other languages.
- **Hopelink** (<u>www.hopelink.org</u>) support with transportation, gas cards and translation services.
- Informing Families (https://informingfamilies.org/): statewide resource with regional contacts for information on developmental disabilities and the systems that can provide support, including how to apply for DDA and SSI.

- Miss Shayla's List (https://medicalhome.org/quick-key-resources/shaylas-list-family-support/), written by a parent, is a list of key financial, transportation and recreation resources to support people with intellectual and developmental disabilities and their families.
- **Supplemental Security Income** (SSI; https://www.ssa.gov/ssi/eligibility) provides financial support for low-income individuals with disabilities and their families.
- WA State Health Care Authority (HCA; https://www.hca.wa.gov/) maintains a list of WA COE Providers by region (https://www.hca.wa.gov/assets/billers-and-providers/index-coe-applied-behavioral-analysis.pdf).
- Washington Mental Health Referral Service for Children and Teens (https://www.seattlechildrens.org/clinics/washington-mental-health-referral-service/) connects families with providers in their local area who fit their child's specialty needs and insurance coverage. They can also help families find an ABA provider.
- Washington State Medical Home Partnerships Project (WA MHPP; https://medicalhome.org/) helps primary health care doctors and nurses, other health care providers, families and communities work together to improve care for children and youth, particularly those with special health care needs, and their families. Information about COE trainings and SMART teams is found here.

Family education, support, and advocacy

- Arc of Washington (https://arcwa.org/) helps parents navigate the maze of special education and connect with other families through their Parent- to- Parent program (https://arcwa.org/parent-to-parent/p2p-coordinator-information/). There are specific coordinators for different regions of the state.
- **Developmental Disability Ombuds** (https://www.disabilityrightswa.org/programs/dd-ombuds/): is a state-wide program to investigate, advocate, and report on services to people with developmental disabilities.
- Partnership for Action. Voices for Empowerment (PAVE; <u>www.wapave.org</u>): source for parents to learn more about the special education process, find community resources, and connect with other families who have children with disabilities.
- **SibShops** (https://www.seattlechildrens.org/health-safety/keeping-kids-healthy/development/sibling-special-needs-sibshops/): interactive workshop for siblings ages 6-13 of children with special needs.
- Washington Autism Alliance (WAAA; https://washingtonautismalliance.org/) works to expand access to healthcare, education and community for people with autism and their parents. They also provide information and support for families who are seeking ABA therapy and can assist with insurance navigation and provide recommendations regarding how to pursue ABA.

Comprehensive, self-directed learning programs for families

*Free program

†Offered in multiple languages

- *†ADEPT (<u>health.ucdavis.edu/mindinstitute/centers/cedd/adept.html</u>): interactive, self-paced, online learning
 module providing parents with tools and training to more effectively teach their child with autism and other
 related neurodevelopmental disorders functional skills using applied behavior analysis (ABA) techniques.
- *†Everyday Parenting: The ABCs of Child Rearing (https://www.coursera.org/learn/everyday-parenting):
 provides a toolkit of strategies and step-by-step instructions to change behaviors for both children and teens.
- *Help is in your Hands (https://helpisinyourhands.org/course): made for parents to teach them more strategies such as these to build social communication skills and engagement
- Essentials of Parenting (https://helpingfamiliesthrive.com/courses/parenting-essentials/; discount code "Seattle Children's"): provides education, interactive workbook and activities, and demonstrations of real families using skills to improve emotional and behavioral outcomes and family relationships for kids ages 2-12.
- **Hanen Program** (https://www.hanen.org/Programs/For-Parents.aspx): provides families of children at different developmental levels with research informed strategies for supporting language and social communication skills.
- **†Triple P** (<u>https://www.triplep-parenting.com/us/triple-p/</u>): an online self-guided version of an evidence-based intervention for parents to address behavioral and emotional concerns for their child age 0-16.

Resources for culturally/linguistically diverse families/individuals and military families

- **Dads MOVE** (https://www.dadsmove.org/) provides support, training and advocacy for parents/caregivers, especially dads, who have children and youth with behavioral challenges.
- Families of Color Seattle (https://www.focseattle.org/) connects families, caregivers, and children of color through peer-led parent support groups; spaces to share culture, skills, and resources; and racial justice education and advocacy.
- Joint Base Lewis-McChord (JBLM) Autism Center (<u>www.operationautism.org/base-post/joint-base-lewis-mcchord/</u>): Military families may wish to contact the JBLM Autism Center called Operation Autism, for local support and resources for military families.
- Manos Unidos International (https://www.manosunidasinternational.org/) a global learning community for families and educators of children with disabilities
- Mother Africa (https://www.motherafrica.org/)
- Open Doors for Multicultural Families (https://www.multiculturalfamilies.org/) provides a variety of supports to families in King county by matching them with a staff member who shares their cultural and/or linguistic background.
- Rooted in Rights (https://rootedinrights.org/) uses accessible digital media to advance the dignity, equality, and self-determination of people with disabilities through storytelling (videos, documentaries etc). They have a wonderful series of stories told by parents with disabilities: "Parenting Without Pity: https://rootedinrights.org/stories/collections/parenting-without-pity/
- Somali Health Board (https://somalihealthboard.org/) works to address health disparities that disproportionately affect new immigrants and refugees within King County, with ambitious goals of eliminating and reducing health disparities.
- Square Pegs Adult Autistic Meetup Group (https://www.meetup.com/Squarepegs/) is a place for those of us who are on any part of the spectrum, diagnosed, self-diagnosed, or questioning to get to know one another and make new friends without having to explain our eccentricities. If you are otherwise neurodivergent, you are welcome to join us as well. The group focuses on adults, not children.
- Vietnamese Family Autism Advisory Board (VFAAB; https://vfaab.org/) resource to Vietnamese families, assisting people with navigating the care system to connect to support services and educating the community about autism and developmental delay.
- **WA Multicultural Link** (<u>www.wmslink.org</u>) provides support services to African Diaspora and African American families, especially individuals with disabilities, and health care needs.
- Washington State Fathers Network (https://fathersnetwork.org/) connects fathers and families of children with a disability or special health care need with each other and with resources and information, by training men to tell their story and advocate for change, and by working to promote inclusion.

Safety

- **Big Red Safety Box** (https://nationalautismassociation.org/big-red-safety-box/) offers downloadable information about resources to help caregivers prevent and respond to wandering incidents. They also offer a free safety kit to families when supplies allow.
- **Disability Parking Permits** (https://www.dol.wa.gov/driver-licenses-and-permits/get-or-renew-disabled-parking-permits) may be available for individuals with disabilities who are not able to safely walk independently due to behaviors like wandering and elopement.
- Smart 911 (https://www.smart911.com/) is a free service that allows families to provide information about their household, such as having a child with autism or other developmental disabilities, to 911 in case of emergencies.
- Washington State Mental and Behavioral Health Crisis Information (health-care/i-need-behavioral-health-support/mental-health-crisis-lines): provides information on how to access crisis lines, as well as what to expect when you call them.

Appendix D. Evaluation set up tips, toys, and observation examples

For **young children**, consider using a set of toys specifically designed to elicit social communication and play behaviors in toddlers. The STAT (<u>Screening Test for Autism in Toddlers and Young Children</u>) is a tool that can be used to facilitate an interaction between the provider and the child with a specific set of toys to identify *risk* for autism. The TAP (<u>TELE-ASD-PEDS</u>) is a guided parent-child observation that can be used *as part of* an in-person or telehealth visit; it includes a script and scoring form for the provider, as well as additional supports for conducting telehealth assessments, such as videos for caregivers on how to set up and suggestions for what types of toys to have available for the observation.



STAT administration materials



For **older children**, the most common formal assessment tool is the ADOS-2 (<u>Autism Diagnostic Observation Schedule, Second Edition</u>). The ADOS-2 was specifically designed to provide a comprehensive assessment of behaviors through a variety of specific prompts that vary by age and developmental level. However, this may not be the most accessible option for your practice given the costs, training, and time required to administer it.



ADOS-2 materials kit

(As a reminder, diagnostic tools are proprietary, meaning that you are not able to use the protocols or materials without purchasing them from the publisher and completing any required training.)

If you do not have access to the ADOS-2 – that's okay! You can still complete an autism evaluation with older children. Consider having toys and activities that provide opportunities to observe various social communication and play behaviors for various ages. To do this, you need to be aware of how autism presents differently across the lifespan (review *Box 3* of the <u>NICE summary</u> for potential signs of ASD in older children and teens). For older and/or more verbal individuals, you need to consider conversation starters and questions about social interactions, friends, interests, and experiences (see Table 2 of <u>this article</u> for examples). The *ASD Diagnostic Guidance Documents* from <u>HollandBloorview</u> provides a summary of symptoms, activities, and questions that can help guide your interaction for both younger (Toddler/Preschool) and older (Older/School Age) individuals.

The following page has potential additional activities to incorporate into your visits. [Thank you to the following providers who shared their ideas to add to this list: Karís Casagrande, PhD (Seattle Children's Autism Center), Julie Cheek MD FAAP (PeaceHealth), Vanessa Frank, DNP, ARNP (Columbia Basin Health Association), Jennifer Gerdts, PhD (Seattle Children's Autism Center), Christina Pease, MD FAAP (SeaMar Medical Clinic), Jennifer Mannheim, ARNP (Seattle Children's Autism Center), and Emily Myers, MD, FAAP DBP (University of Washington and Seattle Children's).]

Below are potential toys and activities, with behaviors to observe for each. (You might use bins to keep toys for younger and older children separate, as well as make sure those toys do not wind up in the waiting room or other clinic spaces.)

Toys	Observation tips
Cars and trains	Keeping these high value items in clear, hard to open containers is a great way
(Consider having extra pieces such as a garage, ramps, tracks, road signs, etc. that can be used with them)	to see how an individual directs attention to the objects and requests help. Watch how they play with the toys. For example, are they engaging in functional (e.g., playing with toys as intended) and pretend play (e.g., driving the cars, creating a racetrack, making up/acting out a story), or repetitive play such as lining them up, spinning the wheels, sorting by color?
Plastic figurines, dolls, and pretend play toys (e.g., kitchen, tea set, bedtime) (Consider small and large figurines such as people, animals, dinosaurs, and insects that appeal to a range of ages)	Look for developmentally appropriate pretend play . For example, how are they using the dolls or figurines in their play? Younger children may direct their actions to the figurine (e.g., feeding the doll), while older children may have the figurines interact with each other by talking to each other. See whether they are willing to follow your lead in pretend play or interactive activity with these toys, or if they are resistant to you changing their play.
Building materials like blocks, LEGO, or magnetic tiles (Consider having large blocks, like DUPLOs for fine motor or mouthing concerns, as well as regular LEGO or wooden blocks. Magnetic tiles are another option that are easy to clean.)	Watch for any repetitive patterns or themes in what they choose to build. One way to check for this is to see if the individual is flexible about following your lead in what to build, or whether they will allow you to change what they have built by adding to it or doing it differently. Keep some of the pieces separate and watch how they request additional blocks when needed. You can also see whether they share their creations with others by directing excitement or frustration.
Cause-and-effect toys with lights and sounds (Examples are pop-up toys, electronic musical toys, jack in the box, etc).	Many children engage in some repetitive play with toys like these, but you can watch whether they follow a specific pattern with the buttons they push, or focus in on one specific repetitive action instead of varying their use. See how an individual reacts when you attempt to take turns, turn off the lights or sound, block their ability to push buttons, or remove it from the room.
Puzzles, shape sorters, and letter/number magnets	Set aside some of the pieces so that they are unable to get them on their own. How do they react when a piece is missing? How do they manage frustration? What is their approach for problem solving?
Books, magazines, crayons, paper, coloring books (Make sure to have a range that would appeal to a range of ages and interests!)	Watch whether the individual attempts to share interest or excitement in a book or a drawing with others in the room. Do they invite their parent to color with them or show off something that they have made? When they see something interesting in the book, do they look around the room to check in? Use books or magazines as conversation starters . For example, do individuals respond to your non-directed comments and interests? During conversations, are they able to switch topics away from their interests to follow yours?
Sensory play activities like bubbles, playdoh, water, lights, and mirrors (Make sure you have a way to contain the mess! Bubble machines are great.)	Watch for repetitive movements , sensory seeking , or sensory aversions . For example, when excited about bubbles or lights do they flap, spin, or posture? Do they have a negative reaction to the feeling or bubble liquid or playdoh? Or seek out additional sensory input by licking or smelling the materials?
Floor mats (e.g., foam puzzle mats or gymnastic mats)	Padded puzzle mats or foldable gymnastic mats are a colorful and easy to clean way to set up play materials on the floor for younger children!

Appendix E. Overview of Evaluation Workflow

Evaluation Models

Model Type Summary	Single Discipline A single provider completes all components of the evaluation	Multidisciplinary Each discipline completes a discipline specific assessment, and may make separate diagnoses and recommendations	Interdisciplinary Team members complete various parts of the evaluation, and make the final diagnosis and recommendations in collaboration
Examples	A private practice psychologist	Primary care provider referring to a speech language pathologist for assessment; Community School-Medical Autism Review Teams (SMART)	Tertiary care centers like Seattle Children's Autism Center
Additional details	 Single discipline models vary in depth and breadth of evaluation Can be multiple visits with psychologist with a comprehensive neuropsychological battery Can be medical-based model with medical providers (who may request supplementary assessments to gain information –see multi-disciplinary evaluation model) 	 Can begin as a single discipline assessment with initial screening or assessment, but additional information is needed before a diagnostic decision is made Referral is made for further evaluation or data collection to another provider (e.g., SLP, EI team, OT, school psychologist) Individual reports are compiled, rather than integrated, with minimal to no collaboration between team members 	 Process is more streamlined and direct than a multidisciplinary assessment, but also requires greater coordination and staffing to complete as it is complex Team members may see the patient in tandem or on different days, but the key component is that these teams discuss the patient together and write a single report Findings and recommendations from each team member are fully integrated

Assessment Workflow Ideas

Receive and process referral

- •Internal vs external process
- Standardized referral form
- •ROIs collected (e.g., ESIT team if < 3, school and other therapists if > 3)

Identify referral concerns/intake

- Review referral forms
- •Level 1 screening questionnaires (e.g., AQ, CSBS, MCHAT-R/F, SCQ)
- Intake interview as needed
- Send caregiver and provider questionnaires

Collect (and review) records

- •Educational records (e.g., IEP/504)
- •Therapy records (e.g., ESIT, ABA, ST, OT)
- Caregiver questionnaire (e.g., developmental history form)
- External provider questionnaire (e.g., school or therapist information form)



Evaluation components

- Developmental interview (e.g., DSM-5 interview)
- •Caregiver report forms (e.g., ABAS, SRS-2)
- Direct testing (e.g., Tele-ASD-PEDS, ADOS)
- Provider observation and data organization tools (e.g., CARS-2, MIGDAS-2)

Schedule assessment

- Medical provider
- Psychologist
- Speech-language pathologist



Decision Point

- •Level 2 screening tools (e.g., STAT, RITA-T, ASRS, SRS-2)
- •Use triage tool (e.g., age, complexity, appropriateness)
- Make medical referrals as needed (e.g., audiology, speech, occupational therapy)
- Refer out for further evaluation as needed (e.g., high complexity differential diagnosis)



Complete feedback

- •In-person feedback or follow-up visit
- Written/standardized recommendations
- Referrals



Complete documentation

- Billing for time
- Visit notes
- Diagnostic report writing

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COE Workflow Examples

	Model A	Model B	Model C	Model D	Model E
Intake/Pre-work Gather chief complaint/ referral concern, initial developmental & family history, DSM V information	Internal referral (patient already in practice), or records gathered ahead of time	Phone interview brief history & developmental questions	Developmental intake questionnaire	Review prepared folder before visit (20-30 minutes)	3 visit format. Visit 1: intake/screening 30 mins
Observation Interview In person visit Medical appt Complete DSM V interview, developmental, medical & family history	30 min visit (helpful tip: schedule before lunch or last patient of the day in case it runs long)	40 min initial parent interview	One hour visit (before lunch or last patient of the day)	90 mins (up to 2 hours)	Visit 2: evaluation 60-90 mins In depth family interview, interaction with patient, assessment and observation
Follow up work or developmental testing Obtain outside records to complete assessment or do test/structured survey	Gather more information from EI, IEP, ST/OT, etc. (if not already gathered) or do tele-ASD peds	60 min ADOS		STAT or CAST with behavioral observations as needed. May refer out for ADOS or for OT/ST/IEP.	
Documentation time	45 min	No data	No data	60 mins	No data
Debrief/Follow up visit	30 min visit	20 min visit			Visit 3: follow up 30 mins
Provider	Bianconi, Buzbee	Frank	Rice	Cheek, Peterson-Ventura	Vossenkemper

Appendix F. Autism Primary Care Complexity Triage (APCCT) tool

Complexity Level	Complexity Factors (1 point for each bullet)				
Straightforward • 18mo-5yo • Clear presentation • Records available • All history congruent • Family/CG ready to discuss ASD • Appropriate for Primary Care Autism evaluation	 6yo+ 12yo+ Female, trans, or non-binary Medical complexity, such as: Multiple chronic diagnoses Concussion Genetic dx Gaps in history/limited records, such as: Homeschooled No hx of structured education Foster care hx Multiple (serial) early CG's Adoption Conflicting hx Significant Psycho-Social issues, such as: Family resistance to evaluation Hx of homelessness CG language barrier Cultural barrier (ASD- foreign concept) CG-child conflict CG learning disability/literacy issues CG SUD Hx of institutional care 				
Mild Complexity	Mental Health Complexity Family hx of psychotic disorders 1st degree relative with psychotic disorder SUD Trauma/abuse PTSD dx following trauma				
Moderate Complexity	 Single (1st) psychiatric hospitalization Multiple psychiatric hospitalizations Hx of manic/psychotic episodes Reactive Attachment Disorder dx Multiple (>3) psych dx 				
High Complexity- Refer for specialty evaluation No developmental hx available -or- 2+ Neuro factors -or- 11+ complexity factors -or- 5+ Mental health factors -or- >17yo -or- 18mo -or- Tricare insurance	Neurological Complexity Moderate-Severe TBI Memory impairment Active seizure disorder Cerebral Palsy Severe vision impairment Hearing impairment Other significant neurological conditions Fetal drug/alcohol exposure				

CG - Caregiver, SUD- Substance Use Disorder, hx-history, dx-diagnosis

(Buzbee, 2023)

Background:

In 2019, I completed the Autism Center of Excellence (COE) training through the Washington Health Care Authority, which allows community providers to diagnose autism spectrum disorder (ASD) in straightforward cases in their medical home. This allowed me to diagnose patients who sometimes had been waiting for years to see a specialist. Diagnosing autism in young children is my favorite part of my job. It is meaningful work which can have a significant impact on long-term outcomes. However, I quickly found that there is a great deal of community confusion regarding what the COE training is and which patients it is appropriate for. The situation can be summarized in four connected problems.

- 1. **The demand for ASD evaluations exceeds the capacity of specialists** (both in Washington and nationally), (Johnson, et al., 2023).
 - a. Training primary care providers to diagnose ASD is a partial solution, but even with this system change, wait times to see specialists are excessive.
- 2. Patients presenting to community Autism COE providers are often complex and exceed COE training.
 - a. The Autism COE training (~12h) does not replace the years of training that specialists go through.
 - b. Most parents don't understand the difference between a COE and speciality providers, they're just looking for someone to help their child.
- 3. There are significant racial and SES disparities in access to autism care in the US (Johnson, et al., 2023)
 - a. Families with literacy challenges & lack of documented developmental histories are more likely to present to community providers than specialists who have the time & assessment tools to serve complex patients.
- 4. Patient/system demands that exceed provider time & resources contributes to provider burnout
 - a. I have observed many primary care COE colleagues stop providing autism evaluations or quit entirely due to burnout and patient demands far exceeding what they could manage in a work day.
 - b. Most primary care COE's I know who continue to engage in this work are only able to by devoting many hours of unpaid personal time to record review and documentation. This is not a sustainable expectation.
 - c. Provider burnout is a crisis in the US healthcare system which contributes to decreased health care access and increased health disparities (AAMC, 2020).

Provider burnout increases problem #1. Disorganized systems contribute to problems #2, 3 & 4. The APCCT tool is aimed at triaging patients to make systems more efficient for both patients and providers. I literally dreamed this tool up one night while working on my LEND (Leadership Education in Neurodevelopmental and related Disabilities) project and have made adjustments based on feedback from providers at Seattle Children's Autism Center, the University of Washington Institute of Human Development and Disabilities and Washington Autism COE providers.

Instructions for Use:

The APCCT tool is a triaging framework to be used at provider discretion. Individual providers have diverse experiences, training and backgrounds and should evaluate ASD as is appropriate for their individual scope, training and comfort level. This tool is meant to help sort the very complex cases who need to see specialists get on the appropriate wait-lists sooner and help schedule cases to match provider time and skill capacity. Which specialist a patient should be referred to depends on age, individual complexity factors, and available regional specialty providers. Generally, neurological factors indicate referral to neurodevelopmental or neurology clinics. Mental health factors usually indicate a need for psychiatric and/or psychology assessment. A long list of complexity factors may require a team evaluation at an autism or developmental clinic. Patients with Tri-Care insurance should contact their insurance carrier for prior authorization and list of approved providers. Adults should see providers (usually psychologists) trained in adult ASD evaluations.

Permissions for Use:

The APCCT tool is free for primary care providers and clinics to use to serve young and under-resourced patients with concerns for ASD. If you choose to modify this tool for your individual practice, please note "Adapted from APCCT, Buzbee, 2023". Anyone interested in using the APCCT for commercial or electronic use should contact heatherbuzbeepnp3@gmail.com for permission.

Heather Buzbee, MSN, CPNP-PC, PMHNP-BC, PhD-S

References:

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Appendix G. Intake packet example

CLINIC NAME Autism Center

Greetings. We are pleased to be of service to you and your child. Enclosed are materials we ask for you to fill out as completely as you can and return to us at your earliest convenience. If your child is in preschool or daycare, or receives services with a speech or occupational therapist, please have them fill out the Teacher Interview Form and return it with your other forms. Once we receive everything, we will contact you to set up an appointment for your child's Autism Evaluation with FILL IN PROVIDER'S NAMES. Your appointment cannot be scheduled until we receive your paperwork. You can mail or fax it back. Or to speed up the process, you can drop them off at our location at the address provided on the business card. FILL IN PROVIDER'S NAMES have combined general pediatrics experience of 40+ years and have received certification through the Washington State Autism Center of Excellence (COE).

Your child's first appointment will be done virtually. This is an intake appointment to gather more information about your child. The second appointment will include an autism evaluation tool for toddlers and young children. It can be done virtually or in person depending on their age and your preference. These appointments will last 40-60 minutes. Given the length of the appointments, it is critical that you not miss your appointment and that you are well prepared for the visit. If you are unable to keep your child's appointment due to serious personal issues, you must call at least 48 hours in advance to cancel (425-493-6002). Any unexcused or missed appointments will result in cancellation of your child's evaluation and your child will NOT be rescheduled as we have a waiting list and you may have to seek autism services elsewhere. REVISE THIS ENTIRE SECTION TO MEET YOUR SPECIFICS

The virtual appointment will involve review of the medical and developmental information you submitted and other specific questions that are aimed at understanding who your child is, how they play and interact with other children and adults, and what kinds of behaviors they exhibit in various situations.

At the second appointment, we will observe your child play. There will be an additional appointment after that to give you final feedback and discuss treatment planning.

We are really happy to be here to help you and your child. We know being referred for an autism evaluation can be a difficult situation to face. It is critical for you and the health care providers to understand all your child's needs and conditions as fully as possible in order for them to thrive and blossom to their full potential. Please know that we will continue to be available at later dates as a resource for you, as it relates to special needs services and help you and your primary care provider navigate the system and how to best advocate for your child. We look forward to meeting you and your child, and will work hard to schedule the appointment as soon as we possibly can.

Sincerely,

Your COMPANY NAME Autism Team

Cost for Evaluation COMPANY NAME Autism Center

The estimated cost of our full diagnostic evaluation is approximately [FILL IN]. This includes 7 hours of the physicians' time (intake, assessment, report writing, and treatment planning) over the course of 3 appointments. You will receive an official report at the end of the evaluation.

If your insurance does not cover the entire cost of the appointment, you will be responsible for the remaining balance. EXAMPLE ONLY - DECIDE WITH YOUR FINANCE/BILLING DEPT HOW YOU WILL BILL AND HANDLE COMMERCIAL INSURANCE IF YOU ARE GOING TO ACCEPT IT

Cancellation Policy: All confirmed appointments require 24-hour advance notice for cancellation. If we do not receive at least 24-hour advance notice that you are canceling, you will be billed at the standard rate for that appointment. Exceptions may be made in the case of illness or family medical emergency. Please note that we cannot bill insurance companies for missed appointments. New clients who have not yet been seen, who "no show" for their appointment or cancel more than one appointment, will be removed from the waitlist and will not be seen.

Relationship								
Signature	Date	Printed Name						
Your signature below verifies the pay for care received through the		t, agree to its terms, and agree to						
Print patient's name								
I understand my insurance nor will check with my insurance post I will be responsible for if the	prior to the scheduled appointm							
I understand that some insurance companies do not cover some services provided and it is my responsibility to contact my insurance carrier to determine whether the services by the assigned provider will in fact be covered.								
I am responsible for all charges for services provided to me and/or my child by the COMPANY NAME unless insurance exclusions apply.								
I, the parent/legal guardian/patie	ent understand that: (initial each	n box)						

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If signed by person other than patient, please specify your relationship to patient: Parent/Guardian

Patient History for Neurodevelopmental Assessment

(Note: You can find a fillable PDF version and an editable word of this history form on the COE google drive: https://drive.google.com/drive/folders/1efWB6SqWCN0587tqEJbiZq2q9XwJHyb8)

Today's date:								
Child's name: Date of birth:								
Guardian: ☐ Both parents ☐ Mother ☐ Father ☐ DSHS ☐ Foster Parent ☐ Adoptive Other:								
Parents: Married Separated Divorced								
Current Concerns What are your primary concerns about your child?								
When did you first have these concerns?								
Has your child had previous evaluations for these concerns and what were you told?								
What have you been told about your child's future or any diagnosis?								
Birth and Early Infancy History								
Age of mother at time of birth and age of father at time of birth								
Was the pregnancy planned? ☐ Unknown ☐ No ☐ Yes								
Does the mother have any history of miscarriage or still birth?								
Any difficulty becoming pregnant? No Yes Unsure								
Was the mother exposed to any of the following while pregnant? ☐ None ☐ Yes (check all that apply) ☐ Drugs ☐ Marijuana ☐ Alcohol ☐ Tobacco ☐ Prescription Medications ☐ X- rays								
Did the mother experience any significant illness during pregnancy? Unknown No Yes If yes, please explain:								
Labor and Deliver: Vaginal C-section Forceps Vacuum assist Unknown								
Was the delivery difficult? ☐ Unknown ☐ No ☐ Yes If yes, please explain:								
Age in weeks at time of delivery: weeks Birth Weight:								
Were there any problems after birth? (examples: jaundice, need for oxygen, infections, feeding problems, seizures): ☐ Unknown ☐ No ☐ Yes If yes, please explain:								

Medicine: Dose:	Prescribed to tr	eat:
Please list all current medicines, supplements, and homeopath	·	, -
Medications		
Does your child use corrective or adaptive equipment, such as wheelchair? ☐ No ☐ Yes:		
Does your child have any pain issues or concerns? No Yes		
Does your child have any history of hospitalizations, surgeries, serious or chronic illness? No Yes:		• •
Has your child had their vision tested? ☐ No ☐ Yes Locati		
Has your child had their hearing tested? ☐No ☐Yes Locati	on:	date:
Toilet trained at what age		
Problems with Toileting: Constipation soiling, Bladder control,	Bedwetting (please	se circle) ? \square No \square Yes
What type of food does your child eat? Formula Puree	d 🗌 Finely Chopp	oed 🗌 Regular
\square Feeding self \square Picky eater \square Sitting still for a meal \square Oth	er:	
Does your child have any feeding issues? ☐ No ☐ Yes: ☐ Ga	gging 🗆 Vomiting	\Box Underweight \Box Overweight
☐ Difficulty falling asleep ☐ Sleep walking ☐ Other:		
Is your child having any sleep issues? ☐ No ☐ Yes: ☐ Restles	s□ Snoring □ Pa	auses Night awakenings
Does your child have any allergies? ☐ No ☐ Yes ☐ Unsure		
Medical and Physical History		
Head circumference size normal? : Yes No (please ex	plain)	
Age first pointed: Age first smile:		
Age first word: Age first 2-word phrase:		
Age first sat: Age first crawled: Age first walked:		
Birth Order: 1 st 2 nd 3 rd 4 th child		
Were there any difficulties during infancy? (examples: excessive difficulty): ☐ Unknown ☐ No ☐ Yes If yes, please explain:		

Development/Behavioral/Mental Health History and Therapies Has your child had any of the following? ☐ ADD/ADHD ☐ Anxiety ☐ Depression ☐ Speech/language difficulty Fine/gross motor/coordination difficulty Other: _____ Please list any therapists, counselors, or agencies who have worked with your child: None Service or agency: Location: Dates: Did your child have any attachment or bonding difficulties before the age of 5? \(\subseteq No \subseteq Yes If yes, please explain: _____ Does your child participate in any community activities, such as sports, clubs or religious group? □ No □ Yes: Do you have concerns with how your child plays or interacts with other children? Social skills? Does child seek same age friends? ☐ No ☐ Yes Do same age friends seek out your child? \(\subseteq \) No \(\subseteq \) Yes If your child is talking, are they easy to understand: \square No \square Yes If you child is not talking, how do they communicate? ______ What are your child's favorite activities? ______________________ What do you consider to be your child's strengths? What do you consider to be your child's weakness?

Stressors/Traumas:

List any unusual or traumatic events in child's life which may have impacted development and contribute to current problems. This might include birth or death of loved one, divorce, illness in family, frequent moves, physical/sexual/emotional abuse, bullying etc....

Incident	Child's age	Commen	ts					
School/Education								
Did child attend preschool or Head start?	」No □ Yes:							
Is your child currently enrolled in school? $\ \ \ \ $] No 🗌 Yes							
(name of school and district):								
Grade: Teacher's name:								
Does your child have an IEP (Individualized E	ducational Plan)?	yes						
If yes, what services do they receive:	·							
Child's classroom: General Education	General education with	pull out	f-contaiı	ned classroom				
Has the school voiced any behavioral or acad	demic concerns? ☐No [∃Yes:						
·								
Has your child had any of the following pro	hlams in school?	Yes	No	Grades				
		163	INO	Grades				
Speech or language								
Reading /dyslexia								
Writing problem								
Spelling								
Math								
Learning disability	Learning disability							
Suspensions								
Repeating a grade								

Development

Please list your child's developmental progress in the following areas: (Compare your child's development to other children their age. Please check the appropriate box.)

	Same as			Comments
Areas of Development	others	Slower	Faster	Please note any deterioration or loss of skills
Smile at parent				
Play peekaboo				
Point to show something				
Make good eye contact				
Sit alone				
Crawl				
Walk alone				
Social skills (sharing, taking turns)				
Self-control skills (impulse control,				
delaying gratification				
Make consonant sounds				
(for example: ba-ba)				
First words				
Responds to name				
Use simple command such as "no"				
Speak 2 to 3 word phrases				
Speak full sentences				
Drink from cup				
Eat with utensils				
Undertstands object names				
Obey verbal commands				
("Please come here.")				
Get dressed by self				
running				
drawing and art				
catch and throw a ball				
Building things like Legos				
Ride 2 wheel bike with no training				
wheels				

Family History

Family medical history is an important part of developing a plan of care for your child. Please indicate if anyone in your family has the following conditions:

Condition/Circumstance	Child	Mother	Father	Sibling	Mother's Family	Father's Family
Intellectual disability	0	- Induition				
Learning disorder						
ADHD/ADD						
Seizures or epilepsy						
Alcohol abuse						
Drug abuse						
Physical or emotional abuse						
Sexual abuse						
Depression						
Anxiety disorder or panic attacks						
Schizophrenia						
Visual disability or problems						
Deaf or hard of hearing						
Tics or Tourette's Syndrome						
Chronic illness						
Autism spectrum disorder						
Genetic disorder						
Special education services						
Birth defects						
Arrests or incarcerations						
Other:						

Social History

Caregiver Name:		Relationship:				
Employed: Occupation:		Age:				
Highest grade level completed or highe	er education:					
Caregiver Name:		Relationship:				
Employed:Occupation:		Age:				
Highest grade level completed or highe	er education:					
Sibling Name:	Gender:	Age:	Lives with child:			
Do any other individuals live with the o	hild? No Yes					
Please list:						

Discipline:

What methods have been used to improve the child's behavior at home and what methods have worked best?

	Yes	No	Comments				
Verbal reprimands							
Spanking							
Withdrawal of privileges							
Grounding							
Rewards							
Time Out							
Parent Child Interaction Train	ning (PCIT) ultural b	☐ Triple	s or classes? No Yes (please indicate which one) Pe P (Positive Parenting Program) Incredible Years Other t are important for us to know when providing care?				
Is there anything else that you	ı would li	ke us to I	know about your child?				
My child currently has the following services in place: Developmental Disabilities Administration (DDA), DDA Case Worker: Social Security/SSI Birth – 3 Services (ESIT through Opportunity Counsel or Whatcom Center for Early Learning) Family Resource Coordinator: Occupational Therapy, Physical Therapy, Speech Therapy (where): Applied Behavioral Analysis (ABA):							
I would like more information about: Developmental Disabilities Administration (DDA) Social Security/SSI Counseling Resources (for child, sibling, family members) Transition to Adult Care (guardianship, vocational training, independent living) Parent Support (Parent to Parent, The Arc, etc.) None of the above							

Thank you to Jim Troutman and the Everett Clinic for sharing their intake materials.

Appendix H. COE Evaluation Requirements

The primary responsibility of a Center of Excellence for prescribing ABA treatment under a Medicaid benefit is to accurately diagnose autism spectrum disorders and then to determine the medical necessity for applied behavior analysis therapies (ABA) including multi-disciplinary treatment recommendations.

COE evaluations should include, but not be limited to, the following information:

- COE Information Provider name, organization name, NPI, contact information, including email and perhaps a point of contact if there are issues with the paperwork.
- Client Information ProviderOne number, DOB, parent/guardian names and contact information
- History of present concerns
- Past Medical history
- Child's health history
- Vision and hearing testing results
- Allergies
- Medications
- Review of Systems
- Neurology History
- Current Functioning
- Reported and observed Stereotypical or repetitive behaviors
- Education and Therapy
- Family and social history
- Physical exam/behavioral observations
- Neurodevelopmental assessment
- Diagnosis
- Recommendations including the ABA order, utilizing the provided template
- DSM 5 checklist

Included in this documentation are the steps taken to determine an accurate diagnosis:

- Child's early development: may be obtained from well child visits, family interview, and records of cooperating agencies such as birth to three agencies.
- Results of appropriate hearing and vision screening (to indicate language challenges are not a result of another disorder)
- Any autism screening tools that may have been administered
- Any/all autism specific diagnostic instruments such as ADOS or other validated diagnostic instruments.
- Behaviors observed or reported indicating criteria met based on DSM-5 criteria
- Any pertinent cognitive, speech/language, motor behavioral and/or adaptive instruments that may have been administered as additional evidence of a comprehensive accurate diagnostic.
- Additional studies that may have been administered including laboratory studies.
- Child's behavioral issues, including those that may show his/her problem behaviors that prevent progress in less intrusive more typical learning environments.

Appendix I. Screening and diagnostic tools

List of common tools arranged by type, age range, and other features (last edited 6/7/2024)*

Note: The tools in this chart are not exhaustive or direct recommendations, but options to consider when designing your evaluation workflow.

	Early childhood (approx. up to age 5)	Middle childhood (approx. 6-12)	Adolescents (approx. 13-18)	Adulthood (approx. 19 and up)
Record Review	ESIT (Early Support for Infants and Toddlers) Outside evaluation and therapy records Teacher/provider interview forms	IEP (Individualized Education Outside evaluation ar Teacher/provider inte	nd therapy records	Work/employment history Outside evaluation and therapy records Teacher/provider interview forms
Level-1 screening (questionnaires)	M-CHAT-R/F (Modified Checklist for Autism in Toddlers, Revised with Follow-up) CASD (Checklist for Autism Spectrum Disorder) CSBS-ITC (Communication and Symbolic Behavior Scales, Infant Toddler Checklist)	SCQ (Social Communicat ASRS (Autism Spectrum F CASD (Checklist for Autist SRS-2 (Social Responsive Edition)	Rating Scales) m Spectrum Disorder)	SCQ (Social Communication Questionnaire) †AQ-10 (Autism Quotient) †CAT-Q (Camouflaging Autistic Traits Questionnaire) †RAADS-R (Ritvo Autism Asperger Diagnostic Scale—Revised)
Level-2 screening (observations)	STAT (Screening Tool for Autism in Toddlers & Young Children) RITA-T (Rapid Interactive Screening Test for Autism in Toddlers)		=	r this age range. Recommendation to move view if concerns are present.
Parent/caregiver interview tools	TASI (Toddler Autism Symptomatology Interview) PIA—CV (Parent Interview for Autism—Clinical Version)	MIGDAS-2 (Monteiro In Edition) ADI-R (Autism Diagnostic	·	Diagnosing the Autism Spectrum, Second
Observation and assessment tools	TAP (TELE-ASD-PEDS) CARS-2 (Childhood Autism Rating Scales, Second Edition) ADOS-2 (Autism Diagnostic Observation Schedule, Second Edition)	CARS-2 (Childhood Autis ADOS-2 (Autism Diagnos AMSE (Autism Mental St	stic Observation Schedu	
Adaptive functioning tools	ABAS-3 (Adaptive Behavior Assessment System, The Vineland-3 (Vineland Adaptive Behavior Scales, This	•	regiver self-report)	

^{*}Bolded tools listed first have greater accessibility/ease of use, acceptability to insurance companies, and/or frequency of use in primary care settings.

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[†]These tools have limited to no evidence base for use as screening or diagnostic tool; however, given the lack of validated tools for adult populations that are included as they may help you gather additional qualitative information to use.

List of tools with details training, and costs arranged by type and alphabetically (last edited 5/6/2024).

Please note that costs vary based on which version of the tool you choose to get (e.g., paper or online, hand score or scoring software). Costs in the table below may not reflect your actual start-up costs, but are intended to give an estimate of costs.

Tool	Age-range	Time to administer	Training	Start-up cost	Cost of ongoing use	Languages offered	Publisher link			
Observatio	Observational and interview tools									
ADI-R	All ages	1.5-3 hour interview	Self-study (\$1,142 video)	\$415 kit (manual & 10 protocols)	\$152/pack of 5 +\$32/ per 10 algorithm forms	Many (15+)	https://www.wpspublish.com/adi-r- autism-diagnostic-interviewrevised.html			
ADOS-2	All ages (5 versions)	40-60 minute direct testing	Workshop (\$600) and/ or Self-study (\$1,329 video)	\$2695 kit (manual, test materials, & 50 protocols)	\$90/pack of 10 for each module	Spanish	https://www.wpspublish.com/ados-2- autism-diagnostic-observation-schedule- second-edition			
AMSE	All ages	5-10 minute scoring (based on your clinical observation)		N/A; no standardized test materials	N/A	N/A	https://autismmentalstatusexam.com/			
CARS-2	All ages (2 versions)	5-10 minutes scoring (based on your clinical observation)	,	\$308 kit (manual & 75 protocols; no standardized test materials)	\$76/pack of 25 for each version	Italian, Bulgarian	https://www.wpspublish.com/cars-2- childhood-autism-rating-scale-second- edition.html			
MIGDAS-2	All ages (2 versions)	30-60 minute interview (also has a parent report form)	Self-study (manual)	\$314 kit (manual & 25 protocols; no standardized test materials)	\$46/pack of 5 for each version	N/A	https://www.wpspublish.com/migdas-2- monteiro-interview-guidelines-for- diagnosing-the-autism-spectrum-second- edition.html			
RITA-T	Under 3	5-10 minutes	Self-study (\$175 video)	\$65 kit (test materials & protocols)	N/A	Spanish, Portuguese	https://www.childrenshospital.org/research/labs/rita-t-research			

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STAT	Under 3	20 minutes	Self-study (included w/ kit)	\$500 kit (test materials, manual, & protocols)	\$25/pack of 25 protocols	N/A	https://stat.vueinnovations.com/licensing
TASI	Under 3	30-40 minute interview	Self-study (free manual)	N/A	N/A	Arabic, Czech, Spanish, Portuguese	https://www.mchatscreen.com/tasi/
TELE-ASD- PEDS	Under 3	10-20 minutes	Self-study (free videos & manual)	N/A (need to register first to access)	N/A	N/A	https://vkc.vumc.org/vkc/triad/tele-asd- peds
PIA-CV	Under 6	30-40 minute interview (also has a parent report form)	Self-study	N/A	N/A	Spanish	https://uwreadilab.com/tools-materials/
Questionna	ires						
ABAS-3	All ages (5 versions)	10-20 minutes	Self-study	\$436-\$616 (manual & 25 protocols, varies based on version)	\$122/pack of 25 for each version	Spanish	https://www.wpspublish.com/abas-3- adaptive-behavior-assessment-system- third-edition
ASRS	Ages 2-18 (2 versions)	5-20 minutes	Self-study	\$125 manual; \$105/pack of 25 forms	\$105/pack of 25 for each version	Spanish	https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Behavior/Autism-Spectrum-Rating-Scales/p/100000354.html
AQ-10*	Ages 5+	5 minutes	Self-study	Free	N/A	Many (5+)	https://www.autismresearchcentre.com/tests/
CASD	Up to 16	15 minutes	Self-study	\$150 kit (manual & 25 forms)	\$68/pack of 25 forms	N/A	https://www.wpspublish.com/casd- checklist-for-autism-spectrum-disorder
CAT-Q*	Ages 16+	10-30 minutes	Self-study	Free	N/A	N/A	https://link.springer.com/article/10.1007/s 10803-018-3792-6 (see supplement)
CSBS-ITC	Under 6 (w/	5-25 minutes	Self-study	\$66.95 manual, forms are free	N/A	N/A	https://brookespublishing.com/product/cs bs-dp-itc/

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	language delay)						
M-CHAT- R/F	Under 3	5-30 minutes	Self-study	Free	N/A	Many	https://www.mchatscreen.com/
RAADS:R*	Ages 18+	10-30 minutes	Self-study	Free	N/A	N/A	https://www.ncbi.nlm.nih.gov/pmc/article s/PMC3134766/ (See Appendix A)
scq	Ages 4+ (2 versions)	5-10 minutes	Self-study	\$228 kit (manual & 40 forms	\$20/pack of 20 forms	Many	https://www.wpspublish.com/scq-social- communication-questionnaire.html
SRS-2	Ages 2+	15-20 minutes	Self-study	\$291 child or adult kit (manual & 25 of each version)	\$88/pack of 25 for each version	Spanish	https://www.wpspublish.com/srs-2-social-responsiveness-scale-second-edition
VABS-3	All ages (2 versions)		Self-study (\$185 manual	\$195 manual and \$113/pack of 25 for each version	\$113/pack of 25 for each version	Spanish	https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Behavior/Adaptive/Vineland-Adaptive-Behavior-Scales-%7C-Third-Edition/p/100001622.html

^{*}Use with extreme caution. These tools have limited to no evidence base for use as a screening or diagnostic tool; however, they may help you gather additional qualitative information to use during an evaluation.

Appendix J. Documentation and report templates

Non-EMR template example

ASD EVALUATION VISIT

ASD EVALUATION VISIT
Presenting Concern:
PAST MEDICAL HISTORY:
Perinatal complications or exposures:
Birth/Infancy:
Hospitalizations:
Specialty Care:
Vision:
Hearing:
Family History:
Social History:
EDUCATION:
THERAPIES/SERVICES:
FORMAL TESTING/EDUCATIONAL ASSESSMENTS/QUESTIONNAIRES: (e.g., ASQ, MCHAT, ADOS)
DEVELOPMENT (hx and current):
Gross Motor:
Fine Motor:
Adaptive: (clothes off/on, feeds self, toilet trained)
Social Skills: (played peekaboo, responds to name)
SOCIAL COMMUNICATION DOMAIN.

SOCIAL COMMUNICATION DOMAIN:

- 1. Social/Emotional Reciprocity: difficulty initiating, responding to and sustaining engagement with others; participation in social interactions primarily on own terms; delays in development of shared joint attention; decreased response to name being called; decreased social smiling; communication primarily for needs-based purposes; decreased showing of objects (e.g., decreased showing items to parents without need for help), decreased sharing interest, activities or emotions with others; diminished imitation skills; decreased seeking/offering comfort to others; decreased response to physical affection, and difficulty participating in simple back and forth conversations (e.g. LIST CONVERSATIONAL CHARACTERISTICS).
- 2. Non-verbal communicative behaviors used for social interaction: avoidant OR inconsistent use of eye contact during social interaction, poor coordination of eye gaze with other means of communication (e.g. facial expressions, verbalizations), decreased use of gestures and body language (e.g. diminished pointing and other gestures), use of others' bodies as a tool for communication, and decreased use of facial expressions to communicate feelings.
- 3. Developing maintaining and understanding relationships: including diminished interest in/initiations with peers, reduced interactive play, preference for solitary play, difficulty with turn taking

RESTRICTED AND REPETITIVE DOMAIN:

- 1. Stereotypic or repetitive motor movements, use of objects, or speech: including motor mannerisms (e.g., body tensing when excited, hand flapping, spinning, walking on toes, jumping, rocking), repetitive actions on objects (e.g., lining up, sorting, and/or spinning objects and repeating preferred actions with objects), interest in the mechanics of objects, non-functional/repetitive play (e.g., playing with toys not as they are intended), and repetitive use of language (e.g., presence of echolalia, scripted language, jargon, odd/high pitched vocalizations, use of made-up words).
- 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviors: including difficulty with transitions and change, rigidity (e.g., eating rigidities, items must be in a specific place), insistence on routines/rituals (e.g., certain bath time order, sleep time), becomes upset when routines are disrupted (e.g., upset when parent take an alternate route in car, distressed by change in daycare routine), distress if minor changes occur in environment (e.g., moving furniture, a parent with new hairstyle/glasses), insistence on others' participation in routines.
- 3. Highly restricted, fixated interests that are abnormal in intensity or focus: including presence of restricted interests, preoccupation with unusual objects (e.g., string, tearing paper, water, toilets, vacuums), excessively circumscribed interest (e.g., needing to have something in both hands, carries spoons/unusual object all day)
- **4.** Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment: including tactile (e.g., EXAMPLE), auditory (e.g., EXAMPLE), visual (e.g., EXAMPLE), taste (e.g., EXAMPLE), or smell (e.g., EXAMPLE) sensitivities, as well as sensory seeking behavior (e.g., EXAMPLE).

OTHER BEHAVIORS: self-regulation, attention & executive function, oppositional and aggressive behavior, anxiety, depression.

depression.		
REVIEW OF SYSTEMS:		
Growth:		

Diet/GI: Elimination: Neuro:

Sleep:

Physical Examination/Observations:

(this might refer to previous visit)

ASSESSMENT/DX:

Difficult Behavior Speech Delay

PLAN:

Refer to Early Intervention for SCAP Eval if not already done

? Refer for ADOS

Return for feedback session after SCAP eval and/or ADOS completed/information reviewed (if it's after ADOS then it's Results Visit, if it's after COE eval then it's Eval Visit 2)

- -Given info on ABA and encouraged to call and find out where can be seen and get on waitlist.
- -f/u 4-6 weeks after SCAP eval or ADOS done.

ASD EVAL VISIT 2

HPI:

Seen previously in our office on (dates)

Evaluations completed since last visit (SCAP eval)

Enter any new information into the categories or reference the attached note.

SOCIAL COMMUNICATION DOMAIN:

Social/Emotional Reciprocity:

Non-verbal communicative behaviors used for social interaction:

Developing maintaining and understanding relationships:

RESTRICTED AND REPETITIVE DOMAIN:

Stereotypic or repetitive motor movements, use of objects, or speech:

Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviors:

Highly restricted, fixated interests that are abnormal in intensity or focus:

Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment:

OTHER BEHAVIORS:

PLAN:

- -NOT ASD-->make sure set up with appropriate therapies
- -Suspect ASD-->refer for ADOS, plan to f/u 4-6 weeks

ASD RESULTS VISIT

HPI:

Seen previously in our office on (dates)
Evaluations completed since last visit (ADOS, SCAP eval)
Enter any new information into the categories

ASSESSMENT:

Based on prior evaluations and assessments is found to have

(speech delay as well as deficits in social communication and social interaction across multiple contexts. S/He has abnormal social approach, no conversational skills, minimal social/emotional reciprocity, limited initiation of and response to social interaction, poorly integrated verbal and nonverbal communication, reduced eye contact, and difficulties in sharing imaginative play. He also has restricted, repetitive patterns of behavior such as lining objects, spinning in circles, and difficulty with transitions. He does not share interests with others and does not respond to his name being called. Based on history and examination, the patient meets the DSM V criteria for autism spectrum disorder. It is not clear whether this is with intellectual disability due to the young age and limited specific testing but he does have language impairment.)

Giving results to family, make sure to bring out positives: attention to detail, deep focus/concentration, observational skills, absorb and retain facts, visual skills, expertise, methodical approach/analytical/spotting patterns, novel approaches/unique thought processes, creativity, tenacity&resilience, accepting of difference, integrity/honesty/commitment.

PLAN:

If NOT ASD-->make sure set up with appropriate therapies, refer back for f/u development with pcp in 6 months. If UNCERTAIN ASD-->refer to SCH, refer back to pcp for f/u development in 6months.

If YES ASD-->

- 1. Would greatly benefit from early intervention or an individualized educational program through the school district. Early services can be provided in-home and through the developmental preschools and later services can be provided through public and private schools.
- 2. Would greatly benefit from intensive Applied Behavioral Therapy. Letter supplied to family today that serves as an order for ABA.
- 4. Parent Education and supports: handout provided on Autism resources, DDA, and SSI
- **3. Return to clinic in 1-2months** (at that visit 1-2months later: discuss genetics, find out where things are at with therapies and ABA, refer back to see pcp in 1-2 months)

Thank you to Emily Bianconi, ARNP, Skagit Pediatrics, Mount Vernon, WA for sharing this template.

EMR-compatible template example

ASD EVALUATION VISIT

Patient Name: @NAME@

DOB: @DOB@

Autism Evaluation
Date of Service: @ED@

Primary Care Provider is @PCP@.

Full intake materials provided were reviewed including a detailed health questionnaire and behavioral questionnaire using the Social Communication Observation Tool and the Checklist for Autism Spectrum Disorder - Short Form (CASD-SF) which is a combination of questions from multiple autistic spectrum questionnaires focused on the DSM 5 criteria for autism.

Chief Concern: @FPREFNAME@ is a @AGEPEDS@ @SEX@ who presents for a diagnostic assessment specific to autism spectrum disorder in the context of speech delay and behavioral concerns.

Primary concern(s): ***

Parent first became concerned when @FPREFNAME@ was ***.

@FPREFNAME@ is in *** grade at *** (*** SD). He/she does/does not receive services.

Pregnancy: Mom was *** yo and dad was *** yo at time of delivery. Good pregnancy. No history of miscarriage. No etoh/tobacco/drugs.

Birth: Born at *** weeks via ***. BW ***. Passed newborn hearing screen. No problems after delivery. This is their *** child.

Medical history: Healthy infant. *** No hospitalizations or surgeries.

Developmental history: First sat at *** months, crawled at *** months, walked at *** months. First word at *** months and 2 word phrases at *** months. First point at *** months and first smile at *** months. Head circumference was ***normal.

Medications: @CURRENTMEDS@ Allergies: No Known Allergies

Immunizations: Up to date.

Vision: No concerns.

Hearing: Hearing tested at birth and normal.

Sleep: ***

Diet: ***

Elimination: No constipation. Toilet trained at *** yo.

Family History: No family history of autism.

Social History: Lives at home with mom, dad and ***.

Stressors/Traumas: ***.

Favorite activities: ***.

Strengths: ***. Loving supportive family.

Challenges: ***

Current Development:

Social Communication Observation Tool

Communication:

Delay in, or total lack of, the development of spoken language:

Difficulty holding conversation:

Unusual or repetitive language:

Play that is not developmentally appropriate:

Restricted, Repetitive Stereotyped Behaviors/Movements:

Interests that are narrow in focus, intense, or unusual:

Unreasonable insistence on sameness/routines:

Repetitive motor mannerisms:

Preoccupation with parts of objects:

Social Skills:

Lack of social or emotional reciprocity:

Difficulty using nonverbal behaviors to regulate social interaction:

Little sharing of pleasure, achievements, or interests with others:

Failure to develop age-appropriate peer relationships:

Associated Concerns:

Unusual sensory interests:

Unusual responses to sensory input:

Motor skills:

Gross motor:

Fine motor:

Adaptive:

Checklist for Autism Spectrum Disorder - Short Form (CASD-SF):

Score

FORMAL TESTING/EDUCATIONAL ASSESSMENTS/QUESTIONNAIRES:

Teacher Interview Form completed by ***.

Child's school program: ***

Child's academic functioning: ***
Child's communication skills: ***

Child social functioning in structured settings: ***
Child social functioning in unstructured settings: ***

Quality of student's peer relationships: ***

Restricted or repetitive behaviors: ***

Concerns for autism spectrum disorder: ***

Social problems ***
Academic problems ***
Behavior problems ***

Description of behavior problems at school: ***

Review of systems:

Constitutional: No growth concerns. HEENT: Normal hearing testing at birth. No vision concerns. Cardiac: No heart problems. Respiratory: No breathing problems. GU: No GU problems. GI: No nausea, vomiting, diarrhea or constipation. Selective eater. Skin: No unusual birthmarks and no rashes. Neurological: No history of seizures or head injury. Sleep: There are sleep difficulties.

Physical Examination:

There were no vitals taken for this visit.

General: Alert and well-nourished; No acute distress

Skin: no rashes Eyes: Non-injected. Head: Normocephalic

Ears: Normal position/morphology Nose: No lesions; No discharge Mouth: mucous membranes moist Lungs: Respiratory effort normal

C/V: Not performed Abdomen: Not performed

Neuro: Grossly normal; interaction appropriate for age

Exam done with help of parent.

Assessment/Plan:

@FNAME@ is a @AGEPEDS@ @SEX@ with speech delay and characteristics concerning for autism.

Plan for in person autism assessment tool. Appointment scheduled.

Referral to audiology.

The pros and cons of a video visit for providing this care was reviewed with the patient's parent(s), and their verbal consent has been given to deliver this visit.

This visit was conducted real time, via synchronous interactive video & audio conferencing technology, utilizing the HIPAA compliant MyChart platform. Patient and their family are located at home and PROVIDER NAME is located remotely in his/her home office, both within the state of Washington.

Time spent: E/M code was selected based on *** minutes spent on the date of encounter reviewing pertinent history and previous diagnostics, performing medically appropriate examination and evaluation, ordering diagnostic tests and/or medications, counseling and education to patient/family/caregiver. This excludes activities performed by clinical staff.

ASD RESULTS VISIT

Patient Name: @NAME@

DOB: @DOB@

AUTISM EVALUATION

Date of Service: @ED@

@FNAME@ is seen today for the second part of ***his/her autism evaluation using the ***. He/she is accompanied by *** parent.

UPDATES:

@VITALS@

PROCEDURE: ***

EVALUATION RESULTS: ***

ASSESSMENT/PLAN:

@FNAME@ is a @AGEPEDS@ @SEX@ with speech delay. *** exhibited challenges regarding effective social communication (both verbal and nonverbal), social interaction, as well as atypical restricted and repetitive behaviors (i.e. strong/repetitive interests, characteristic body use). Based on review of records, history, examination and observations, the patient meets the DSM V criteria for autism spectrum disorder. It is not clear whether this is with intellectual disability due to his/her*** young age and limited specific testing but there is language impairment.

- *** demonstrates a number of strengths that include: . *** has supportive family members who are strong advocates for ***. With appropriate intervention to address difficulties in language, social skills, social communication, and behavior, the prognosis seems favorable for *** to make positive gains in these areas.
- 1. Autism Spectrum Disorder with accompanying language impairment, requiring substantial support (level ***)
- 2. Speech and language delay

3. ***

Recommendations were developed based on records review, assessments, observations and caregiver interview completed by PROVIDER NAME as a certified autism specialist through the Washington State Center of Excellence. PROVIDER NAME recommends that the report and recommendations be shared with all professionals providing services for your child.

- 1. Continue regular visits with your doctor. Continue with @FNAME@'s *** therapy.
- 2. If your child is older than 3, it is recommended that @FNAME@'s IEP be revised to incorporate an autism diagnosis.

 *** will benefit from specially designed instruction in the areas of social-emotional, adaptive, cognitive, and communication skills as well as sensory accommodations. Contact ARC for an IEP parent mentor if you wish for extra parental support. If your child is younger than 3, make sure you send this report to your local early intervention program your child is enrolled in so they can have this information and modify their services appropriately.
- 3. @FNAME@ would benefit from evidence-based intensive behavioral intervention using the methods such as applied behavior analysis (ABA) as part of *** educational curriculum at home or school. Intervention centers and private therapists can be located through https://featautismguide.wordpress.com/ and by contacting the ARC in your local

community. Call and get on as many lists as you can and regularly call them back every few weeks to check on your child's status. Be patient, it takes many months to get accepted due to long waiting lists. ABA agencies may request a copy of your child's report and DSM 5 checklist. Item # 4 below is a formal order for ABA therapy which you can highlight and share with the agencies when you apply.

4. Many private insurance companies cover these services; therefore, through this report, I am prescribing ABA services for @NAME@. The behaviors and skill deficits are having an adverse impact on *** development as documented in this report. *** is exhibiting functional impairments across domains that interfere with the ability to participate adequately in home and community settings and will likely impact functioning in school. Applied behavior analysis (ABA) services are ordered given the adverse impact of @FNAME@'s behaviors and core impairments.

ABA therapy has changed over the years since it was first developed. Some in the autism community hold strong views against its application given, in part, to the more negative reinforcement techniques that were previously employed. ABA is an individually designed program that is prescribed to specifically meet the needs of your child and his or her behaviors and social/sensory needs. The more your child has targeted behaviors or social or sensory deficits you really wish to work on and modify, the more likely your child would benefit from ABA therapy. It may not be the best fit for every child. ABA is now primarily based on positive reinforcements and has evolved a lot since its inception and when properly employed by skilled therapists it can have very positive benefits. It is recommended you apply and get on waiting lists and then read more and consider if you feel it would be in the best interest of your child.

- 5. @FNAME@ may benefit from additional intervention with private community-based speech and occupational therapists in order to support *** communication and sensory needs.
- 6. @FNAME@'s family may benefit from continued parent support and education. The ARC of MODIFY FOR YOUR COUNTY (email; phone) offers support groups and lectures for parents of children with special needs.
- 7. @FNAME@'s family may be interested in accessing the 100 day kit from Autism Speaks, which is a resource for newly diagnosed families that can be accessed on the Autism Speaks website: http://www.autismspeaks.org/family-services/tool-kits/100-day-kit
- 8. @FNAME@ may qualify for state support and other funding sources. Developmental Disabilities Administration is part of the Department of Social and Health Services (DSHS). Any person who has a qualifying developmental disability that starts before the age of 18 and is expected to continue indefinitely may be eligible for DDA services. Eligibility is not based on a family's income. The following site includes the application and instructions to fill it out: https://www.dshs.wa.gov/dda/consumers-and-families/eligibility. Supplemental Security Income (SSI) is a federal income supplement program designed to help people with disabilities and the elderly who have little or no income. It is available when a family meets income eligibility guidelines and the child meets SSI disability criteria. For more information go towww.ssa.gov/applyfordisability/child.htm or call 1-800-772-1213.
- 9. Your doctor will order special lab tests to look for genetic causes or reasons for @FNAME@'s delays. You are busy now so it is ok to wait on these tests for a few months. There is also a research study that is being conducted at Children to look for genetic causes of autism, if you are interested.

https://sparkforautism.org/why/

Your doctor can also write a prescription for diapers or pull-ups (if needed).

- You can also get a prescription for a disability parking placard.
- 10. Contact Ben's Fund (www.bensfund.org) to apply for up to \$1000 in free grant money to help with any necessary items, like things to keep *** safe. It is pretty easy to get this money so definitely apply! It is specifically for kids with ASD.
- 11. @FNAME@ is also eligible to participate in Camp Prov, a supported summer camp experience for children with

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special needs (3+ years old) and siblings too! (https://washington.providence.org/locations-directory/r/regional-medical-center/donate-and-volunteer/volunteer/summer-opportunities/camp-prov). Other summer programs for children with special needs can be located through local parks and recreation centers or at www.cshcn.org.

- 12. There are informative videos you can watch through the Autism Clinic at Seattle Childrens

 Hospital. https://www.seattlechildrens.org/health-safety/keeping-kids-healthy/development/conversations-about-autism/
- 13. I will follow up with you in a few months to see how @FNAME@ is doing.

It was a pleasure to work with you and @FNAME@. *** is fortunate to come from a very loving and supportive home. Please feel free to call me or send me a message with any questions regarding this report.

Peds time spent: Total of *** minutes spent today with patient/patient family and in counseling and/or activities in coordination of care related to play observation- chart review, report writing and communication, labs and referrals as described and recorded today in the visit.

Thank you to Susana Myers, DO, for compiling and sharing this template

	<u> 5 Criteria</u>	Autism Spectrum Disorder
NOTE:	If the individual has a well established DSM-IV diagnosis of autistic disorder, Asperger's	
disord	er, or PDD-NOS, please check this box. Please then either reclassify them using the below	
criterio	a or complete and attach the DSM-IV checklist to verify diagnosis.	
A. Per	sistent deficits in social communication and social interaction across multiple contexts, as	
manife	ested by the following, currently or by history:	
1.	Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach	
	and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions,	
	or affect; to failure to initiate or respond to social interactions.	
2.	, c c,	
	example, from poorly integrated verbal and nonverbal communication; to abnormalities in	
	eye contact and body language or deficits in understanding and use of gestures; to a total	
	lack of facial expressions and nonverbal communication.	
3.		
	from difficulties adjusting behaviors to suit various social contexts; to difficulties in sharing	
	imaginative play or in making friends; to absence of interest in peers.	
	Social-Communication Domain Total (must meet all 3):	
	Specify Current Severity:	Requires:
	(circle on in column on right)	
		Substantial
		Support (2)
		Very Substantial
		C
D Door	tuisted monetative matterns of helicitics interests on cativities or monifested by at least two	Support (3)
	tricted, repetitive patterns of behavior, interests, or activities as manifested by at least two	Support (3)
of the	following, currently or by history:	Support (3)
	following, currently or by history: Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor	Support (3)
of the 1.	following, currently or by history: Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases).	Support (3)
of the	following, currently or by history: Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or	Support (3)
of the 1.	following, currently or by history: Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid	Support (3)
1. 2.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).	Support (3)
of the 1.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong	Support (3)
1. 2.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or	Support (3)
1. 2. 3.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).	Support (3)
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1. 2. 3.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests). Hyper-or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific	Support (3)
1. 2. 3.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests). Hyper-or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or	Support (3)
1. 2. 3.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests). Hyper-or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).	Support (3)
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1. 2. 3.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests). Hyper-or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement). Restricted and Repetitive Domain Total (must meet at least 2): Specify Currently Severity:	Requires:
1. 2. 3.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests). Hyper-or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement). Restricted and Repetitive Domain Total (must meet at least 2):	Requires: Support (1)
1. 2. 3.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests). Hyper-or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement). Restricted and Repetitive Domain Total (must meet at least 2): Specify Currently Severity:	Requires: Support (1) Substantial
1. 2. 3.	Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypeis, lining up toys or flipping objects, echolalia, idiosyncratic phrases). Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day). Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests). Hyper-or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement). Restricted and Repetitive Domain Total (must meet at least 2): Specify Currently Severity:	Requires: Support (1)

C. Symptoms must be present in the early developmental period (but may not become fully	
manifest until social demands exceed limited capacities, or may be masked by learned strategies	
later in life).	
D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.	
E. These disturbances are not better explained by intellectual disability or global developmental	
delay.	
Autism Spectrum Disorder Criteria Met?	YES/NO
With or Without Intellectual Impairment?	WITH/WITHOUT
With or Without Language Impairment?	WITH/WITHOUT
Associated With Any Known:	
(1) medical/genetic/environmental condition/factor: 2) neurodevelopmental /mental/behavioral	
disorder, 3] catatonia)	
Provider name:	
Date:	
Signature:	

Appendix K. Reimbursement and billing guides

CPT billing codes, descriptions, and reimbursement rates (as of March 2023)

Category	CPT Code	Estimated Medicaid Reimbursement as	Descriptions	Provider Types	
		of March 2023* (can vary by setting)			
Evaluations	99205	\$83.03 to \$101.27	Office Visit, New Patient	MD, ARNP, ND	
		\$124.68 to \$153.15 for ages 0-20 only			
	99215	\$66.03 to \$83.03	Office Visit, Established Patient	MD, ARNP, ND	
		\$99.07 to \$125.63 for ages 0-20 only			
	G2212 (the Medicaid	\$18.25 to \$18.84	Prolonged services (must be used with	MD, ARNP, ND	
	version of 99417)		99205 or 99215. up to 3 hours)		
	90791	\$100.28 to \$117.47	Psychiatric Diagnostic Evaluation	Psychiatrist, Psychiatric ARNP	
	90792	\$99.62 to \$114.38	Psychiatric Diagnostic Evaluation with	Psychiatrist, Psychiatric ARNP	
			Medical Services		
	96130	\$61.95 to \$69.14	Psychological Testing	Psychologist	
	96131	\$45.44 to \$51.27			
	[EPA if 16 years or older,				
	cannot exceed 7 in				
	combination with 96131]				
	96136	\$13.59 to \$26.02	Psychological Testing	Psychologist	
	[PA if 16 or older]				
	96112	\$72.83 to \$73.80	Developmental Testing	MD, ARNP, ND, Psychologist,	
	96113	\$32.43 to \$34.76		SLP	
	92521	\$78.26	Speech and Hearing Evals	SLP	
	92522	\$65.45			
	92523	\$133.61			
	92524	\$64.47			
Treatment	99367	\$47.38 to \$63.89		MD, ARNP, ND, Psychologist	
Planning	[0-18 years]				
Records	90885	Considered a bundled service, not		MD, ARNP, ND, Psychologist	
Review		payable separately.			
Add on	90785	\$8.49 to \$9.82	Interactive complexity	Psychiatrist, Psychiatric	
Codes				ARNP, Psychologist	

^{*}Medicaid reimbursement rates from Health Care Authority fee schedules, specifically the "Physician-related/professional services fee schedules" here: https://www.hca.wa.gov/billers-providers-partners/prior-authorization-claims-and-billing/provider-billing-guides-and-fee-schedules

EPA - Expedited Prior Authorization

PA - Written or Fax Prior Authorization

Evaluation and Management Time Based Billing Table (Effective January 1, 2021)

New Patient	Time Range	G2212/99417 Add-On	Established	Time Range	G2212/99417 Add-On
E/M CPT			Patient E/M CPT		
99202	15-29 minutes	n/a	99212	10-19 minutes	n/a
99203	30-44 minutes	n/a	99213	20-29 minutes	n/a
99204	45-59 minutes	n/a	99214	30-39 minutes	n/a
99205	60-74 minutes	+1 unit for 75-89 minutes	99215	40-54 minutes	+1 unit for 55-69 minutes
		+2 units for 90-104 minutes			+2 units for 70-84 minutes
		+3 units for 105-119 minutes			+3 units for 85-99 minutes
		+4 units for 120-134 minutes			+4 units for 100-114 minutes
		+5 units for 135-149 minutes			+5 units for 115-129 minutes
		+6 units for 150-164 minutes			+6 units for 130-144 minutes
		+7 units for 165-179 minutes			+7 units for 145-159 minutes
					+8 units for 160-174 minutes
					+9 units for 175-189 minutes

Diagnosis Codes

CDC ICD-10 Information: https://www.cdc.gov/nchs/icd/icd-10-cm.htm

World Health Organization ICD-10 Browser tool (look up codes): https://icd.who.int/browse10/2019/en

For first visits at the Seattle Children's Autism Center before a diagnosis has been established, we often bill "F88: Delayed Social and Emotional Development" and have had good success in getting reimbursed (Jen Gerdts, PhD, Clinical Psychologist at Seattle Children's Autism Center)

- F84.0 Autistic disorder
- Z13.41 Encounter for autism screening

Billing resources

- AMA Guidelines https://www.ama-assn.org/system/files/2019-06/cpt-office-prolonged-svs-code-changes.pdf
- HCA Provider billing guides and fee schedules https://www.hca.wa.gov/billers-providers-partners/prior-authorization-claims-and-billing/provider-billing-guides-and-fee-schedules
- CMS Improving the Collection of Social Determinants of Health (SDOH) Data with ICD-10-CM Z Codes https://www.cms.gov/files/document/cms-2023-omh-z-code-resource.pdf

Last revision Mar 2023. Tables adapted from Suggested Codes for COE Evaluations. Information compiled by Sophie Lu, MN, PPCNP-BC, ARNP for the Medical Home Partnerships Project (MHPP). If you have comments or questions, please reach out to Sophie Lu, ARNP at sophielu@uw.edu.

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Last Updated June 12, 2024

Appendix L. Medicaid ABA order template

ABA Order template for autism diagnosis

CHILD was formally evaluated on DATE at PRACTICE by PROVIDER, DEGREE. CHILD demonstrated impairments in social interaction, social communication and atypical behavior consistent with Autism Spectrum Disorder (DSM-5 criteria; ICD-10 code F84.0). CHILD's behaviors and skill deficits are having an adverse impact on: 1) development, and 2) social communication. CHILD demonstrates atypical behaviors, as documented on DATE, including functional impairments that interfere with her ability to participate adequately in home, school and community environments.

Since that time, CHILD has continued to have deficits in his functioning. Applied behavioral analysis (ABA) services are ordered at this time, given the adverse impact of CHILD's behaviors and core impairments. There is no equally effective alternative available for 1) reducing severe interfering or disruptive behaviors and 2) increasing pro-social behaviors, and achieving desired behaviors and improvements in functioning. Applied behavioral analysis services are reasonably expected to result in a measureable improvement in CHILD's skills and behaviors.

If further information is required, please do not hesitate to contact PROVIDER at NUMBER.

Sincerely, PROVIDER PRACTICE

[Attach the completed DSM-5 checklist and any other supporting documentation from your evaluation, with appropriate ROIs, to reduce the need for back-and-forth communication. Full template can be found here]

ABA order template for non-autism diagnosis

NAME (DOB:) is a	year-old	with a history/diagnosis of		
	_,		. NAME is a patient at	for	symptoms as
noted in his/her clinic	c note(s)	dated	-		

Applied behavioral analysis (ABA) services are ordered at this time and deemed medically necessary, given the adverse impact of NAME's behaviors and core impairments. There is no equally effective alternative available for reducing severe interfering or disruptive behaviors, and achieving desired behaviors and improvements in functioning. Applied behavioral analysis services are reasonably expected to result in a measureable improvement in NAMES's skills and behaviors. Please see attached reference article to support ABA in neurodevelopmental disorders by Drs. Hagopian and Boelter. If further information is required, please do not hesitate to let me know.

NAME is able to actively participate in ABA therapy.

If further information is required, please do not hesitate to contact CLINICIAN at NUMBER

Sincerely, Provider Name Title

[Full template with article and additional references attached can be found here]