

3 Understanding Children with an Autism Spectrum Disorder

CHECKLIST OF QUESTIONS TO ASK FAMILIES OF ALREADY DIAGNOSED INDIVIDUALS

(Provide families with the handouts listed below the questions, as appropriate)

DIAGNOSIS

- ▶ Have you had a chance to ask questions about the diagnosis?
- ▶ Do you feel that you understand the diagnosis?
 - Common Misconceptions about Autism Spectrum Disorders, page 94
 - Autism Spectrum Disorders Overview, page 111
- ▶ Do you feel that your extended family understands your child's diagnosis?
 - Autism Spectrum Disorders Overview, page 111
 - Common Misconceptions about Autism Spectrum Disorder, page 94
- ▶ Do you need information to help your other children better understand the diagnosis?
 - Autism Resources, page 30
 - What is Autism Brochure, page 109

SUPPORT OPTIONS

- ▶ Do you know about the Medicaid Waiver?
 - Medicaid Waiver Information, page 95
- ▶ Do you know where to go to learn more information about the diagnosis?
 - Autism Resources, page 30
- ▶ Do you feel you have an adequate support system in place to help you as you work to help your child in the community (e.g., intervention, respite, financial support, emotional support)?
 - Autism Resources, page 30
- ▶ Would you like resources about places to find additional support?
 - Finding the Right Support Group, page 98
 - Autism Resources, page 30

COMMUNICATION SKILLS

- ▶ Is your child using age-appropriate speech? Does your child use gestures or understand the gestures that you use? Have you accessed speech-language services for your child?
 - Autism Resource, page 30
- ▶ Does your child have any consistent means of communicating his/her desires and needs? Do you feel that you have to anticipate or assume your child's desires and needs? Does your child (or

do you) become frustrated due to communication difficulties?

Why do we use visual strategies with ASD children, page 96

▶ Have you tried presenting information visually rather than verbally? Have you considered using social stories, wait cards, or other visual strategies to help him/her better understand your expectations?

Social Stories, page 60

Visual Schedules, page 47

Other Useful Visual Supports, page 52

Visual Communication Supports, page 49

▶ Does your child seem to better process information presented visually? Have you tried using tools such as a visual schedule or first-then board?

Why do we utilize visual strategies with ASD individuals?, page 96

REPETITIVE BEHAVIORS/SENSORY ISSUES

▶ Does your child eat a range of foods? Has your child ever stopped eating foods s/he previously ate? Does your child avoid any sensory input (sounds, smells, textures, etc.)? Does your child seem especially interested in any sensory input (sounds, textures, images, etc.)?

Sensory Kits, page 63

▶ Does your child play with toys the way you would expect?

Enjoying your child in play, page 97

▶ Can your child handle minor changes in daily routines (e.g., driving to school a new way, having a different person do bath)?

Social Stories, page 74-89

▶ Do you have difficulty engaging with your child in play activities?

Enjoying your child, page 97

CHARACTERISTICS OF AUTISM

COMMUNICATION

EXAMPLES OF COMMUNICATION DIFFICULTIES

- ◆ Often very limited verbal communication
- ◆ Communicates primarily to have needs met and not for social reasons
- ◆ Language develops late
- ◆ Prior to language development:
 - ◇ poor receptive language
 - ◇ gestural deficits (lack of use/understanding)
 - ◇ jargon/unusual noises
- ◆ After language develops:
 - ◇ echolalia (repeats words/phrases; immediate or delayed)
 - ◇ idiosyncratic language (makes up words, words in wrong order)
 - ◇ difficulty maintaining conversations
- ◆ If standard communication is difficult, behavior serves as communication
 - ◇ Behavior (appropriate or not) will continue as long as it works
 - ◇ Inappropriate behavior makes it difficult to fit into the community

TIPS FOR PROFESSIONALS REGARDING COMMUNICATION

- ◆ Understand that behavior is often the most basic form of communication. Individuals will continue to use behavior if it works for them. Remember not to take an individual's behavior personally.
- ◆ Acknowledge the individual, not simply the caregiver - even if the individual with ASD cannot answer your questions, s/he appreciates your attention.
- ◆ When an individual presents with communication deficits, remember...
 - ◇ not to simply talk louder or talk more to the patient.
 - ◇ s/he may not know how to express ailments, even if s/he is verbal.
 - ◇ avoid figures of speech, use concrete and precise language.
 - ◇ talk slowly—allow time for him/her to process what you are saying.
 - ◇ the patient may hear or see in a distorted fashion, so enunciate your words; put yourself and the activity in his/her field of vision.
 - ◇ pair instructions with visual supports to ensure s/he understands.
 - ◇ encourage the caregiver to bring a communication tool the individual uses (e.g., picture binder, computerized communication tool), if applicable.

SOCIAL RELATEDNESS

EXAMPLES OF SOCIAL RELATEDNESS DIFFICULTIES

- ◆ Difficulty relating to or expressing emotions
- ◆ Limited eye contact (i.e., may vocalize without eye contact)
- ◆ Limited use or understanding of nonverbal gestures
- ◆ Flat or limited range of facial expressions
- ◆ Minimal initiation (e.g., pointing out a plane flying by) or response to joint attention (i.e., focusing on the same object as another person)
- ◆ Lack of social/emotional reciprocity (e.g., difficulty taking perspective of another)
- ◆ Difficulty making friends (e.g., lack of apparent interest and skill in social interaction)
- ◆ Trouble understanding abstract words and concepts (e.g., analogies, sarcasm, love)
- ◆ When social understanding is impaired, inappropriate behaviors may occur due to anxiety and discomfort

TIPS FOR PROFESSIONALS REGARDING SOCIAL RELATEDNESS

- ◆ Individuals may have a limited understanding of the social/environmental cues that others use to understand their surroundings and modify their behavior.
- ◆ Use natural motivators to encourage desired response.
- ◆ Visual processing is strongest, so use visual supports whenever possible.
- ◆ Individuals behave differently at home versus clinic; ask about modifications and strategies that help in other settings.
- ◆ Generalization is difficult; it may take lots of repetition to learn expectations. Also, learning how to respond in one setting does not ensure appropriate response in others; it must be taught.
- ◆ Discuss goals with caregivers; encourage consistency.
- ◆ Limit the number of staff who interact; consistency is often calming.

REPETITIVE INTERESTS AND ACTIVITIES

EXAMPLES OF REPETITIVE INTERESTS AND ACTIVITIES

- ◆ Has a limited range of interests
- ◆ Is comforted through the predictability of structure and repetition
- ◆ May be very rigid and have excessive interest in unusual objects/activities
- ◆ Has atypical play behaviors (e.g., spinning car wheels, banging toys, mouthing toys)
- ◆ When interests and activities are repetitive and restricted it may:
 - ◇ cause individuals to appear to be distracted/inattentive
 - ◇ cause individuals to be viewed as inflexible and disobedient

TIPS FOR PROFESSIONALS REGARDING RESTRICTED INTERESTS/ACTIVITIES:

- ◆ Remember, everyone can have difficulty in new situations.
- ◆ Ask the individual or his/her parents about the individual's interests.
- ◆ Use their interests wherever possible (token systems, rewards, social stories, etc).
- ◆ Provide opportunities for engagement in interests to calm the individual.

SENSORY ISSUES

OVERVIEW OF SENSORY ISSUES

- ◆ Characteristic sensory issues seen in individuals with ASD may include:
 - ◇ An over- or under reaction to common environmental stimuli
 - ◇ Stimuli may relate to any sense: auditory, tactile, olfactory, visual or gustatory
 - ◇ Stereotyped body movements (e.g., flaps hands, rocks, bounces repetitively)
 - ◇ Unusual behaviors (e.g., looks from angles, sniffs/licks objects, toe walks, appears deaf/overreacts to sound)
- ◆ Sensory issues may make it difficult to filter out input, impacting attention.
- ◆ Difficulties with uncomfortable sensory input can lead to anxiety and distress.

TIPS FOR PROFESSIONALS REGARDING SENSORY ISSUES

- ◆ Sensory responses suggest likely motivators as well as difficulties for the individuals.
- ◆ Find out what is calming for the individual and have it available.
- ◆ Avoid exposure to the sensory aspects that are issues for the individual (e.g., dim the lights if the lights are disturbing to him/her, let him/her sit by window if proximity presents issues).

FAMILY ISSUES

EXAMPLES OF FAMILY ISSUES

- ◆ Families must learn about the disorder, education options, treatments, etc.
- ◆ Families may worry about co-morbid disorders and behavioral difficulties
- ◆ Primary caregivers may be susceptible to feelings of depression and anxiety

TIPS FOR POSITIVE INTERACTIONS BETWEEN PROFESSIONALS AND FAMILIES:

- ◆ Validate caregiver concerns.
 - ◇ If they have no reason for concern, you have eased their anxiety.
 - ◇ If they do have reason, you have given the gift of early intervention.
- ◆ Encourage them to attend to their well-being (emotional, physical, mental)
- ◆ Write down information for the caregiver (or use tapes). If their child is difficult to manage, they likely will not remember what you say.
- ◆ Model calm behavior.
- ◆ If the individual is difficult for the parent to manage, provide a private room.
- ◆ Talk to parents together, if possible, so both can have questions answered.
- ◆ Advocate for families with insurance, agencies, and schools, when needed.
- ◆ Refer the family to community support services for education and treatment.

PERSPECTIVES OF PROFESSIONALS AND PARENTS

- ◆ Remember that professionals and parents hold different perspectives.
- ◆ “Family members are the most stable, influential, and valuable people in the child’s environment” (Iovannone, Dunlap, Huber, & Kincaid, 2003, p. 161).
- ◆ Collaborative partnerships with the family impact treatment efficacy (Iovannone et al., 2003).

SPECIFIC COMPARISONS OF PERSPECTIVES*

PROFESSIONALS

Some knowledge of many different individuals with ASD

Have or have not chosen to work with individuals with disabilities

Interaction with the individual is time-limited

Often focus on behavioral concerns and academic deficits/goals

Motivated to use the best-suited intervention

CAREGIVERS

Expert on own child

Most likely, did not choose to have a child with a disability

Interaction with the individual is daily and life-long

Focus on whole person - behavioral deficits and functional deficits/goals

Motivated to live in harmony with the individual and for him/her to live harmoniously with the family and community

* Adapted from TRIAD Teacher Training Manual by Vanderbilt Child Development Center, Nashville, TN, 1999

RESOURCES

Autism Society of America: <http://www.autism-society.org/site/PageServer>
 Autism Society of Indiana: <http://www.inautism.org/>
 HANDS in Autism: <http://www.handsinautism.org/>
 Indiana Resource Center on Autism (IRCA): <http://www.iidc.indiana.edu/irca/>
 MAAP Services for Autism and Asperger Syndrome: <http://www.maapservices.org/>
 National Alliance of Mental Illness – Indiana: <http://www.nami.org/MSTemplate.cfm?MicrositeID=169>

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