

FAMILY MODULE FOUR: INTERVENTION AND EDUCATION

*Developed by the Indiana Resource Center for Autism
Indiana Institute on Disability and Community
Indiana's University Center for Excellence on Disabilities
Indiana University*

I. INTRODUCTION

While there is disagreement about the specific type of program that may be most effective for an individual child, there is general agreement about the characteristics of effective programming. It is generally agreed upon that programs should reflect established evidence-based or proven practices and that they should demonstrate an understanding of the characteristics associated with autism spectrum disorder. Unfortunately there is inconsistency about what is considered to be evidence-based.

It is important to keep in mind that treatment programs represent varying philosophies concerning the core deficit areas and possible causes of autism. Treatment approaches that look at autism as being primarily a sensory-based disability, would involve sensory integration strategies. Those that look at autism as being composed of behavioral excess and deficits would take a behavioral approach such as Applied Behavioral Analysis and Pivotal Response Training. Those that look at autism as primarily a social disorder would use approaches such as Greenspan or peer-mediated instruction. And those that primarily see autism as a medical condition may pursue dietary approaches or other biomedical strategies. The reality is that autism is comprised of all these difficulties. In other words, a child may have behavioral excesses and deficits, biomedical conditions, and social and communication challenges. As a result, programming should look at the total child. This module discusses some intervention recommendation. It is not inclusive of all, but hopefully will provide a first step.

II. SOCIAL SKILLS INTERVENTIONS

Social skill deficits are a central feature of autism spectrum disorders. As such, social skills training should be an integral part of a child's overall programming. When teaching social skills to children with ASD, it is important to use a large repertoire of strategies to teach social skills. It is also important to teach social skills across a variety of settings, and with multiple persons (teachers, parents, therapists, peers, etc.). Finally, it is imperative that social skills programs are

guided by a conceptual framework that informs our decisions and enlightens our practice. The model articulated on the website at <http://www.iidc.indiana.edu/irca/SocialLeisure/socialskillstraining.html> provides a framework to guide your social skills program and recommendations for programming.

Social Accommodation versus Social Assimilation

Prior to beginning a social skills program, it is also important to consider the concepts of social accommodation and social assimilation. *Accommodation*, as it relates to social skills instruction, refers to the act of modifying the physical or social environment to promote positive social interactions. Examples include training peer mentors to interact with the child throughout the school day, conducting autism awareness training or sensitivity training for classmates, and signing the child up for various group activities, such as Little League, Boy or Girl Scouts and so on. Whereas accommodation addresses changes in the environment, *assimilation* focuses on changes in the child. Specifically, it refers to instruction that facilitates skill development that allows the child to be more successful in social interactions. By their nature, social accommodations enhance social performance, and social assimilation involves promoting skill acquisition.

The key to a successful social skills training program is to address both accommodation and assimilation. The key is to teach skills *and* modify the environment. The balance between accommodation and assimilation is determined by the child's developmental skill levels. For instance, children with lower developmental skill levels (for instance, severe cognitive difficulties and limited language) require a higher level of social accommodations to promote meaningful social relationships. That is, instead of spending hours trying to teach a nonverbal child how to initiate and maintain conversations, you would instead teach her how to use her augmentative communication system to join in activities with peers. In this case, a high level of social accommodations are required to ensure that peers are aware of the augmentative system and make an effort to include the child in more social activities (via peer training and disability awareness training). This is not to suggest that children with more significant disabilities do not need social skills programming or want meaningful social relationships. They absolutely do! However, the focus of the intervention has to be modified (i.e., more social accommodations) to promote their social success.

III. PLAY INTERVENTIONS

Play is important for a number of reasons. It is important for the development of social competence, imagination, self-esteem, friendships, and helps prepare children for societal demands and roles. Independent play skills reduce problem behaviors and decrease parent stress. Children who can engage in play require

less constant and intense supervision. Finally, children on the autism spectrum need time to be children.

There are various skill deficits that inhibit productive play. As a result of these deficits, peers may exclude children with autism from play or may not understand how to effectively engage children in play. The various skill deficits include:

- Inflexible, repetitive, and stereotypical play patterns;
- Restricted interests, perseveration on a topic or activity;
- Problems with sequencing and motor planning;
- Too literal, and lack of symbolic and pretend play skills;
- Pretend play may be limited to reenacting scenes from favorite movies, videos, TV shows; and
- Lack of reciprocal social exchanges, inability to understand feelings of others or read non-verbal social cues.

There are various models for enhancing play skills. For information on play interventions, visit the IRCA website at <http://www.iidc.indiana.edu/irca/SocialLeisure/playtime.html> and at <http://www.iidc.indiana.edu/irca/SocialLeisure/playlives.html>.

IV. Speech, Language and Communication

To some parents it will be no surprise that they need to be concerned about speech, language, and communication problems for their newly diagnosed child. A significant delay in developing speech and language skills was probably what sent you to someone for a diagnosis and explanation. For other parents whose children talk fairly fluently, it may come as more of a surprise that this is an area of concern. In actuality, problems in communication may be present even through adulthood, so it is important to identify where help is needed and to get the appropriate assistance.

The needs of children on the autism spectrum can vary considerably from child to child. By being aware of some of the common problems or challenges, you will be better able to request evaluations and services, if they seem warranted. Some challenges may be more common at certain ages than others.

The means of evaluation for expressive and receptive skills are interview, observation, informal tasks, and formal assessment. Some skills such as pragmatics are difficult to assess through a formal instrument and best evaluated through the other three avenues. See IRCA communication articles at the following websites for articles about communicative function, pragmatics and social language characteristics:

Communicative Functions:

<http://www.iidc.indiana.edu/irca/communication/communicfun.html> for the article

Social Pragmatic Skills:

<http://www.iidc.indiana.edu/irca/communication/socialpragmatic.html>

Social Communication and Language Characteristics Associated with High Functioning, Verbal Children and Adults with Autism Spectrum Disorders:

<http://www.iidc.indiana.edu/irca/communication/socialcomm.html>

Support Comprehension Abilities

Your speech pathologist should be able to provide you with specific ideas on how to increase comprehension of language. More general ideas are included the IRCA articles on comprehension, following directions and visual resources.

Aiding Comprehension of Individuals with Autism Spectrum Disorders during One-on-One Interactions:

<http://www.iidc.indiana.edu/irca/communication/aidingComprehension.html> for

Comprehension of the Message: Important Considerations for Following Directions: <http://www.iidc.indiana.edu/irca/communication/compremessage.html>

Visual Resources for Enhancing Communication for Persons with Autism Spectrum Disorders:

<http://www.iidc.indiana.edu/irca/communication/pictureres.html>

Visual supports are a prime comprehension support that can be used for a variety of situations in which the person with ASD may experience anxiety, confusion and a need for reassurance. Visual supports may take a variety of forms but their function may be to offer choice, information, and guided structure. Pictured or text information can provide a backup to the verbal message. Picture or text supports can also promote self initiation and self management. Many children process visual information better than auditory because the information doesn't disappear in a fraction of a second like spoken messages do. Visual supports are necessary both for children who don't talk as well as for those who talk fairly fluently. See the following few examples of visual supports that might support the needs of a young communicator.

Choice- Pretzel or Popcorn



Direction- Go Get Your Backpack



Short Schedule Sequence-Store, Gas, Home



Support Expressive Abilities

Every parent, of course, wants his or her child to talk. Most eventually do, but some do not achieve this goal. It is hard to predict who will become verbal. In the interim while working to increase expressive communication, it is practical to provide another means of communication. This might include gestures, signs, communication displays or communication devices that provide a voice output. Using these techniques is called augmentative and alternative communication. See the IRCA article on developing a communication program at <http://www.iidc.indiana.edu/irca/communication/InitialGuidelinesCommun.html> .

A popular approach used by some students that helps them learn the power of communication and to become better initiators is called PECS or the Picture Exchange Communication System. For an overview of PECS, visit the website at: <http://www.iidc.indiana.edu/irca/communication/WhatisthePEC.html> .

Using an augmentative system will not prevent your child from talking. Instead, it can be a bridge to help them as they journey to become verbal. Having an alternative communication system available is important because without some other effective means of interacting with people, your child will resort to hitting, kicking, screaming, and other means to convey the message of what he or she wants or does not want.

Much work lies ahead. But, the first hurdle is identifying what needs to be monitored and taught. There is much information available to guide everyone in terms of identification of need and intervention and the literature base is growing everyday. At this point you have only a small bit of general information but it can put you on the path toward developing an appropriate program for your son or

daughter in terms of speech, language, communication and pragmatics. Consider the following as you travel on your journey:

- Be sure that a speech pathologist is part of the team for your child, even if your child seems to be fairly verbal. Look toward the following two articles to get ideas about how this professional can help you and your child at school and at home. Visit the website at <http://www.iidc.indiana.edu/irca/communication/LanguagePathologist.html> and at <http://www.iidc.indiana.edu/irca/communication/roleslp.html> to learn about potential roles for the speech language pathologist.
- Remember that your child is communicating even when you see negative behavior. You may not always understand the message but you can add up the clues and guess at the meaning. Visit the website at <http://www.iidc.indiana.edu/irca/communication/messagesbe.html> for more discussion on this topic.
- Remember that communication begins with a need to communicate and includes many forms of communication. Addressing the issue of need is an important aspect regardless of level of skill.
- Along with a need to communicate comes an equally important factor called “opportunity to communicate.” Visit the website at <http://www.iidc.indiana.edu/irca/communication/OptoCommunicate.html> for an article on creating opportunities.
- Remember comprehension of many aspects of language and daily life will be overlooked or not understood by your child. Make a point of aiding comprehension as much as possible. Conversely, as your child increases in age, encourage him or her to seek clarification of meaning. He needs to know that his interpretation may not be what others have inferred, so it is important to check it out with a trusted individual.
- Use visual supports to aid all aspects of daily life. See Linda Hodgdon’s books: *Visual Strategies to Improve Communication* (1995) and *Solving Behavior Problems in Autism* (1999) at CeDIR by visiting their website at <http://www.iidc.indiana.edu/cedir/>.
- Model and suggest ways your child might express him or herself in selective situations; this will supplement more formal instruction. Don’t do it all the time or he or she will resent the constant instruction.
- Understand that if your child asks lots of repetitive questions, he may or may not be seeking the associated answer; he may not know how to initiate a conversation in any other way. The obvious is not always what we think it is. Visit the website at

<http://www.iidc.indiana.edu/irca/communication/longtermstr.html> strategies to reduce repetitive questions.

- Be sure to explain the meaning of figurative language phrases to your child and encourage him to use them, if possible. Visit the website at <http://www.iidc.indiana.edu/irca/communication/figlanguage.html> for an article on building competency in this area.
- Remember communication training, to paraphrase Hilary Clinton, takes a village, or in your child's case, a team. With everyone fostering communication/language skills, your child will experience a variety of communication partners in a multitude of situations with a plethora of messages and information.

V. Sensory Integration

Sensory integration is based on the idea that people with autism have a difficult time organizing incoming sensory stimuli. Some may be over-responsive to input and others may be under-responsive. For those who are over-responsive, an increased arousal level that interferes with learning process may occur. For those who are under-responsive, they may not respond to pain as others do. The goal of the therapy is to help the child regulate incoming stimuli thereby controlling arousal level and avoiding meltdowns. Therapy is conducted by occupational therapists and consists of techniques designed to calm the child who is experiencing various sensory sensitivities. One of the primary goals of therapy is to help the child become calm and alert. Techniques include deep pressure, application of lotion, brushing, swinging, jumping, and balancing. While the research on sensory integration is minimal, many families report success with their sons and daughters. For more information on sensory integration, visit the link at <http://www.sinetwork.org>. An article on sensory integration can be found on the IRCA website at <http://www.iidc.indiana.edu/irca/Sensory/sensoryIntegrate.html>.

VI. Medical Services and Interventions

While there is no specific medication for autism, various medications are used to address difficulties associated with anxiety, depression, attention, aggressive behaviors, sleep disorders, and seizures. Medicating a child on the autism spectrum is more of an art form than a science. As such, be sure that the physician involved in medicating your child has knowledge about the effects of various medications on the child with autism.

As research continues into the biomedical basis for autism, many families are trying various vitamin and diet therapies. On the website at <http://www.iidc.indiana.edu/irca/Medical/Biomedical.html> is a discussion of the various biomedical approaches being used with individuals with ASD.

VII. GOING OUT IN THE COMMUNITY

Seemingly simple activities such as going to church, the grocery store, out to eat at a restaurant or to visit a family member can be complex. For example, families have to consider the sensory demands of the situation, including the noise level, smells, or number of people in a setting. Time of day for an outing might be selected to minimize the crowd and other potential sensory stimulation in an environment. Also length of time for an outing needs to be considered. Consider what supports your child needs to be successful. Sitting at church or in a restaurant may be too much for your child, at first. Prepare ahead by arranging for your child to visit and practice needed skills for a shortened length of time. This is sometimes called desensitization. Give your child as much information (visually) about what will happen in advance, as possible. Also develop a familiar routine that can be part of an outing to church, a particular store, or a visit to a friend's house.

The purpose of developing a routine is to provide predictability and consistency which will greatly reduce your child's anxiety and enhance his or her ability to be successful. It is important to note that preparation ahead may actually heighten anxiety in some children. So, know your child well when organizing an event. Consider and articulate the routine your child may have to follow in a grocery store, such as:

- Sitting in the shopping cart or pushing the shopping cart (or other information on how the child will physically maneuver through the store);
- Holding a list of items to purchase. It may be helpful to limit the number of items to very few at first so the child can be successful. If the child is holding the list, consider crossing off each item as it is put into the cart. Help the child to mark off items if necessary. If you are able to put together picture cards for items, these picture cards can be put away in an envelope when an item is found.
- Putting the item in the cart. Some children will be happy to help put the item in the cart as you cross it off on the list;
- Going through check out and paying; and
- Giving the child a reward for completing the task. Excited praise for a job well done may be a sufficient reward for your child. Some families purchase or bring a favorite food item which can be opened once the cashier has been paid. Always praise while giving this "tangible" type of reward so that eventually, praise alone can be rewarding to your child.

Make an effort to make advance arrangements when you take your child on an outing. For example, if you hope to eat at a restaurant, call ahead for reservations if possible. Explain the need to be seated quickly in an area away from a lot of stimulation. Your child will likely benefit from bringing something to focus on, such as a favorite toy or book, while waiting for food. Also consider where is the best place to sit in case you need to remove your child quickly because of a meltdown or other behavioral issue. Some families try to take two cars when planning outings to unfamiliar places or events. If your child needs to leave, then one parent or caregiver can take over and the rest of the family members can still stay out.

Similar desensitization and advanced planning strategies can be used for going to church, the grocery store or other community outings. Once your child is familiar with a particular place and routine, s/he is more likely to enjoy the outings and stay through to the end of the event. Consider if there are other supports that you need to provide to help him/her be successful. It is important to remember that given time, thoughtful planning, and the right supports a variety of outings can be successful.

There may be times when your child is not able to able to participate even with extensive supports. Particular activities may be too stressful. In some specific situations it may be best to make other arrangements for your child with an autism spectrum disorder, so that everyone else can enjoy an outing. It is possible that if you wait 6 months or a year that your child may be able to participate if you begin the planning and desensitization all over again.

VIII. Personal Management

Personal Management

Let's end this section with a discussion of four issues that are of importance to families: eating, sleeping, toilet training, and puberty. On the IRCA website at <http://www.iidc.indiana.edu/irca/Medical/goodnight.html> is an article on sleeping and on the IRCA website at <http://www.iidc.indiana.edu/irca/Medical/mealtime.html> is an article on eating. Visit these websites for information on these topics.

Now, let's get to toilet training. Toilet training consists of three major components: 1. skill development; 2. the biological act of eliminating; and 3. associative learning.

Skill development consists of teaching the child the basic skills necessary for successful toileting. These skills typically consist of:

1. Going into the bathroom;

2. Undressing;
3. Sitting on the toilet;
4. Eliminating in the toilet;
5. Properly taking paper off the roll;
6. Wiping self properly and effectively;
7. Flushing the toilet;
8. Dressing;
9. Washing hands; and
10. Leaving the bathroom in an appropriate manner.

Although we have very little control over the **biological act of eliminating**, we can record the times of the day the child is most likely to urinate or have a bowel movement. The use of charts is very helpful for this process. The last stage is to take your child to the bathroom at the most opportune time (through the use of your charts), to facilitate **associative learning** (bathroom is the place to eliminate).

Generally, there are three main factors to consider when determining the readiness of your child to begin toilet training. These include:

- a. The ability to follow simple directions;
- b. The ability to sit in a chair for at least 5 minutes; and
- c. The ability to wait 1.5 hours between elimination times.

Initially you should liberally reinforce efforts, then gradually provide reinforcement for partial success, then finally total successes. This strategy is referred to as shaping. The reinforcer used for toilet training should be extremely desirable to the child—your child’s favorite toy, activity, or food. This reinforcer should only be used for toilet training in order to maintain its desirability to the child. If the child becomes disinterested in the toilet training reinforcer, find a new one. This link takes you to a TEACCH website on a specific toilet training program you can use at home <http://www.teacch.com/toilet.htm>.

If your child is constipated or has ongoing diarrhea, it may be helpful to get input from a medical provider who can determine if there is a medical basis for this difficulty. Remember the earlier discussions about the biomedical condition of autism.

Puberty

Your child on the autism spectrum will experience the normal developmental stages of puberty at or around the same time as his or her neurotypical peers. For boys, their bodies start to change around 13 years of age and for girls between 7 and 14 years of age. As parents, a plan must be developed to teach your adolescent an awareness of how their bodies will change, proper hygiene,

menstrual cycles, and issues related to sexuality. The strategies that have been used in the past to teach other social skills situations can apply well in this area (e.g., use of visual supports, social stories). It is important to be open about discussing these private issues with family members. Use your family supports to problem solve how to best educate your adolescent of changes in a positive manner in order for them to grow into healthy adults. Refer to the website at <http://www.iidc.indiana.edu/irca/Medical/Puberty.html> for an article on Puberty.

Finally, this module is not inclusive of all the issues you will face with your child. Our hope is to give you only a glimpse and hopefully some helpful recommendations. Visit the website at www.iidc.indiana.edu/irca for more articles on a range of topics.

Now let's think about your child:

1. What are goals you hope to achieve for your son/daughter (e.g., communication goals, social goals, etc)? Before you choose programs or strategies, it is important to be clear about expected outcomes.

2. Based on the information presented in this module and from the website, what are specific ideas you have for teaching your child and/or supporting them in community settings?

For more information about the Indiana Resource Center for Autism, visit our website at www.iidc.indiana.edu/irca or email Dr. Cathy Pratt at prattc@indiana.edu.

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- ◆ Early intervention and education;
- ◆ School improvement and inclusion;
- ◆ Transition, employment, and careers;
- ◆ Aging issues;
- ◆ Autism spectrum disorders;
- ◆ Disability information and referral;
- ◆ Planning and policy studies; and
- ◆ Individual and family perspectives.

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