Provider's Guide to Effective Communication with Families Affected by Autism

![autism speaks ATN — Autism Treatment Network logo][AIRP — Autism Intervention Research Network on Physical Health logo]

My Autism Guide
SIGN UP
Information based on your needs

guide.autismspeaks.org

Table of Contents

INTRODUCTION

**The purpose of these materials is to provide health care professionals
with instructional support for leading a productive diagnostic feedback session.**

It is anticipated that faculty will be able to use the manual and quality checklists to prepare for teaching a class on interpreting the findings of the evaluation. The video presents parents and clinicians discussing their positive and negative experiences with feedback sessions and can be shown in class or viewed on line to illustrate key concepts and best practices. The quality checklist is designed to identify the critical components of a successful feedback session as well as the ideal characteristics demonstrated by the clinician during feedback.

While we are primarily targeting psychology trainees who are giving an autism spectrum disorder diagnosis to families, the principles involved apply to all clinicians who deliver evaluation results, diagnoses and/or treatment recommendations to their clients. Good feedback practices are universal and apply to clinicians in other professions including pediatricians, speech/language therapists, occupational therapists and physical therapists. Therefore, it is our hope that the feedback video and materials will be widely disseminated and promote thoughtful discussion about how best to give families critical information when their children receive a difficult diagnosis.

> *feed·back* /ˈfēdˌbak/
>
> Noun
>
> **As defined in this tool, a feedback session in autism is when the individual clinician or team meets with the family after the evaluation process to discuss the findings from the assessments, the diagnoses and the recommendations.**

The components of the feedback presented here are not meant to be all-inclusive or set in stone. *Clinicians will need to adopt strategies that fit their own style and meet the needs of the families with whom they are working.* A key point discussed in these materials is the importance of a clinician's ability to establish a warm and supportive relationship with the family. While a clinician's empathy and good faith efforts to assist families will always be paramount, the specific strategies that we outline in these materials will facilitate a successful feedback session.

WHAT IS A FEEDBACK SESSION?

After a child is evaluated, the results of the assessment are shared with family members. Clinicians give family members quantitative results from standardized testing, behavioral observations and specific diagnoses. Clinicians also provide families with recommendations based on the results of the evaluation.

During a feedback session, clinicians provide verbal / written facts about a child's strengths and needs. They also provide non-verbal information/cues conveyed through facial expressions, body language and emotional response.

This manual and the accompanying video focus on **all** aspects of providing information about a diagnosis of autism-verbal, written and body language.

Receiving a diagnosis of autism for their child can be a very stressful and overwhelming experience for parents (Herbert et al., 2011; Jedlicka-Kohler, Gotz, & Eichler, 1996) and this stress may negatively impact parent engagement with a child (Konstantareas and Homatidis, 1992) and further impact treatment involvement (Boyd & Corley, 2001). However, while this is a difficult diagnosis to provide to a family, *a well-run feedback session may also be a positive experience* (Sardell & Trierweiler, 1993). Effective communication between the clinician and the family can lead to parents feeling supported and empowered to use the information that they receive to begin to address their children's needs.

An autism diagnosis leaves families with questions...

- *Will my child live a normal life?*
- *Is it my fault?*
- *How will we tell friends / relatives?*
- *What does the future hold?*
- *What do we do now?*

Effective communication can lead to parents feeling supported and empowered to address their children's needs.
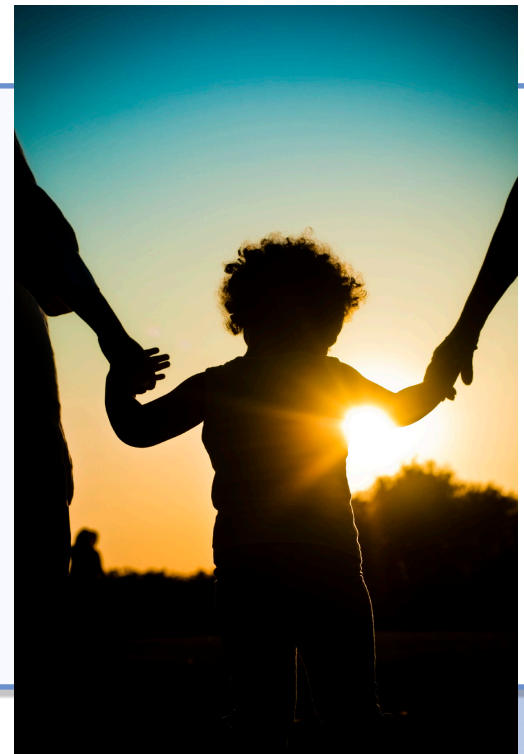
Why is it important to learn how to give feedback to families?

Parents never forget the feedback session (Nursey, Rohde, & Farmer, 1991; Sharp, Strauss, & Lorch, 1992). For many, it is the moment when they cross the line between suspecting something is different about their child and discovering that their child has an official diagnosis. It may be an emotional time that brings up a variety of fears and concerns (Jedlicka-Kohler, Gotz, & Eichler, 1996; Nissenbau, Tollefson, & Reese, 2002). Some of the questions that can arise include the following: Will my child live a normal life? Is it my fault? How will we tell friends and relatives? What does the future hold? What do we do now? The feedback session may set the tone for the grieving process and is often a crucial touchstone on the journey of having a child with a disability. The feedback session also provides the best window of opportunity for parents to understand the evaluation results. While families should always have the opportunity to talk with or meet with the clinician after a feedback session (Cottrell & Summers, 1990; Quine & Pahl, 1986), they may not have another chance to discuss their child's specific psychological strengths and challenges in such detail with a professional again while the information is fresh and current. Giving parents a clear understanding of the results is the best route to acceptance of the diagnosis and development of an action plan (Svarstad & Lipton, 1977).

Finally, a successful feedback session will clearly delineate what steps family members need to take to help their child (Graungaard & Skov, 2006). It is a chance for the clinician to provide guidance as a family prioritizes these steps and to also discuss the future in whatever way is best for the family: what school setting might work best, family planning, issues with other family members or when to tell the child about the diagnosis, for example. Again, it is a window of opportunity for the family to cover these specific questions and issues with a professional who knows their child's profile.

How does one learn to give feedback?

Learning how to tell families about a child's autism spectrum disorder takes time and practice. Many clinicians report a lack of formal training in providing feedback to families (Baile et al., 2000; Merker, Hanson, & Poston, 2010). A good first step is to observe experienced clinicians and receive consultation from them. We have provided a checklist that details the components of a successful feedback session and this may be useful when the novice clinician is given opportunities to observe a feedback session. Students may want to practice giving feedback to each other and to videotape their sessions. In addition, trainees should meet with their supervisors to discuss issues related to giving feedback and think about the best ways to provide feedback to a family given their specific strengths and needs (Baile et al., 2000; Hiley et al., 2011). Every clinician develops their own style and strategies. For example, numerous models for providing feedback have been proposed in the literature (e.g., Baile et al., 2000; Hiley et al., 2010). In addition, most clinicians maintain some flexibility during feedback so they can tailor the session to the particular family and change their approach as needed. For instance, some families may need detailed information about why a child's behavior is consistent with an autism spectrum disorder while other families may want to spend most of the feedback session discussing treatment recommendations.

Regardless of style, two key components of a successful feedback session are:

*1) A **personal connection** with the family; a feeling that the clinician genuinely cares*

*2) The clinician is **open and honest***

(Osborne & Reed, 2008; Hasnat & Graves, 2000).
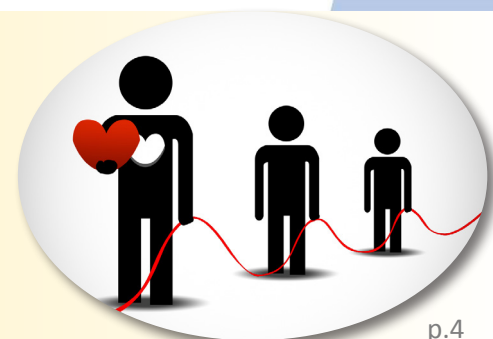
COMPONENTS OF THE FEEDBACK SESSION

A feedback session may be divided into five main areas:
1. Evaluation of the Child
2. Preparation for the Feedback Session
3. Beginning the Feedback Session
4. Providing the Diagnosis
5. Discussing Recommendations and Next Steps

1. The evaluation of the child

Think about feedback throughout the entire evaluation process. Setting up for a successful feedback session begins with and extends through the evaluation process. In many ways, the child's evaluation is similar to a well-written article that includes a summary to bring together all of the information that has been discussed. An experienced author knows the importance of the summary and is mindful of how a book will end when he or she first starts writing. The feedback session is like the summary or ending chapter of a child's evaluation. Experienced clinicians know that everything that happens throughout a child's evaluation can help prepare a family for the feedback session and they begin thinking about how they will present feedback to a family when they first review a child's file and start planning the evaluation. As the evaluation progresses, clinicians are viewing all events through a lens that helps them conclude the assessment with an effective feedback session. It may be helpful for clinicians to use the feedback quality checklist as they anticipate presenting feedback to a family. For instance, clinicians are encouraged to discuss a child's strengths during both the evaluation and feedback process (Graungaard & Skov, 2006). One of the keys to a successful feedback session is working well with a family throughout a child's evaluation.

One of the keys to a successful feedback session is working well with a family throughout a child's evaluation. Clinicians often consider incorporating the following points during the evaluation process:

• Families should be encouraged to ask questions, offer observation, and provide information at any time.

• Parents and other caregivers should be explicitly told that they are part of the evaluation team and shown that their input is valued (Brogan & Knussen, 2003).

• They should have an understanding of why their child is being evaluated and how clinicians are attempting to assess their child's skills.

• During the course of an evaluation, clinicians should ascertain whether family members believe that a child is demonstrating the types of behaviors that are seen in other settings and whether behaviors seen during the evaluation are typical for this child.

• If additional work is needed to obtain a more representative picture of a child, attempts should be made to do so. For example, it may be necessary to schedule an additional evaluation session, speak with other providers or observe a child in another setting (either through live observation or review of video recordings). A good feedback session is a natural conclusion to a collaborative process that starts when clinicians and family members first meet.

• Clinicians should also be prepared to process new information that is disclosed during a feedback session. Be flexible and to be ready to change plans if necessary (Baile et al., 2000). New information may require additional evaluation, a delay in providing feedback or an "on the spot" change in the diagnosis that is being given.

• Clinicians always need to be aware of any safety issues and address these in the feedback session. Clinicians should be aware of whether any family members are at risk to themselves or others. This may include assessing for suicidal or threatening behavior. It may also include determining if other safety issues exist, such as children habitually running and darting from their parents when they are out in the community.

2. Preparing for the feedback session

➤ *Consider the timing of feedback.*

Research indicates that delay in providing a diagnosis to families is associated with family dissatisfaction (Baird, McConachie, & Scrutton, 2000; Howlin & Moore, 1997; Quine & Pahl, 1986). In fact, most families prefer to receive feedback about an evaluation on the same day as the assessment or as soon as possible after the evaluation is complete. Try to schedule feedback sessions at a time that works for family members and allows them to invite whomever they would like to include. Schedule enough time to discuss the results in an unhurried manner that will allow the family to ask questions and process their feelings (Hiley et al., 2011).

➤ *Discuss who will attend the session.*

If the child has completed an interdisciplinary evaluation, determine which team members will be present at the feedback session. Factors to consider include the relative importance of each team member's results and the family's potential response to sitting in a meeting with a large number of people. Consider whether all team members should be present throughout the entire feedback session or whether some team members may join the session after some results have been shared. When students are involved in an evaluation it is useful to discuss the relative merits of having both students and supervisors present during the feedback session.

Talk with family members about whom they would like to include in the feedback session. Families should be encouraged to invite others who may provide support (Herbert et al., 2011). Cultural considerations should guide decisions about who needs to be included in a feedback session. If, for example, a child's grandparent is an authority figure in the family, it may be critical to include this family member in the feedback session.

If a family wants the children included in the session, develop a plan with the family about how to do this in an effective manner. This is a clearly a family decision, but families may value a clinician's input. There are several factors to consider (e.g., Claflin & Barbarin, 1991; Wiener, Battles, & Heilman, 1998):

• When evaluating young children, it may be distracting to have the child present, and it may be beneficial to arrange a time when the family can meet without child being present. Alternatively, some parents may not have the resources to leave their children at home and clinicians may need to be creative about finding solutions.

• When evaluating older children, think about whether these individuals will also be given feedback. There are various ways to approach these issues and a child's family should be consulted about how to proceed. Some families choose to have an older children present for the entire feedback session, others invite the child in toward the end of the session after the adults in the family have heard the results or on a separate day and other families choose to tell their child on their own.

• Whenever feedback is given to a child, it is essential to stress his or her strengths and to put his or her challenges into the proper context.

➢ *Cultural considerations.*

The clinician should remember to consider the impact of a family's cultural values and beliefs during all parts of the process, including the feedback session (see McGoldrick, Giordano, & Garcia-Preto, 2005; Smith, 2004; Wing Sue & Sue, 2008). For example, how do religious and faith-based traditions affect a family's understanding of a child's diagnosis and treatment recommendations? Consider a family's educational background, level of literacy and learning style when providing information and recommending specific resources. Give careful thought to identifying characteristics of a family including age, race, educational level, marital status, financial status and sexual orientation. Take care to reflect on how these factors may impact a family's ability to voice concerns, ask questions or disagree with the information that is being provided. Be sensitive to the ways cultural perceptions about status may affect interactions between a clinician and a family. These factors may impact the way a clinician behaves throughout the entire evaluation. Thus, cultural or identifying factors may affect how a clinician first greets family members and maintains eye contact in a respectful manner, as well as how to give families permission to ask questions or challenge clinician statements when feedback is provided.

➢ *Prepare the physical environment.*

Shea (1993) emphasized the importance of the physical environment to a successful feedback:

• Feedback needs to be given so that privacy is ensured.

• If possible, choose a room with comfortable chairs.

• Arrange the room so that it is conducive to conversation.

• Make sure that tissues are available.

• If the child and/or siblings are going to be present, consider having toys or activities in the room that will engage them during the feedback session.

• Consider having staff available to assist in playing with the children during feedback.

➢ *Review and organize the information that needs to be presented*

A competent clinician will have taken the time to thoroughly review all paperwork provided by the parents ahead of the evaluation. If the child has completed an interdisciplinary evaluation, all team members should understand each discipline's results and formulation. The team should meet before the feedback session to discuss all the results and develop a diagnostic picture of the child that is well-integrated and consistent among disciplines. Team members should also work together to develop a well-defined set of recommendations; a consensus should be reached about prioritizing next steps for the family.   Work together as a team to build a clear plan for providing feedback; be clear about which team members will present what information and have a   general order for how this information will be conveyed.

If there has been a gap in time since the evaluation results were first examined, review them again before the feedback session if at all possible. Confirm that all necessary forms and paperwork are readily available for the session. Have written notes about key points, as the order in which information is provided may influence a family's understanding and retention of information (Greenberg et al., 1984), but do not rely on written information to present results. If feedback is not presented on the same day as the evaluation, it is useful to have a written draft of the report that will be given to the family. This report does not have to be given at the feedback session, but writing a draft version will help a clinician formulate the key information that needs to be provided to a family.

3. Beginning the feedback session

There are a number of first steps that a clinician can take to start a feedback session on a positive note:

➢ *Greet the family with a warm welcome.*

Shake hands (if culturally appropriate), make any necessary introductions, and thank the family for coming.

➢ *Determine whether there have been any changes since the evaluation.*

If any time has elapsed between the evaluation and the feedback session, the clinician should ascertain whether there have been any significant changes in the child's behavior or family circumstances. Have there been new stressors or changes in the family's routine? What happened at the end of the evaluation day? How did the child behave once the evaluation was completed and how did the rest of the family react?

➢ *Acknowledge the positive contribution that family members made to the evaluation process.*

Again, families are more likely to respond positively to feedback when their observations are respected (Brogan & Knussen, 2003). Give specific details about the family member's role in the evaluation process. For example, a clinician may choose to briefly mention how certain family member observations or actions made a positive difference. Acknowledge that the family was correct in deciding to have their child evaluated. Bringing a child in for an evaluation is often difficult for families and families appreciate this being acknowledged. Emphasize that there were many areas in which family observations and clinical observations were congruent. Note any differences between family and clinician observations; either state the reasons for these differences or let the family know that this will be discussed later in the session. Many family members take comfort in learning that while their children demonstrated a number of skills, the clinician also saw behaviors that warranted an evaluation. In other words, the family did the right thing by bringing their child in for an evaluation.

➢ *Provide an overview of what will occur during the feedback session.*

Let the family know what will occur during the feedback session and give them a brief outline. Providing families with the opportunity to ask questions is a key component to a successful feedback (Sloper & Turner, 1993). Tell them that they can ask questions or make comments at any time during the session. Mention that the family will be receiving a report that details all the information that will be covered during the feedback session. If any members of the evaluation team are not present for the feedback session, be sure to inform the family that these individuals will be available at a later time if the family has specific questions for them.

➢ *Review the evaluation process.*

Take the time to tell the family what evaluation measures were given, who administered the measures and why they were administered. Tell family members if a child's teachers or other treatment providers were interviewed. If a child completed a team evaluation, mention that team members shared their observations and results with one another before the feedback session. Be sure to reiterate the family's role in the evaluation process.

➢*Detail a child's strengths.*

Before giving an autism spectrum diagnosis, be sure to talk about a child's strengths. These may be discussed at other times as well, but be sure to talk about a child's positive qualities before discussing his or her needs (Graungaard & Skov, 2006).

4. Providing the diagnosis

➤ *Clearly state the child's diagnosis*

It is now time to provide a specific diagnosis. This needs to be delivered in a straight-forward manner. Here are a few points to consider:

- Use clear language and be direct (Hasnat & Graves, 2000; Sloper & Turner, 1993; Svarstad & Lipton, 1977). Try to simplify complicated diagnoses so that the family has an understanding of the key aspects.

- Once the diagnosis is given, make sure that the family has time to process any feelings or questions that they may have before moving on to specific details. Take the time to specifically ask the family if they have questions or concerns.

- Be prepared for a wide range of reactions and emotions. Give the family the time they need to talk about their fears and concerns (Sharp, Strauss, & Lorch, 1992).

- Clinicians need to be honest and direct in their responses while also providing reasons for hope and optimism. Provide specific examples of the child's strengths to reinforce that the child has positive attributes, too.

Family members are unlikely to process other information before they have a chance to talk about their feelings and have their questions answered. At this point in the feedback session, the clinician should follow a family's agenda while also providing the structure that will allow time for the family to process the other main points that need to be discussed.

➤ *Discuss details of the diagnosis.*

The clinician should be sensitive to the needs of a family in providing this information (Herbert et al., 2011). Some families may need many specific details about how a diagnosis was made and why their child is being given that diagnosis. Other families may be overwhelmed by too much information.

Clinicians will almost always explain the three main areas that are affected by an autism spectrum diagnosis (social interaction, communication and the presence of restricted or stereotyped behavior) and to give specific examples of a child's behavior that are consistent with this diagnosis. Providing examples of behaviors that were observed during the evaluation as well as family observations is often beneficial. Families may obtain information about autism spectrum disorders from many different sources of varying quality (Mansell & Morris, 2004) and it is useful to ask families what they have learned about autism spectrum disorders and how they have acquired this information.

Some families may need many specific details about how a diagnosis was made and why their child is being given that diagnosis. Other families may be overwhelmed by too much information.

Be sure to clearly state that autism spectrum disorders are neurobiological disorders that are present from birth and that family members are not responsible for their child's diagnosis. A recent survey through the University of Rochester indicated that parents often have significant feelings of guilt about their child's diagnosis (Herbert et al., 2011), so it is necessary to address this point. Clinicians should also be prepared to talk with families who do not understand why their child is not being given an autism spectrum diagnosis. Many families see a diagnosis of an autism spectrum disorder as a way of understanding their children's difficulties and also are hopeful that their children will receive specific services if their behavior is consistent with this diagnosis. Thus, clinicians may need to talk with families about how to understand their children and how to obtain the interventions that are warranted given the results of the evaluation.

➢ **Be prepared to answer difficult questions.**

Be sure to ask families if they have any questions throughout the feedback session. Many families ask a wide range of questions. Therefore, it is imperative that clinicians continue to increase their knowledge of autism spectrum disorders and relevant interventions (Nissenbau, Tollefson, & Reese, 2002).

- Families may ask detailed questions about alternative and complementary treatments, the availability of services and logistics about funding as well as wide-ranging questions about their child's future and chances for improvement.

- Many families have concerns about their child's ability to function independently. It may be beneficial to discuss the difference between research findings and an individual's own trajectory for learning and development. Each individual with an autism spectrum disorder may grow and develop at different rates and at different times. Once again, clinicians should be honest and direct, while providing as much hope and optimism as possible (Cottrell & Sommers, 1990).
- A clinician should feel free to say, "I don't know", in response to a family's question. We often do not have the research evidence to answer a question or simply do not have the knowledge base. Families value a clinician's honesty and the ability to acknowledge that a question is unanswerable (Quine & Pahl, 1986). Families will also appreciate a clinican's willingness to obtain more information for a family and to provide this information at a later date.

➢ **Discuss other diagnoses.**

A child may have more than one diagnosis and diagnoses other than autism spectrum disorders should also be clearly stated and discussed. For the majority of feedback sessions, it is usually advisable to discuss the ASD diagnosis before discussing any other diagnoses. Most families have requested an evaluation to determine if their child has an ASD diagnosis and this is their main question. Often, other diagnoses are best explained within the context of an ASD diagnosis. Some children may also be given a diagnosis of an intellectual disability. This is often a very difficult diagnosis for families and it may be challenging to help families understand this diagnosis (Shea, 1984). One strategy is to ask families to estimate the age level at which their child is functioning. Most families will describe their child as functioning at a lower age than their chronological age and this often provides a framework that aids their understanding and acceptance of this diagnosis.

5. Discussing recommendations and next steps

➤ *Outline recommendations.*

Once diagnoses have been discussed, it is time to give families information about key recommendations. This may include actions to take in several areas such as medical, speech/language, motor, safety, educational and behavioral aspects of a child's functioning. A clinician may often start with a broad outline of suggested therapeutic services before giving specific advice. For example, the clinician may discuss the need for behavioral intervention, give some general information about how how this may be effective and give the family referrals and ways to obtain this service. Once this information has been discussed, a clinician may choose to provide detailed information about the specific behavioral approach (such as ABA therapy) that is being recommended. As always, follow a family's lead while providing the necessary structure and support.

Recommendations frequently include learning ways to work with a child with an autism spectrum disorder at home. Often, families are learning about these techniques for the first time during this session. Clearly state that it will take time to learn to use these approaches and that families may need assistance to do so.

➤ *Prioritize next steps for the family.*

Many recommendations and ideas will be discussed during the feedback session. This may often be overwhelming for families and organizing services may be a significant challenge (Cottrell & Sommers, 1990; Turner & Sloper, 1992). The clinician should review the key recommendations and help the family decide on what their first steps will be after leaving the feedback session. Families need to know both what action steps to take as well as how to take them. For families who want written information, clinicians may recommend one or two key websites or books. The Autism Speaks "100 Day Kit" is an excellent first step for many families and is available in English and Spanish language versions.

The clinician should review the key recommendations and help the family decide on what their first steps will be after leaving the feedback session.

➤ *Discuss ongoing support.*

There may be a range of support options available to families after their child receives an autism spectrum diagnosis. Clinicians should give referrals to in-house resources such as a social worker and to parent or advocacy groups that can continue to support the family once they leave the clinic. If the clinician is available for additional meetings, the family should be aware of this and another appointment should be scheduled before the end of the session, if necessary. At a minimum, families should have a way to contact the clinician if they have questions. Clinicians may also recommend agencies or support groups that can address a family's most pressing needs.

➢ *Give the family written information*

During a feedback session, families are given an overwhelming amount of information. They need to process a great deal while also experiencing a wide range of emotions that may negatively impact their ability to understand and retain information (Jedlicka-Kohler, Gotz, & Eichler, 1996). Families benefit from having written information to which they can refer after a feedback session has ended (Brogan & Knussen, 2003; Jedlicka-Kohler, Gotz, & Eichler, 1996). This may include a written summary of their child's diagnosis, factual information about autism spectrum disorders or other diagnoses that are relevant and information about resources for the family. Clinicians may also want to develop a short form that can be individualized for each family and provide this information in writing. Providing families with a business card or including the clinician's phone number on the one-page summary also reinforces the message that families can call if they need to do so.

➢ *Talk about the written report that will follow.*

Diagnostic evaluation reports are likely to include a considerable amount of detailed information. Much of the report will focus on a child's needs and this may be overwhelming and difficult for a family member to read. It helps to prepare families for this. Remind them that a report should include specific information about a child's difficulties so that treatment providers can provide needed services. A family should not be surprised by what they read in a report. All pertinent information should be reviewed during the feedback session. Once again, remind family members that they can call with any questions about the report.

➢ *End the session on a positive note.*

As the session ends, remind family members about their child's strengths. Talk about the family's strengths as well. Be specific about ways in which they have helped their child and be sure to acknowledge how valuable it was for them to request this evaluation. Review reasons for hope and optimism as they move forward. State clearly that their child still has all the strengths and positive attributes that he or she had before the autism spectrum diagnosis was given. Remind them that the diagnosis will direct a child's treatment and provide needed services. Thank the family once again for their participation in the evaluation process and shake hands (if culturally appropriate) when you say goodbye.

State clearly that their child still has all the strengths and positive attributes that he or she had before the autism spectrum diagnosis was given.

LEARNING TO PROVIDE
EFFECTIVE FEEDBACK TO FAMILIES

QUALITY CHECKLIST

Instructions for Use:

The following checklist is designed to be used by trainees in psychology and other professions that provide evaluation results, feedback and recommendations to families of children with an autism spectrum disorder or other similar diagnosis.   The checklist reviews the most important components of a good feedback session as presented in the Feedback Training Video and Instructor's Manual as well as the clinician characteristics we consider most likely to result in a successful interaction with the family during feedback.

The checklist may be used in a variety of ways. Students may use the checklist as a summary of important points to remember prior to going into a feedback session or afterward as part of the learning process. Instructors or supervisors may also use the checklist to rate the trainee's performance and gauge improvement. The checklists may be used in the clinical setting or with videotaped feedbacks and for individual learning or as part of group discussion.

Feedback Session Quality Checklist

Preparing for the Feedback Session

Components of the Session	Rating			Examples
	Absent	Emerging	Present	
1. Clinician has reviewed results and planned for the session. If the child has completed a team evaluation, team members have met and worked together to organize the session.	☐	☐	☐	
2. Families have been told that they can invite other family members or friends to attend.	☐	☐	☐	
3. Feedback session has been scheduled to allow all interested participants to attend.	☐	☐	☐	
4. Clinician has scheduled enough time to allow for questions and discussion.	☐	☐	☐	
5. Feedback room ensures privacy.	☐	☐	☐	
6. Feedback room is organized with enough chairs in a manner that is conducive to discussion.	☐	☐	☐	
7. Tissues are available.	☐	☐	☐	
8. The clinician has all necessary forms and paperwork readily available.	☐	☐	☐	

Beginning the Session

Components of the Session	Rating			Examples
	Absent	Emerging	Present	
1. Clinician greets family with introductions (if necessary) and a handshake (if a handshake is appropriate within the family's culture).	☐	☐	☐	
2. Clinician determines whether there have been any changes since the assessment.	☐	☐	☐	
3. Clinician makes positive comments about the family's participation in the evaluation.	☐	☐	☐	
4. Clinician provides the family with an overview of what will occur during the feedback session.	☐	☐	☐	
5. Assessment process is reviewed.	☐	☐	☐	
6. Child's strengths are noted.	☐	☐	☐	

Feedback Session Quality Checklist

Presenting the Diagnosis

Components of the Session	Rating			Examples
	Absent	Emerging	Present	
1. Clinician describes the diagnosis in a clear, direct, and understandable manner.	☐	☐	☐	
2. Clinician discusses the diagnosis and supporting evidence in adequate detail.	☐	☐	☐	
3. Clinician provides reasons for hope and optimism.	☐	☐	☐	
4. Clinician explains the difference between a research outcome and an individual trajectory.	☐	☐	☐	
5. Clinician explicitly explains that family behavior is not the cause of their child's ASD diagnosis.	☐	☐	☐	
6. Clinician discusses diagnoses other than ASD, if appropriate.	☐	☐	☐	
7. Clinician asks the family for their reactions, questions and comments.	☐	☐	☐	
8. Clinician accurately summarizes the family's statements and questions.	☐	☐	☐	
9. Clinician answers family questions in an honest and direct manner.	☐	☐	☐	

Discussion of Next Steps

Components of the Session	Rating			Examples
	Absent	Emerging	Present	
1. Clinician makes key recommendations.	☐	☐	☐	
2. Clinician discusses and prioritizes next steps.	☐	☐	☐	
3. Follow-up meetings and/or phone calls are scheduled.	☐	☐	☐	
4. Clinician discusses ongoing support (if available).	☐	☐	☐	
5. Clinician provides written information.	☐	☐	☐	
6. Clinician gives information about the written report and what to expect.	☐	☐	☐	
7. The session ends on a positive note.	☐	☐	☐	

Feedback Session Quality Checklist

Characteristics of the Clinician

Components of the Session	Rating			Examples
	Absent	Emerging	Present	
1. Clinician maintains eye contact in a way that is appropriate within a family's culture.	☐	☐	☐	
2. Clinician has a good working knowledge of the results that are presented; the clinician is focused on talking with the family and does not spend too much time looking through papers.	☐	☐	☐	
3. Clinician does not interrupt family members.	☐	☐	☐	
4. Clinician patiently addresses all concerns.	☐	☐	☐	
5. Clinician serves as a mediator if family differences arise.	☐	☐	☐	
6. Clinician demonstrates a friendly and supportive tone throughout the session.	☐	☐	☐	
7. Clinician respects andresponds to family's need for more or less detail about each topic that is discussed.	☐	☐	☐	
8. Clinician gently and respectfully refocuses family's attention to assist in maximizing benefit from the feedback, if redirection is needed.	☐	☐	☐	
9. Clinician maintains a positive and supportive attitude throughout the evaluation session.	☐	☐	☐	
10. Positive statements about the child and family are made whenever possible.	☐	☐	☐	
11. Clinician conveys an appropriate balance between being professional and being approachable. Clinician is confident but empathetic.	☐	☐	☐	
12. Clinician maintains a positive or neutral stance about family beliefs and practices.	☐	☐	☐	

Bibliography

Clinician perspectives on feedback

Greenberg, L.W., Jewett, L.S., Gluck, R.S., Champion, L.A., Leikin, S.L., Altieri, M.F., & Lipnick, R.N. (1984). Giving information for a life threatening diagnosis. *American Journal of Diseases of Children, 138,* 649-653.

Harnett, A., Tierney, E., & Guerin, S. (2009). Convention of hop:Communicating positive, realistic messages to families at the time of a child's diagnosis with disabilities. *British Journal of Learning Disabilities, 37*, 257-264.

Knussen, C., & Brogan, C. A. (2002). Professional practice in the disclosure of a diagnosis of an autistic spectrum disorder: Comparing the perspectives of parents and professionals in Scotland. *Journal of Applied Health Behaviour, 4*, 7-14.

Lipton, H.L. & Svarstad, B. (1977). Sources of variation in clinicians' communication to parents about mental retardation. *American Journal of Mental Deficiency, 82*, 155-161.

Merker, B. M., Hanson, W. E., & Poston, J. M. (2010). National Survey of Psychologists' Training and Practice in Breaking Bad News: A Mixed Methods Study of the MUM Effect. *Journal of Clinical Psychology in Medical Settings, 17*, 211–219.

Nursey, A.D., Rohde, J.R., & Farmer, R.D. (1991). Ways of telling new parents about their child and his or her mental handicap: A comparison of doctors' and parents' views. *Journal of Mental Deficiency Research, 35*, 48-57.

Turner, S., & Sloper, P. (1992). Pediatricians' practice in disclosure and follow-up of severe physical disability in young children. *Developmental Medicine and Child Neurology, 34,* 348-358.

Disclosing diagnoses to children

Claflin, C. J., & Barbarin, O. A. (1991). Does 'telling' less protect more? Relationships among age, information disclosure, and what children with cancer see and feel. *Journal of Pediatric Psychology, 16*, 169-191.

Wiener, L. S., Battles, H. B., & Heilman, N. E. (1998). Factors associated with parents' decision to disclose their HIV diagnosis to their children. *Child Welfare: Journal of Policy, Practice, and Program, 77*, 115-135.

Vaz, L. E., Eng, E., Maman, S., Tshikandu, T., & Behets, F. (2010). Telling children they have HIV: Lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS Patient Care and STDs, 24*, 247-256.

Guidelines for providing feedback

Baile, W.F., Buckman, R., Lenzi, R., Glober, G., Beale, E.A., & Kudelka, A.P. (2000). SPIKES--A six-step protocol for delivering bad news: Application to the patient with cancer. *The Oncologist, 5*, 302-311.

Hiley, L, Mruzek, D., Herert, E.B., Yingling, J.T., Dambra, C.M., & Brown, H. (2010, May). SUPPORT: A protocol for disclosure of an ASD diagnosis with families. Poster session presented at the International Meeting of Autism Research, Philadelphia, PA.

Shea, V. (1984). Explaining mental retardation and autism to parents. In E. Schopler & G.B. Mesibov (Eds.), *The effects of autism on the family* (pp. 265-288). New York: Plenum Press.

Shea, V. (1993). Interpreting results to parents of preschool children. In Schopler, M. Van Bourgondien, & M. Bristol (Eds.), *Preschool issues in autism* (pp. 185-198). New York: Plenum Press.

Parent recommendations for feedback

Cottrell, D.J. & Summers, K. (1990). Communicating an evolutionary diagnosis of disability to parents. *Child: Care, Health and Development, 16*, 211-218.

Gaspar de Alba, M.J. & Bodfish, J.W. (2011). Addressing parental concerns at the initial diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders, 5,* 633-639.

Harnett, A., Tierney, E., & Guerin, S. (2009). Convention of hope communicating positive, realistic messages to families at the time of a child's diagnosis with disabilities. *British Journal of Learning Disabilities, 37*, 257-264.

Drouillard, B.E., Gragg, M.N., Miceli, R.T., Mullins, A.M., Beneteau, A.J., & Tiede, A.L. (2011, May). Parents' advice for professionals working with children with ASD and their families. Poster session presented at the International Meeting of Autism Research, San Diego, CA.

Osborne, L. & Reed, P. (2008). Parent's perceptions of communication with professionals during the diagnosis of autism. *Autism, 12,* 309-324.

Sharp, M.C., Strauss, R.P., & Lorch, S.C. (1992). Communicating medical bad news: Parents' experiences and preferences. *Journal of Pediatrics, 121,* 539-546.

Turnbull, H.R., & Turnbull, A.P. (1985). *Parents speak out: Then and now.* Columbus, OH: Charles E. Merrill.

Parent responses and coping following feedback

Boyd, R. D., & Corley, M. J. (2001). Outcome survey of early intensive behavioral intervention for young children with autism in a community setting. *Autism, 5*, 430-441.

Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism, 15,* 83-97.

Graungaard, A.H., & Skov, L. (2006). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health, and Development, 33,* 296-307.

Herbert, E.B., Mruzek, D.W., Yingling, J.T., Vogler-Elias, D., Barzott, L, Brown, H., Dambra, C., Galaspie, M., Hiley, L, & Nichols, S. (2011, May). An interdisciplinary LEND research practicum: A sequential mixed methods study of the disclosure of autism:

Parents' perspectives, current practices and the SUPPORT protocol. Poster session presented at the International Meeting of Autism Research, San Diego, CA.

Holst, Y., Nyman, H. & Larsson, J. (2009). Predictors of patient satisfaction with the feedback after a neuropsychological assessment. *The Open Psychiatry Journal, 3,* 50-55.

Jedlicka-Kohler, I., Gotz, M., & Eichler, I. (1996). Parents' recollection of the intitial communication of the diagnosis of systic fibrosis. *Pediatrics, 97,* 204-209.

Konstantareas, M., & Homatidis, S. (1992). Mothers' and fathers' self-report of involvement with autistic, mentally delayed, and normal children. *Journal of Marriage & the Family, 54*, 153-164.

Mansell, W. & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service: Access to information and use of services. *Autism, 8,* 387-407.

Moh, T.A. & Magiati, I. (in press). Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum Disorders.*

Myers, B.A. (1983). The informing interview: Enabling parents to "hear" and cope with bad news. *American Journal of Diseases of Children, 137,* 572-577.

Nissenbau, M.S., Tollefson, N., & Reese, R.M. (2002). The interpretive conference: Sharing a diagnosis of autism with families. *Focus on Autism and Other Developmental Disabilities, 17,* 30-43.

Pueschel, S.M., (1985). Changes of counseling practices at the birth of a child with Down syndrome. *Applied Research in Mental Retardation, 6,* 99-108.

Quittner, A.L., DiGirolamo, A.M., Michel, M., & Eigen, H. (1992). Parental response to cystic fibrosis: A contextual analysis of the diagnosis phase. *Journal of Pediatric Psychology, 17,* 683-704.

Sardell, A.N. & Trierweiler, S.J. (1993). Disclosing the cancer diagnosis. Procedures that influence patient hopefulness. *Cancer, 72*, 3355-65.

Svarstad, B. & Lipton, H.L. (1977). Informing parents about mental retardation: A study of professional communication and parent acceptance. *Social Science and Medicine, 11*, 645-6511.

Parent satisfaction with feedback

Baird, G., McConachie, H., & Scrutton, D. (2000). Parents' Perceptions of Disclosure of the Diagnosis of Cerebral Palsy, *Archives of Disease in Childhood, 83*, 475–80.

Brogan, C.A. & Knussen, C. (2003). The disclosure of an autistic spectrum disorder: Determinants of satisfaction in a sample of Scottish parents. *Autism, 7,* 31-46.

Cunningham, C.C., Morgan, P.A., & McGucken, R.B. (1984). Down's syndrome: Is dissatisfaction with disclosure of diagnosis inevitable? *Developmental Medicine and Child Neurology, 26,* 33-39.

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism, 10*, 439-451.

Hasnat, M.J. & Graves, P. (2000). Disclosure of developmental disability: A study of parent satisfaction and the determinants of satisfaction. *Journal of Pediatrics: Child Health, 36,* 32-35.

Howlin, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients in the UK. *Autism, 1*, 135-162.

Quine, L., & Pahl, J. (1986). First diagnosis of severe mental handicap: Characteristic of unsatisfactory encounters between doctors and parents. *Social Science and Medicine*, *22,* 53-62.

Sloper, P. & Turner, S. (1993). Determinants of parental satisfaction with disclosure of disability. *Developmental Medicine and Child Neurology, 35,* 816-825.

Recommendations regarding written feedback reports

Towle, P., Farrell, A.F., & Vitalone-Raccaro, N. (2008). Early Intervention Evaluation Reports: Guidelines for writing user-friendly and strength-based assessments. Zero to Three, 53-60.

References regarding multicultural considerations

McGoldrick, M. (Ed.), Giordano, J. (Ed.), & Garcia-Preto, N. (Ed.). (2005). *Ethnicity and family therapy (3rd ed.)*. New York, NY: Guilford Press.

Smith, T.B. (2004). *Practicing multiculturalism: Affirming diversity in counseling and psychology*.

Wing Sue, D., & Sue, D. (2008). *Counseling the culturally diverse: Theory and practice (5th ed.)*. Hoboken, NJ: John Wiley & Sons Inc.

A Clinician's Guide to Providing Effective Feedback to Families Affected by Autism:
An Autism Speaks ATN/AIR-P Guide for Providers

p.21

ACKNOWLEDGEMENTS

The Autism Speaks Family Services Department offers resources, tool kits and support to help manage the day-to-day challenges of living with autism (www.autismspeaks.org/family-services). If you are interested in speaking with a member of the Autism Speaks Family Services Team, contact the Autism Response Team (ART) at 888-AUTISM2 (288-4762) or by email at familyservices@autismspeaks.org. ART
En Español al 888-772-9050.