

Maintaining Healthy Relationships

An OCALI Parent Package




Ohio | Department of Education
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Welcome to the presentation on maintaining healthy relationships. This presentation is part of the Ohio Center for Autism and Low Incidence's (OCALI) Parent Packaged materials series; materials designed to be used by parents and parent groups to increase knowledge about topics important to families of those with disabilities. These materials were developed by the expert staff at OCALI with funding from the Ohio Department of Education, Office for Exceptional Children. For further information on all the parent packaged materials please contact Donna Owens, family and adult services administrator at OCALI, 614-410-0381 or donna_owens@ocali.org

Objectives

- Participants will gain a greater understanding of the impact a child with a disability has on family life
- Participants will gain information on building parent-professional relationships
- Participants will learn strategies to support communication, collaboration, and relationship building in their child with ASD

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This session is designed to bring to the fore-front the issues that surround healthy relationships for those living and working with individuals with disabilities, especially autism spectrum disorder. For most living and working with individuals with ASD or other complex disabilities, the journey can be stressful and collaboration and partnerships are key to success. The significant and varying needs of this population can take a toll though, and adults need to build relationships to get the support that they need. This session will focus on YOU, the adult and highlight some of the issues you may be facing, along with some strategies to help you along the journey you are facing. You are not alone.

Relationships are everywhere!



Relationships are everywhere. As important as it is for you to support your child with a disability in developing relationships, it is equally important that YOU take care of your relationships apart from your child with a disability. Studies have shown that there is a need for “care for the caregiver”, and that adults that work and live with individuals with disabilities are not as good at taking care of THEIR needs, as they are of taking care of those of the individual with a disability.

FACILIATOR – take a minute and think of the relationships you might want to improve if you could.... Would they be the relationship with your spouse? Family relationships? Friend relationships? Relationships with school or other professional personnel?

How might improvement of these relationships provide support or care to YOU?

Take a minute and discuss this with a partner.

Does anyone want to share??

What relationships can be affected or changed when a child with special needs is part of the family?



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Can you think of any other relationships that may be influenced by having a member of the family with special needs?

Relationships to Explore Today

- **Inter-family relationships:** those within the family unit
- **Family and Professional/Service Provider relationships:** those with professionals providing services to an individual or others in the family
- **Relationships with friends:** those outside the family such as friends and those in the community



Individuals with disabilities must overcome many challenges throughout their lifetime, including barriers to learning, socializing, and accessing the community. These challenges often require an intense and ongoing effort by parents. So consuming are these needs that parents may overlook or forgo a focus on their own needs and challenges. The professional community has begun to realize the need to “care for the caregiver” and thus supports such as respite care and efforts to include children with disabilities in community programs are more common. However, the need to cultivate and care for relationships outside of the parent-child relationship has not received as much emphasis.

As we work through today’s presentation we will be focusing on 3 areas. We realize in the short time we have together we will just graze the surface of these issues, but hope that what we can cover will provide a spark for further discussion after you leave here today.

The Family



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Demands and challenges of raising a child with special needs can be overwhelming for everyone in the family. The child with the special needs can undo the balance of attention within a family, just because of the time it may take to meet their unique needs. Let's talk about some issues that you may be facing and how you might get some support.

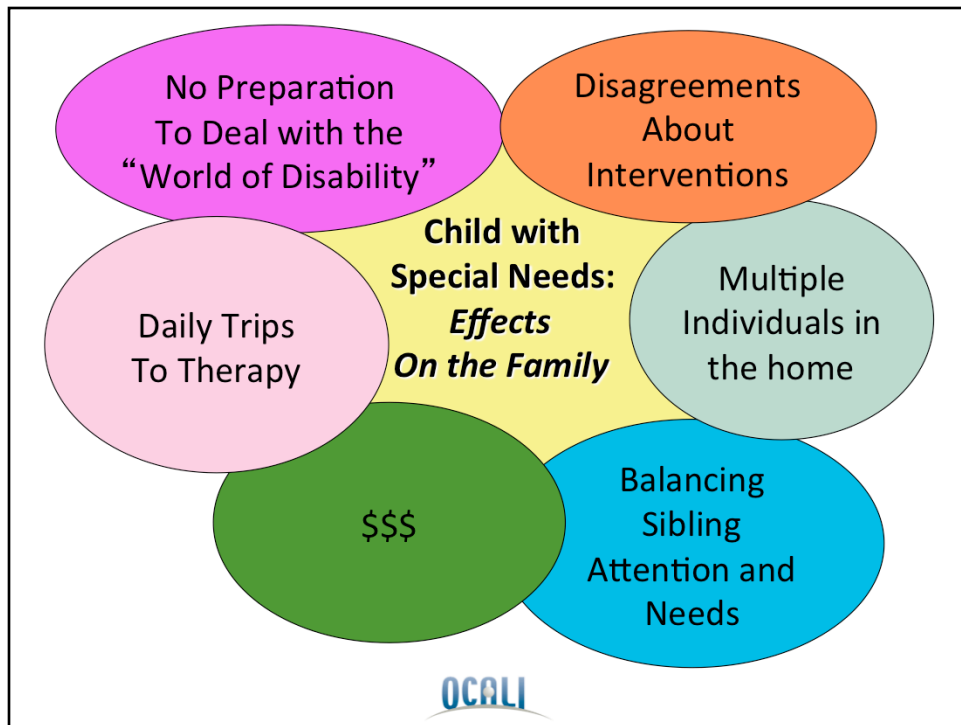
“..sometime around age five to ten years the marital deficits and inadequacy of the traditional roles began to show evidence of strain and even open dissatisfaction. Dads became frustrated at the demands of their wives to “play with” a son or daughter who didn't know how to play, and moms became frustrated at the lack of involvement of their mates. In retrospect, this appears to be the time that the existing intra-marital separation starts the couples on a path towards formal separation and divorce.”

William M. Bolman, M.D., University of Hawaii - John A. Burns School of Medicine, Child Psychiatrist (ASA's 37th National Conference on Autism Spectrum Disorders, 2006)

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The parental relationship is at great risk of being impacted by the intense needs of the child with a complex disability. Dr. Bowman described this stress during an Autism Society of America conference.

While not all couples experience this specific scenario, Dr. Bolman describes the tremendous stress that families face when attempting to balance parenting with maintaining intimate relationships. Media reports indicate that the divorce rate among parents of children with autism is as high as 85%! Although this number has yet to be validated, professionals and media continue to support the notion that families of children with autism and complex needs face unusual and sometimes overwhelming stress that leads to the breakdown of relationships.



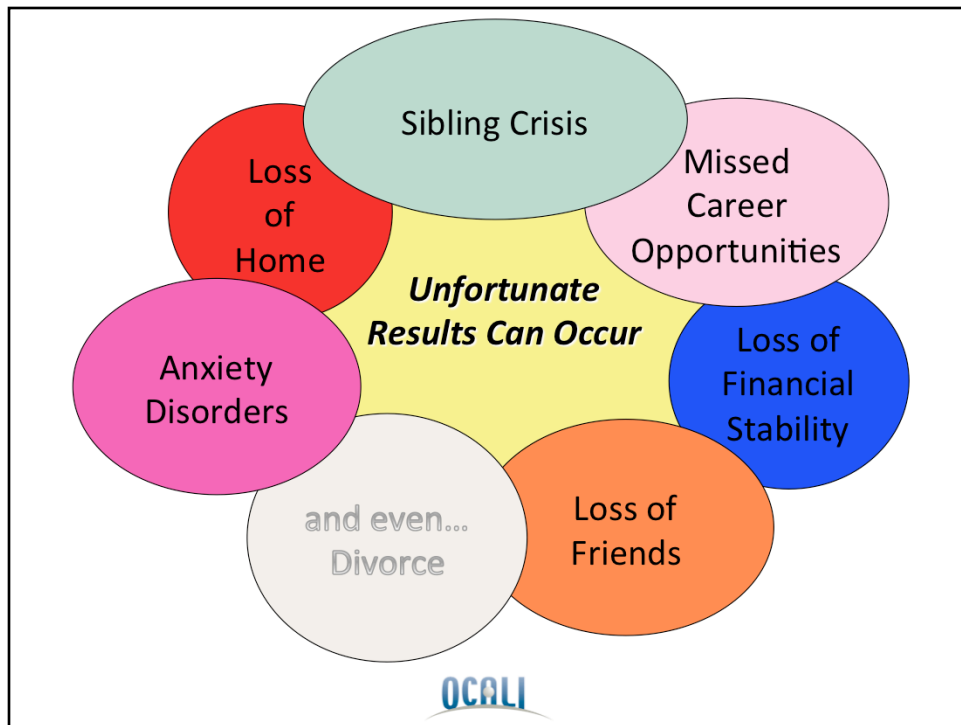
Triggers or sources to these stressors include:

- Balancing the parental roles and responsibilities
- Lack of time and ability to act as a couple, instead each fulfills isolated roles
- Sibling needs
- Identifying and locating appropriate services and supports
- Disagreements about the types of interventions to use
- Lack of or slow progress in skill development
- Child's behavioral challenges that can place limitations on typical activities
- Financial issues and needs
- Lack of understanding and support from extended family and friends

Parenting a typical child can place stress on a marriage, and parenting a child with special needs can be especially challenging.

If everything in your family revolves around the child with special needs, other family members can become resentful.

Do you define your family as a special needs family or a family with a special needs child?



If support is not available and the work on healthy relationships is not a priority, these are some of the unfortunate results that can occur with families.

Relationship Building Within the Family

- Communicate often
- Share feelings
- Set alone time
- Express emotions
- Needs change
- Ask for help



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There are no easy answers, because each family is different, but here are some suggestions and strategies that others have found to be effective to building and maintaining healthy relationships with in their families.

Take time to communicate. Make it a priority, set aside time whether it be at dinner together, whether it be first thing in the morning, whether it be at night... make it a time that does not get overlooked, or moved. Make this time a mandatory time that both parents and siblings can count on.

Provide a place and openness to share feelings. Provide some guidelines so that screaming and shouting does not become the language of the day, but make sure that all feel comfortable with being frustrated. Make it a solution focused time. It is OK to have frustration, but the goal of expressing it is to help all to figure out a solution.

Make sure that parents and siblings get alone time on a regular basis. Again, like communication and sharing feelings we want to stress how important it is to maintain your sense of self. Do things you enjoy during this alone time – whether it be to go have coffee with friends, or read a book, or take a hike – keep the things you love as part of your routine.

Communicate Often



- Vocally or written
- Allow time to just talk (reduce distractions such as TV, computer, phones, etc.)
- Exchange information (share what happened today)
- Don't make all conversations about the disability

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-Communication is key! It's important to always be open with one another.

*Make time to communicate whether it is vocally or written (which ever one works better).

Share Feelings

- All emotions need to be shared (anger, happiness, depression, sadness, excitement)
- Don't keep thoughts bottled up inside
- Allow tears



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Ask for Help

- Seek others in the family unit who can assist (financially, emotionally, spiritually)
- Don't be afraid to ask!



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-Sometimes our family members are not aware of our feelings or our needs.

*We often become resentful if they do not respond the way we think they should.

* But do they really know what is going on?

What to Avoid

- Shutting down
- Not seeking help
- Denial the we need help

Sometimes we need a break from the constant challenges that face us

- Constant anger



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It's important to recognize that you can't do it all! When we close out the ones who love us, it can be very unhealthy.

Everything is “Balance”! How can you add balance to your life?

- Therapy options
 - What works for your child and family?
- Set priorities
 - What truly IS important?
- Family time
 - Begin with what you can do



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- Evaluate your decisions carefully and try to keep some balance in your everyday life.
- Consider how decisions will impact your whole family and not just the child with a disability.
- Unfortunately, there are people out there who take advantage of families that are desperate to help their child: research carefully the services/treatments that are being offered and select them according to what works **best for your family**.
- Take one day at a time and try to keep routines as normal as possible: it will help provide some consistency when things are hectic.

Prioritize your family.



- Make time for YOU!
- Make time for communication!
- Make time for fun!



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The relationships within your family are unique and different from any other families. Figure out what works for your family, and make your family a priority!

Parent- Professional Relationships



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Our second area of focus for building and strengthening relationships is on those between the family and the professionals who work with the child with disabilities. Some of the best resources and respite for your internal family issues can be provided by professionals that work with your child with a disability. Many of these professionals are extremely dedicated and will be glad to work with you, so that relationship you establish is key.

Here's a small example. A special education teacher who taught a class of 6 students with autism was very lucky that the parents of the students within her class wanted to develop a relationship with her. When Josh received a diagnosis of severe and profound retardation from a private provider, Josh's mom felt comfortable coming in to talk about that diagnosis with the teacher. The teacher was able to talk with that private provider and share information that directly contradicted the report. Josh was very bright, just non-verbal, and the private provider didn't have experience working with children with ASD. Because of that relationship, the teacher felt very comfortable advocating on behalf of the parent. Another student in the class suffered from sleep issues – he didn't sleep. Due to safety concerns, when he didn't sleep, his parents didn't sleep either. Through the relationship with the parents, and clear communication, the teacher knew that on those days he didn't get any sleep, she could accommodate for the child within the classroom, thus allowing the parents to have a break and to get some sleep.

Each Family Has a Unique Culture

Professionals recognize:

- The importance of relationships with families
- The uniqueness of each family



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Research on parent/professional partnerships shares the importance of understanding the unique culture of an individual family. For professionals working with families, there is increased coursework in pre-service programs that focuses on importance of meeting the family where they are and working with them from there. The task of understanding this family dynamic cannot rest solely on the professional though.

Your family is as unique as your child. You have schedules, customs, food preferences, etc. that are unique to you. Although school and community are important, the family unit is the center of the individual child's life. Taking time to help the professional understand the dynamics of your family is important in building and maintaining healthy relationships with that professional. Both parents and professionals get busy moving forward in their days – each taking on their unique role in caring for the child with a disability. It is important though to step back and take the time to EXPLAIN your role to your parent/professional partner. Help them see the world through your eyes – this knowledge fosters understanding, and understanding facilitates more effective communication.

Help the professional understand the unique culture and dynamics of your family.

Differing Perspectives

- Parents and professionals may view each others roles differently
- They may have different expectations
- Barriers to a partnership can develop



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Without taking the time to develop the relationships barriers can occur.

Importance of Parent-Professional Relationships

- Families who have higher satisfaction with partnerships tend to have more communication with their child's teacher and to participate more in school activities
(Summers, Gotto, Epley, & Zuna, 2007)
- Family-professional partnerships explain a significant portion of variance in the extent of parent involvement and the nature of parent-teacher communication
(Zuna, 2007)

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Studies have been conducted on the importance of parent or family and professional partnerships. Results have shown (READ SLIDE)

Importance of Parent-Professional Relationships

- Families who have higher satisfaction with partnerships also have higher family quality of life

(Hoffman et al., 2006)



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In addition it was found that (READ SLIDE)

What Parents Are Looking For

Parent research indicates that parents want a professional to:

- Listen
- Respect Families
- Accept them as important team members



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This list helps us to see what families truly want from professionals.

So, what is my role in the parent-professional relationship?



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Nothing is more close to a parent's heart than their children. Meetings or conversations that concern your child's educational program can be emotional and confusing. One of the best thing you can do for your child is to establish a working relationship with your child's professional team.

Relationship Building with Professionals

- Collaborate
- Listen to each other
- Share information about your family
- Gather information



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Parents should see each interacting with the professional as the opportunity to build a relationship. It is an opportunity to collaborate, to listen, to share and to gather information.

So What is the Parent's Role?

- I am not objective, nor should I be, it is my child we are discussing
- The parent viewpoint is unique and vital, like no one else on the team
- However, I do not have all the answers, and neither does anyone else
- I do not need to make decisions alone



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Professionals should be objective when talking about your child, but you, as the parent aren't expected to be.

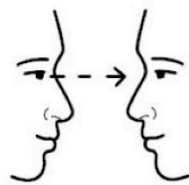
Knowing the basics of effective communication will help as the parent works as a member of the team.

Strategies to Support Communication:

Monitor Body Language

Eye Contact

- Try to periodically look at the speaker
- When speaking, look at all individuals in the room



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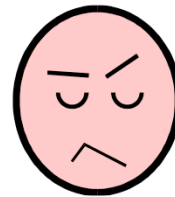
Remember that body language and tone affect what is understood.

Strategies to Support Collaboration:

Monitor Body Language

Body Language

- Monitor your facial expressions- You may not be sending the message that you want to send!
- Nod head in acknowledgement
- Look interested-Lean Forward



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Strategies to Support Collaboration:

Develop Active Listening Skills

- Acknowledge
 - Value the importance of what everyone brings to the table, no matter how difficult
 - Use words such as “right, really, yes”
- Reflect, Paraphrase, Summarize
 - Use speaker’s exact words
 - Re-state information to assure a clear understanding of the basic thoughts and ideas of the speaker



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Avoid blaming, gather information and move to problem solving.

Strategies to Support Collaboration:

Develop Active Listening Skills

- Elaborate
 - Build on information the speaker has given you
- Ask
 - Relevant questions for clarification and do not continue until clear



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Be sure to ask to repeat what is said to you to confirm your understanding. It ensures accurate understanding on your part and also shows respect.

Strategies to Support Collaboration:

Be Proactive

Gain Information

- Read all pertinent information before face to face contact
- Explore any and all statements, ideas and requests
 - Do not need to agree, just agree to explore and consider



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-Be prepared: plan ahead and write down the points you want to make before you come face to face.

*It helps you stay focused on the issues that are important to you.

Strategies to Support Communication and Relationship Building

- Think before you respond- “Wait time”
- Communicate ideas, goals, visions early in the process
- Develop a consistent and ongoing communication process



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Be respectful of others. Effective communication takes place in a relaxed and safe environment. Communication is a team activity.

Strategies to Support Relationship Building

Communication

- Don't let concerns develop into problems
- Verbally acknowledge areas of disagreement. Find a point of agreement to begin



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-Participation in the team is influenced by the energy each participant brings to the discussion.

*Understand that disagreements are not inherently bad: they may actually produce better solutions and can build stronger and more productive teams.

*Compromise and creativity should be a part of any type of communication.

What to Avoid: Red Flags!

If you find yourself doing or thinking these, be aware that you may be setting up a more difficult situation

- Not seeing others viewpoint
- Assuming the professionals do not care
- Forgetting to thank them or refusing to thank them
- Making (or considering making) threat

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-We often forget that many professionals go into this line of work because of their care and interest in children

*They too have families and responsibilities

-Maybe not on the same level as us but we need to look at it from their level too

Relationships with Friends



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Where would we be without our friends? In times of emotional crisis- seek personal support!

Friends

- Allow laughter
- Be honest
- Share emotions
- Spend time
- Share interests
- Seek support
- Allow new friends



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Your friends can be a true source of support and encouragement. Unfortunately sometimes we get so caught up in the world of disabilities that we forget to seek out our friends.

-Some friends can be uncomfortable talking to you about your child with a disability.

*They may withdraw in fear that they would say or do the wrong thing.

*Be open with them, share your feelings but remember to allow them to share what is going on with their life too.

-We make friends by being a friend

-Laughter is therapeutic and is certainly healthy

What to avoid...

- Not making time for friends
- Comparing yourself
- Not listening to their needs and concerns



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Don't let the world of disabilities dominate every conversation you have with your friends.

Find time to do the things you used to do before a child with special needs came into your life.

It is a mistake to compare their life to yours.

So, “Been There Done That”?

- Nothing new here?
- Tried all these ideas and strategies?
 - Sometimes it may take longer than you expect
 - You may not initially see the impact
 - Sometimes you may need to go the next step
 - Legally (i.e. procedural safeguards)
 - Outside assistance
 - Advocates, Mediators and Lawyers
 - Therapists and Counselors



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-This slide is the “so what “ slide.

*This allows us to address what some may be thinking which is that they have tried all these things and nothing works.

*That this is “old news” .

-Some people may be in a situation where they are so stressed or overwhelmed that they cannot see that the strategies may be working.

-Some may need more time or more effort.

-Some people greatly need to consider outside help.

*Legal options with professional relationships and Counseling/Therapy options with the family and personal issues.

Red Flags for Help!

If you see yourself in several of the following situations, you may need some outside help to move through the issues you face:

- Constant sadness, hopelessness, agitation and/or irritability
- Generally feeling anxious, sometimes for no obvious reason
- Trouble sleeping, low energy, fatigue, difficulty concentrating
- Feeling worthless or guilty
- Significant weight change
- Loss of interest in favorite activities



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This slide allows us to tell people to seek help or to encourage someone else to seek help if they see themselves in several of these bullet points.

We need to acknowledge that sometimes we need help and it is not as simple as the strategies we offered earlier in the presentation.

And that is okay- there is no fault.

Short Quiz

1. List a few teachers who aided your journey through school.
2. Name three friends who have helped you through a difficult time.
3. Name five people who have taught you something worthwhile.
4. Think of a few people who have made you feel appreciated and special!
5. Think of five people you enjoy spending time with.

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Again just think in your head.

How did you do?



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The people who make a difference in your life are not the ones with the most credentials, the most money, or the most awards. They simply are the ones who care the most.

Everything is about Relationships!



It's the people in our lives and the relationships we create with those that keep us grounded especially during hard times.

Reminders:

- Be a child advocate, not a program advocate
- Prioritize the goals with the needs of the family
- Give time to the family: work as a team
- Suspend judgment: assigning fault is useless
- Be open and consider possible benefits from interventions
- Get away occasionally
- LAUGH



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Parent Package Materials series was developed by the expert staff at OCALI, in collaboration with the Autism Society of Ohio, and funded by the Ohio Department of Education's Office for Exceptional Children



Thank you for your participation today. We hope you have enjoyed this presentation on the healthy relationships.