

**Home vs. Center EI Visits:
 Strategies to Encourage
 Caregiver Participation**
 Teresa A. Cardon PhD CCC-SLP
 Utah Valley University

Introduction

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Who's Here?

- Caregivers
- Special Educators
- Social Workers
- Behavior Specialists
- SLP's
- OT's
- Psychologists
- Grandparents
- General Educators
- Paraprofessionals
- PT's
- ????
- ????

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Note Taking . . .

- A = AHA moment – these are the moments when the light bulb goes off!
- D = Duh! You probably already new it – but a reminder won't hurt!
- S = Say what?! New and useful information you REALLY don't want to forget!

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Facts & Figures . . .

- Over 1.77 million cases of autism in the US
- New case is diagnosed every 20 minutes
- 1 in 88 children currently being diagnosed – 1 in 47 in Utah
- Boys are 5x more likely than girls
- Autism is the fastest growing developmental disability in the US
- Costs 126 billion annually in the US
- 2.3 million dollars to care for an individual with autism over their life span

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What is Autism?

- A developmental disorder characterized by marked difficulty in communication and social relations and by the presence of atypical behaviors such as unusual responses to sensation, repetitive movements, and insistence on routine or sameness.
- The Autism Encyclopedia, 2005

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Definition:

Always
Unique
Totally
Interesting
Sometimes
Mysterious

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Recommendations from the National Research Council over 10 years ago:

- As part of local educational programs and intervention programs for children from birth to age 3, families of children with autistic spectrum disorders should be provided the opportunity to learn techniques for teaching their child new skills and reducing problem behaviors. These opportunities should include not only didactic sessions, but also ongoing consultation in which individualized problem-solving, including in-home observations or training, occur for a family, as needed, to support improvements at home as well as at school.

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Recommendations from NRC:

- Entry into intervention programs as soon as an autism spectrum diagnosis is seriously considered;
- Active engagement in intensive instructional programming for a minimum of the equivalent of a full school day, 5 days (at least 25 hours) a week, with full year programming varied according to the child's chronological age and developmental level
 - Hint: Caregivers are with their children all day!!!

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Early Intervention – the LAW!

- The 1997 amendments of Public Law 105-17 of the Individuals with Disabilities Education Act (IDEA) include that Part C services for eligible infants and toddlers must be provided in “natural environments”
- September 6, 2011, the U.S. Department of Education announced the release of the final regulations
 - Strengthening the role and responsibility of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home;
 - special education can become a service for such children rather than a place where such children are sent;
 - Mandate for family centered practice!

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Early Intervention – The Reality!


- According to research, EI services are provided most frequently via traditional model where a provider-directed activity is used to help a child learn new skills.
 - Regardless of location!!!
 - (Campbell & Sawyer, 2007)
- Traditional provider-directed services moved from the center to the home
- “Parent as Observer” therapy!

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Ask yourself these questions -

- Do you bring a bag full of toys to the child's home?
- Do you provide the intervention during the entire session?
- Do you incorporate the child's daily routines and activities into your sessions?
- Does a parent hang around during therapy?

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Make the switch from “traditional therapy” to Family Centered Intervention!

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Including Caregivers in Early Intervention!





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Role of the Provider in EI

- Parents are Partners!
 - Include them in intervention
 - Practical & Functional
 - Daily routines and activities
 - Direct teaching vs. Indirect teaching
 - Coaching & Modeling
 - Praising & Encouraging
 - LISTEN!!!


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Parent Learning Stages

- Thinker → 
- Conscious → 
- Skeptic → 
- Partner → 

Thinker

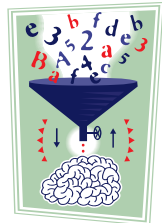
- This is the parent who has done some research and knows some terms but does not apply this knowledge to actual interactions with their child.
 - Signs to look for
 - Lots of *terms*
 - “Everything is going fine”
 - “We have been trying to extinguish him” – use of jargon without true understanding
 - “We are going to try PRT.”



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Thinker’s in Transition

- Caregiver’s who are “thinker’s” may have already looked into a lot of programs and done the “research”, but may not really now what the want for their child.



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Conscious

- This is the parent who consciously understands what they should be doing but hasn't put it into action yet.
- Signs to look for
 - "I realized that I give her things without waiting for her to request."
 - "I noticed that she is waiting for me to help her all the time."
 - "I think she is starting to understand more because _____."
 - "We should follow his lead" – gives advice but doesn't do it themselves



Conscious Caregiver's in Transition

- May have ideas about what they want for their child, but not be confident enough to share those ideas with the team right away.



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Skeptic

- This parent is a thinker and is already conscious of what their child is doing but they don't really buy into the whole thing. They may accept or reject your entire approach!
- Signs to look for
 - "I don't think this really applies to my child."
 - "One Dr. said his sensory system is just overloaded, so that doesn't seem like autism to me."
 - "We tried that and it doesn't work!"
 - "Have you heard of _____?"



Skeptic's in Transition

- This caregiver is already sure that regardless of what happens or what changes take place, they will not be the right things and their child is not going to get the help they need!



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Partner

- This parent has the desire to change the way they interact with their child based on what you are teaching them. They are conscious thinkers who are ready to DO!
- Signs to look for
 - "I am starting to ask fewer questions and she is really responding more"
 - "I need more ideas on how to follow his lead when we read books."
 - "How do I get him to use two word requests?"



Partner's in Transition

- The partner caregiver is ready to discuss and hear ideas and thoughts about transition. She may have ideas of her own, but wants input and feedback!



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How to Include Caregivers

- Direct teaching vs. Indirect teaching
 - Modeling with verbal narrative
 - Coaching with corrective feedback
 - Praising & Encouraging

Modeling

- You need to tell parents what you are doing while you are doing it
 - why are you doing it, what is the purpose, specific language you are using
- Do not assume that just because they are watching that parents understand what is going on
- Model with a verbal narrative describing key elements of the intervention

Coaching

- After you model the intervention offer the parent a turn
- Coach them through each step using similar terminology to what you just modeled.
- Provide immediate feedback – do not let them practice it the *wrong* way!
- Stay positive and give specific instructions

Praising & Encouraging

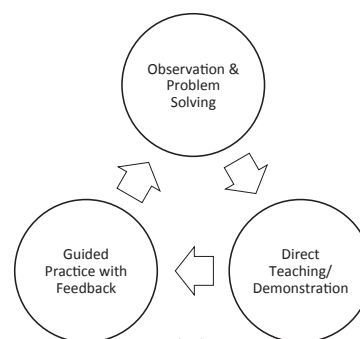
- Praise specific actions
 - “I like how you waited for him to try to say something before you offered the prompt.”
 - “The way you stated the direction one time and then followed through with a physical prompt was right on target!”
- Encourage them to keep on going!

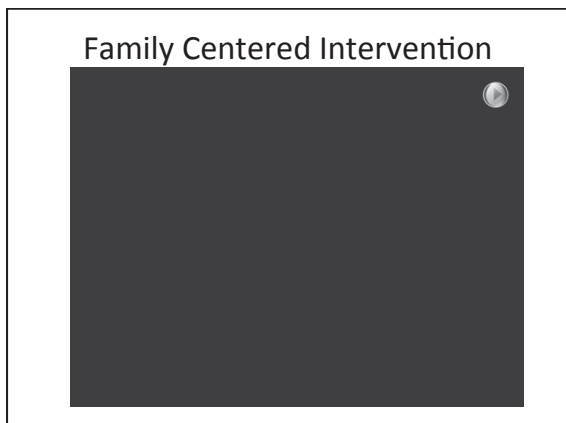
LISTEN!!!!

- You become
 - a more effective provider
 - a more empathetic provider
 - a more effective partner
 - a better provider

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Coaching Caregivers





- ### Including Caregivers
- Intake
 - Vin at 1 month
 - Vin at 1 month turn taking
 - 2 months
 - 2 months turn taking
 - 4 months
 - 4 months questions

Daily Activities & Routines

Including Caregivers in the
Assessment and Intervention Process

- ### “Caregiver Assessment of Activities/ Routines” (Campbell & Wilcox)
- Early intervention programs in all states require some type of assessment of a child’s “natural environment” and the activities/routines in which a child is typically expected to participate. This might include:
 - Caregiver assessment of a child’s performance within an activity/routine
 - Caregiver identification of activities/routines that are of concern
 - Caregiver satisfaction with a child’s participation in activities/routines
 - Extent to which a child’s performance in an activity/ routine might meet a caregiver’s expectations

Caregiver’s of children with autism: Reports of problem routines

Routine (n=134)	Problem Count (%)
Bathing	111 (82.8)
Morning Routine	90 (67.2)
Evening Routine	69 (51.5)
Mealttime	86 (64.2)
Play	65 (48.5)
Leaving the House	40 (30.0)
Running Errands	33 (24.6)
Family Routines	43 (32.1)
Physical Activities	42 (31.3)
Family Outings	45 (33.5)

(Cardon & Wilcox, 2011)

Caregiver support sources (for AT specifically)

Information/Training Source	Count (%)
Formal Workshops	31 (23.1)
Local Expos/Fairs	24 (17.9)
Local Lending Library	32 (23.9)
Program Specific Training	11 (8.2)
EI Personnel Provided Information	65 (48.5)
EI Personnel Referred to Resources	45 (33.6)
Help from another Caregiver	52 (38.8)
Other	0--

(Cardon & Wilcox, 2011)

12 Key Activities/Routines

1. Morning routine (getting up, getting dressed, etc.)
2. Bath time
3. Nighttime (getting ready for bed, going to bed, sleeping)
4. Mealtime (appetite, level of assistance)
5. Playtime (indoor play with family members, other caregivers, friends)
6. Story time
7. Outside play (riding a bike, playing outside, playing on playground equipment, swimming)
8. Chores (cleaning, preparing meals, watching TV, caring for pets, etc.)
9. Leaving the house to go somewhere (e.g., getting ready to go)
10. Travel time (in the car)
11. Running errands (grocery store, mall/store shopping, banking, wash/cleaners)
12. Community outings (visit a friend/relative, eat at a restaurant/fast food, go to museums, amusement parks, zoo, etc.)

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Goals of Routines Based Assessment

- Key areas of discussion with caregivers include
 - Activities and routines that are not going well
 - Activities and routines that are not going well and communication appears to be the primary barrier for participation
 - Activities and routines that are going well and can serve as a context for learning new communication skills
- Goals of early communication interventions are to
 - Enhance participation in activities/routines
 - Embed learning opportunities for acquiring functional skills within activities/routines
 - Scaffold activities/routines to provide learning and practice opportunities for more complex skills

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A Format for Caregiver Assessment

DIRECTIONS FOR THE CAREGIVER ASSESSMENT AS AN INTERVIEW/CONVERSATION

1. Ask the caregiver open ended questions about each activity/routine. For example, start by saying "tell me about bathtime and how your child participates during bathtime." Follow up by asking additional questions so that you gain an understanding, a picture, of what the routine or activity looks like. Then ask the caregiver to rate the child's participation in terms of the caregiver's expectations (e.g., weekends, meals, occasionally meals, does not meet). If you wish, you may ask the caregiver about how satisfied they are with how the activity/routine is going. For some families, you may want to decide the routine on which they may want to focus.
2. Ask the caregiver to rate their child's use of functional skills (e.g., socializing, communicating) within activities and routines and their satisfaction with the child's abilities. You are not trying to find out about the child's deficit (e.g., speech) but rather the extent to which problems with speech interfere with a child's participation.
3. Identify any routines which may not be going well (so that you can help families make them go better). Identify routines that are positive for families/children as these will provide a context in which to show families how to teach their children identified skills.

ROUTINE/ACTIVITY	EXPECTATIONS				COMMENTS	SATISFACTION				
	Always	Sometimes	Occasionally	Does not meet		Always	Sometimes	Occasionally	Does not meet	Does not meet
BATHTIME	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MORNING ROUTINE (getting up, getting dressed, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
NIGHT TIME (getting ready for bed, going to bed, sleeping)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Caregiver Assessment/P. Campbell 6-2009REV/page 1 of 4
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MEALTIME (appetite, level of assistance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PLAYTIME (with family members, other caregivers, friends)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
STORYTIME (reading books with caregivers)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
OUTSIDE PLAY (riding a bike, playing outside, playing on playground equipment, swimming)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
AT HOME CHORES (cleaning, preparing meals, watching TV, caring for pets, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEAVING THE HOUSE TO GO SOMEWHERE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
TRAVEL TIME (in the car)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
RUNNING ERRANDS (grocery store, mall/store shopping, banking, wash/cleaners)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
COMMUNITY OUTINGS (visit a friend/relative, eat at a restaurant/fast food, go to museums, amusement parks, zoo, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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USE OF FUNCTIONAL SKILLS IN ROUTINES/ACTIVITIES	Always	Sometimes	Occasionally	Does not meet	Always	Sometimes	Occasionally	Does not meet	Does not meet
COOPERATION (e.g., interacting with peers and adults)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
COMMUNICATING with peers and adults	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
GETTING AROUND (mobility at home/community)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
USING HANDS & ARMS for functional tasks (e.g., range of motion, holding objects, manipulation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use blanks to add activities or routines not included in categories									
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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Based on your answers above, list the routines/activities that do not meet your expectations.

ROUTINE/ACTIVITY	What would you like to see happening? What would the child be doing? What would you or other family members be doing? What strategies have you tried?
1.	
2.	
3.	

Based on your answers above, list the routines/activities that are enjoyable for you and your child.

ROUTINE/ACTIVITY	
1.	
2.	
3.	

Additional Comments:

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Tips for Conducting the Interview

- Remember, it is a conversation
- You may need more than one session to gather all the information
- You may need to talk to more than one caregiver, particularly when young children are receiving care outside the home
- Be sure and get a rating of expectations and satisfaction, they are not the same concept!

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Keep it Simple: Steps for EI during Daily Routines and Activities

- Step 1
 - Help the child participate in daily routines and activities
- Step 2
 - If the child is already participating – embed learning opportunities in the daily routine!
- Step 3
 - Teach the caregiver how to do Step's 1 and 2!

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Step 1: Strategies to Increase Participation

- Have a conversation when observing the activity/routine
 - Hypothesize (“I wonder”)
 - Comment (“That went very smoothly, you put her in the car seat while you sang a song!”)
 - Reinforce (“That worked well, you knew just when Sara wanted to go outside.”)
- Model: Offer to help, ask if you could try something and talk about what you are doing)
- Coach: You and the caregiver take turns
- Problem-Solving: Discuss problems in the activity/routine and identify possible solutions to try
- Praise & Encourage!

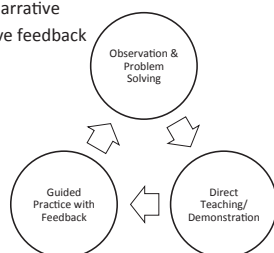
Step 2: When routines are going well – embed learning!

- Communication behavior and opportunities
 - Intentional communication
- Teach caregivers how to model (requests, comments, etc.)
- Teach caregivers about contingencies (if/then)
 - Increase timely responses
 - natural vs. unnatural consequences
 - Be sure to reinforce the behavior you want!
- Teach caregivers about consistency
 - Establish a set order in the activity/routine so children can anticipate what comes next
 - Consistent language for labels and action
 - Consistent responses to children's behavior
 - Consistent cues and prompts

Step 3: Teach caregivers

–Direct teaching

- Modeling with verbal narrative
- Coaching with corrective feedback
- Praising & Encouraging
- LISTEN



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TEAM approach!

- T:** Talk **to** the family not *at* them!
- E:** Everyone needs to be heard!
- A:** Assess what works for the whole family!
- M:** Monitor progress and keep it motivating!

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Thank you!!
Any questions?

