I-ACQUIRE Research Coordinator Parent Measures

Parent Measures

Standardized Parent Measures: Blinded Assessors can help with these

Pre, Post, 6 months

- Infant Motor Activity Log (IMAL)
- MacArthur Bates Communicative Development Inventories (CDI-III)
- Perceived Stress Scale-14 (PSS-14)

12 months

- Child Motor Activity log (C-MAL)
- LUI
- YC-PEM
- PSS-14

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Parent Measures- BAs cannot Help

Parent Experiences and Background:

Pre, Post-1, 6 month, 12 month

- Parent Report of Other Life and Treatment Stressors
- Parent Report of Therapy

Post Assessment

- Information Exchange (Parent and Therapist)

Post-2 (6month)

- Parent Survey- regarding parents experience of participation in a clinical trial
  - Completed at post-2 (6 month assessment)
  - Qualtrics survey- parent OR research coordinator to enter

12 Month

- Parent interview
- AC will coordinate with site coordinator

Parent Measure Packets

- Develop a binder separated by each time point
- Research coordinators will be responsible for mailing <u>all</u> PRE-test forms one to two weeks prior to scheduled assessment date
- If parents have questions they can ask the assessor:
    - For help with standardized measures (IMAL, C-MAL, PSS-14, CDI, LUI, YC-PEM)
    - <u>Cannot</u> assist with Parent Report of Other Life and Treatment Stressors, Parent Report of Therapy, or Information Exchange
- Research coordinators should advise and remind all parents to not discuss which randomization they have received.
- Research Coordinators will enter all these measures into WebDCU within 5 days of assessment visit.
- It is possible you will have to reach out to the parents if the forms are not completed to finish them over the phone.
- Communicate with the assessors and the parents to be sure you receive all the forms in a timely manner.

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Logistics for Research Coordinators

- You will need to:
  - Ensure that parents have returned **FIVE** forms at pre-test and at 6-month follow up assessment
    - (I-MAL, CDI-III, PSS-14, Parent Report of Other Stressors, and Parent Report of Therapy)
    - Also to complete parent survey via Qualtrics (at 6 months)
  - Ensure that parents have returned **SIX** forms at post-test 1.
    - (I-MAL, CDI-III, PSS-14, Parent Report of Other Stressors, Information Exchange, and Parent Report of Therapy)
  - Ensure parents have returned **SIX** forms at 12 month assessment
    - CMAL, PSS-14, Parent Report of Therapies, Parent Report of Stressors, YC-PEM, and LUI
    - Also, coordinate with AC for parent interview

Logistics for Research Coordinators

- Parents may:
    - Forget to bring their forms to the assessment.
        - This is OK and will happen. As the RC, you will need to make sure there have extra forms and envelopes with the child's ID on them for the families at each assessment.
    - Ask you questions about the forms.
        - You may help them with all of the measures and can assist them with filling them out.

- All data is entered into WebDCU by the Research Coordinator
- Data should be entered within 5 days of the assessment visit

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I-MAL

- Collected at pre-test, post-1 (after treatment), post-2 (6 month follow up)
  - Unilateral scales (15 questions)
  - Bilateral scales (5 questions)

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I-MAL : Adding and Imputing Scores

		0-Not used	1-Very rarely	2-Rarely	3-Sometimes	4-Often	5-Normal
Q01	How often does your child hold a bottle/cup	○	○	○	○	●	○
Q02	How often does your child pick up and hold a small item while sitting in a chair	○	○	○	●	○	○
Q03	How often does your child eat finger foods	○	○	○	○	●	○
Q04	How often does your child pick up an object out of arm's reach	○	○	○	●	○	○
Q05	How often does your child push a button	○	○	○	○	●	○
Q06	How often does your child open a door or cabinet	○	○	○	●	○	○
Q07	How often does your child take off shoes or socks	○	○	○	●	○	○
Q08	How often does your child pull a toy with a string	○	○	●	○	○	○
Q09	How often does your child turn a knob	○	○	●	○	○	○

		0-Not used	1-Very rarely	2-Rarely	3-Sometimes	4-Often	5-Normal
Q10	How often does your child pick up a cylindrical object *e.g., crayon, marker, bottle, cup, or rattle.*	○	○	○	●	○	○
Q11	How often does your child throw a ball or similar object	○	○	○	●	○	○
Q12	How often does your child hold an item while in standing position	○	○	●	○	○	○
Q13	How often does your child carry an item from place to place	○	○	○	●	○	○
Q14	How often does your child push into sitting position	○	●	○	○	○	○
Q15	How often does your child push arm through sleeve of clothing	○	○	●	○	○	○
Q16	Assessor calculated total unilateral how often score	42					
Q17	Total unilateral how often score *Derived by WebDCU.*						

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I-MAL

- Add all numbers up and place totals in 'Assessor calculated total unilateral/bilateral score'

Q16	Assessor calculated total unilateral how often score	42
Q17	Total unilateral how often score *Derived by WebDCU.*	

![I-ACQUIRE logo]

MacArthur Bates- CDI

- Collected at pre, post-1, post-2 (6 month)
- Three Forms
  - Infant (W & G) = up to 18 months
  - Toddler (W & S) = 19-29 months
  - CDI-III: (WS3)= 30- 37 months
- Download the app

https://mb-cdi.stanford.edu/scoringdb_p.htm
  - README2013.doc
  - DBINFO.doc
  - DO NOT DELETE ANY FILES (causes issues with printing score report)
- Trouble downloading? May need to work with your local IT

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MacArthur Bates Scoring

- Select Participants and Records
  - Select New Participant > Child ID > Name > DOB > Gender
- CDI Tab > Date of CDI > CDI Language> CDI Form (word & gestures, words and sentences OR WS3)
- Enter Data in the Inventory Tab
  - If you are unsure what the letter means, click 'View or Edit Item responses' and it'll provide a key
  - You can also input item by item
- Supplemental Data Tab (Only for Toddler & CDI-III)
  - Data must be hand entered
  - Use Dbinfo.doc for specifics

MacArthur Bates- CDI-III

- Printing Child Report Form for WebDCU data

MacArthur Bates-CDI

- Child Report
- Input all scores from this page into WebDCU

MacArthur-Bates Communicative Development Inventory
Words and Gestures
Child Report Form

Child's Name:		**Date of Report:**	9/23/2019
Id Number:	ARITT	**Date of CDI:**	9/18/2018
Gender:	M	**Date of Birth:**	3/13/2017
Parent/Guardian:	Ms.	**Age in months:**	18

Early Words

First Signs of Understanding — Percent of "yes" answers at this child's age

Responds when name is called:	Yes	99%
Responds to "no no":	Yes	99%
Responds to "there's mommy/daddy":	Yes	99%

Phrases Understood   Number: 18 (of 28)   Percentile: 20th

Starting to Talk — Percent of "yes" answers at this child's age

Imitation:	Yes	92%
Labeling:	Yes	77%

Vocabulary Checklist

Understands	Number:	353	(of 396)	Percentile:	95th
Understands & Says	Number:	132	(of 396)	Percentile:	83rd

Actions and Gestures

Early Gestures	Number:	17	(of 18)	Percentile:	55th
Later Gestures	Number:	33	(of 45)	Percentile:	55th
Total Gestures	Number:	50	(of 63)	Percentile:	70th

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MacArthur Bates- CDI

- WebDCU-
  - The ages of children on the forms overlap, therefore WebDCU produces two forms.
    - Infant (W & G) = up to 18 months
    - Toddler (W & S) = 19-29 months
    - CDI-III: (WS3)= 30- 37 months

  - Select "no data entered" for the form that does not apply

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C-MAL (Child Motor Activity Log)

- C-MAL
  - Collected only at the 12 month assessment
  - Unilateral (14 questions)
  - Bilateral (5 questions)

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C-MAL (Child Motor Activity Log)

Unilateral Activities	How Often	How Well	If "No" or "0" explain using appropriate codes
1. Hold a bottle or cup			
2. Eat finger foods (e.g. cookie, sandwich)			
3. Wave bye-bye or hello			
4. Push arm through sleeve of clothing			
5. Pick up a small item (e.g., cheerio, raisin, marble, small peg puzzle)			
6. Turn a page in a book			
7. Point to a picture in a book			
8. Reach for an object above head or to be picked up			
9. Push a button or key (e.g., toy			

10. Open a door or cabinet		
11. Take off shoes or socks		
12. Turn a knob (e.g., toy, door)		
13. Pick up a cylindrical object (e.g., crayon, marker, drumstick)		
14. Throw a ball or other object		

Bilateral Activities	How Often	How Well	If "No" or "0" explain using appropriate codes
1. Hugs person or toy			
2. Uses arm for transitioning			
3. Push large object (e.g., box, chair , stool)			
4. Hold a large ball			
5. Hold a handle on a riding, pulling, or push toy (e.g., tricycle, shopping cart, baby buggy)			

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YC-PEM

- Collected only at 12 months
- Parent Survey (20-30 minutes)
- Provides information about the child's participation among a variety of activities within the home, preschool/daycare, and community.
- 2 Parts
  - Part 1- Participation: asks about the child's participation in activities that take place at home, community and daycare/preschool
    - How often, How involved, Not very involved
    - Would you like your child's participation to change
  - Part 2- Environment: ask questions about the home, daycare/preschool, or community settings that help or make it more difficult to participate

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YC-PEM

SURVEY INSTRUCTIONS

The foundation for lifelong health begins during the first five years of your child's life. When young children ages 0-5 years participate in activities that take place at home, at daycare/preschool, and in the community, they can experience healthy living and learn new skills.

Young children often participate in activities with important people like you, their parent or primary caregiver. Since you spend a lot of time with your child, you know how often and how much your child participates in different activities. You also know what helps and what makes it harder for him or her to participate in different activities. We made this survey to help you record and share what you know and want to change about your child's participation with professionals who can help you reach your goals.

Please watch this short video to learn more about the YC-PEM. Click on the link: https://vimeo.com/534888823

This survey has 3 sections: home, daycare/preschool, and community. Each section has 2 key parts: 1) a part where we ask you about your child's participation in activities in that setting, and 2) a part where we ask you about the impact of the environment on your child's participation in that setting.

Part 1 – Participation. We begin each section of the survey by asking you about your child's participation in types of activities that take place at home (13), daycare/preschool (3), or in the community (11). We give a few examples of each type of activity, but you should think about all of the activities in each category that apply to your child when answering these questions. For each type of activity, we ask you to evaluate your child's participation in three ways:

1. How often has your child participated in this type of activity over the last 4 months?
2. How involved is your child when participating in 1 or 2 activities of this type that he or she does most often?
   • **Very involved** = your child is actively engaged most of the time. He or she interacts and/or is helpful during most of the activity.
   • **Somewhat involved** = your child is actively engaged some of the time. He or she interacts and/or is helpful for some of the activity.
   • **Not very involved** = your child is seldom engaged in the activity. He or she rarely interacts or helps out very little during the activity.
3. Would you like your child's participation to change, and if so, how you would like for it to change?

IMPORTANT: Involvement means active engagement in activities no matter how much assistance or adaptation is used. When selecting your response, think about how interested your child is in the activity and how interactive and/or helpful he or she is during the activity.

Part 2 – Environment. After answering questions about your child's participation in different activities, we ask you if things about the home, daycare/preschool, or community setting help or make it harder for your child to participate in activities.

PLEASE NOTE: If there are things that you have done or are doing now to help your child to participate, you can describe them in this survey. These questions about strategies will appear as you move through the first part of each section and answer questions about your child's participation and also at the end of each section after you answer questions about your child's environment.

HOME PARTICIPATION

A **Basic Care Routines:** This type of activity involves parts of an established daily or weekly routine that are essential to the child's basic health and well-being.

	A. Typically, how often does your child participate in this type of basic care routine? CHECK ONE RESPONSE ☑								B. Think about 1 or 2 activities of this type that your child does most often. Typically, how involved is your child when doing this type of basic care routine? CHECK ONE RESPONSE ☑			C. Would you like your child's participation to change in this type of basic care routine? IF YES, CHECK ALL THAT APPLY ☑					
	Never (skip to Question C)	Once in the last four months	Few times in the last four months	Once in the last month	Few times in the last month	Once each week	Few times each week	Once or more each day	Not very involved	Somewhat involved	Very involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more interactive	Yes, be more helpful	Yes, participate in a broader variety of activities
A1. Getting rest (e.g., routines for bedtime, nap time)																	
A2. Personal care management (e.g., getting dressed, brushing teeth or hair, using toilet/ diaper change)																	
A3. Getting clean (e.g., wash or wipe hands and face, taking a bath)																	
A4. Mealtime (e.g., breakfast, lunch, dinner, snack times)																	

If you selected **YES to Question C**, please describe up to three strategies that you have tried to help your child participate successfully in this type of activity. If you responded 'no change desired' to all of the questions above, please proceed to the next page.

1. _____

_____

2. _____

_____

3. _____

_____

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HOME ENVIRONMENT

Do the following things in your home environment help or make it harder for your child to participate in these activities at home?

	No impact	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout (having organized, open, clean, safe space at home)				
2. Sensory qualities of home (e.g., amount and/or type of sound, light, smell, temperature, texture of objects)				
3. The physical demands of typical activities (e.g., strength, endurance, coordination)				
4. The cognitive demands of typical activities (e.g., concentration, attention, problem-solving)				
5. The social demands of typical activities (e.g., communication, interacting with others)				
6. Your child's relationships with family members in the home (e.g., spouse or partner, siblings, grandparent, extended family)				
7. The attitudes and actions of babysitters, therapists, and other professionals who care for your child at home				
8. Policies (residential and workplace policies, such as family leave or working from home, time off, work hours)				

Are the following available and/or adequate to support your child's participation at home?

	Not needed	Usually, yes	Sometimes yes; sometimes no	Usually, no
9. Services in the home (e.g., therapists, babysitters, etc.)				
10. Supplies in the home (e.g., having toys, food, furniture, diapers, clothes, money, television, computer, phone, heat, electricity, internet access)	N/A			
11. Information (e.g., about activities, services, programs)	N/A			
12. Do you (and your family) have enough time to support your child's participation at home?	N/A			
13. Do you (and your family) have enough money to support your child's participation at home?	N/A			

What are some things that you or other family members do that help your child participate successfully in activities at home? PLEASE LIST UP TO 3 STRATEGIES.

1. _____

_____

2. _____

_____

3. _____

_____

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DAYCARE/PRESCHOOL PARTICIPATION

A **Educational Programming:** This type of activity involves planned activities within an organized early childhood education program or preschool that helps the child learn new skills.

	A. Typically, how often does your child participate in this type of educational activity? CHECK ONE RESPONSE ☑								B. Think about 1 or 2 activities of this type that your child does most often. Typically, how involved is your child when doing this type of educational activity? CHECK ONE RESPONSE ☑			C. Would you like your child's participation to change in this type of educational activity? IF YES, CHECK ALL THAT APPLY ☑					
	Never (skip to Question C)	Once in the last four months	Few times in the last four months	Once in the last month	Few times in the last month	Once each week	Few times each week	Once or more each day	Not very involved	Somewhat involved	Very involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more interactive	Yes, be more helpful	Yes, participate in a broader variety of activities
A1. Group learning (e.g., circle time, story time, music and movement, art projects)																	
A2. Socializing with friends (e.g., mealtime, snack time, outdoor play)																	
A3. Field trips and events (e.g., parent night out, going to the library, school concert or fundraiser)																	

If you selected **YES to Question C**, please describe up to three strategies that you have tried to help your child participate successfully in this type of activity. If you responded 'no change desired' to all of the questions above, please proceed to the next page.

DAYCARE/PRESCHOOL ENVIRONMENT

Do the following things in the organized daycare/preschool environment help or make it harder for your child to participate in activities?

	No impact	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout (having organized, open, clean, safe space in the classroom; having ramps, stairs and elevators in the school building)				
2. Sensory qualities of the organized daycare or preschool (e.g., amount and/or type of sound, light, smell, temperature, texture of objects)				
3. Outside weather conditions (e.g., temperature, climate)				
4. The physical demands of typical activities (e.g., strength, endurance, coordination)				
5. The cognitive demands of typical activities (e.g., concentration, attention, problem-solving)				
6. The social demands of typical activities (e.g., communication, interacting with others)				
7. Your child's relationships with peers				
8. The attitudes and actions of directors, teachers, therapists, and other staff who care for your child at daycare or preschool				

Are the following available and/or adequate to support your child's participation at organized daycare/preschool?

	Not needed	Usually, yes	Sometimes yes, sometimes no	Usually no
9. School-related policies and procedures (e.g., enrollment and attendance policies; check-in procedures and incident reporting to ensure safety; rules for behavior)				
10. Access to personal transportation to get to daycare/preschool (e.g., personal car)				
11. Access to public transportation to get to daycare/preschool (e.g., bus, train, subway)				
12. Programs and services at the organized daycare or preschool (e.g., educational assistant, special resources, etc.)				
13. Supplies (e.g., assistive devices, adapted toys, craft supplies, organic food choices, modular furniture, accessible bathrooms, classrooms and playgrounds, access to internet and technology to support learning)	N/A			
14. Information (e.g., about activities, services, programs)	N/A			
15. Do you (and your family) have enough time to support your child's participation at daycare/preschool (e.g., transporting your child, preparing for the school day, keeping current about your child's learning at school)?	N/A			
16. Do you (and your family) have enough money to support your child's participation at daycare or preschool (e.g., paying tuition, purchasing supplies, participating in fundraisers)?	N/A			

What are some things that help your child participate successfully in activities at organized daycare/preschool? PLEASE LIST UP TO 3 STRATEGIES.

![i-ACQUIRE logo]
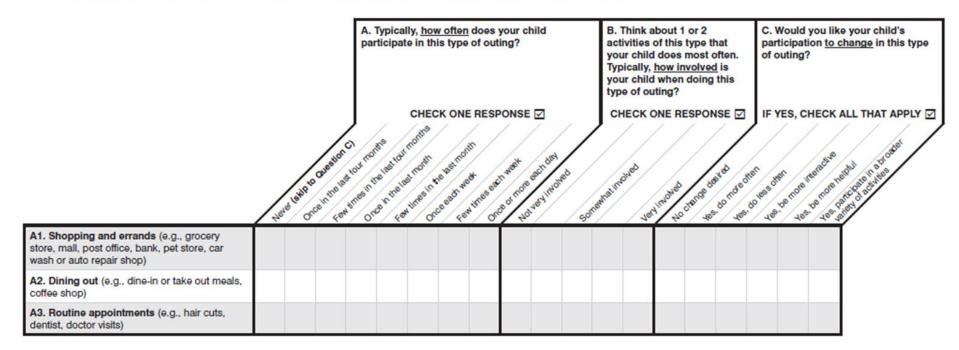
COMMUNITY PARTICIPATION

A **Neighborhood and Community Outings:** This type of activity involves a child joining family members in accessing their local neighborhood or larger community to gather goods and necessities or to meet basic needs for maintaining self or household.

A. Typically, how often does your child participate in this type of outing?

CHECK ONE RESPONSE ☑

B. Think about 1 or 2 activities of this type that your child does most often. Typically, how involved is your child when doing this type of outing?

CHECK ONE RESPONSE ☑

C. Would you like your child's participation to change in this type of outing?

IF YES, CHECK ALL THAT APPLY ☑

	Never (skip to Question C)	Once in the last four months	Few times in the last four months	Once in the last month	Few times in the last month	Once each week	Few times each week	Once or more each day	Not very involved	Somewhat involved	Very involved	No change desired	Yes, do more often	Yes, do less often	Yes, be more interactive	Yes, be more helpful	Yes, participate in a broader variety of activities
A1. Shopping and errands (e.g., grocery store, mall, post office, bank, pet store, car wash or auto repair shop)																	
A2. Dining out (e.g., dine-in or take out meals, coffee shop)																	
A3. Routine appointments (e.g., hair cuts, dentist, doctor visits)																	

If you selected **YES to Question C**, please describe up to three strategies that you have tried to help your child participate successfully in this type of activity. If you responded 'no change desired' to all of the questions above, please proceed to the next page.

1. _____

_____

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COMMUNITY ENVIRONMENT

Do the following things in your community environment help or make it harder for your child to participate in these activities in the community?

	No impact	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. **Physical layout or amount of space outside and inside the buildings** (e.g. distance to stores, presence of sidewalks, availability of ramps or elevators)				
2. **Sensory qualities of community settings** (e.g., noise, crowds, / temperature, lighting)				
3. **The physical demands of typical activities** (e.g., strength, endurance, coordination)				
4. **The cognitive demands of typical activities** (e.g., concentration, attention, problem-solving)				
5. **The social demands of typical activities** (e.g., communication, interacting with others)				
6. **The attitudes and actions of other members of the community towards your child** (e.g., staff at stores and restaurants, instructors, coaches, child care provider, other families)				
7. **Your child's relationships with peers**				
8. **Outside weather conditions** (e.g., temperature, climate)				
9. **The safety of the community** (e.g., traffic, crime, violence)				
10. **Policies** (e.g., neighborhood, childcare, and employer policies)				

Are the following available and/or adequate to support your child's participation in the community?

	Not needed	Usually, yes	Sometimes yes, sometimes no	Usually, no
11. **Access to personal transportation** to access community activities (e.g., car, bike)				
12. **Access to public transportation** to access community activities (e.g., bus, subway)				
13. **Programs and services** in the community				
14. **Equipment or supplies** (diaper bag (food, toys, diapers, clothes), assistive technology)	N/A			
15. **Information** (e.g., about activities, services, programs)	N/A			
16. **Do you (and your family) have enough time** to support your child's participation in the community (e.g., how schedule looks after considering work schedule(s) and activity schedules of other family members)	N/A			
17. **Do you (and your family) have enough money** to support your child's participation in the community?	N/A			

What are some things that help your child participate successfully in activities in the community? PLEASE LIST UP TO 3 STRATEGIES.

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Language Use Inventory

- AKA- "LUI"
- 12 month assessment only
- Replaces the Mac Arthur Bates
- There's only one form for parents to complete
- It can be completed online OR a hard copy
- Need to set up an account
  - https://languageuseinventory.com/Login
- Online version
  - Send a link to parents OR complete at assessment via tablet
  - Link expires 48 hours after it has been sent
  - The program will calculate all raw scores and generate a score report form automatically
- Hard Copy
  - You will need to calculate raw scores and enter into the program

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Child's Raw Scores and Corresponding Percentile Scores Per Subscale and Part:

Part 1: How your child communicates with gestures - OPTIONAL		raw score	percentile
Subscale A: How your child uses gestures to ask for something	Total score out of 11	11	-
Subscale B: How your child uses gestures to get you to notice something	Total score out of 2	2	-
	Total score out of 13	**13**	**99**

Part 2: Your child's communication with words		raw score	percentile
Subscale C: Types of words your child uses	Total score out of 21	19	80
Subscale D: Your child's request for help	Total score out of 7	6	76
	Total score out of 28	**25**	**76**

Part 3: Your child's longer sentences		raw score	percentile
Subscale F: How your child uses words to get you to notice something	Total score out of 6	5	97
Subscale G: Your child's questions and comments about things	Total score out of 9	6	83
Subscale H: Your child's questions and comments about self and others	Total score out of 36	22	91
Subscale H1: Total score out of 14 "About Self" items (odd items 1, 3, 5 to 23; items 26, 27)	Total score out of 14	11	97
Subscale H2: Total score out of 18 "About Others" items (even items 2, 4, 6 to 24; item 25; items 28 to 32)	Total score out of 18	7	78
Subscale I: Your child's use of words in activities with others	Total score out of 14	11	97
Subscale J: Teasing and your child's sense of humour	Total score out of 5	1	61
Subscale K: Your child's interest in words and language	Total score out of 12	6	77
Subscale M: How your child adapts conversation to other people	Total score out of 15	7	82
Subscale N: How your child is building longer sentences and stories	Total score out of 36	6	62
	Total score out of 133	**64**	**83**

Total Score for Parts 2 & 3	raw score	percentile
PART 2: Total summed score out of 28	25	76
PART 3: Total summed score out of 133	64	83
LUI TOTAL SCORE: (sum of Parts 2 and 3 out of 161):	**89**	**83**

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Other Parent Measures

- <u>Perceived Stress Scale</u>
  - Pre-Test, Post-Test 1 (after treatment), post-2 (6 month), 12 month
- <u>Parent Report of Other Life and Treatment Stressors</u>
  - Completed at Pre-, Post, 1, Post-2, 12 month
- <u>Parent Report of Therapy</u>
  - Pre-Test, Post-Test 1 (after treatment), post-2 (6 month), and 12 month
  - Those in the treatment arm, select I-ACQUIRE
- <u>Information Exchange Parent AND Therapist</u>
  - Post-1 ONLY
  - Two separate forms completed by parent AND therapist
  - UCC Group-
    - Therapists are not completing this form, select "no data collected"
    - Parents are completing, you are to enter their data
- <u>Parent Survey</u>
  - ONLY at Post-2 (6 month assessment)
- <u>Parent Interview</u> (Only at 12 month assessment) - NEW

	PRE	POST-1	POST-2 (6 months)	12 months
I-MAL	X	X	X	
Mac Arthur Bates CDI	X	X	X	
PSS-14	X	X	X	X
Parent Report of Other Life and Treatment Stressors	X	X	X	X
Parent Report of Therapy	X	X	X	X
Information Exchange (Parent and Therapist)		X		
C-MAL				X
LUI				X
YC-PEM				X
Parent Survey			X	
Parent Interview				X

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