

Empowering families in decision making during parent training: Developing an accessible intake form for Parent Home Training that emphasizes strengths and family goals.

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NM LEND FELLOW, 2021-22

About This Project

Families of individuals who are diagnosed with Autism Spectrum Disorder through clinics at UNM CDD gain access to Parent Home Training – a program of 6 hour-long sessions, designed to “meet families where they are at” when their child first receives a medical diagnosis of ASD.

This LEND capstone is designed to:

- Provide a suggested prototype intake form for future families engaging with the PHT program for the first time;
- Examine the current intake process for Parent Home Training to facilitate a good balance between family centered and evidence based interventions;

LEND Competencies:

- 1. Family-centered/culturally competent practice
- 2. Interdisciplinary practice
- 5. Research and critical thinking.

Current Intake Process for PHT

Eligibility – child receives diagnosis of ASD through UNM CDD evaluation clinics or an independent clinical psychologist; child should be a NM resident under 6 years of age.

Family is referred to UNM CDD for Parent Home Training Program.

Family receives application package via mail or email:

- Application form – Demographic information, information about current concerns related to autism, other factors
- Consent to treat form
- Rights and Responsibilities form

Family added to waitlist for PHT following CDD receiving completed application.

Family assigned to PHT provider – first contact made via phone/email to schedule first visit.

First PHT visit completed.

Current Form

First page contains open and closed questions regarding:

- First point of contact with PHT program
- Family History related to languages spoken in the home, people who live in the home, regular caregivers, information about current stressors, and family history of developmental and health issues.



For use by CDD staff only:

Referral Date:

Autism Client #:

Intake Date:

Child's Name:

How did you hear about the Parent Home Training Program?

Where and when was your child diagnosed with an autism spectrum disorder?

Family History

What languages are used in your child's home?

Who lives in your child's home?

Does anyone else regularly provide care for your child?

Has your child recently been impacted by any major family changes?

Adoption	Y <input type="checkbox"/> N <input type="checkbox"/>	Moving	Y <input type="checkbox"/> N <input type="checkbox"/>
Serious Illnesses	Y <input type="checkbox"/> N <input type="checkbox"/>	Domestic Violence	Y <input type="checkbox"/> N <input type="checkbox"/>
Foster Care	Y <input type="checkbox"/> N <input type="checkbox"/>	Divorce	Y <input type="checkbox"/> N <input type="checkbox"/>
Remarriage	Y <input type="checkbox"/> N <input type="checkbox"/>	Substance Abuse	Y <input type="checkbox"/> N <input type="checkbox"/>

Does anyone in the child's immediate family have any developmental problems?

Does anyone in the child's immediate family have any mental health or psychiatric issues?

Current Form

Second page contains open questions regarding:

- Current educational/therapy services
- Current concerns the family has for their child related to communication, challenging behavior, play, and sensory differences.

Education

Does your child currently receive educational/therapeutic services from and of the following?

An early intervention program Y N A school program Y N

If so, what services does your child receive and how often does he/she receive them?

Current Concerns

Do you have any concerns about your child's communication? How does your child currently communicate with you?

Do you have any concerns about your child's behavior? If so, what are your concerns?

How does your child play and get along with others?

Does your child display any sensory concerns? Does your child seem over or under responsive to certain stimuli?

Current Form

Third page contains open questions regarding:

- Progress with toilet training
- Any other concerns.

Have you started toilet training yet?

Are there any other concerns that you would like to share?

Current Form

Final page contains open and closed questions regarding current medical concerns, and gives instructions regarding form submission.

Medical Concerns

Does your child have any medical diagnoses other than an autism spectrum disorder?

Is your child currently on medication? (If so please list with milligrams)

Has your child ever had any of the following?

- | | | | |
|------------------|---|-----------------------|---|
| Hospitalization | Y <input type="checkbox"/> N <input type="checkbox"/> | Seizures | Y <input type="checkbox"/> N <input type="checkbox"/> |
| Allergies | Y <input type="checkbox"/> N <input type="checkbox"/> | Significant Illnesses | Y <input type="checkbox"/> N <input type="checkbox"/> |
| Injuries | Y <input type="checkbox"/> N <input type="checkbox"/> | Vision problems | Y <input type="checkbox"/> N <input type="checkbox"/> |
| Hearing problems | Y <input type="checkbox"/> N <input type="checkbox"/> | Sleeping problems | Y <input type="checkbox"/> N <input type="checkbox"/> |
| Eating problems | Y <input type="checkbox"/> N <input type="checkbox"/> | | |

Please describe any items marked "Yes" below:

PLEASE INCLUDE ANY ON HAND/AVAILABLE COPIES OF YOUR CHILD'S IFSP'S OR IEP'S AND ANY OTHER MEDICAL, SCHOOL OR THERAPY REPORTS

Please send or scan and email your completed application to:
University of New Mexico HSC
The Autism Programs Center for Development and Disabilities' Division
Parent Home Training Program
2300 Menaul NE
Albuquerque, New Mexico 87107

Your family will be placed on the waiting list as soon as we receive your application, so please do not delay.

If you have any questions about this application or this program, please contact Sylvia Acosta 505-272-4725 or SyAcosta@salud.unm.edu

Family Feedback, re: Current Form

Brief interviews with current families completed during Parent Home Training Sessions; families based across New Mexico, various demographics.

No IRB Process required – no identifying information published.

Families identified that the current form was:

- relatively helpful in addressing current *challenges*,
- Somewhat easy to fill out,
- but less emphasis was given to current *successes* and hopes for the future.

Pertinent comments:

- “I would have liked more chance to talk about my hopes for the future.”
- “The form is quite negative, and it makes me think more about what is hard right now”
- “I didn’t feel like the form allowed me to talk about what is going well”
- “I would like more space to talk about more complex history”

Provider Feedback

Regarding the *form*, providers identified that:

- Form should lead and end on optimistic note – “positive vibes”
- Form should focus on brief information – more detailed information can be gathered during the first visit.
- The form should contain language at an appropriate literacy level for all families
- The form should briefly describe the scope of the PHT program

The Problem

Questions related to autism are focused on current **concerns**; limited opportunity for families to focus on current **strengths** and **goals/aspirations**.

Reading level of current form is beyond 3rd-5th grade, and response level required to complete form may dissuade families from engaging with the program and/or providing useful information for PHT providers.

Review of current literature

Family-Centered Care (FCC) – Measure of Processes of Care (MPOC-20)

- Items relevant to this study:
 - *Enabling and Partnership*
 - *Respectful and Supportive Care*
 - Providing General Information
 - Providing Specific Information
 - Showing *Interpersonal Sensitivity*
 - Treating People *Respectfully*

MPOC-20: Measure of Processes of Care (20 item version; King, Rosenbaum & King, 1998).

MPOC-SP: Measure of Processes of Care (Service Provider version; Woodside, Rosenbaum, King & King, 1998).

Implications on this project: Form should enable families to access PHT as a *partner* in their learning; families should be given space to discuss goals and aspirations, and these be given at least as much emphasis as current challenges.

Review of current literature

Steiner (2010)

- Compared interventions focused on deficits vs interventions focused on strengths
- Found that strengths-based interventions:
 - Improve parent affect;
 - Increase positive statements made by parent about their child;
 - Help parents to display more physical affection towards their child.
- *Implications on this project:* strengths-based approaches to intervention increase positive reactions from parents with regards to their children, and may also increase caregiver engagement with the intervention/program.

Review of current literature

Baker et al (1996)

- Patients with lower literacy levels experience difficulties accessing healthcare:
 - Understanding forms;
 - Understanding instructions from providers;
 - Understanding recommended treatments.
- Patients may feel embarrassed about their literacy level: feelings of embarrassment have a negative effect on engagement in healthcare programs, and patients may decide not to access programs if they are unable to understand healthcare literature.
- *Implications on this project:* ensuring the form is at a correct reading level is critical to maximizing the number of families who engage in the program.

Review of current literature

Eltorai et al (2014)

As part of an study into whether or not information published by the American Association for Surgery of Trauma (AAST) used recognized reading level standards for consumer oriented medical literature, this study established that the American Medical Association (AMA) and the National Institutes of Health (NIH) both recommend readability of patient materials not to exceed a **sixth grade** reading level.

Implications on this project: to aim between a 3rd-5th grade reading level for the redeveloped form to maximize accessibility.

Flesch-Kincaid Grade Level Formula: $0.39 \left(\frac{\text{total words}}{\text{total sentences}} \right) + 11.8 \left(\frac{\text{total syllables}}{\text{total words}} \right) - 15.59$

The Product

A form for the Parent Home Training program that enquires about families' hopes for their experience of the program as opposed to being problem-focused. The new form will help families to identify quickly areas in which they would like to receive support, and will guide PHT providers to plan bespoke PHT programming for families more efficiently.

Proposed Form

First page:

Brief explanation of PHT

“Current Interests” questions directly related to current family wants and needs;

- “Sandwich” approach, emphasizing positive aspects either side of potentially more difficult topics.
- Check boxes to guide families towards answers more pertinent to the PHT service offering; dual purpose, also indirectly shows families what topics we typically discuss during PHT.

For use by CDD staff only:

Referral Date: _____

Autism Client #: _____

Intake Date: _____

**Parent Home Training
Family Intake Form**

Parent Home Training (PHT) is a 6-session program for families who want to learn about how to support their child with Autism. Families can attend the program in-person or via telehealth (Zoom). PHT families should:

- Live in New Mexico;
- Have a child who has a diagnosis of Autism Spectrum Disorder;
- The child should be under 6 years of age.

Child's Name: _____ Language(s): _____

Current Interests:

What do you hope to learn from PHT?:

What does your child enjoy, and what is important to your family?

What works well for your family right now? (Check all that apply)

- Toileting Sleep/bedtime Eating
 Transitions Play Communication
 Community Understanding challenging behaviors
 Daily living activities (e.g. bathing, teeth brushing, etc).

Other: _____

Proposed Form

Second Page:

Continuation of “Current Interests” questions, concluded with question about long-term aspirations.

Family History

- Language simplified to increase access to form, e.g., “...right now”, instead of “...currently”, shorter, less wordy sentences.

What is challenging for you and your child right now? (Check all that apply):

- Toileting
- Sleep/bedtime
- Eating
- Transitions
- Play
- Communication
- Community
- Understanding their challenging behaviors
- Daily living activities (e.g. bathing, teeth brushing, etc).

Other: _____

What are your long-term hopes for your child and your family?

Family History

Who lives in your child's home?

Does anyone else provide care for your child often?

Has your child had any major family changes recently?

Adoption	Y	N	Moving	Y	N
Serious illnesses	Y	N	Domestic Violence	Y	N
Foster Care	Y	N	Divorce	Y	N
Remarriage	Y	N	Substance Abuse	Y	N

Does anyone in your child's immediate family have any developmental disabilities?

Does anyone in your child's immediate family have any mental health issues?

Proposed Form

Third Page:

Changed heading “Educational” to “Current Services”;

- More representative of what the question asks

Continued simplification of language

- In original form, many questions stated “If so.”; “If yes...” statements increase clarity.



Current Services

Does your child receive educational or therapy services?

Early intervention program Y N School program Y N

If “yes”, what services does your child receive and how often do they receive them?

Medical Concerns

Does your child have any other medical diagnoses? If “yes”, please list.

Does your child take any medication? If “yes”, please list.

Has your child ever had any of the following?

Hospitalization	Y	N	Seizures	Y	N
Allergies	Y	N	Significant illness	Y	N
Injuries	Y	N	Vision problems	Y	N
Hearing problems	Y	N	<u>Sleeping problems</u>	Y	N
Eating problems	Y	N			

Please describe any “Yes” answers below:

Please send or scan and email your completed application to:

University of New Mexico HSC
The Autism Programs Center for Development and Disabilities’ Division
Parent Home Training Program
2300 ~~Manuel~~ Blvd. NE
Albuquerque, New Mexico 87107

Please send this application back as soon as possible so we can add your family to the waitlist for Parent Home Training.

If you have any questions, please contact Dr. Sylvia Acosta:

~~Phone:~~ (505) 272-4725; Email: SyAcosta@salud.unm.edu

Summary of alterations

Added description of Parent Home Training program on first page

- Clearly describes what the program is, and who is eligible.

Used Flesch Kincaid Grade Level assessment to ensure reading level *did not exceed* 5th Grade reading level

- Aimed for 3rd Grade or below *where possible*.

Underlined pertinent words and phrases to highlight the topic of each question.

Changed the order of the form to engage families in questions about personal aspirations more quickly.

“Positive” Question Reformulation

New question	Rationale
“What do you hope to learn from PHT?”	Allows the family to discuss ideal outcomes of attendance with the program.
“What does your child enjoy?”	Allows the family to acknowledge positive aspects of their relationship with their child.
“What is important to your family?”	Allows the family to discuss their values.
“What works well for your family right now?”	Allows the family to acknowledge current successes.
“What is challenging for you and your child right now?”	Allows the family to outline current challenging areas; potential goals for PHT.
“What are your long-term hopes for your child and your family?”	Allows the family to discuss aspirations beyond PHT.

Information Dissemination

Dissemination completed to date:

Brief feedback interviews with families in PHT, comparing initial form to re-developed form.

- Most common themes:
 - Families like that the new form is shorter, with less writing required to complete it;
 - Families like the new emphasis on strengths and aspirations;
 - Families like that the form gives an indication of areas covered by the program and allows them to select areas of interest specific to them.

Proposed future actions

Continue consultation with PHT stakeholders (families, providers) to establish potential areas of improvement in form and intake process to remove redundancy;

Consult with bilingual providers to develop a Spanish-language version of the new form;

Establish a standardized format for sending the new intake form (i.e., email, mail, HIPAA-compliant online form client)

References

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Steiner, A. M. (2010). A Strength-Based Approach to Parent Education for Children With Autism. *Journal of Positive Behavior Interventions*, *13*(3), 178–190. <https://doi.org/10.1177/1098300710384134>

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