

Exploring Parental Perceptions and Satisfaction with Partnership in a Participation-Based Intervention for Autistic Children

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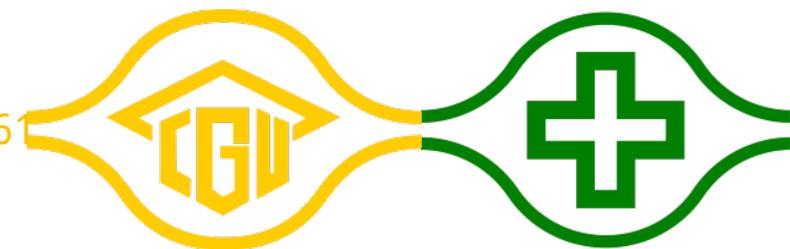
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Needs for interventions to support parents

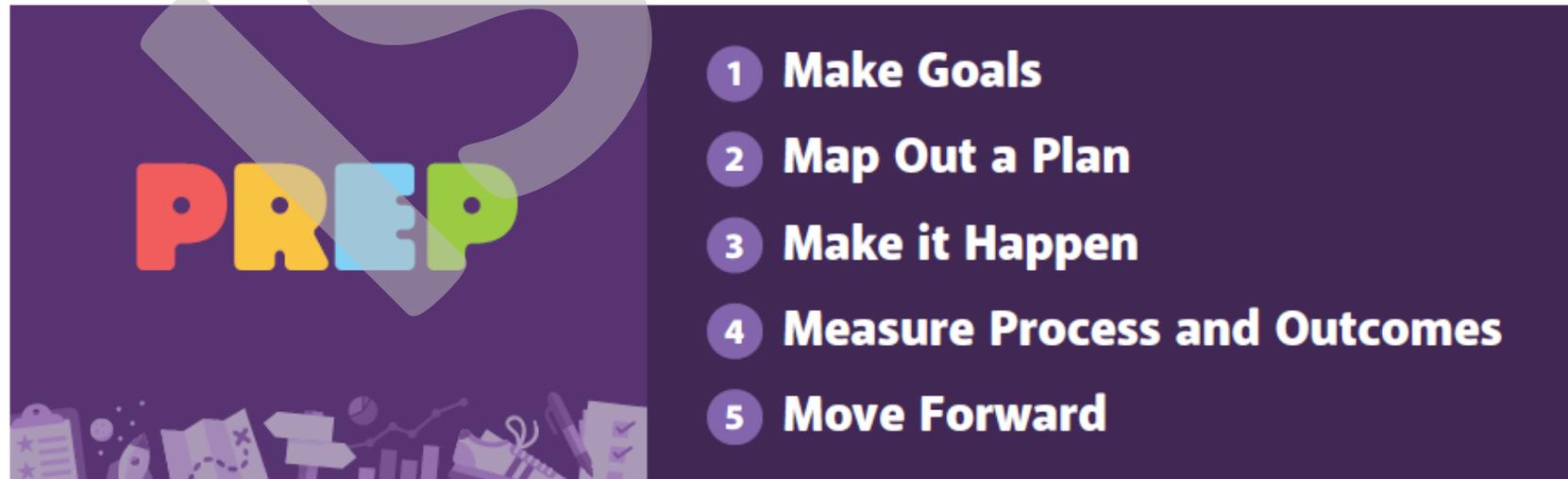
- Parents of autistic children act as **advocates** and **facilitators** to plan, adapt, and coordinate services (Simpson & Adams, 2023).
- **Psychological burden** on parents, such as negative emotions, parenting stress, and feelings of helplessness (Osborne et al., 2008).
- Intervention approaches that support the parents to navigate complex environments for their children
 - organize family routines and structure, obtain external resources, and personalize to address the child's needs
 - potentially beneficial to improve parental quality of life and foster meaningful participation (Fante et al., 2024).

Pathways and Resources for Engagement and Participation (PREP)

- A strength-based and environment-focused intervention
- PREP supports participation through changing the activity demands and environment (Anaby et al., 2018)

What Steps are Involved in PREP?

“Let the child participate as he/she is.”



The image shows a graphic with the PREP logo on the left and a list of five steps on the right. The logo consists of the letters P, R, E, and P in red, yellow, light blue, and green respectively. The steps are numbered 1 through 5, each in a white circle. The background is dark purple with a faint illustration of school supplies at the bottom.

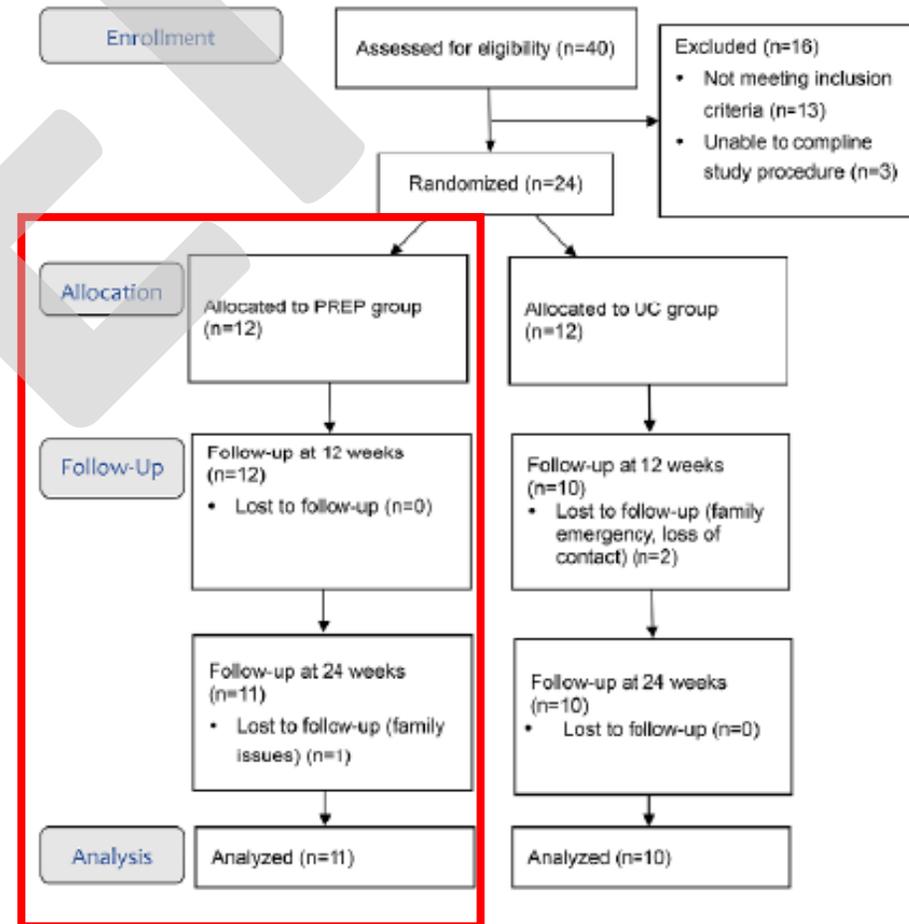
- 1 **Make Goals**
- 2 **Map Out a Plan**
- 3 **Make it Happen**
- 4 **Measure Process and Outcomes**
- 5 **Move Forward**

Initial evaluation of the environment-based intervention in autistic children (Kang et al., 2024)

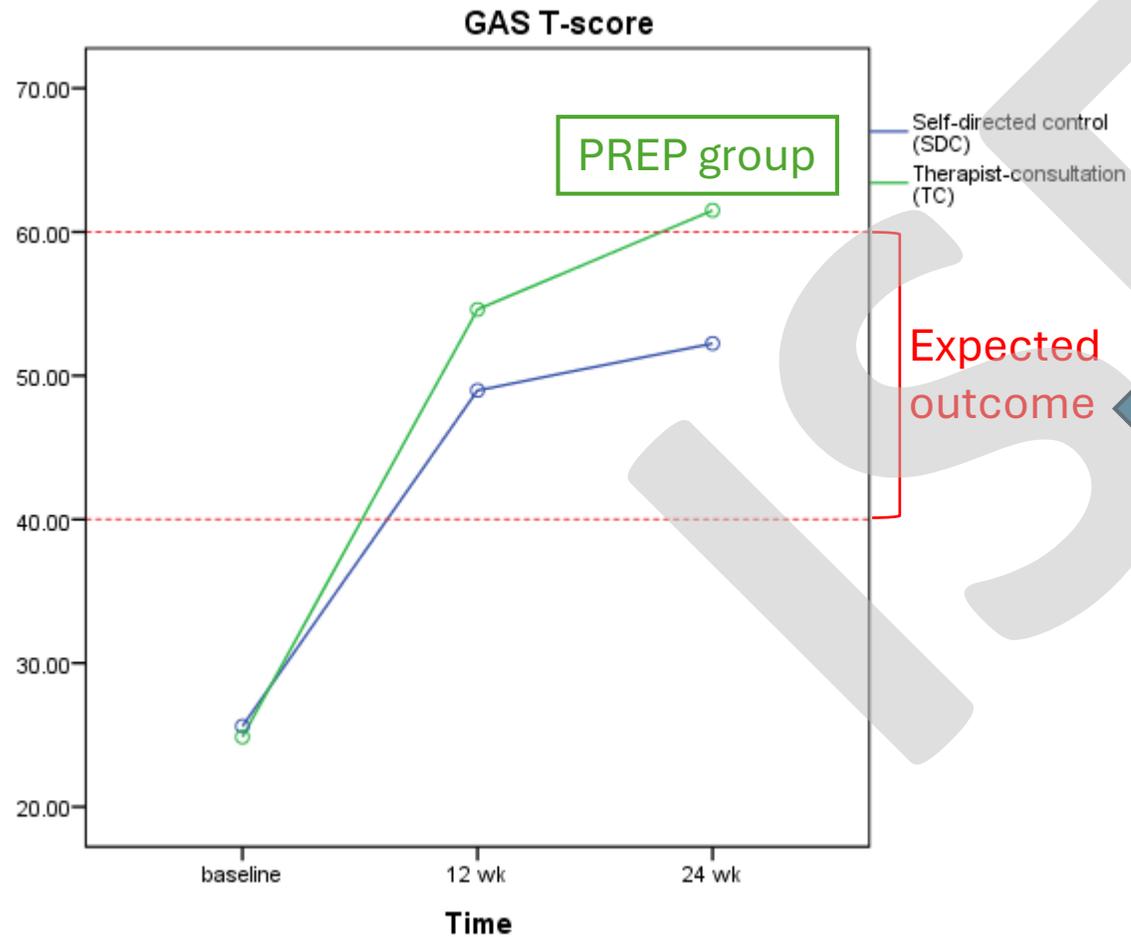
- A randomized controlled trial (RCT) was conducted to evaluate the efficacy of the PREP compared to a goal-setting comparison condition
- 11 autistic children 6-10 years old and their parents in the PREP group

Self-chosen participation goals:

- Socializing activities (6)
- Outings or travelling (6)
- Active physical recreation (5)
- Quiet recreation (4)
- Shopping or money management (4)
- Cultural or religious activities (3)



Initial evaluation of the environment-based intervention in autistic children (Kang et al., 2024)



Parent-reported outcomes indicated improvements in their child's performance and satisfaction with self-chosen participation goals, as well as in goal attainment following the PREP intervention.

Parental perceptions underlying the score changes warrant further investigation.

Aims

This study presents subsequent **qualitative and quantitative analyses** following the original RCT study (Kang et al., 2024).

Primary aim: to investigate the **parents' experiences and perceptions** regarding the intervention process

Secondary aim: to investigate the **parents' satisfaction with the partnership with the therapists** during the intervention

Methods

Institutional Review Board of Chang Gung Medical Foundation (No. 201800429A3)
ClinicalTrials.gov (No. NCT03721913)

- Children aged 6–10 years with a clinical diagnosis of Autism (DSM-V criteria)
 - an intelligence quotient (IQ) of 70
 - communicate verbally, in writing/typing, or with AAC
- Eleven parents of autistic children participated in the PREP group.
 - Mean age=7.7 (SD=1.7); 9 boys; all in mainstream classes + 8 also attended resource classes; all received other regular therapies
- 12-week intervention: Six biweekly family-therapist sessions
 - Intervention guided by the PREP
 - Each session lasts around 2 hours

Intervention protocols guided by the PREP

(Anaby et al., 2018)

Set baseline participation goals with children & parents

Identify and evaluate goal-specific environmental barriers/facilitators to be changed

Consider the child's behavioral characteristics or personal factors, but not target for change

Form strategies jointly with the parents to provide social and environmental supports

e.g., family or peer supports, community programs & resources

Coach the parents to implement the strategies, monitor and evaluate outcomes

Environment-based strategies for autistic children (Kang et al., 2024)

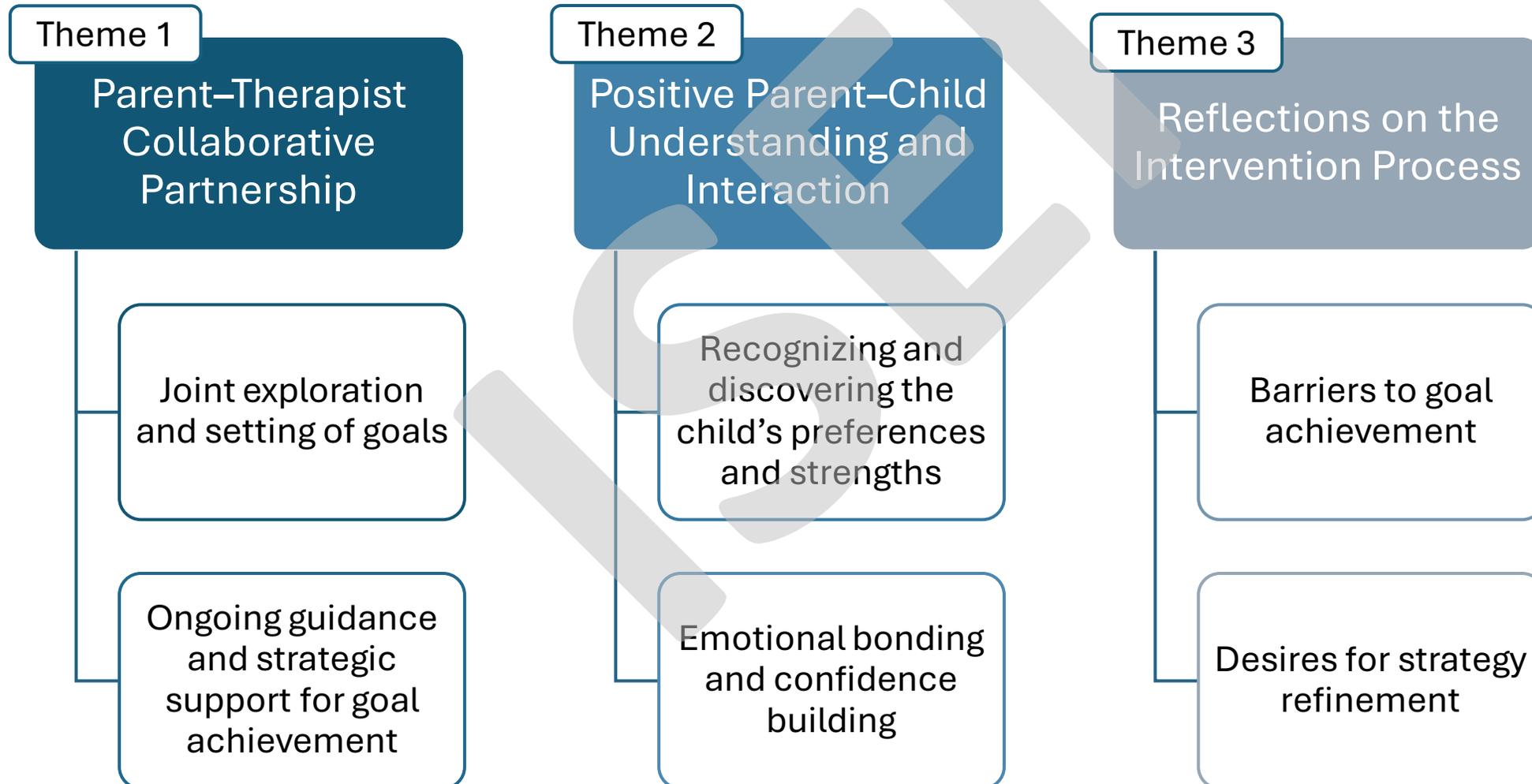
Aspects	Strategies focusing on modifying the environment
Social support	<ul style="list-style-type: none">Instruction to involve a sibling (e.g., sister) in making the rules for playing competitive games.Instruction to involve other children to prepare for camping equipment.Suggestions for parental interaction to maintain the child in a chess game.Discussion around potential friends of the child to invite for a birthday party.Suggestions for arranging family outdoor activities and exercises.
Physical/built environment	<ul style="list-style-type: none">Suggestions for finding a nearby mountain with beautiful scenes to start trying mountain climbing.Suggestions for providing the child with a GPS watch to ensure safety when the child moved around the market for shopping.Instruction to find a safe space to practice a new physical activity.Recommendations to provide books or online learning materials.Suggestions for providing a structured environment for learning a new activity.
Institutional	<ul style="list-style-type: none">Share information about sports clubs (e.g., inline skating) and camps.Provide resources to re-arrange activities if a raining weather.Provide Internet resources about online games (e.g., chess).Communicate with a coach for the child's needs
Activity demands	<ul style="list-style-type: none">Adapt activities with visual cues, such as making pictures to illustrate activity steps.Simplify tasks by reducing the steps needed to complete an activity.Provide a variety of fun options to engage the child in an activity.Adjust motor and sensory demands of the tasks based on the child's activity competence.Allow the child to rehearse and practice before going for outdoor activities (e.g., shopping or playing games with other children).
Temporal	<ul style="list-style-type: none">Activities are pre-planned, and the child is informed about the incoming events.Discussion about family routines to find a non-rush hour time to go out.Set a timetable for the steps to achieve the goals.Have enough time to plan and schedule the activity (e.g., an overnight trip) with the child.

Measures and Data Analysis

- Parents completed the feedback questionnaire at 12 weeks:
 - Perceptions and suggestions for goal-setting
 - Perceptions and suggestions for implementing strategies
 - Parental qualitative data were analyzed by 2 independent researchers using thematic analysis (Braun & Clarke, 2021).
- Parents' satisfaction with the partnership with the therapists was measured by the **Family-Professional Partnership Scale (FPPS)**, an 18-item questionnaire (Summers et al., 2005; Kang et al., 2020).
 - Example item: Provides services that meet the individual needs of your child.
 - 5-point Likert Scale from 1 (*Very dissatisfied*) to 5 (*Very satisfied*)
 - Mean (SD) scale scores and item scores were calculated.

Results:

Parents' experiences and perceptions



Theme 1: Parent–Therapist Collaborative Partnership

- **Subtheme 1.1: Joint exploration and setting of goals**
- Parents appreciated therapists' collaborative and guiding roles with professional tools and advice to clarify direction and *“set goals together”*. Parents described the *“step-by-step” guidance* to set *“positive and achievable goals”* and monitor goal progress as helping them grow a stronger sense of direction and confidence to work on the goals.
- ***“The conversation was on the right track. The therapist provided professional advice as a reference for positive and reasonable goals.” (Case#07)***

Theme 1: Parent–Therapist Collaborative Partnership

- **Subtheme 1.2: Ongoing guidance and strategic support for goal achievement**
- Parents perceived that therapists “*continuously provided good advice*” and “*was always there*” with parents and children, offering timely feedback, strategic advice, and situational adjustments to help parents implement and refine goals in daily life. Parents perceived their child’s needs were being met and thus “*make steady progress.*”
- “*I’m grateful the therapist was always there with me and my child, giving immediate feedback or direction when needed.*” (Case#22)

Theme 2: Positive Parent–Child Understanding and Interaction

- **Subtheme 2.1: Recognizing and uncovering the child’s preferences and strengths**
- As the therapists’ approaches encourage parents to set “*a shared goal*” and implement strategies with children, parents gain clearer insights into their child’s capabilities and preferences, and learn how to provide just-right challenges based on the child’s current functioning and wishes.
- ***“Through this intervention, my child and I had a shared goal, and through repeated communication, I understood my child better.” (Case# 06)***

Theme 2: Positive Parent–Child Understanding and Interaction

- **Subtheme 2.2: Emotional Bonding and Confidence Building**
- Parents described the collaborative process as *“a great experience”* and *“definitely increased opportunities for parent–child interaction.”* Such a process also helped *“reduce parenting stress”* and foster lasting positive experiences and confidence.
- *“Because we worked hard together, my child felt supported and became more confident.”* (Case# 25)

Theme 3: Reflections on the Intervention Process

- **Subtheme 3.1: Barriers to goal achievement**
- Parents think they sometimes “*unintentionally overprotect their child,*” which limits opportunities to take on new goals. Parents also reported that the child’s “*lack of motivation*” or “*rigid behaviors and emotional reactions*” could hinder goal achievement, leading to parents’ “*feelings of helplessness and frustration*”.
- “*Sometimes the child has no interest in completing the goal tasks, which makes me feel helpless.*” (Case# 01)

Theme 3: Reflections on the Intervention Process

- **Subtheme 3.2: Desires for strategy refinement**
- Parents suggested more finely broken-down steps and more discussion with the child throughout the intervention. They also desired more strategies to address the child's emotional and behavioral challenges to enhance engagement and goal attainment.
- *“There was only one interview with the child. If the therapist could briefly discuss with the child after discussing goals and strategies with the parents, it might further improve goal completion.” (Case# 01)*

Parents' satisfaction with the partnership with the therapists: Scale scores

The Family-Professional Partnership Scale (FPPS)

5-point Likert Scale

1 (*Very dissatisfied*)

5 (*Very satisfied*)

	Total	Child-related	Family-related
Mean	4.43	4.39	4.46
Median	4.56	4.67	4.78
SD	0.63	0.62	0.67
Range	3.06-5.00	3.11-5.00	3.00-5.00
IQR	4.00-5.00	4.00-5.00	4.00-5.00

Parents' satisfaction with the partnership with the therapists: Item-level scores

Items	Mean	SD
1. Helps you gain skills or information to get what your child needs.	4.18	0.75
2. Has the skills to help your child achieve the goal.	4.27	0.79
3. Provides services that meet the individual needs of your child.	4.27	0.65
4. Speaks up for your child's best interests when working with other service providers.	4.27	0.65
5. Lets you know about the good things your child does.	4.64	0.50
6. Is available when you need them.	4.45	0.69
7. Treats your child with dignity.	4.45	0.69
8. Provides services based on your child's strengths.	4.45	0.69
9. Values your opinion about your child's needs.	4.55	0.69

Items	Mean	SD
10. Is honest, even when there is bad news to give.	4.27	0.79
11. Keeps your child safe when your child is in his/her care.	4.36	0.67
12. Communicates with you in a way that you understand.	4.45	0.69
13. Protects your family's privacy.	4.45	0.69
14. Shows respect for your family's values and beliefs.	4.45	0.69
15. Listens without judging your child or family.	4.55	0.69
16. Is a person you can depend on and trust.	4.55	0.69
17. Pays attention to what you have to say.	4.55	0.69
18. Is friendly.	4.55	0.69

Conclusion

- Environment- and strength-based interventions foster **meaningful parent–child interactions**, strengthen emotional bonds, and enhance parental understanding of children’s preferences and strengths.
- A **collaborative partnership with therapists** was key to supporting parents in exploring and setting feasible goals, while continuous professional guidance facilitated sustained progress.
- Parents’ constructive feedback informs refining strategies to better align with their needs.

Take Home Message

- Clinicians should **actively involve parents as partners, and incorporate children's perspectives where possible** in the intervention process, emphasizing shared goal-setting and ongoing coaching.
- Clinicians use **goal-setting tools** (e.g., Goal Attainment Scaling) and a **coaching approach** can help children and parents identify realistic, strength-based goals and apply strategies more consistently in daily routines.

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