UC DAVIS HEALTH | MIND INSTITUTE

Identifying Culturally Relevant and Family-Centered Feedback for Integration into the 'Lets Talk' Seminar Series

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INTRODUCTION

- Research has found that support group programs show a positive effect for parents and their children, but they're often not accessible to underserved populations (Mandell & Salzer).
- A study also found that most parents of children with autism feel their needs for support are not being met (Siklos &Kerns).
- These findings highlight the importance of support group programs for parents of autistic children, however there is a gap in research when it comes to implementing useful and impactful programs for Spanish-speaking families.
- At UC Davis' MIND Institute, the 'Lets Talk' program is a 6-week series for parents to share experiences and to learn about their child's diagnosis and specific needs and how to help them achieve their full potential.

OBJECTIVE

Conduct a seminal evaluation of the 'Lets Talk' series, improve future seminars, and to identify culturally relevant and family centered feedback that can be integrated into this series.

METHODS

- Demographic questionnaire was developed to better understand participating family members (e.g., stage in disability journey, access to information, age/developmental level of child, support systems, etc.).
- Focus group was completed using 13 open-ended questions with six parents on Zoom, conducted in Spanish.
- Parents received monetary compensation.
- The audio recording was downloaded from Zoom and a transcription was obtained using the online Microsoft Word transcribe function.
- The Word transcription document was uploaded to Taguette *(online software)* and responses were coded based on 4 categories: positive statements, negative statements, ambivalent statements, and recommendations.
- Responses were grouped and further analyzed to identify themes.

RESULTS

Positive Statements (34.7%)

Community	Sharing	Learning from other members	Learning from the presenters
"It benefited me more globally because I have an identity, I have a community to which I belong"	"I felt respected, I felt listened to. I felt that I was in the right place to be able to express my situation and all its emotion"	"Grasp other people's experiences, what they have gone through so that if they have made a mistake, maybe you won't make a mistake or if they have found some resource to take advantage of it or the experience they have."	"I also learned what science said...I learned and they helped me a lot and gave me a lot of peace and tranquility."

Figure 1. Four themes identified from the tagged positive statements, with an example quote.

Negative Statements (2.8%)

Quote: "I've seen some of these sessions and it says we're going to talk, but time is really so short that we don't have time."

100% of the negative experience instances related to the theme of low sharing opportunity

Figure 2. Quote representing the negative experience theme identifies.

PARTICIPANT TOPICS OF INTEREST FOR SESSIONS

- how to be a good peer to others group members
- how to talk to providers, teachers, etc.
- how to take leadership as a parent
- How to help others (i.e. learn about other diagnoses)
- How to be resilient/help yourself.
- How to get to know your child (e.g., if he/she is nonverbal)
- How to accept the diagnosis and learn and cope with the grief stage
- How to find and use specific resources
- How to create a support system for your child.
- How to grow from and cope with adversity (how to learn from adversity or change)
- How to generalize and apply what you have learned

Figure 4. Comprehensive list of topics participants are interested in learning more about in sessions

11 PROGRAM RECOMMENDATION THEMES

- time management(and more time options)
- more organized session structure
- opportunity for personal sharing from the participants
- promote connection between parents
- emphasize importance of the program (e.x. with parent experiences, infographic or sharing)
- incorporation of topics in which the participants are interested
- variation of presenters
- focus on parent's personal/emotional well being as much as their child's.
- Have more specific resources available (ex: resources for newly diagnosed families)
- incorporate experience/knowledge of other parents in learning
- focus on application of information being taught into the real world

Figure 3. List of 11 main program recommendation themes

Coding Category Frequency

Negative statements: n = 4 (2.8%)
Ambivalent: n = 10 (6.9%)
Positive statements: n = 80 (34.7%)
Recommendations: n = 50 (55.6%)

SUMMARY

- Parent responses were qualitatively coded based on whether they were positive statements, negative statements, ambivalent statements, or recommendations.
- Themes were then identified. Positive statements fit under four themes (community, sharing, learning from other group members, and learning from providers).
- Negative experiences were related to limited group time for members to share.
- Recommendations revealed 11 areas for growth (see Figure 4).

CONCLUSIONS

- Overall, parents' responses were largely positive, guiding areas to focus on for future program development.
- Parent feedback was also used to create a questionnaire to gather information on participants to better inform future sessions and programming.
- Results of this project should be used to improve the 'Let's Talk' series for parents and guide program development.
- Due to the paucity of evidence related to Spanish parent-support groups, this research should be replicated under guidelines for scholarly peer-reviewed studies (e.g., IRB approval).

STRENGTHS & LIMITATIONS

- Strengths were the ease of data collection via an online format, and the safe, open-space environment for participants to share their experiences.
- Limitations were small sample size, focus group was only conducted once, and sample was not randomly selected

ACKNOWLEDGEMENTS

CONTACT INFO

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SOURCES

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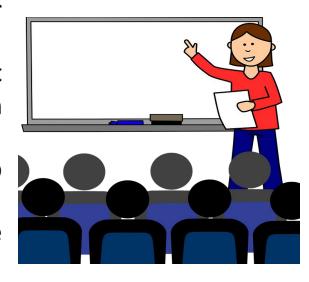
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ACKNOWLEDGEMENTS

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Thank You

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