

# The CAMP Model: A Culturally Adapted Mentoring Program for Latine Families of Autistic Youth During the Transition into Adulthood



C- Compassion

A- Acceptance

M- Meaningful

P- Patience

# TABLE OF CONTENTS

## **Part 1: Introduction and Background**

- A. Cultural Adaptations to the Transition to Adulthood
- B. Challenges Faced by Latine Families during the Transition Period

## **Part 2: How to Organize a Parent Mentoring Program**

- A. Overview of our Parent Mentoring Program
- B. Preparing for the Parent Mentoring Program
- C. Perspectives from Parent-Mentees

## **Part 3: Recommendations for future Parent Mentoring**

- A. Recommendations & Conclusions
- B. Additional Resources

## **Part 4: Appendices**

- A. References
- B. About the SEARCH Center
- C. Acknowledgements
- D. Contact
- E. Suggested Citation

# Part 1: Introduction and Background



Original quote from a Latine mother of a child with autism and ADHD who attended a Parent Mentoring Session through the SEARCH Center:

**“Primera vez que un programa de tutoría me hace sentir que realmente alguien me puede guiar. Generalmente, otros programas nos dan un monton de papeles a leer. El equipo que me toco fue excelente”**

Translated in English:

**“The first time that a [mentoring] program makes me feel that someone can really guide me. Generally, other programs just give us a lot of papers to read. The team that worked with me was excellent.”**



## Cultural Adaptations to Transition Programs for the Transition into Adulthood

Latine<sup>1</sup> children and their families often encounter barriers within medical, educational, and cultural systems in the U.S. Reported barriers include later diagnosis of autism spectrum disorder or ASD (i.e., compared to their White counterparts), poor health care experiences (e.g., lack of translated materials), and disability-related stigma within the Latine community (i.e., some Latine communities have negative perceptions of disability)<sup>2-4</sup>. Research and community collaborations exist to provide more widespread education about ASD and improve early identification and diagnosis among Latine populations<sup>5-6</sup>.

Although programs have been adapted for Latine families and culturally diverse families, these programs tend to target early childhood<sup>7</sup>, and there needs to be more communication and support provided to these families during the transition to adulthood<sup>8</sup>. Of note, it is useful to consider existing programs for parents of children and youth with autism and other intellectual and developmental disabilities (IDD) in developing programs that target the transition to adulthood. Our aim is to fill a gap for young adult programming for the transition into adulthood, while also understanding the value of current programs provided for younger children.

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<sup>1</sup>The term Latine\* is used throughout this guide to provide full inclusivity of language and gender neutrality. Zentella (2017) found that Latine overcomes the barriers of binary gender from Latino/a. We acknowledge that Latinx can also be used as an inclusive gender neutral term. Yet, the “x” can be hard to pronounce and therefore does not achieve language inclusivity among Spanish speakers. The “e” in Latine mimics existing sounds in the Spanish language, such as estudiante and usted.

**Study case example.** For individuals with ASD and IDD, support services should not be a one-size-fits-all approach<sup>9</sup>, but rather, it should involve individualization and attention to cultural context. In 2020, Kuhn and researchers<sup>10</sup> published a paper on a culturally adapted program for Latine families during the transition period. To our knowledge, this paper is the first to address cultural competence and adaptations of a transition program to support Latine families of youth with ASD. Kuhn and researchers provided detailed information as to why there is a strong need for culturally adapted programs for Spanish-speaking and Latine families. To culturally adapt a parent mentoring program, Kuhn's team identified the needs and interests of families and youth by consulting with Latine community members, developing relationships with them, and reviewing previous studies to determine what had been done (and what was missing).

They also solicited feedback on the program from local stakeholders through focus groups and, from that input, made appropriate changes to their program. The developed transition program involved four meetings with parents that lasted about 2.5 hours. Program sessions were held on the weekends since most parents voiced that week-days were not preferred due to their work schedule. Each session focused on important aspects of the transition into adulthood, such as the developmental course of autism, community involvement, guardianship, transition planning (e.g., employment, postsecondary school), and health and well-being. Overall, parents reported being satisfied with the program; they noted that although they had attended other workshops about transition, previous workshops were not as individualized. Lastly, parents indicated that they needed more time, if possible, to continue their session since they expressed wanting to discuss more topics, to connect with other parents about other useful resources, and to build relationships with other parents.

Based on guidance provided by Kuhn and colleagues on the structure and cultural adaptations of transition programs, *we adapted this model to implement a parent mentoring program for Spanish-speaking and Latine families who reside in Inland Southern California, and who have youth with ASD or intellectual or developmental disability (IDD)*. The program considered culture, language, perceptions, and needs to help build greater trust between families and clinical teams.

## Challenges Faced by Latine Families during the Transition Period

Once individuals turn 21-22 years of age, state-mandated services are no longer available, making it challenging to navigate adulthood<sup>11-12</sup>. Due to the loss of services, transitioning youth struggle to attain independent living, postsecondary educational enrollment, and employment; this is especially pronounced for minoritized populations, such as Latine and Spanish-speaking families. For example, language barriers may make it more difficult to attain translated resources and supports, including interventions provided in their native language.

An additional stressor for Latine families is the lack of accessible and affordable services. Many Latine and Spanish-speaking families face poor preventative health care due to cultural barriers, language difficulties, and the need to travel great distances as some services are not always available in under-resourced or minoritized communities<sup>15</sup>. To help alleviate this burden during the transition process, families need support centered around their home and in their community<sup>16</sup>.

A common challenge for parents is searching for developmentally appropriate and quality resource and support services for their youth or young adults with IDD. In so doing, Latine parents have expressed the following challenges: poor communication with school/community providers, varying satisfaction with services, lack of access to coordinated services, lack of access and knowledge of appropriate services, experiencing stigma and discrimination, and lack of access to support groups specifically for minority autistic youth and their families<sup>17-21</sup>. Due to these negative experiences, Latine parents often struggle to advocate effectively for their youth with IDD.

Researchers have addressed some of these barriers and have provided strategies to provide greater support. In previous research studies, parents have voiced wanting the following to provide them needed resources for a support system:



- build a trustworthy and reliable support system
- increase knowledge of special education policy (e.g., parent special education rights) and advocacy resources
- get to know other Latine parents of children with IDD to feel empowered to advocate for their child
- increase parent-school communication about transition plans
- initiate more communication and build *confianza* (i.e., trust that results in developing rapport)
- reduce stigma and discrimination between the family and schools and/or outside services<sup>17, 22-23</sup>



Thus, this guide will focus on working with families to help address their transition planning goals and priorities for their youth with IDD, through a streamlined, 2-hour parent-mentoring meeting.

# Part 2: How to Organize a Parent Mentoring Program



## Who Can Utilize this Guide



Our goals of the parent mentorship meetings were to create trusting relationships, individualize attention, and provide a safe space in which parents of youth with IDD could discuss their concerns and challenges with each other and with us. Therefore, this guide is designed to assist service providers, community organizations, and key stakeholders (e.g., parent self-advocates) who are interested in supporting the needs of the Latine community and assisting them through transition service planning. *This is a step-by-step guide to replicate our parent mentor meetings within the community.*

## Overview of the Parent Mentoring Program

Based on the barriers and facilitators expressed by Latine parents, our team at the UC Riverside SEARCH Family Autism Resource Center created the Parent Mentoring Program to inform and support parents, guardians, and family members of youth with IDD. Before the mentor meeting, to build *confianza* (trust), our team asked parents about their concerns for their youth with IDD and what language they preferred for discussions. Although our main focus of the program was to address challenges about the transition to adulthood, not all parents who attended had these concerns. For example, some Latine parents requested information about virtual learning (current concerns raised as important during the COVID-19 pandemic), employment, and socialization opportunities. Thus, our staff had to adjust and adapt our responses to address these timely issues. By collecting this information beforehand, our team was prepared to address parents' needs during the meeting and, in turn, built trust and rapport with parents prior to the meeting.

Our staff consisted of both monolingual English and bilingual Spanish speakers. To prevent linguistic barriers between staff and parent participants, we provided a translator and translated materials before and on the day of the meeting. We also asked parents to introduce themselves to each other and, depending on their comfort level, share any challenges with their children to build a supportive parent network. Thus, parents had the opportunity to see what they had in common with others and voice their concerns.

Following the parent mentoring meeting, a team member re-contacted each family about additional support service information and resources discussed during the mentor meeting. The individual engagement by our team clearly and consistently communicated to parents that their unique needs and concerns were important. Finally, to improve and adapt a future parent mentoring program, we obtained parent feedback, providing social validity data about the program. Overall, the parent-mentoring meeting helped address challenges that parents were facing and highlighted the importance of building rapport and a trusting relationship.

**Key Questions:**

1. What transition goals do parents have for their children or adolescents?
2. What are the substantial challenges and barriers that these families are facing?
3. What resources and supports do they report needing?

## Preparing for Parent Mentoring Programs

### Steps

1

**Planning-** The first step to conducting parent mentoring programs is to decide on potential dates and who will be part of the support team. If you anticipate Spanish-speaking parents, provide multiple translators; sometimes, it is helpful to recommend that the participating parent invite someone they trust to translate for them (e.g., friends, family members).

2

**Event Promotion-** You should begin recruiting parent participants through flyer distribution and event promotion.

3

**Initial Phone Call-** A script is provided as Appendix A to help structure the phone call when recruiting parent participants; this can be adapted as an electronic survey (whichever is most convenient for collecting information before the meeting).

As a reminder, parent participants should be provided detailed information regarding the mentoring program. Parent participants should understand that the mentoring program will involve one-on-one mentoring based on their goals and priorities for their child with IDD.

While *not* a requirement of participation, parents can share additional information with the team (for example, documents provided by the school and/or the child's support team) prior to the meeting via email (Parent participants should be informed that all information shared will be kept confidential/private). This is offered primarily to allow the team to confer about the case and determine appropriate support for the family and child before meeting with them individually. It's important to keep in mind potential local resources for parents and the child (e.g., support groups, advocacy groups, employment opportunities, postsecondary opportunities).

## Tips for service providers:

- To initiate the parent mentor program, send out a call or announcement in both English and Spanish through community organizations or churches, in addition to notices that appear on Regional Center websites. This initial announcement should inform parents that there will be an opportunity to receive individualized support and information on transition for their youth with IDD. Handing out flyers or making announcements within community events (that may or may not focus on disability) can also be effective for reaching Latine parents.
- Service providers should be prepared to receive phone calls in Spanish and have phone scripts in Spanish (see Appendix B).
- When parents express interest, build trust through consistent communication, which may involve contacting the parents 2-3 times before discussing their main child-related concerns or sending them multiple emails and phone reminders for the upcoming parent mentor meeting.
- Team members will more easily build rapport and establish a trusting relationship with parents by obtaining information about the child and asking about parents' primary concerns during the initial phone call prior to the mentoring meeting.

## 4

**Assessing Parent Concerns-** During the initial phone call, team members can gather information on parents' concerns for their child with IDD. See Appendix B for an intake form that can be completed by phone or through an online survey software (e.g., Survey Monkey, Qualtrics). There are a few feasibility and practical considerations when deciding whether to use phone or online administration: e.g., Do you or your organization have access to an online survey system? How many intake forms are you expecting to complete? Would your community of parents or family stakeholders be more likely to respond to a phone call or an online survey?

Information gathered on the intake form can be used to (a) prepare resources to present during the meeting and (b) match parents with team members who had specific expertise in parents' areas of concerns. To prepare resources, team members can engage in a brainstorming session to think of local, accessible, and effective services and programs that target the needs of this population. Some of the resources our research team provided can be found in the "Additional Resources" section (see page 16), for example the Inland Regional Center. Regional centers, funded by the Department of Developmental Disabilities in California, are publicly funded organizations that help support individuals with intellectual and developmental disorders. Using connections within the community, team members can collect flyers and handouts for upcoming events that would be of potential interest to parents and youth

5

**Mentorship groups-** During the meeting, the parent meeting can begin with all participants and staff in one group (e.g., online, in-person) for introductions and an overview of the meeting (i.e., purpose, structure, length of time). Each parent is then assigned to a team member who will work with them individually to help answer any questions they may have, which may be related to their child's educational status (general or special education), school-based services, postsecondary education, employment, service needs, and parent well-being.

Our team prepared interview questions to gather detailed information about the child's current services, the parent's experience with current service providers, and their child's goals. The team member prefaced the individual interview by reviewing the purpose behind the parent mentoring meeting and the questions they will be asked. The team members can utilize this interview sheet during the meeting to help ensure a standardized protocol (see Appendix C).

6

**Wrapping up-** Following the parent interview, the interviewer can summarize the parent's primary concerns, goals, and priorities to show understanding of expressed difficulties. To close out the meeting, the interviewer can compile a list of recommendations and resources to address the parent's primary concerns, goals, and priorities. These recommendations are explained and shared with the parent before ending the meeting. If the parent is unable to take notes on offered recommendations or resources, a follow-up email with the list of recommendations may be required.

# Perspectives from our Parent-Mentees

## General Findings from our Parent-Mentees

Our team conducted a parent-mentor meeting with five mothers of children with disabilities, which provided the prototype for these recommendations. Children's ages ranged from 7 to 19 years; they had either a diagnosis of ASD or ASD and ADHD. Prior to the meeting (during the initial intake phone call), mothers expressed their primary concerns about transitioning to adulthood, employment, distance learning, and socialization. During individual meetings, parent concerns were shared, appropriate recommendations were made, and resources were provided. You can find more information about three “composite” families below (to preserve confidentiality) along with further recommendations.

### Mother 1

A mother of a 19-year-old female with ASD. Mother 1 was registered with the Inland Regional Center (IRC). At the time of the parent mentor meeting, Mother 1 had frequent positive interactions with her service coordinator at IRC and felt like she had been treated well. Yet, she mentioned that IRC did not provide a lot of information and did not fully understand what services would be helpful for her child. Now that her child is transitioning from school services, Mother 1 was most concerned about employment and socialization with peers. Some goals Mother 1 had for her child were appropriate employment training based on her specific interests and independence (e.g., living on her own, making her own decisions). Based on these expressed goals, our team recommended the following:

- Exploring options such as shadowing a professional or visiting college programs that may provide her daughter with opportunities to know more about her specific area of interest for future employment. This parent was given information about a specific college nearby that the parent and daughter could call and ask about necessary steps needed to apply to the program.
- Accessing resources from the Department of Rehabilitation
- Enrolling her daughter in PEERS® for Careers (virtual employment-related social skills group)
- Provided a flyer for a virtual job skills event
- Follow-up phone call with our team to practice job interviews or how to advocate during an IEP meeting

### **Mother 2**

A mother of an 8-year-old male with ASD. Mother 2 was not registered with Inland Regional Center but was registered at East Los Angeles Regional Center (ELARC). At the time of the parent mentor meeting, Mother 2 had frequent contact with her service coordinator at ELARC. She commented that their interactions have been nice and respectful, but it would sometimes take a while for her service coordinators to respond to her when she had additional questions. Mother 2 was most concerned about remote learning (e.g., organization and focusing on schoolwork at home), her child's current Individualized Education Program (IEP), and peer socialization. Some goals Mother 2 had for her child were related to socializing with peers (i.e., initiating conversations, developing relationships) and organization/maintaining focus, preparation for high school and beyond. Based on these goals, our team recommended the following:

- Enrolling her son in a social skills intervention program (e.g., the PEERS® Program)
- Creating visual schedules and use a timer to improve independence during remote learning
- Providing the child with positive or rewarding reinforcements (e.g., playing with video games during break time after completing specific homework assignments)
- Introduce the child and parent to possibilities for the future (e.g., going to high school, IEP transition planning after high school, living in the community, etc.)

### **Mother 3**

A mother of a 7-year-old male with ASD and ADHD. Mother 3 was not registered with the IRC. She tried to register her son with the IRC; however, they were declined. Her son currently has an IEP at school under ASD and ADHD. He is currently receiving accommodations in the classroom, receiving speech therapy, and had previously received occupational therapy. Mother 3 was most concerned about her child's sensory issues, navigating the IEP process, and what implications this may have for future schooling. Some goals Mother 3 had for her child were attending college and living independently when he is older. Based on these goals, our team recommended:

- A follow-up phone call with the team to provide guidance for upcoming IEP meeting to learn how to advocate during the meeting
- To work on adaptive skills with her son (e.g., continuing to assign him chores, which was mentioned by parent during the interview) to help improve independence
- An autism assessment (at no cost) at the SEARCH Family Autism Resource Center to help the family try to enroll into the regional center
- Introduce the mother to possible post-high school outcomes for her child and transition planning required if he chose to pursue college

## Social Validity of the Meeting

Following the parent-mentor meeting, our team assessed the *social validity* (see Appendix D) of these meetings. Social validity refers to the impact that our program had on the recipients themselves, and is an important factor in evaluating interventions or programs. All three mothers (100%) expressed that they enjoyed the meeting and the information presented was accessible in their preferred language. Most importantly, all three mothers (100%) agreed that our research team was respectful of their culture. They also reported that the information, recommendations, and resources discussed were beneficial. Furthermore, all three mothers (100%) would highly recommend the parent-mentor meeting to other parents and attend the mentor meeting again next year.

# Part 3: Recommendations for Future Parent Mentoring Program

## Conclusion

There is a strong need for service providers to offer mentoring style programs for Spanish-speaking parents. Thus, this Parent Mentoring Program is meant to provide individualized support and information about transition services to Spanish-speaking and Latine parents to help them navigate the transition into adulthood. Meetings with parents can become stepping stones for discussing future employment, postsecondary education, or housing options for their youth with IDD.

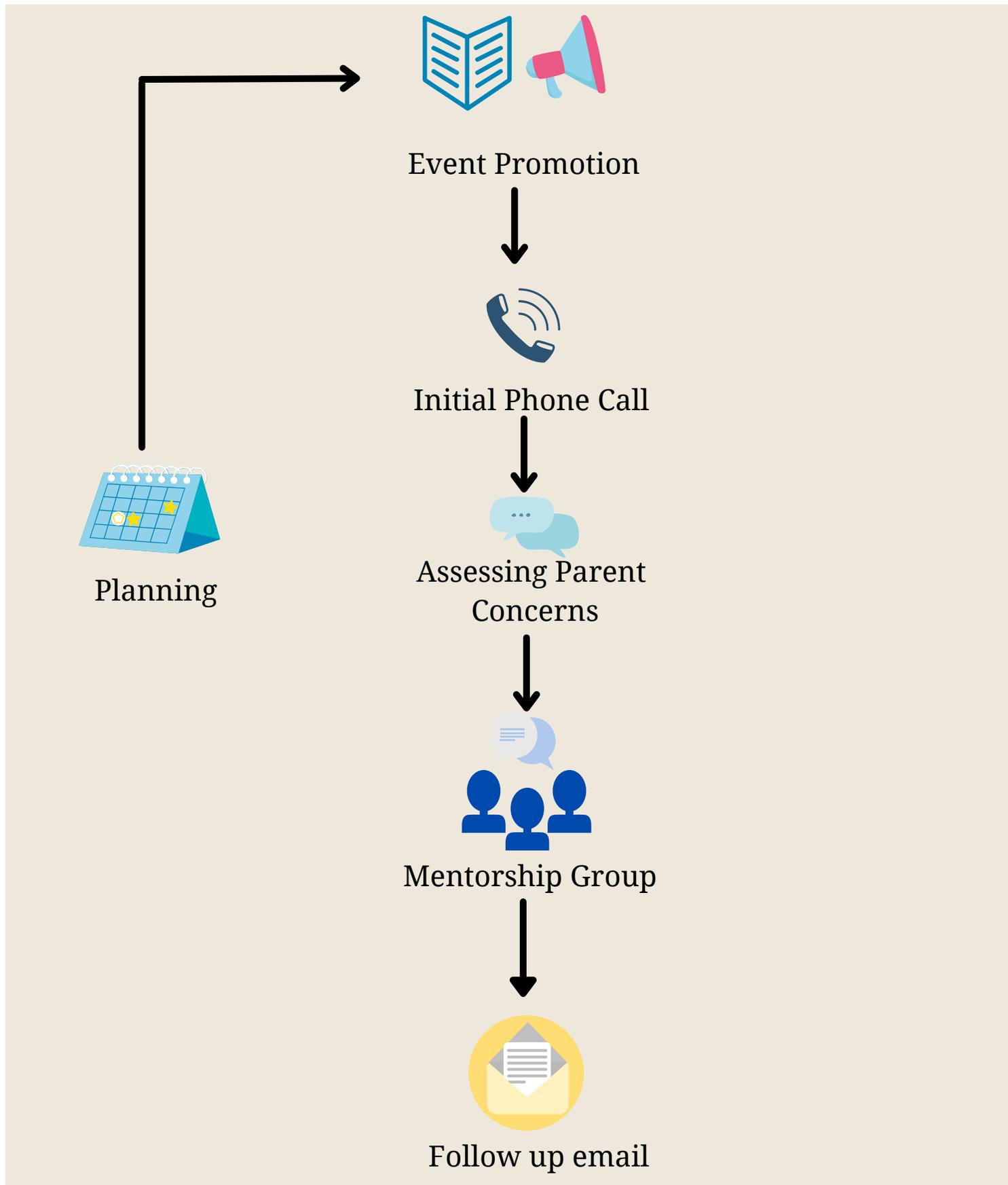
Overall, parents who participated in this program found the mentoring meeting to be helpful. As one mother put it, *Primera vez que un programa de tutoría me hace sentir que realmente alguien me puede guiar. Generalmente, otros programas nos dan un montón de papeles a leer* (English translation: *The first time that a [mentoring] program makes me feel that someone can really guide me. Generally, other program just give us a lot of papers to read*). By providing the initial phone call with parents, teams can assess and discuss parents' priorities rather than inviting parents to a general information meeting. Taking this more individualized approach can help build rapport with families. Overall, providers and those working closely with Spanish-speaking families need to consider creating programs that take into account parents' language, values, and priorities. In creating this guide, we hope that service providers, community organizations, and key stakeholders develop and implement culturally adapted mentoring meetings that will, in turn, help the Spanish-speaking community with the transition to adulthood and help spread the word about available resources.



## Checklist for a Mentoring Meeting

1. Designate your bilingual team, including any translators, and translate your materials (e.g., event flyers).
2. Reach out to the community (e.g., visit local community centers, churches, organizations that work with families of youth with IDD).
3. Call interested families and ask critical questions about what they would like to focus on during the meeting.
4. Select team members to work with certain parents based on their expertise and identify possible resources that might meet the needs of parents and youth.
5. Meet with parents and listen to their priorities and concerns.
6. Regroup with your team to generate a list of resources to provide to parents.
7. Send a follow-up email to parents with a list of resources.

# Flow Chart for Planning your Mentor Meeting



## Recommendations

For future parent mentoring meetings, we recommend having a maximum of 5-7 parents within each mentoring session paired with one mentor and translator, if needed. This may help parents feel more comfortable sharing their current experiences as well as resources with each other. One way to promote engagement and conversation between parents may be allowing time for discussion questions prior to individual meetings. Questions might be based on challenges that most parents may be experiencing (e.g., “How many of you have struggled with transitioning services from schools?” “How and where have you obtained the best family and child support?”). Another way may be to break out into smaller groups, led by two mentors and a translator, with parents who have youth *in the same age* range to discuss resources and challenges. While our current parent mentoring meetings provide individualized support to parents, by providing an open space for parents to share resources and challenges, parents may also build a sense of community with other parents.



### Youth’s Involvement in the Transition Planning

Youth should be involved in the transition planning when possible, with some researchers recommending that parents begin talking to their youth earlier than the age of 16 about their youth’s goals for the future sooner than later<sup>14</sup>. Earlier transition planning can help youth and their families prepare and tackle the necessary skills to attain those goals. Parents should consider whether their youth want to go to college or enroll in employment/vocational opportunities and whether they can adapt to independent living. Parents can begin by skill-building with their youth in areas such as independence, daily living, and communication<sup>24</sup>. Systematically discussing and working on these skills can facilitate realistic choices and future opportunities. For example, when adolescents express interests in certain fields, parents and educators can locate available volunteer or vocational opportunities within that field of interest. Not only can these early discussions of future goals or interests help parents and service providers prepare for their youth’s future, but they can also begin teaching their youth about self-advocacy<sup>25</sup>.

## Additional Resources

The program described within this guide uniquely tailors specific recommendations and support to parents and their youth. Although other organizations provide parent mentoring and support to parents, they are often generic and not individually tailored as the one described here. There are other programs currently available that provide general information for parents, especially those who want to learn more about the transition period for their children. Below we have included links for available resources and organizations within the United States that can provide further education, training, and tips.

Organization	Description	Website
Department of Developmental Services (DDS)*	To locate your closest regional center, please visit the DDS website	<a href="https://www.dds.ca.gov/rc/lookup-rs-by-county/">https://www.dds.ca.gov/rc/lookup-rs-by-county/</a>
Fiesta Educativa*	Programs and services (one-on-one mentoring) for those with a new diagnosis	<a href="https://fiestaeducativa.org/programs-services/">https://fiestaeducativa.org/programs-services/</a>
Inland Regional Center (IRC)*	For up-to-date information on local programs offered through the IRC, please visit the IRC website to see upcoming programs listed in their calendar	<a href="https://www.inlandrc.org/calendar/">https://www.inlandrc.org/calendar/</a>
PACER Center	Educational resources on working with diverse families	<a href="https://www.pacer.org/cultural-diversity/">https://www.pacer.org/cultural-diversity/</a>
	Information on available free webinar/trainings for both parents and educators	<a href="https://www.pacer.org/cultural-diversity/resources-for-educators.asp">https://www.pacer.org/cultural-diversity/resources-for-educators.asp</a>
	Further information on transition planning tips for culturally diverse youth with disabilities	<a href="https://www.pacer.org/parent/php/PHP-c250.pdf">https://www.pacer.org/parent/php/PHP-c250.pdf</a>

Organization	Description	Website
PEERS® Program	Evidence-based social skills program for children, youth, and young adults with ASD, ADHD, anxiety, and depression	<a href="https://www.semel.ucla.edu/peers">https://www.semel.ucla.edu/peers</a>
Organization for Autism Research	Further information on transition planning and how to best prepare guide	<a href="https://researchautism.org/resources/a-guide-for-transition-to-adulthood/">https://researchautism.org/resources/a-guide-for-transition-to-adulthood/</a>

*\*For individuals residing in the state of California*

# Appendices

## Appendix A. Phone Script

[Introduce self and organization]. I am calling you to tell you about the Transition to Adulthood mentorship program that we will be hosting on [Date and time]. We are inviting you to participate. Would you like to hear more about this?

Great! If you choose to participate, you will receive an email to confirm your enrollment. The email will also include [optional if conducting parent mentoring online: a Zoom registration link to take part in the online meeting] and information to help prepare you for the meeting.

Our team will review any documents that you've shared with us to personalize your one-on-one parent mentoring and determine how to best support you and your child through this session. The meeting itself is scheduled for 2 hours, during which you will have a chance to meet with other participating parents and our team. You will also have the opportunity to have an optional one-on-one session with a member of our team.

Are you still interested?

Great!

Lastly, I'd like to gather some basic information about you and your child. If you do not feel comfortable answering any of these questions, you don't have to.

## Spanish Phone Script

[Preséntese a sí mismo y a la organización]. Lo llamo para informarle sobre el programa de mentores de transición a la edad adulta que organizaremos el [Fecha y hora] y lo invitamos a participar. ¿Le gustaría saber más sobre esto?

¡Excelente! Si elige participar, recibirá un correo electrónico para confirmar su inscripción. El correo electrónico también incluirá [opcional si realiza tutorías para padres en línea: un enlace de registro de Zoom para participar en la reunión en línea] e información para ayudarlo a prepararse para la reunión.

Nuestro equipo revisará cualquier documento que haya compartido con nosotros para personalizar su tutoría individual para padres y determinar la mejor manera de brindarles apoyo a usted y a su hijo durante esta sesión. La reunión en sí está programada para 2 horas, durante las cuales tendrá la oportunidad de reunirse con otros padres participantes y con nuestro equipo. También tendrá la oportunidad de tener una sesión individual opcional con un miembro de nuestro equipo.

¿Estás interesado aún?

¡Excelente!

Por último, me gustaría recopilar información básica sobre usted y su hijo. Si no se siente cómodo respondiendo alguna de estas preguntas, no es necesario.

## Appendix B. Parent Intake Phone Call or Administered via Online Survey System

1. First name: \_\_\_\_\_
2. Last name: \_\_\_\_\_
3. Email: \_\_\_\_\_
4. What is your primary language?
  - a. English
  - b. Spanish
  - c. Other: \_\_\_\_\_
5. What is your role?
  - a. Mother (biological or adoptive)
  - b. Father (biological or adoptive)
  - c. Grandmother
  - d. Grandfather
  - e. Other: \_\_\_\_\_
6. What is the name of your child with autism and/or intellectual disability? \_\_\_\_\_
7. What is this child's age? \_\_\_\_\_
8. What is your child's diagnosis? \_\_\_\_\_
9. What is your child's gender? \_\_\_\_\_
10. What is your child's race/ethnicity?
  - White
  - Black or African American
  - Hispanic, Latine
  - American Indian or Alaska Native
  - Asian
  - Native Hawaiian or Pacific Islander
  - Other: \_\_\_\_\_

*Questions 11 and 12, below, are for families in California:*

11. Is your child registered with a regional center? \_\_\_\_\_
12. If your child is not registered with regional center, would you like to be?
  - a. Yes
  - b. No
11. Do you have another child with autism and/or intellectual disability? \_\_\_\_\_  
If yes, please answer below.

	Child Name	Child age	Child gender	Child race/ethnicity Y (1=White, 2=Black or African American, 3=Hispanic or Latine, 4=American Indian or Alaska Native, 5=Asian, 6=Native Hawaiian or Pacific Islander, 7=Other: _____)	Child Dx	Registered with Regional Center? (yes   no)	If not, would they like to be? (yes   no)
1							
2							
3							

## Spanish Parent Intake Phone Call

1. Nombre: \_\_\_\_\_
2. Apellido: \_\_\_\_\_
3. Correo electrónico: \_\_\_\_\_
5. ¿Cuál es su idioma principal?
  - a. Inglés
  - b. Español
  - c. Otro: \_\_\_\_\_
6. ¿Cómo se llama su hijo con autismo y / o discapacidad intelectual? \_\_\_\_\_
7. ¿Qué edad tiene este niño? \_\_\_\_\_
8. ¿Cuál es el diagnóstico de su hijo? \_\_\_\_\_
9. ¿Cuál es el género de su hijo? \_\_\_\_\_
10. ¿Cuál es la raza / etnia de su hijo?
  - Blanco
  - Negro
  - Hispano, Latino
  - Indo americano o nativo de Alaska asiático
  - Nativo de Hawái o de las islas del Pacífico
  - Otro: \_\_\_\_\_

*Las preguntas 11 y 12, a continuación, son para familias en California:*

11. ¿Tiene otro hijo para el que asiste a esta reunión? \_\_\_\_\_
12. ¿Está su hijo registrado en el centro regional? \_\_\_\_\_
13. Si su hijo no está registrado en el centro regional, ¿le gustaría estarlo?
  - a. Si
  - b. No

	Nombre del niño	Edad del niño	Género del niño	Raza/etnia del niño (1=Blanco, 2=Negro, 3=Hispano o Latino, 4=Indoamericano o Nativo de Alaska, 5=Asiático, 6=Nativo de Hawái o de las Islas del Pacífico, 7=Otro: __)	Diagnóstico o del niño	¿Registrado en el Centro Regional? (si   no)	Si no es así, ¿les gustaría serlo? (si   no)
1							
2							
3							

## Appendix C. In-Person Interviews with Parent Mentees

The purpose of our meeting with you today is to help you learn about your child or young adult's education and service options, particularly as they relate to developmental disabilities.

To learn more about what your child's school and the regional center could be doing better and how we can help, we have a few questions to ask you. All of your answers will be written down. We will NOT use your name; everything will remain confidential.

**First, we would like to ask you a few questions about the regional center. Is your child registered with the regional center?**

1. Have you ever been to your nearby regional center or had a virtual visit?
  - a. If yes, about how many times have you been there or had a virtual appointment?
  - b. Did you contact the regional center or did someone from regional center contact you?
2. What was the reason for contacting the regional center, or the regional center contacting you?
3. Who did you talk to there? What was their role? (Note: *Try to at least learn about the role that person had – service coordinator; psychologist, etc. If unclear, ask parent who they talked to at the regional center.*)
4. Was he/she/they helpful?
5. How were you treated?
6. What kinds of services do you hope to obtain from the regional center?
7. How long have you been a client of the regional center?
8. Are there things that the regional center could be doing to help you more?
  - a. What would you change?
  - b. What do you like that the regional center does?

Now I'm going to ask you about your child's school.

1. Does your son or daughter have an IEP or ITP (Individualized Transition Plan)?
2. If you have an ITP, how involved has the school been in your child's or young adult's transition?
3. What is your child's disability/ eligibility category in their IEP?
4. What are some accommodations or services your child is receiving?
5. Has your child been able to receive services over distance learning?
  - If yes, ask: What kind of services did your child receive?
  - If no, what services did you or your child miss the most?
6. What are some goals and priorities you have for your child/young adult? (e.g., postsecondary school, employment)
7. Are there still services that you need for your child either in the school or community?
8. How would these help with the transition to adulthood?

## Entrevistas con padres

El propósito de reunirnos con usted hoy, y de la conferencia virtual que tuvimos el verano pasado, es ayudarlo a conocer las opciones de educación y servicios de su hijo o joven adulto, particularmente en lo que respecta a las discapacidades del desarrollo.

Para obtener más información sobre lo que la escuela de su hijo y el centro regional podrían estar haciendo mejor y cómo podemos ayudar, tenemos algunas preguntas para hacerle. Todas sus respuestas se anotarán. NO usaremos su nombre; todo seguirá siendo confidencial.

**Primero, nos gustaría preguntarle sobre el centro regional. ¿Está su hijo registrado en el centro regional?:**

1. ¿Ha estado alguna vez allí o ha tenido una visita virtual?
  - a. En caso afirmativo, ¿cuántas veces ha estado allí o ha tenido una cita virtual?
  - b. ¿Se comunicó con el centro regional o alguien de el centro regional se comunicó con usted?
2. ¿Cuál fue la razón por la que se comunicó con el centro regional o el centro regional se comunicó con usted?
3. ¿Con quién hablaste allí? ¿Cuál fue su rol? (Nota: intente al menos aprender sobre el rol que tenía esa persona: coordinador de servicios, psicólogo, etc.)
4. ¿Le ayudo?
5. ¿Cómo te trataron?
6. ¿Qué tipo de servicios espera obtener del centro regional?
7. ¿Hay cosas que el centro regional podría estar haciendo para ayudarlo más?
  - a. ¿Qué cambiarías?
  - b. ¿Qué te gusta que hace el centro regional?

**Ahora le voy a preguntar sobre la escuela de su hijo.**

1. ¿Tiene su hijo o hija un IEP o ITP (Plan de transición individualizado)?
2. Si tiene un ITP, ¿qué tan involucrada ha estado la escuela en la transición de su hijo o adulto joven?
3. ¿Cuál es la categoría de discapacidad / elegibilidad de su hijo en su IEP?
4. ¿Cuáles son algunas adaptaciones o servicios que recibe su hijo?
5. ¿Ha podido su hijo recibir servicios de aprendizaje a distancia?
  - a. En caso afirmativo, pregunte: ¿Qué tipo de servicios recibe su hijo?
6. ¿Cuáles son algunas metas y prioridades que tiene para su niño / joven? (por ejemplo, estudios postsecundarios, empleo, etc.)
7. ¿Todavía hay servicios que necesita para su hijo en la escuela o en la comunidad?
8. ¿Cómo ayudarían estos con la transición?

## Appendix D. Social Validity Questionnaire

1. I enjoyed this parent mentoring meeting.
  - a. Strongly agree
  - b. Agree
  - c. Disagree
  - d. Strongly disagree
2. I received information about autism and intellectual disabilities.
  - a. Strongly agree
  - b. Agree
  - c. Disagree
  - d. Strongly disagree
3. The mentors and leaders of this meeting were respectful of me and my culture
  - a. Strongly agree
  - b. Agree
  - c. Disagree
  - d. Strongly disagree
4. The presentation and materials of the meeting were accessible in my preferred language.
  - a. Strongly agree
  - b. Agree
  - c. Disagree
  - d. Strongly disagree
5. The questions and responses during the meeting were:
  - a. Very useful
  - b. Useful
  - c. Somewhat useful
  - d. Not useful
6. I would recommend this type of parent mentoring meeting to other parents.
  - a. Very likely
  - b. Likely
  - c. Somewhat likely
  - d. Not likely
7. It is likely that I will attend this meeting next year.
  - a. Very likely
  - b. Likely
  - c. Somewhat likely
  - d. Not likely
8. My general opinion of the SEARCH Center is:
  - a. Very positive
  - b. Positive
  - c. Negative
  - d. Very negative

## Cuestionario de validez social

1. Disfruté de esta reunión de tutoría para padres.
  - a. Totalmente de acuerdo
  - b. Estar de acuerdo
  - c. Discrepar
  - d. Muy en desacuerdo
2. Recibí información sobre autismo y discapacidad intelectual.
  - a. Totalmente de acuerdo
  - b. Estar de acuerdo
  - c. Discrepar
  - d. Muy en desacuerdo
3. Los mentores y líderes de esta reunión fueron respetuosos conmigo y con mi cultura.
  - a. Totalmente de acuerdo
  - b. Estar de acuerdo
  - c. Discrepar
  - d. Muy en desacuerdo
4. La presentación y los materiales de la reunión fueron accesibles en mi idioma preferido.
  - a. Totalmente de acuerdo
  - b. Estar de acuerdo
  - c. Discrepar
  - d. Muy en desacuerdo
5. Las preguntas y respuestas durante la reunión fueron:
  - a. Muy útil
  - b. Útil
  - c. Algo útil
  - d. Inútil
6. Recomendaría este tipo de reunión de tutoría para padres a otros padres.
  - a. Muy probable
  - b. Probable
  - c. Algo probable
  - d. No es probable
7. Es probable que asista a esta reunión el próximo año.
  - a. Muy probable
  - b. Probable
  - c. Algo probable
  - d. No es probable
8. Mi opinión general del SEARCH Center es:
  - a. Muy positivo
  - b. Positivo
  - c. Negativo
  - d. Muy negativo

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## About the SEARCH Center

The University of California, Riverside SEARCH Family Autism Resource Center has been funded by the Department of Developmental Services (DDS) to provide resources, education, and support to families with intellectual and developmental disabilities (IDD). The mission of SEARCH is to provide Support, Education, Advocacy, Resources, Community, and Hope to families who have autistic children and to individuals with ASD themselves. In partnership with DDS, the SEARCH center has organized family conferences, webinar series, and parent mentoring programs to assist families in their journey to obtain services and resources for their children with IDD. Our hope is to provide parents and families in the Inland Empire with individualized support, education, and advocacy-related services during key transitional periods.

## Funding and Contact

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### Contact Information:

SEARCH Center  
searchcenter@ucr.edu

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