Identifying Barriers to Accessing Supports and Services for Chinese American Families who Have Children with Disabilities

LEND Capstone Project

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Capstone Project Objectives

• Improve communication with Chinese families from different cultural backgrounds
• Increase cultural responsiveness
• Increase knowledge about supports child with disability in the Chinese-American community
• Increase service utilization by Chinese American families who may be underserved
Methods

1. Literature review
2. Gathered information from families at PRO
3. Analyzed transcripts for themes
4. Comparing the findings from the literature and actual experiences of families
5. Present at PRO conference (4/19/18)
6. Share the results and recommendations with PRO
7. Develop next steps with PRO
Literature Search & Review

• Search terms “Chinese American Families” and “Children with Disabilities”
  “Developmental Disabilities”
  “Family-Centered Services”
  “Access to Services & Resources for disabilities”
  “Views of disabilities”
  “Advocacy for children with disabilities”

• Chose 10 articles and focused on 8 articles

• Summarized review by author, title, purpose and issues identified.
Literature Review Summary

• Identified issues related to barriers between the family of child with disability and the service of providers.

• 1st major issue: barriers related to language:
  • Accessibility of quality interpreters
  • Home-school communication
  • Poor interpretation services
  • The lack of bilingual service providers
  • The lack of communication concordance between Chinese American families and service professionals
  • The lack of knowledge about resources because of the language barrier
Literature Review Summary

• 2\textsuperscript{nd} major issue
  • Challenges related to service providers lacking knowledge about working with Chinese American families – need for cultural sensitivity

• 3\textsuperscript{rd} major issue
  • Barriers related to lack of knowledge about disabilities and services as a result of language issues including lack of parent education, lack of resources in Chinese, mismatched expectations, and cultural beliefs
Supporting organizations to serve Chinese American families

• Based on the literature review, I believe parent service organizations should:
  • Provide bilingual services that includes interpretation and translation of Chinese materials related to disability information
  • Identify agencies to partner in developing resources
  • Create opportunities for professionals to learn and know different cultures to improve quality of services
  • Provide some training for Chinese American families who have children with disabilities to educate and empower them
PRO Program Improvement Process

- Identify partners (PRO, Asian Center)
- Secure meeting place & develop flyers
- Develop process of information gathering:
  - Pre assessment, Word Association,
  - Questions for information gathering for program improvement
- Invite participants and conduct the meeting
- Analyze transcripts from the meeting by identifying themes
- Compare experiences of participants with findings from the literature
• Collaborated with PRO to gather information on experiences of Chinese American families
• There were 16 participants in this activity including four facilitators
• Purpose:
  ▪ Bridge any gaps in supports and knowledge base between families and providers.
  ▪ Increase understanding of their experiences including any challenges they face in accessing services and supports;
Pre-Assessment survey

• Results:
Participiants responded “limited” or “None”:
  • What do you know about disability? 7/10
  • What do you know about accessing services? 8/10
  • What do you know about disability rights? 7/10
  • What do you know about PRO? 8/10
  • What do you know about the Asian Family Center? 6/10

• The participants had limited knowledge of disability, services available, rights, and resources

• The meeting was the first time they learned about Parents Reaching Out.
Word Association Activity: (词语联想活动)

1. When you hear the word “disability” what comes to mind? What do you think about? 当你听到“残障”这个词时，会想到什么？你有什么想法？
   “Child with disability” “残障儿童”

2. What are the Asian views of disability? (Causes? Intervention? Beliefs?) 亚洲人对残障人士的看法是什么？(原因？干预？信仰？)
## Emerging Themes

**Word Association Activity:**

1. When you hear the word “disability” what comes to mind? What do you think about?

<table>
<thead>
<tr>
<th>Social Issues</th>
<th>Cultured Views</th>
<th>Feelings</th>
<th>Equipment-Supports</th>
<th>Stressors</th>
<th>Needs</th>
<th>Types of Disabilities</th>
<th>Stereotype</th>
</tr>
</thead>
<tbody>
<tr>
<td>Be discriminated and isolated</td>
<td>• It is possible that a child has a disability when a woman got pregnant as the full moon. • The ancestor did a bad thing • Bewitched • It's the retribution of God</td>
<td>• Inconvenient</td>
<td>• Cane</td>
<td>• Poor</td>
<td>• Educational support • The attitudes of parents towards disability should be improved because of parents who born in China. • Sympathy, respect, and understanding as possible.</td>
<td>• No communication • Abnormal behavior • Physical disability • Heterogeneous</td>
<td>• Stupid • Blind • Deaf • Autism • Physical disability</td>
</tr>
<tr>
<td>Family shame</td>
<td></td>
<td>• Exhausting</td>
<td>• Braille</td>
<td>• Need help and financial aid</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Stigma</td>
<td></td>
<td>• Hopelessness</td>
<td>• Wheelchair</td>
<td>• The stress of financial</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parental rejection</td>
<td></td>
<td>• Heavy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Discrimination</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Isolated</td>
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</tr>
</tbody>
</table>
Summary of Word Association

Examples of each theme:

- Social Issues
  E.g., Be discriminated and isolated
- Cultured Views
  E.g., The ancestor did a bad thing
- Feelings
  E.g., Hopelessness
- Stressors
  E.g., Need help and financial aid
- Types of disabilities
  E.g., Physical disability
- Stigma
  E.g., Stupid, Abnormal
Needs and Challenges (需求/挑战)

1. What kind of needs do you think as a family of child with disability?
   您认为作为一个残障儿童家庭有什么样的需求？

2. In your experience, what are some challenges (barriers, difficulties) the families may face or experience? (#2)
   根据你的经验，这样的家庭可能面临或遇到哪些挑战（障碍，困难）

3. What makes it difficult to access services and supports for the family of child with disability? (#2)
   根据你的经验，是什麽使得这样的家庭难以获得支持和服务？

4. What makes it hard for the family of child with disability to get assistance? (#2)
   根据你的经验，是什麽使得这样的家庭难以获得援助？
## Emerging Themes: Needs

<table>
<thead>
<tr>
<th>Advocacy</th>
<th>Services</th>
<th>Information</th>
<th>Adult</th>
</tr>
</thead>
</table>
| • Protect the siblings of child with disability to avoid the bully.  
• Improve the awareness of the public. | • Available related services at no cost  
• Evaluation system  
• Lifespan supports  
• Sped referral procedures  
• Taking care, love, money, and time  
• Transition services  
• Listen to the voice of parent of child with disability. | • Guardianship  
• Educational supports  
• Information about DD waiver and Mia waiver. | • Independent living skills  
• Job-related skills training. |
Summary of Needs

Example of each theme:

- **Services**
  E.g., Lifespan supports

- **Information**
  E.g., Information about DD waiver and Mia Waiver in native language

- **Advocacy**
  E.g., Improve the awareness of the public

- **Adult**
  E.g., Independent living skills
### Emerging Themes: Challenges

<table>
<thead>
<tr>
<th>Language Barriers/ Information</th>
<th>Knowledge</th>
<th>Belief/ Culture</th>
<th>Stressors: Problem/ Social Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Don't know the related information of services and the related law/policy</td>
<td>• Need more knowledge of the U.S. welfare system</td>
<td>• Others have superstitions affecting individuals.</td>
<td>Financial stress:</td>
</tr>
<tr>
<td>• Lack of information of referral procedures</td>
<td>• Newly immigrated families may not know about the medical services available to them</td>
<td>• The cultural shame cause people not seeking out help</td>
<td>• The stress of financial</td>
</tr>
<tr>
<td>• Lack of understanding of self-advocacy</td>
<td>• Don't know the about disability</td>
<td>• Family rejection</td>
<td>• Limited employment</td>
</tr>
<tr>
<td>• Lack of information of how to access to the related services</td>
<td>• Don't know how to ask for help</td>
<td>• Being shamed to ask for help</td>
<td>• The stress of financial cause tough relationship between the mother and the father.</td>
</tr>
<tr>
<td>• Lack of understanding of U.S. educational system</td>
<td>• Misunderstanding</td>
<td>• The barrier of culture and beliefs</td>
<td>• If the related services are affordable</td>
</tr>
<tr>
<td>• Lack of words to accurately describe certain disabilities</td>
<td></td>
<td>• Stigma</td>
<td>Psycho-emotional stress:</td>
</tr>
<tr>
<td>• The limited information and resource</td>
<td></td>
<td></td>
<td>• It's hard to find the hope of life because of child with disability</td>
</tr>
<tr>
<td>• Information related to special education services</td>
<td></td>
<td></td>
<td>• Psychological frustration</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Having no normal life</td>
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<td></td>
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<td></td>
<td>• The problem of emotion</td>
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<td></td>
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<td></td>
<td>• All kinds of inconvenient in routines</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• It's hard to engage in the society and the human</td>
</tr>
</tbody>
</table>
Summary of Challenges

Examples of each theme:

• Language Barriers
  E.g., Lack of information of referral procedures

• Knowledge
  E.g., Newly immigrated families may not know about the medical services available to them

• Belief/Culture
  E.g., The cultural shame cause people not seeking out help

• Stressors: Problem/ Social Issues
  E.g., Narrow employment
1. What are ways that PRO can connect with Asian families? (#1)
你认为父母拓展中心与这样的家庭建立联系的方式有哪些？

2. What resources and information will be helpful? (#3)
你认为什么样的信息资源对这样的家庭最有帮助？

3. What supports and services do families need? (#3)
你认为这样的家庭最需要什么样的支持和服务？

4. What suggestions do you have to improve advocacy? (#4)
你对提高政策倡导有什么建议？

5. How can families get more involved in Pro or other programs? (#4)
你认为这样的家庭如何参与到父母拓展中心或者类似的项目中？
## Emerging Themes: Strategies for PRO

<table>
<thead>
<tr>
<th>Establish the effective approaches to connect with family of child with disability.</th>
<th>Build up the convenient resources for the family of child with disability</th>
<th>Develop and explore the useful services for the family of child with disability</th>
<th>Create the social media such as the film, the story, and so on to advocate.</th>
<th>Create more opportunities for the family of child with disability engage in the Parents Reaching Out.</th>
</tr>
</thead>
</table>
| - **PRO** can cooperate with other organizations such as AFC, and disseminate the mission of PRO to different people.  
  - Sharing the links of other organizations on the website of PRO.  
  - Spread the information about PRO program, so friends may give the information to those who needed.  
  - Looking for opportunities to connect with Asian/Chinese oriented organizations.  
  - **PRO** should reach out the Chinese American family with proactive.  
  - **PRO** should establish the good relationship with the visit family, and provide the specific and effective strategies such as how the parents communicate with the school, how the parents bring their child to do the medical examination, and so on.  
  - **PRO** should collaborate with APS, the Chinese School in Albuquerque, and AFC.  
  - Providing the service information and disseminate the mission of organization by some kinds of social activities.  
  - Enhance the relationship with different communities. | - First of all, providing a guidance of service with the native language, and this guidance list several ways to access the service.  
  - **PRO** should provide the guidance of service with the native language, and this guidance list several ways to access the service. | - Depending on severity or nature of the disability, a dedicated bilingual liaison to work on the individual case in question may be needed.  
  - **PRO** should consider the severity or nature of the disability, and assign a dedicated bilingual liaison to work on the individual case in question. | - Release some stories of people with disability through the social media like the internet and TV, and make people with disability be known with sincerely by the society.  
  - Filming a documentary about the Chinese American experience, to populate media sources with issues in the Chinese American community.  
  - Making a law and disseminate the awareness of people with disability.  
  - Propose the bills to the legislators. | - **PRO** can cooperate with other organizations such as AFC, and disseminate the mission of **PRO** to different people.  
  - Providing the service information and disseminate the mission of organization by some kinds of social activities.  
  - Enhance the relationship with different communities.  
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  - **PRO** should collaborate with APS, the Chinese School in Albuquerque, and AFC.  
  - Providing the service information and disseminate the mission of organization by some kinds of social activities.  
  - Enhance the relationship with different communities. | - Regular training, lecture, and other activities to build up the relationships with parents.  
  - Providing the real help for parents. For example, how to eliminate the negative thoughts such as giving up because of exhausted or frustrated.  
  - Proactive parenting. Parents need to care about their children. Incentives for such parents to need to participate in.  
  - Creating an opportunity of sharing family stories to make **PRO** find the strategies match their needs.  
  - Conducting a support group to share and support for each other in this group.  
  - Recruit the volunteers |
Strategies for PRO

• Establishing effective approaches to connect with families
  • E.g., Looking for opportunities to connect with Chinese/Asian oriented organizations during events and festivities.
• Building up accessible, linguistically and culturally appropriate resources
  • E.g., Providing a guidance of service with the native language, and this guidance list several ways to access the service.
• Developing and exploring useful services and training
• Creating social media such as the film & the story for advocacy
• Creating more opportunities to engage families
Tour of PRO highlighted reality that resources are in Available in English and Spanish but not Mandarin
1. The barriers identified in literature review and families sharing their experiences were similar in 3 areas: language, lack of knowledge about disabilities, and cultural beliefs.

2. One difference that participants shared in the information gathering session were barriers related to the social issues including stressors:
   • Financial stress causing difficulties in relationship between the mother and the father or being able to afford therapies
Conclusions/Recommendations

1. Disabilities must be viewed within a cultural context. In addition, people from different cultures sometimes view the causes of disabilities in children in various ways.

2. Based on my literature review and the information gathering, I think it is common that those from other cultures may consider fate, bad luck, sins of a parent, the food the mother ate, or evil spirits to be potential causes of disabilities.

3. These alternative views affect the way a child with a disability is viewed within the culture and the types of intervention services that a family may be willing to pursue to address the child's disabilities or special needs.
4. As professionals or educators work with families, we should address these issues and reflect sensitivity to the various perspectives family members bring to conversations about individuals.

5. As a professional service organization, we should pay attention to listen to the voices of Chinese American families who have children with disabilities. Provide the native language service information as well.
What I have learned from LEND

- LEND program created and provided opportunities for me
  - to learn with interdisciplinary friends;
  - to do my capstone project, and offer me a great mentor;
    - I can make sense what is the capstone project
    - My mentor taught me how to narrow down my topic and how to do the literature review
    - My mentor taught me how to analysis the information or data
    - My mentor always be there to provide me strong supports
  - to have a chance to enter into a family and to identify their voices, needs, challenges;
  - to learn what I should learned more practical knowledge such as elevator speech, evidence-based research, ABA, FASD, and so on;
  - to have many great chances to widen my perspectives such as going to roundhouse in Sante Fe, attending the Imagine Conference Information, and the Disability Policy Senimer in Washington DC.
What I want to say

For more appreciation, I can not believe I attained this great learning opportunity meanwhile I can have the stipend. To be frankly, the stipend is helpful a lot for me to support my learning without distraction.

In a word, I do appreciate all of programs provided supports for me including Mrs.Sandy, Alyx, Angela, Mr. Max, and my mentor Prof. Christine, and so on.
References


Thank you very much for your patience!