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CA-LEND Leadership Project
Final Presentation

Parent Peer Mentor Program for Families of Children with Initial Autism Diagnosis

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ABSTRACT

In August 2024, a Surgeon General report identified parental stress as an urgent public health issue. Parents of children with neurodevelopmental disorders often experience even higher rates of stress. Drawing on research related to parent mentor programs for other pediatric chronic medical conditions and informed by clinical insights, our leadership project resulted in a proposal for a parent peer mentor program for families of children with an initial autism spectrum disorder (ASD) diagnosis.

The goals of our program are to:

1) Decrease initial and ongoing levels of reported parental stress associated with managing a new and lifelong diagnosis
2) Provide pertinent information about and facilitate connections to supportive local resources, such as the Regional Center, local school districts, local family resource centers, and/or parent support groups or networks
3) Improve knowledge of and increase the rates of parent connections with essential resources and services related to families with children with ASD.

Project Plain Language Summary

- Parental stress is a growing public health concern, especially among parents of children with neurodevelopmental disorders such as autism spectrum disorder. To help address this, a parent peer mentor program was proposed to support families after an initial autism diagnosis, where a more experienced parent peer provides initial parent-to-parent support and resource navigation. The program aims to reduce stress, share helpful information, and connect families with local support services and with other families with a similar lived experience. It draws on successful models used in other pediatric conditions and clinical experience.

Project Rationale

- Parental stress + even further increased rates of parental stress in parents of children with NDDs
- Variation in initial information received by families around diagnosis and available resources
- Variability in health literacy, preferred methods of receiving information
- Cultural and language considerations; this may include parental/family understanding or acceptance of NDD
- Potential delays to care/therapeutic interventions
- Differences in structure and available services amongst clinics, Regional Centers, Family Resource Centers, and schools (public vs. non-public)
- Value of parent/peer mentoring with other disease processes (Berry-Carter et al., 2021)
- Benefits of experienced parent mentorship as shared during the LEND Lived Experience panels and in clinical practice

Literature Review Summary

- Peer/parent mentoring programs are effective at reducing stress and anxiety and increasing parent confidence navigating systems of care for other chronic conditions (Berry-Carter et al., 2021; Kidd et al., 2022)
- Parent-to-Parent programs for parents of children with NDDs have the potential to improve emotional well-being and improved satisfaction with disability services. However, in one ASD specific study, utilization of outside services (outside of school) still did not meet the national recommendation (Moody et al., 2019)
- Pre-existing programs like JumpStart provide adaptable program frameworks (Tolmie,Bruck, & Kerslake, 2017; Matthews et al., 2018).

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Stakeholder Interview

- Attempts were made to connect with Regional Center contacts
  - Unsuccessful despite multiple attempts, including multiple RCs
- Informal interview with Children's Hospital Los Angeles Rett Syndrome parent mentor, Sherri Brady, who is also the local SoCal representative for the International Rett Syndrome Foundation
  - Family Empowerment Representative
  - Benefits: shared lived experience, connectedness, language to use, flexibility, opportunities for ongoing support and involvement
  - Barriers: changes to CHLA policies around in-person volunteers during COVID-19, time commitment, and initial engagement with families
- Informal interview with CHLA Family Resource Center

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Project Objectives

- To decrease initial and ongoing levels of reported parental stress related to managing a new and lifelong diagnosis
- To provide pertinent information about and facilitate connection to supportive, local resources such as the Regional Center, local school district, local family resource center, and/or a parent support group or network
- To improve knowledge of and rates of parent connection with important resources and services related to families with children with ASD

Formal Needs Assessment

Given the time constraint and scope of this initial proposal, this was not completed

Needs assessment based on research findings, (informal) interviews with parents and stakeholders, and clinical experience

In the future, a needs assessment survey would be completed after receiving initial ASD diagnoses and before connection with a parent peer mentor (included in Service Model Proposal on the next slide)

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Service Model Proposal

- Parent-to-parent navigator program piloted at the CHLA NDD clinic
  - Parent(s)/Family offered a referral to participate in the program and connect with a parent mentor upon receiving a new ASD diagnosis
  - Parent(s)/Family complete an initial survey (needs assessment) before the first meeting with the parent mentor
    - Includes parent stress measures (Likert Scale), knowledge assessment of available resources, availability, and preferred method of contact
  - Parent mentor, ideally in the local area, contacts new diagnosis parent(s)/family
    - Parent mentor allows time/space for parent(s)/family to bring up initial questions, concerns, and then runs through an established initial checklist
    - Schedule follow-up connection x 1 (within 3 months) and then again on an as-needed basis, offered at 6 and 12 months.
  - Follow-up surveys completed at 12 months.

Project Plan

CDCynergy Model for Health Communication

- Phase 1: Review of existing literature pertinent to parental stress and parental peer mentorship programs for NDDs and other chronic medical conditions (ongoing)
- Phase 2: Consult with family resource support experts (CHLA, LEND, Family Resource Center, Regional Center, existing peer mentor programs)
- Phase 3: Draft outline of project pilot proposal
- Phase 4: Administer pilot program starting at CHLA
- Phase 5: Identify plans for project expansion based on pilot results

Barriers

- Bureaucratic challenges getting program approved
- Volunteer vs. Employee status of parent mentors
  - Compensation for time
  - Credentialing and/or hospital access
    - Phone or virtual meetings alternatively
- Availability of parent mentors
- Standardization
- Personal biases

Alignment with LEND Values

- Plan for Family- Person- Centered Perspective
  - Will allow families the opportunity to connect, receive standardized information about navigating a new ASD diagnosis but also the opportunity to receive informal colloquial insight from peers
- Plan for Interdisciplinary Perspective
  - Requested consultation with family support scholars, regional center leadership, and parents with lived experience
- Plan for Health Equity Perspective
  - Ensure all families receiving a new ASD diagnosis are provided with the opportunity to participate in a parent/peer-driven support program
  - Cultural sensitivity- having multiple parent leaders from diverse backgrounds

Community (Title V) Agency Interface

- DDS/Family Resource Centers/Regional Center
  - Contacts:
  - Yvette Baptiste, PhD, Executive Director of Eastern LA Family Resource Center
  - Liz Spencer, Executive Director, Westside Regional Center Family Empowerment and Resource Center
- *As people familiar with these agencies it is hard to establish contact with relevant contacts. This underscores the frustration many families likely feel in navigating these systems without high levels of baseline institutional knowledge.*

Lessons Learned/ Next Steps

- Time, resources, dedication, and initial and ongoing support are needed to bring a project like this to life
- Resources and services exist in many areas or may be available virtually/remotely. However, families don't know what they don't know.
- Challenges families likely face when attempting to contact supportive service providers
- Alternatives that can be created or developed in the meantime
  - One to two-page key information sheet that can be provided to families after a diagnostic evaluation
  - Partnership with local Family Resource Center or Regional Center to offer parent mentorship through existing support services, network

Questions for the Audience, Invitation for Feedback

- Have patients/families you have worked with experienced similar challenges connecting with key service providers such as the Regional Center? What was the most helpful information they received regarding approaching/contacting these organizations?
- Any feedback on information to include on a one to two-page initial information sheet

Sources

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