LEND Leadership Project

Proposal for a Parent Peer Mentor Program for Families of Children Newly Diagnosed with Autism Spectrum Disorder

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Project Goal: To develop an outline for a parent-to-parent mentor program to support parents and caregivers of children newly diagnosed with Autism Spectrum Disorder. The target location for the initial pilot program is the Neurodevelopmental Disabilities (NDD) Clinic at Children's Hospital Los Angeles, with the possibility of expanding to additional local clinics.

Background

A Surgeon General report in August 2024 identified that over half of parents felt overwhelming amounts of stress, labeling parental stress an urgent public health issue. Rates of parental stress can be even higher in parents of children with neurodevelopmental disorders (NDDs) (Craig et al., 2016). As has come to light in recent discourse around families of autistic children, rates of stress may arise from a lack of access to comprehensive, coordinated services from systems of care dedicated to serving this population of children. A proposal for a parent mentoring program for parents of children newly diagnosed with autism spectrum disorder (ASD) arose from research, informal interviews, and clinical experience navigating the post-diagnosis period with families and recognizing a need for increased support, particularly with the learning curve associated with connecting to both child and family-oriented services. There can be significant variability in the information families receive and the timeline in which they receive it. This can be influenced by various factors, such as parental health literacy, parental learning styles, language and cultural barriers, total time spent with the diagnostician and the provider works alongside with a multidisciplinary care team that also provides initial and ongoing support, and variability in the infrastructure or availability of resources based on a family's residence.

Of note, parent-to-parent mentoring programs have been found to be valuable for both neurodevelopmental disorders and other chronic medical conditions. A study by Barry-Carter et al. reviewed the benefits of connecting parents of children newly diagnosed with cancer with veteran parents and found that doing so reduces feelings of anxiety and isolation (2021). Parent programs connecting parents of gender diverse youth have also demonstrated utility in relieving parental stress and increasing connection to appropriate services (Kidd et al., 2022). Well-developed parent mentoring programs, such as Arizona's JumpStart, which provides parent resources and information around topics such as Applied Behavioral Analysis, Challenging Behavior, and other Autism Services for parents of children with a new ASD diagnosis or high suspicion and pending a formal evaluation, provide a structured framework for consideration when developing a similar program in our clinical communities.

Based on information gathered through informal interviews with family support personnel at Children's Hospital Los Angeles (CHLA), parent-to-parent mentor programs exist informally in various clinics and may be affiliated with larger foundations, as is the case with the Rett Clinic at CHLA. Through an informal phone interview with Sherri Brady, the parent mentor for the CHLA

Rett Clinic and the International Rett Foundation, our team gathered relevant information about program development and structure, implementation, key resources and stakeholders, potential barriers, and alternative parent educational materials that could be developed while trying to get a similar program for the CHLA NDD clinic initiated. Additional details can be found in the Objectives and Service Model Proposal sections.

Overall, parent-to-parent mentoring programs are generally feasible, relatively low-cost, sustainable over time, and may reduce feelings of stress and isolation that are prevalent in parents and caregivers of children newly diagnosed with ASD. They may also support timely connections to appropriate resources and services, which can improve both patient and family health outcomes.

Assessment of Need

As mentioned, the idea for a parent-to-parent mentoring program was born from clinical experience and parent narratives detailing the significant degree of stress felt in the first 6-12 months following a neurodevelopmental diagnosis. This clinical experience is corroborated in the literature. Studies show that parents of children with ASD and ADHD report the highest levels of stress under the umbrella of children with NDDs (Craig et al., 2016). Several theories and frameworks, along with everyday qualitative observations in the clinical environment, underscore why this may be the case. One such framework is the transactional model of parenting (Abidin, 1995), which outlines the bidirectional nature of sociological, psychological, and environmental factors that influence parental stress levels. The Abiden Parental Stress Index (PSI) assesses parental stress across three domains: parent characteristics, child characteristics, and situational/life demographics. In addition to using a validated measure like the PSI in a formal assessment of need, the framework supports the inference that parents of children with special health and behavioral needs may face increased amounts of stress, especially when their particular life circumstances prevent them from accessing necessary resources. Prompt referral and connection to appropriate and available resources is crucial for mitigating the stress that families may feel from being under-supported, particularly as this stress may prohibit families from accessing important services and therapies known to improve developmental outcomes in the long term, such as those offered by the Regional Center and local school districts.

While this current project proposal is informed primarily by clinical experience and literature review, below outlines the process for a more formal needs assessment to take place to justify the utility of a parent-to-parenting mentoring program in the CHLA setting:

- Gauging parent interest in a parent-to-parent mentoring program as part of intake information when receiving evaluation, assessment, and treatment at CHLA's Neurodevelopmental Disorders Clinic. A simple Likert scale could be administered to families at or shortly after their initial visit and upon receiving an ASD diagnosis, to help clinicians understand how helpful parents would find such an intervention.
- Additional information can be collected through the above survey to identify specific areas of parental need or educational opportunities due to a lack of knowledge of available resources. The program can then target specific areas of concern or address pertinent resources that families are not yet familiar with.

- Use of a more formal parental stress measure, like the PSI, could provide information about which types of parents are most likely to benefit from connecting to a parent mentor.
- To understand broader community needs, similar scales could be administered in community and private clinics to help expand both the pool of veteran parents and new parents interested in parent mentorship.
- Connect with local Regional Centers (RC) or Family Resource Centers (FRC) to see if a parent-to-parent mentor program is already established and if a warm handoff could be made. However, there may be barriers due to inconsistencies across RCs and FRCs.

Of note, attempts for an informal needs assessment were limited by our inability to connect with local Regional Center leaders. Although attempts were made, we believe this highlights the frustration parents often feel when navigating large bureaucratic systems after receiving new diagnoses. We believe that parent mentoring programs can be a tool in helping parents build resilience as they continue to advocate for their children within slow-moving public systems.

Objectives

The primary objectives of a parent-to-parent mentoring program for parents of children newly diagnosed with ASD are 1) to decrease initial and ongoing levels of reported parental stress related to managing a new and lifelong diagnosis 2) 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 3) improve knowledge of and rates of parent connection with important resources and services related to families with children with ASD. Related metrics include parent-reported stress levels and reported confidence in navigating relevant systems of care at 6 and 12 months following the initial diagnosis.

Service Model Proposal and Process- General Overview

- Parent-to-parent navigator program piloted at 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 prior to meeting with parent mentor
        - Includes Likert scale, knowledge of available resources, availability, and preferred method of contact
    - Parent mentor, ideally in 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 established initial checklist
        - Schedule follow-up connection x 1 (within 3 months) and then again on an as-needed basis, but offered at 6 and 12 months.
    - Follow-up surveys completed at 12 months

Potential Barriers include:

- 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

Alternatives to the Proposed Parent-to-Parent Program include:

- Connect families with available parent mentor navigator programs (RC, FRC, other community programs), ideally through an organized referral process to ensure families are able to make contact with a family or resource support person
- Providing families with a 1 to 2 page handout during the clinic visit with resource and service information and guidance on how to access
    - Included topics: Regional Center, Family Resource Center, and School District roles and contact; Individualized Education Program; Broad overview of evidence-based services and therapies; Other state & national support groups
    - Would need to evaluate readability and cultural sensitivity
    - Translate into multiple languages

Future Directions

Based on the success of the initial pilot program, the goal is to expand the program to additional clinics or organizations in the Los Angeles area that diagnose and serve children and families with ASD. A partnership with local RCs and FRCs could foster the growth and longevity of the program through established infrastructure, resources, and a large network of potential parent mentors. This would, no doubt, allow for the opportunity to reach more parents of children with an initial ASD diagnosis with the overarching goals of decreasing parental stress, improving knowledge and access to important resources and services, and thus improving timeliness of connection to these key resources and services. With decreased parental stress, improved knowledge, and timely access to resources and services, children with ASD and their families will experience improvements in health outcomes and feelings of connectedness, which can support the child's ongoing growth and development.