

## ABSTRACT

Healthcare transition for Children & Youth with Special Healthcare Needs [CYSHCN], particularly for those with cognitive and behavioral diagnoses such as autism spectrum and intellectual/developmental disorders [ASD/IDDs], has become a major focus recently as efficacious interventions have increased quality of life for some, and life expectancy for many.<sup>1-3</sup>

➤ Barriers to successful and effective transition include the lack of exposure to ASD/IDDs in adult-focused training programs, and the resulting lack of practical experience in management of the requisite highly complex care for adults with ASD/IDDs.

LoneStar LEND developed a Transition Fellowship Curriculum to address such training gaps, which is applicable to multiple adult specialties, to improve the care of transitioning youths, and ultimately adults, with ASD/IDDs who are in such dire need of continuity of care.

➤ Program Goals include the acquisition of competency and comfort in providing long-term complex care through comprehensive training experiences, including:

- ✓ Rotations in specific child/ adult clinical disciplines,
- ✓ Focusing on the social, legal, economic, and policy aspects of appropriate transition and adult care for those with ASD/IDDs.

## INTRODUCTION

Healthcare transition for CYSHCN is a recent focus, largely because more efficacious interventions have increased overall life expectancy for many diagnoses.<sup>1-2</sup> CYSHCN with neurodevelopmental conditions pose particular challenges, and their transitions have therefore lagged behind other pediatric specialty disciplines.<sup>2-3</sup> A wide spectrum of neurodevelopmental disorders exist, including those with typical development, cognitive function, and/or behaviors, and those without, e.g., ASD/IDDs.<sup>2</sup>

- For children and adolescents with ASD/IDDs in particular, the transition process continues to be quite difficult to successfully implement.<sup>3</sup>
- Barriers include the lack of exposure to ASD/IDDs in adult specialty training programs, and the resulting lack of practical experience in managing the requisite highly complex care for adults with ASD/IDDs.
- Using recent data on neurological care as an example, in a 2012 survey of 103 adult neurologists in Quebec, Canada, none ‘strongly agreed’ and only 56% ‘somewhat agreed’ that their “residency... provided adequate training to care for young adults with childhood onset neurologic conditions.”<sup>4,5</sup> In addition, 89% reported they were either not comfortable [58%] or that it was not possible [31%] for them to treat adults with ASD, and 50% expressed similar feelings about the topic of other ‘cognitive or behavioral disorders.’<sup>4-5</sup>

## METHODS

- The LoneStar LEND developed a full-time PGY-5/6 Transition Fellowship Curriculum in memory of recent LEND graduate Akanksha Kamal, addressing her passion for appropriate transition services, especially for the underserved
- It is applicable to multiple adult disciplines, to achieve competency in treatment of adults with ASD/IDDs.
- In addition to the standard LEND curriculum, adult providers are exposed to pertinent child, adolescent & youth IDD/ASD experiences to create a foundation for the management of long-term care in adults.
- The Curriculum also provides sufficient flexibility to adjust the rotations according to the expertise of the Fellow.

## AKANKSHA KAMAL MEMORIAL LEND TRANSITION CURRICULUM

### PROGRAM GOALS:

1. To train adult-trained healthcare providers in the evaluation and management of common and rare ASD/IDDs through the lifespan, focusing on transition into adult care.
2. To facilitate clinical competence in the assessment of ASD/IDDs in adult-trained healthcare providers by:
  - performing detailed histories and examinations of the children, adolescent and adult patients presenting to a variety of pertinent clinic settings; and
  - by developing a working diagnosis and treatment plan for each patient to present to the supervisory attending faculty/ physician, and ultimately, to the family.

### CLINICAL ROTATIONS:

In addition to the standard components of the LoneStar LEND Curriculum:

- Seminars
- Clinical Practicums
- Families-as-Teachers
- Service-Learning Projects or Research
- Interprofessional Learning Leadership Weekend [UNC Model]
- Cultural & Linguistic Competency Workshops [NCCC Model]

the following rotations are included for a one-year full-time PGY-5 or 6 fellowship [ACGME approval pending]:

- *DEVELOPMENTAL NEUROLOGY CLINIC* [UTHealth, Filipek]
- *CHRONIC HEALTH ORIENTED SERVICES EL NIÑOS (CHOSen) Clinic* [Title V CYSHCN Complex Care, UTHealth, Holly Smith & Ebony Beaudoin]
- *MEDICAL GENETICS CLINIC & INPATIENT CONSULT SERVICE* [UTHealth, Hope Northrup]
- *MITOCHONDRIAL MEDICINE CLINIC* [UTHealth, Mary Kay Koenig]
- *TUBEROUS SCLEROSIS CLINIC* [UTHealth, Mary Kay Koenig & Hope Northrup]
- *PEDIATRIC EPILEPSY CLINIC* [UTHealth, Gretchen von Allmen]
- *CHANGING LIVES THROUGH AUTISM SPECTRUM SERVICES (CLASS) Clinic* [UTHealth, Kate Loveland]
- *SHRINERS HOSPITAL CHILD NEUROLOGY CLINIC - HOUSTON* [UTHealth, Multiple]
- *SOUTHWEST ADA CENTER/ INDEPENDENT LIVING RESEARCH UTILIZATION (ILRU) PROGRAM*, Memorial Hermann Texas Institute for Rehabilitation and Research [TIRR, UTHealth, Lex Frieden]
- *TRANSITION CLINIC* [Primary Care, Baylor/ Texas Children’s Hospital [BCM/TCH], Cynthia Peacock]
- *RETT RESEARCH CLINIC*, [ BCM/TCH Blue Bird Clinic, Daniel Glaze]
- *TEXANA IDD/MH CLINIC* [Texas State Agency “Local IDD Authority,” Multiple]
- *DOWN SYNDROME/ ALZHEIMER’S RESEARCH PROGRAM* [University of California-Irvine, Ira Lott]
- *TEXAS PARTNERS IN POLICYMAKING ADVANCED LEADERSHIP DEVELOPMENT TRAINING PROGRAM*, [Texas Council for Developmental Disabilities, Austin TX, Multiple]

## DISCUSSION

- Transition education is an essential component of continuity of care for individuals with ASD/IDDs. There are currently significant gaps in the training of adult specialists in regard to their knowledge and exposure to patients with ASD/IDDs, especially adult Neurologists and Psychiatrists.
- To our knowledge, this is the first clinical fellowship of its kind and we believe that this program will define the standards for specialty-specific transition training with a foundation based on the goals and objectives of the LEND Program.
- This Curriculum was designed to provide more than just comprehensive clinical training to care for adults with ASD/IDD, but also offers pertinent education regarding the socioeconomic and policy needs of these patients and clear understanding of the family/caregiver relationships which are essential to the support of the patient.

## CONCLUSIONS

The LoneStar LEND Transition Fellowship Curriculum provides foundational knowledge necessary for adult-trained providers to appropriately manage the care of individuals with ASD/IDDs, providing social, legal and economic aspects of transition care and beyond, and producing the expertise and ‘level of comfort’ necessary to provide adequate services to adults with ASD/IDDs who are in dire need of continuity of care.

## REFERENCES

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4. Oskoui M, Wolfson C. Treatment comfort of adult neurologist in childhood onset conditions. *Can J Neurol Sci* 2012a; 39:202-205.
5. Oskoui M, Wolfson C. Current practice and views of neurologists on the transition from pediatric to adult care. *J Child Neurol* 2012b; 27:1553-1558.

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