

Leadership Education in Neurodevelopmental Disabilities (LEND) Program
Westchester Institute for Human Development
University Center for Excellence in Developmental Disabilities
And
New York Medical College
Team Project Abstract
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Title: Transition of Young Adults who Receive Healthcare Services at the Renal Unit in the Pediatric Hospital of Puerto Rico

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Proposal Description

To evaluate parent's perception on the readiness of the young adults who participate at the Pediatric Renal Unit at the Pediatric Hospital of Puerto Rico and identify the needs and resources that parent consider must be present in the transition process from pediatric to adult services.

In order to achieve a transition process from a child/family-centered care to an adult-oriented healthcare system it becomes necessary to develop a purposeful and planned course of action that makes it possible for young adults with chronic conditions transition fluidly (Watson, Harden, Ferris, Kerr, Mahan & Ramzy, 2011).

Objectives:

- ❖ Develop a socio-demographic profile of the families of the young adults receiving dialysis treatment at the Renal Unit in the Pediatric Hospital
- ❖ Describe the aspects identified by the families as necessary for the transition process of their young adults from pediatric care to adult care
- ❖ Identify the services needed by the parents in charge of the care of young adults receiving dialysis treatment at the Renal Unit in the Pediatric Hospital

Method:

- ❖ Non-experimental transversal- descriptive design
- ❖ Data collection use of a questionnaire with close and open-ended question
 - Socio-demographic data (family composition and level of knowledge in diagnosis, treatment and medical condition)
 - Scale from the *Readiness for transition Questionnaire- RTQ* where parents rated the young patient's readiness level in activities related to personal care. $\alpha=.88$ (Gilleland & Sandra Amaral, 2012). Adapted and translated to Spanish.

Results:

- ❖ The majority of patients receive hemodialysis treatment (73%)
- ❖ The mean age of the patients was 18 years ($s= 1.66$), a time when they should already be in the final stages of the transition plan
- ❖ Most of the respondents were from monoparental families and unemployed
- ❖ The majority of the patients have both Medicare and Medicaid and private coverage
- ❖ Respondents perception about the patients' healthcare behaviors reveal that they are less involved in activities like Scheduling primary care

appointments, knowing details about your insurance coverage and attending medical appointments independently.

- ❖ The data also revealed that the patients possess skills that strengthen their social and emotional skills. These skills can help them to empower and adapt more easily to the transition, to get more involved with peers and to access support networks
- ❖ 46% of the study sample reported having no knowledge about the health care of adults while 54% have knowledge
- ❖ 73% of the study sample don't have a transition plan
- ❖ 70% of the parents consider that the young adults will be ready for transition within the next two years

Conclusion:

- ❖ The majority of the young patients don't have a transition plan.
- ❖ Families' perception about the patient's readiness to transition reveals that they are less involved in behaviors related to health care. Little involvement in such activities may result as a consequence of not having a formal transition plan
- ❖ Systems of care should develop transition protocols that benefit the population of children with chronic conditions
- ❖ The development of further research about transition with the population of children with chronic conditions in Puerto Rico is recommended