Assessing Educator Perceptions and Needs Regarding Guardianship and Supported Decision-Making

Zoey Calderon-Weinstein, Becky Cook, Trudy Fenster, & Sharon Williams, LEND Trainees; Tricia Patrick, DrPH, LEND Faculty

Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program
Westchester Institute for Human Development, University Center for Excellence in Developmental Disabilities and New York Medical College

Background

As students with disabilities approach adulthood, families are typically faced with the question of how to handle decision-making for them as legal adults. Options include:

- **Guardianship** is a legal process by which the courts take authority for decision-making away from the person with an intellectual disability and give it to parents or other interested parties.
- **Supported decision-making (SDM)** is a process by which a supportive network of individuals helps the person with a disability make his or her own legally-enforceable decisions.

This process is usually started at school with the distribution of materials regarding transition planning.

Methods

**Study Design.** A cross-sectional study has been done to gather information from educators and related professionals by using an online anonymous self-administered survey.

**Participants and Setting.** Educators and related professionals who have previously worked with the Community Support Network (CSN) at WIHD.

**Recruitment.** An introductory email and link to the online project survey (SurveyMonkey) was sent to CSN's established email distribution list as well as via CSN’s Facebook page and Twitter account. A reminder email was sent one month after introductory email. Survey was available for two months thru April of 2020.

**Data Collection Methods.** Investigators used SurveyMonkey to develop and distribute the online project survey. A sample of survey questions are shown below.

**Data Analysis.** Demographic data were first summarized; frequencies of responses to the survey questions were then calculated for the overall group.

This study has been approved by the IRB at New York Medical College.

Results

A total of 38 participants completed the survey as of April 2020:

- 81.6% were educators or related professionals who work with individuals with disabilities
- 61.1% were involved in the transition planning process
- 48.7% were both educators and parents of individuals with disabilities
- 59.4% were between 40 and 59 years of age; 37.7% were 60+
- 94.3% were female
- 91.2% were white
- 75.7% worked in the public school system
- 67.7% worked in a high school setting
- 32.3% have worked within the education system for 0-19 years; 67.7% have 20+ years

When asked if additional information was desired, 46% of participants wanted information on guardianship, 57.1% wanted information on SDM. Most requested this information via online resources/link (72.7%), brochures (50.0%), and webinar (40.9%).

Figure 1. Participant level of understanding (n=38)

- Guardianship is a legal process that gives a parent or family member custody of a child 18 years of age or older, especially if that child is unable to care for himself/herself.
- Once guardianship is given to a parent or family member, the adult with disabilities no longer has authority over his/her own legal decision-making.
- SDM allows individuals with disabilities to make their own decisions regarding finances, employment, living arrangements and healthcare with the support of identified adults who are aware of their preferences.

- 76.3% Strongly Agree
- 13.5% Agree
- 10.5% Uncertain

Figure 2. Participant perceptions/attitudes (n=38)

- Guardianship is the only option for my child and my family.
- Guardianship takes away the rights of an individual with disabilities.
- SDM empowers the individual with disabilities.
- SDM requires the individual with disabilities to have a certain level of understanding and independence.

- 73.7% Strongly Agree
- 23.7% Agree
- 2.6% Uncertain

Discussion

Educators who have previously served or engaged with WIHD's CSN have some understanding about guardianship and SDM; however, many participants did not realize that once a guardian is appointed, the individual with disabilities no longer has legal capacity. In addition, almost half of the participants disagreed with the notion that guardianship takes away the individual’s rights to make decisions. These findings indicate a lack of understanding of the legal construct of guardianship, which is especially of concern considering that the sample was predominantly comprised of educators working in public high school settings, one-third of whom have greater than 20 years of experience. Participants appeared open to the idea that SDM empowers individuals, provided that the individual has a certain level of understanding and/or independence. Approximately half of the participants were interested in receiving more information regarding guardianship and SDM, primarily via online resources and/or brochures. Given the misperception regarding guardianship, this presents an opportunity for further education on this topic as well as SDM.