Institute on Disability and Human Development (IDHD), University of Illinois at Chicago Susun Xiong, Meghan Burke and Tamar Heller August 2014

The IDHD through a contract from the Illinois Department of Public Health is conducting an evaluation of the *Ligas* Consent Decree. This brief focuses on the experiences of families/guardians of individuals with intellectual and developmental disabilities (IDD) who, as a result of *Ligas*, have recently moved out of a private Intermediate Care Facility (ICF/DD). A total of 101 surveys were completed.

Characteristics of Persons with Disabilities

Persons with disabilities (PWD) were on average 51 years of age (range: 22-89 years). The majority were White (82%), followed by African American (16%), Hispanic or Latino (1%), and two or more races (1%). Thirty-three percent of the individuals had lived in an ICF/DD for 21 years or more.

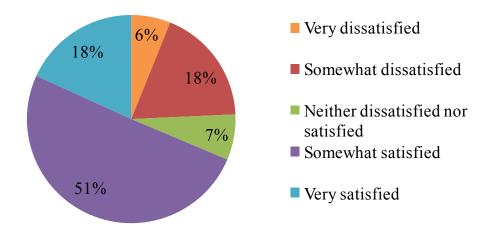
The family/guardian respondents were primarily women (59%). Over half of the respondents were family members: parents (33%), siblings (14%), and other relatives (7%). Twenty—two percent reported "other" (this may include but is not limited to: friends, extended relatives, guardians) as their relationship while almost a quarter of respondents were state guardians (24%).

Past Experiences with ICF/DD

As shown in **Figure 1**, 69% of family/guardians were satisfied with their past overall private ICF/DD experience. Among family/guardians:

- 55% felt that their *choices* were respected by the ICF/DD, 21% felt their choices were occasionally respected, and 24% that their choices were not respected.
- 59% of family/guardians felt their *concerns* were respected, 18% that their concerns were occasionally respected, and 23% that their concerns were not respected.

Figure 1: Family/Guardians Overall Satisfaction with Former ICF/DD





Transition Experience from ICF/DD to Current Placement

- About 56% of family/guardians were satisfied with the transition process. Eight percent were neither satisfied nor dissatisfied, while 36% reported dissatisfaction.
- During the transition, 47% of family/guardians felt their family member's opinions were often respected, 28% that they were occasionally respected, and 25% that they were not respected.
- With respect to the family/guardians' opinions during the transition process, 54% felt that their opinions were respected, 30% that their opinions were occasionally respected, and 16% that their opinions were not respected.

Experiences in the Current Setting

The majority of individuals moved from the ICF/DD to a community integrated living arrangement [CILA] (93%). Six percent moved to a family home, while 1% moved to an "other" setting. On average, the individuals with IDD had lived in their new setting for four months.

• About half (51%) of the individuals now have their own room (versus 22% in the ICF/DD).

The vast majority of respondents (92%) reported satisfaction with their current placement, including:

- 91% of family/guardians of individuals with <u>moderate</u> <u>maladaptive behaviors</u>,
- 96% of family/guardians of individuals with <u>severe</u> maladaptive behaviors, and
- 90% of those with <u>fair to poor health</u>.

"The CILA that is his current placement has surpassed all expectations."

Figure 2: Satisfaction with Current Placement

