

RESEARCH BRIEF

An update on HDI's research in the field of developmental disabilities

Mental Indices in Consumers with Disabilities

Kathy Sheppard-Jones, Ph.D.

Training Director, Human Development Institute;
Adjunct Assistant Professor, Department of Early
Childhood, Special Education and Rehabilitation
Counseling

Laura Smith Butler, M.R.C.

Policy Analyst, Belonging in the Community,
Human Development Institute

and

H. Thompson Prout, Ph.D.

Director of Research, Human Development Institute;
Professor, Department of Educational, School, and
Counseling Psychology

Kentucky's National Core Indicators project exists to develop a set of data elements that are used to report, on a statewide and national basis, the quality of services supporting people with disabilities. This is accomplished in Kentucky by performing a minimum of 400 direct interviews with consumers and their families annually. Collected data elements include outcomes related to quality of life, specifically: work, choice, independence, relationships, health and satisfaction. These elements represent an outcome oriented approach to quality assurance, and measure impact of services on peoples' lives. Given the longstanding involvement of Kentucky in this ongoing effort, additional examination of variables that have been the focus of policymakers is warranted. This research brief provides additional analysis of several mental health items, including loneliness, friendships, and use of psychotropic medications.

Method

Participants

Individuals age 18 and over who are receiving at least one service (in addition to case management) from the Kentucky Division of Intellectual and Developmental Disabilities (DDID) participate in NCI. Verbal and written consent must be obtained by the participant and the

Mental wellness is not a given for some of our state's most vulnerable citizens.

legal guardian (if applicable) prior to the interviewer contacting the individual. Key project personnel obtain this consent. Approximately 8,000 people have participated in NCI in Kentucky since 1999. The purpose of this study was to examine two dimensions of mental health status in consumers with disabilities, specifically loneliness/ friendship patterns and use of psychotropic medications.

Procedures and Instruments

A random sample of 1000 people is drawn annually from the universe of people receiving supports and services from the Division of Developmental and Intellectual Disabilities (DDID). In some years, the sample has consisted solely of Supports for Community Living waiver participants. Project interviewers contact potential participants to provide background on the project and

continued inside

obtain consent. Interviews are scheduled and conducted, primarily in a face to face format. Data are analyzed longitudinally and across states.

The study design is a form of survey research using a face to face format. Interviews are conducted with people receiving services from the state developmental disability authority or with people who know the consumer well (proxy). If a proxy participates, that respondent is not asked items that are subjective and relate to satisfaction or emotional state. Demographic information, including psychotropic medication use, is completed by case managers prior to the interview.

Data Analysis

Data analysis includes descriptive techniques, trend analyses, scale development, and other statistical tests to determine if differences exist over time and between participating states. Modifications to the survey instrument are discouraged, because they make comparisons over time more difficult. Yearly reports are compiled for the use of all participating states (available at www.nationalcoreindicators.org).

Reporting

The Division of Developmental and Intellectual Disabilities utilizes Kentucky's NCI data in planning and evaluation of state-funded services for people with developmental disabilities. NCI data are reported to the HB144 Commission on Services and Supports for People with Intellectual Disability and to Kentucky's NCI Quality Improvement Committee, consisting of members from KY NCI, KY DDID, consumers, families and researchers. The recommendations of the Quality Improvement Committee were instrumental in amendments to the SCL waiver that were rolled out earlier this year. Recommendations included making improvements in the areas of employment, health and wellness, use of psychotropic medications, and self-reported loneliness.

Results

Loneliness/Friends

Loneliness has been an item of great interest. Particularly in Kentucky, this item has shown increases over time. 2012-13 national data indicated that 41% of people felt lonely at least half of the time (n=8,486) versus 85% in Kentucky (n=290). This is the same percentage for SCL recipients.

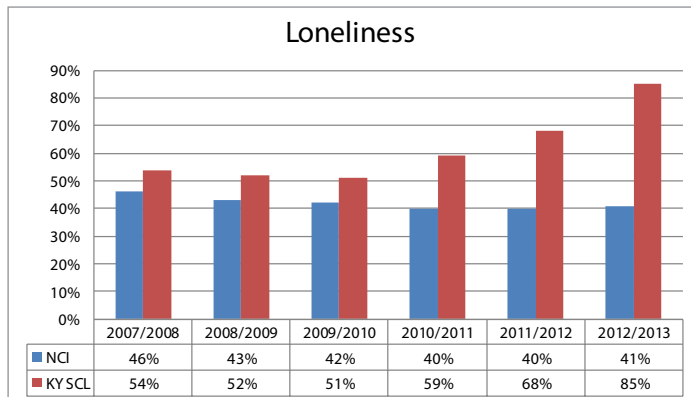


Table 1

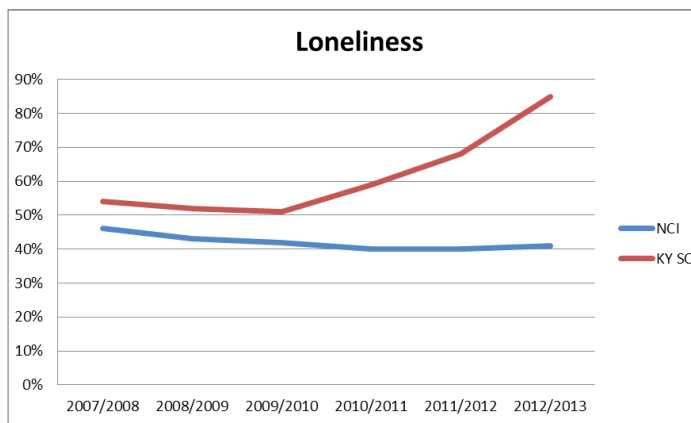


Table 2

Loneliness has been increasing over time in Kentucky, yet showing modest decreases nationally (see Tables 1 and 2).

To further assess the status of relationships, respondents were asked about relationships. In Kentucky, 37% of individuals on the SCL waiver reported having friends (who were not staff or family), as opposed to 77% nationally (n=8731). This item increased in Kentucky in 2012-13 from 2011-12 (see Tables 3 and 4) for SCL recipients. However, this item has also shown marked fluctuations over time in Kentucky. The national average has remained relatively consistent. It is interesting to note that other states also experience variation across years, but none are as marked as the changes in Kentucky.

Use of Psychotropic Medications

The use of psychotropic medications has been controversial both in the general population and with persons with disabilities. To assess this, items were asked about whether individuals took any medications for mental health purposes. These items were responded to primarily by case managers. As can be seen in Tables 5 and 6, consumers in Kentucky on the Supports for Community

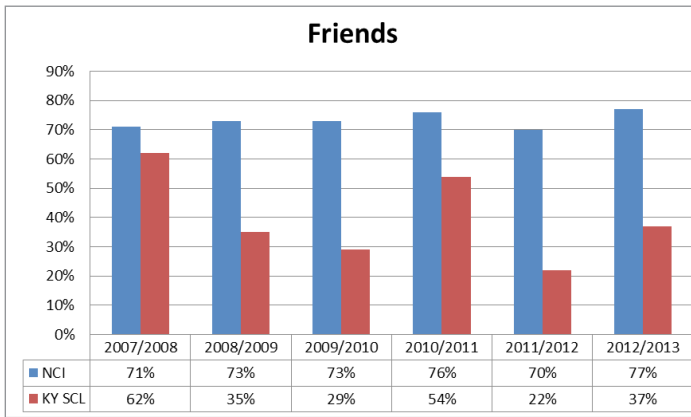


Table 3

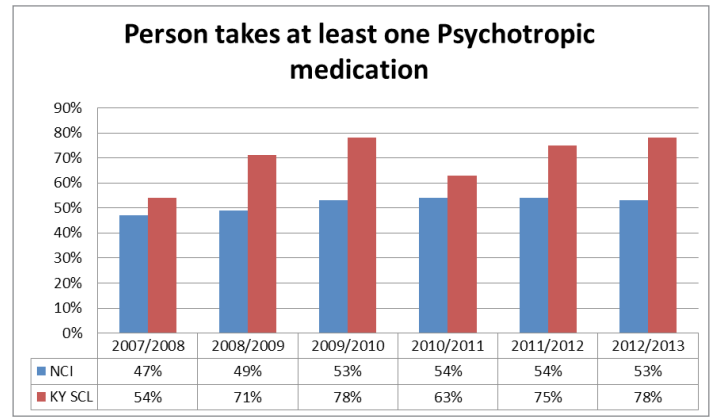


Table 5

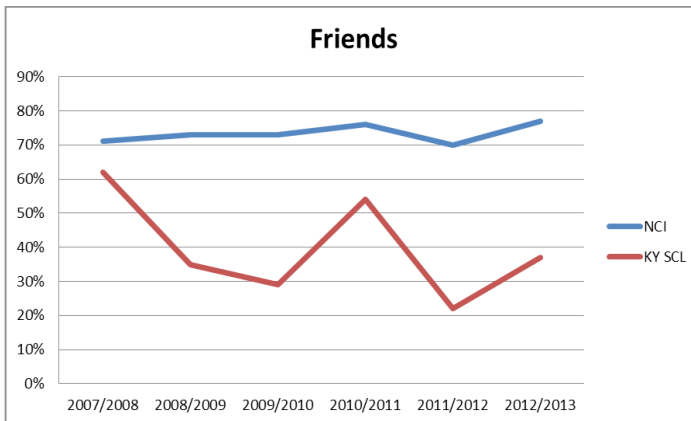


Table 4

Living waiver are being prescribed these medications at a higher rate than the national average and that the rate of medication use has increased from 54% to 78% from 2007-2008 to 2012-2013.

Discussion

This study was not a comprehensive study of mental health issues with persons with disabilities. The study focused on two indices of mental health: loneliness/friendship patterns and use of psychotropic medications. Mental health indicators for people receiving the SCL waiver show that loneliness is a pervasive and ongoing issue. While the most recent Kentucky data find there is increase in friendships, there is also an increased report of loneliness. The report of friendships still lags behind national averages. This has implications for future research. Further assessment of “who” friends are is warranted. It is possible that friends are those with whom the individual resides or attends day activities. Friends may actually be an SCL recipient who is often in the company of the individual, but who may not share the same interests or outlook.

From a practice standpoint, professionals may investigate avenues for consumers to have more social opportunities,

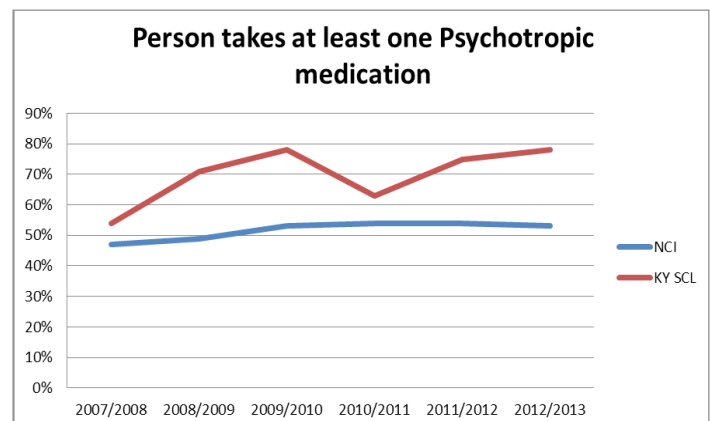


Table 6

integrated work settings, and increased community/ social contacts. Finally, are there unique challenges to service provision in Kentucky that makes loneliness such a pervasive and long-standing issue for individuals receiving SCL and other state-funded services?

The data on psychotropic medications also yield a somewhat disturbing trend. The rate of prescribing these medications appears to have increased by nearly 50% since 2007-2008, and is considerably above the national rates, which have held relatively steady over that time frame. This finding is sort of a “snapshot” of the issues and yields many questions about who is prescribing, how carefully diagnoses are made, and whether medication usage is accompanied by psychosocial intervention. Professionals may wish to monitor these prescribing and diagnosing patterns, as well look for other mental health treatment options beyond medication.

Mental health is an essential element for all of us, and it is a pre-requisite to functioning well in every other life domain. Yet, based on these analyses of KY National Core Indicators for our state's SCL recipients, mental wellness is not a given for some of our state's most vulnerable citizens.

About HDI Research Briefs

HDI Research Briefs were initiated to highlight the research activities at HDI. Projects at HDI focus on individuals with disabilities and include projects with emphases in early childhood, school age persons, adults, and issues across the lifespan. Many of these projects have significant research components and involve HDI staff, students in graduate programs, and other faculty at UK. With each issue of **HDI Research Briefs**, we will try to provide a cross-section of HDI's research activities. The brief reports are typically "mini" versions of more involved studies. The brief reports are intended to give an overview of the research project and emphasize the implications of the studies.

You can find more examples of our research on our website at www.hdi.uky.edu.