

# ANNUAL STATUS REPORT



The Kentucky Commission on Services and Supports for  
Individuals with Intellectual and Other  
Developmental Disabilities

Submitted in Accordance with KRS 210.577 to:

Governor Matt Bevin  
and the General Assembly  
October 2017

# **KENTUCKY COMMISSION ON SERVICES AND SUPPORTS FOR INDIVIDUALS WITH INTELLECTUAL AND OTHER DEVELOPMENTAL DISABILITIES**

## **Fiscal Year 2017**

### **INTRODUCTION**

The Kentucky Commission on Services and Supports for Individuals with Intellectual and Other Developmental Disabilities was created and established by KRS 210.575 through the enactment of House Bill 144 by the 2000 General Assembly. This commission hereafter referred to as the HB 144 Commission or the commission, serves in an advisory capacity to the Governor and the General Assembly concerning the service system that impacts the lives of people with intellectual and other developmental disabilities (I/DD).

The commission's membership in 2017 included 24 individuals representing an array of stakeholders. Nine of these positions are appointed by the Governor to serve four-year terms and include representation of family members, provider organizations, advocacy groups, and self-advocates. Four members of the General Assembly are appointed and the remaining 11 members are stipulated in KRS 210.575 and include representation from the Secretary of the Cabinet for Health and Family Services (CHFS), departments within CHFS, the University Center of Excellence in Disabilities at the University of Kentucky, and the Commonwealth Council on Developmental Disabilities. During the reporting period, recruitment for a replacement self-advocate was conducted and eligible applicants were submitted to the Office of Boards and Commissions for review and appointment. The reason for seeking a replacement to represent self-advocates was the death of James Chesser. The list of commission members and their term expirations as of June 30, 2017, are included in Appendix A of this report.

During FY 2012, the commission formed 3 committees to address issues and concerns identified from data collected through the National Core Indicator (NCI) project, in which Kentucky has participated since 1998. The committees are: (1) Health and Wellness, (2) Participant Directed Supports, and (3) Community Integration. The NCI survey provides a variety of data reported by individuals with intellectual and developmental disabilities, their family members, and caregivers about the quality of services and supports received through a variety of funding sources. An NCI Quality Improvement committee was established to analyze the data and provide the commission with information that resulted in the identification of 4 priority areas: (1) health and wellness; (2) employment; (3) psychotropic medication usage; and (4) relationships and community inclusion. These priority areas were passed onto the committees that continued to meet throughout FY 2017.

## COMMITTEE INFORMATION

The three committees met on a regular basis throughout the reporting period and each committee identified issues of concern to its members. Committees included commission members who serve in leadership capacities, such as the chair and co-chairs of the committee; self-advocates; family members of individuals with disabilities; and representatives from the Department for Behavioral Health, Developmental and Intellectual Disabilities (DBHDID), the Department for Aging and Independent Living (DAIL), and the Human Development Institute (HDI) at the University of Kentucky. Following is a brief synopsis of the identified goals and objectives of each committee for FY 2017.

### **Health and Wellness**

Vast health disparities exist for Kentuckians with disabilities. Kentuckians with disabilities are more likely to have high blood pressure, be obese, smoke, and be inactive than those without disabilities in the Commonwealth and the nation.<sup>1</sup> The committee continued to work toward the goal to:

- 1. Increase the overall percentage of Supports for Community Living (SCL) Medicaid Waiver (SCL) recipients who engage in moderate physical activity for 30 minutes a day at least three (3) times a week by 5% as reported in the next NCI 12-month data cycle.*

The 2014-2015 National Core Indicators (NCI) data indicated that 16% of all Kentuckians with I/DD and 12% of individuals receiving SCL supports engaged in moderate physical activity for 30 minutes a day at least three times a week, which remains below the national average of 23%. The 2015-2016 NCI data had not yet been released during the committee meeting cycle, which ended on June 30, 2017.

Over the past year, there has been emphasis on expanding the committee to include self-advocates who are champions in promoting health and wellness. Four self-advocates from the community have participated in the committee activities.

### **Participant Directed Services (PDS)**

The PDS committee seeks to promote the principles and tools of self-determination that are used in the PDS program to assist participants in the creation of meaningful, culturally appropriate lives within their community in order to develop relationships, learn, work, and earn income, and actively participate in community life.

The PDS committee established the following priority issues for FY 2017:

- 1. Reducing employment related costs incurred by waiver recipients.*
- 2. Examining the redundancy of regulatory requirements pertaining to multiple background screenings.*

3. *Matters surrounding the Direct Support Professional workforce crisis.*
4. *Participation in waiver redesign and amendments with potential impact to waiver recipients.*
5. *Improvements upon training and communication from the Commonwealth of Kentucky to waiver recipients, families, and service providers.*

Out of the aforementioned items, the PDS committee made a number of recommendations addressing these areas of concern. The committee has remained primarily focused on working with cost saving initiatives for waiver recipients so they may continue to hire employees without overwhelming administrative burden in terms of the fiscal impacts occurred. This included a review of waiver regulation wording that is overly restrictive to waiver recipients in regards to background screenings. The committee examined both items as a way to contain costs.

### **Community Integration**

The Community Integration committee met on a quarterly basis throughout the reporting period. During quarters 1 and 2 of FY 2017, the Community Integration committee and the Participant-Directed Services committee collaborated on: (1) participant incurred costs of being an employer; and (2) the direct support professional workforce crisis. Beginning in January 2017, the Community Integration committee refined their focus on the topics of Medicaid Waiver Redesign, transportation, and access to services by persons with medically complex needs.

The Community Integration committee's activities primarily focused on waiver redesign and transportation.

## **FY 2017 GOALS, INITIATIVES, and ACTIVITY UPDATES**

In 2012, HB 144 Commission members, in collaboration with DBHDID, established five long-term goals as part of a 5-10 year plan. The commission reviewed the goals in FY 2017 and agreed these goals are still applicable to its work. The following goals, updates, and committee reports reflect commission activities in FY 2017.

**Goal 1: Community education and outreach must combine efforts to create an awareness of need and available services for people with intellectual and other developmental disabilities (I/DD).**

### ***Initiative 1***

**2015 Joint Needs Assessment.** Dr. Chithra Adams, Director of Evaluation at the University of Kentucky's Human Development Institute presented highlights of the 2015 Joint Needs Assessment Survey at the September 8, 2016 quarterly meeting. The 10 areas of need identified in the survey were:

1. Self-advocacy;
2. Education and early intervention;
3. Childcare;
4. Healthcare;
5. Health and wellness;
6. Employment;
7. Housing;
8. Transportation;
9. Recreation; and
10. Community.

The top 3 areas of need identified were: transportation, employment, and housing. The findings were used to plan the commission's quarterly meetings to access information from relevant sources. Throughout the remainder of the fiscal year, representatives from the Kentucky Education and Workforce Development Cabinet, Kentucky Transportation Cabinet, Kentucky Housing Corporation, and the Office of Health Policy within the Cabinet for Health and Family Services provided information to the commission related to areas of need.

The HB 144 Commission did not provide recommendations related to goal 1 to CHFS during FY 2017.

**Goal 2: Promote inclusion of citizens with disabilities to increase natural supports in the community and in the workplace.**

The HB 144 Commission did not provide recommendations related to goal 2 to CHFS during FY 2017.

**Goal 3: Advocate for adequate funding for a system of services and supports throughout the individual's lifespan.**

The Department for Medicaid Services and DBHDID experienced a delay in the approval of waiver programs by the Center for Medicare and Medicaid Services (CMS). This delay resulted in a lack of slots available for a significant portion of the year. Therefore, the HB 144 Commission did not provide recommendations related to goal 3 to CHFS during FY 2017 although advocacy is ongoing.

**Goal 4: People with disabilities and their families will have continued access to services and supports that meet their needs and expectations.**

***Initiative 1***

The Health and Wellness committee continued its efforts to positively impact the overall health and well-being of individuals through involvement with the following activities:

**Activity:** In partnership, the Kentucky Department for Public Health, BHDID, and HDI received the Community Health Education and Exercise Resources (CHEER) grant from the Centers for Disease Control and Prevention (CDC) to improve health outcomes for people with intellectual disabilities and mobility impairments. The grant was launched in July, 2016.

**Activity:** The Health and Wellness committee members were invited to serve on the Project CHEER advisory committee. The advisory committee held its first meeting May 1, 2017. The advisory committee evaluated and provided feedback on developed resources and website (<http://www.wellness4ky.org>) content. The committee provided guidance to the Project CHEER leadership related to project goals and deliverables.

**Activity:** The Health and Wellness committee also reviewed NCI data around psychotropic medication. The percentage of people reported to take at least one medication for mood disorder, anxiety, and/or behavior disorder was 71% and the NCI national average was 49%. The percentage of people reported to take at least one medication for behavior challenges was 34% and the NCI national average was 24%. The committee continues to research and explore viable recommendations for consideration.

## ***Initiative 2***

The PDS committee proposed the following recommendations to the commission in June, 2016. The recommendations were accepted by the commission and submitted to the Cabinet for Health and Family Services for review and response. The Cabinet for Health and Family Services, Department of Medicaid Services (DMS) and the Department of Aging and Independent Living (DAIL) submitted responses to the commission during FY 2017.

**Recommendation 1:** *Change the language regulating waivers to allow for flexibility in paying for the pre-employment and ongoing employment costs.*

KRS 205.6317 includes language prohibiting paying for “non-direct services”. Removing this language or amending it to “Direct services shall include costs associated with pre-employment and on-going employment requirements as dictated by regulations” in the Supports for Community Living waiver and then replicating it through the other waiver programs may allow for more flexibility in paying the pre-employment costs.

**Response:** The Department does not support changing the statutory language at this time. Participant direction is an option and requires responsibility of the participant as employer. Within this choice, participants are able to choose their employees and decide a pay rate. Employee requirements are a common occurrence and are typically, per the Department of Labor, paid by the employer. Changing the statute to allow employment-related costs to be considered direct services costs would reduce the funding available to the participant to purchase waiver services.

**Recommendation 2:** *Reduce employment related costs.*

Costs are being substantially increased as waivers are being updated. New requirements in SCL II are expected to be incorporated into other waivers (as each is revised). Costs that could be eliminated (and made optional) include:

- First Aid and CPR (CPR/FA) training provided through American Red Cross or Heart Association (cost \$70-\$125);
- TB screening (cost varies dramatically, up to \$75);
- Drug testing – regulation is unclear on what is required, and many individuals believe it is ineffective and overly invasive (cost varies dramatically, up to \$75).

**Response:** This recommendation is being considered. DMS will continue to look at this issue. Employment-related requirements will be reviewed as part of the overall review of home and community-based waiver structure and functioning currently under way to determine if each is essential. Currently, the Home and Community Based (HCB) waiver has removed the drug screening and allowed CPR/FA to be completed from sources other than American Red Cross and American Heart Association.

**Recommendation 3:** *Kentucky Medicaid should request technical assistance and implement suggestions from Centers for Medicare and Medicaid Services (via Molly Murphy) regarding how to adapt the infrastructure for the self-directed model to ensure that participants are not responsible for employment-related costs.*

**Response:** This recommendation is not being considered, since paying for employment related costs would reduce the funding available to the participant for direct services.

**Recommendation 4:** *Eliminate the 40-hour per week rule in the Michelle P Waiver regulations and maintain current system that allows flexibility to meet the needs of the participant.*

**Response:** The Michelle P. waiver was originally developed to make home and community based services available to individuals with intellectual or developmental disabilities within overall Medicaid financial constraints – the 40-hour limit was an integral part of the original design to provide an effective, yet financially manageable service package. DMS continues to experience significant financial constraints, so any effort to eliminate the 40-hour per week rule would need to include an alternative mechanism to control waiver costs. With this concern in mind, this recommendation will be considered as part of the overall review of home and community-based waiver structure and functioning.

**Recommendation 5:** *Eliminate the redundancy of multiple background checks for the same direct support professional who supports multiple individuals by amending regulations to*

*reflect that a background check conducted within 30 days prior to date of employment of a direct support professional may be used to fulfill regulatory requirements.*

**Response:** The Department for Medicaid Services will investigate the feasibility of this recommendation and implement if possible.

### ***Initiative 3***

The PDS committee focused on a number of items over the past year. These include the following:

- Reducing employment related costs incurred by waiver recipients; and
- Examining the redundancy of regulatory requirements pertaining to multiple background screenings.

Out of the aforementioned items, the PDS committee proposed 4 recommendations during FY 2017 addressing the areas of concern; however, the committee has remained primarily focused on cost saving initiatives for waiver participants so they may continue to hire employees without overwhelming administrative burden. In tandem with this, the committee focused on waiver regulation wording that is overly restrictive to waiver participants regarding background screenings. The committee examined both these items as a way to contain costs. The committee believes very little was accomplished in terms of providing relief to PDS participants regarding the costs associated with hiring employees.

**Recommendation 1:** *Change the language regulating waivers to allow for flexibility when seeking First Aid and CPR training.*

Current Supports for Community Living (SCL)/Michelle P. (MP) waiver language indicates CPR and first aid training must be accredited through either the American Red Cross or American Heart Association. We recommend that SCL and Michelle P waiver regulation be amended to follow regulatory guidance currently outlined in HCB 2 Waiver that does not stipulate trainings must be accredited through these organizations, just simply accredited. This allows participants to access additional accredited training for CPR and first aid that is not as costly.

**Response:** The requested flexibility in first aid and CPR training accreditation is included in the SCL regulation that took effect in April 2017. That regulation requires first aid and CPR training certified by a nationally accredited entity, but does not specific that the American Red Cross or American Heart Association must accredit the training (see 907 KAR 12:010, Section 10(1)(b)(2)a).

**Recommendation 2:** *In addition to the aforementioned (Recommendation 1 above), we ask that SCL/MP waivers be amended to reflect current HCB 2 waiver language that has*



*removed the drug-screening requirement from pre-employment criteria, and that this be left to the discretion of the employer/participant.*

Drug screening requirements in the waiver language is vague at best, leaving many participants to potentially misinterpret the requirement and ultimately leading to increased cost for an array of testing that may not be necessary and overly burdensome/costly.

**Response:** Additional research is necessary before the response to this recommendation is finalized.

**Recommendation 3:** *Current waiver language across all waivers should examine the employee limit of 40-hours per week as well as the issue with only being allowed to pay one caregiver at a time.*

Many participants self-directing supports have difficult times locating employees or may need additional assistance. As part of being the employer and supervising their employees, people who utilize the self-direction model should be able to access a staff person over 40-hours per week if this is their only option. Furthermore, some participants that choose to self-direct their supports need additional assistance beyond one paid caregiver at a time. In particular, some people need extra assistance with transfers from physical disabilities that require, at times, two caregivers to ensure not only the safety of the participant but also that a caregiver is not injured.

**Response:** The individual employee limit of 40-hours per week is designed to eliminate the need to pay PDS employees overtime. While this can be reviewed during the waiver redesign, allowing over 40-hours per week per PDS employee is anticipated to increase waiver services expenditures. Paying more than one caregiver at a time can also be considered, but raises a complex issue with avoiding duplication of services and/or effectively documenting that the services are not duplicative. It also has the potential to increase waiver services expenditures.

**Recommendation 4:** *The committee has yet to hear additional comment on this previously recommended item and requests updates and/or clarification on feasibility:*

Eliminate the redundancy of multiple background checks for the same direct support professional who supports multiple individuals by amending regulations to reflect that a background check conducted within 30 days prior to date of employment of a direct support professional may be used to fulfill regulatory requirements.

**Response:** The written response to the June 2, 2016 PDS committee recommendation on multiple background checks indicated that the Department for Medicaid Services would investigate the feasibility of the recommendation and implement if possible. The cabinet is supportive of the concept of eliminating multiple background checks during the same time

period for the same direct support professional who supports multiple individuals. This recommendation will be considered during waiver redesign.

#### ***Initiative 4***

The PDS committee and a number of its members were involved with a waiver redesign group comprised of advocates, participants and providers in order to examine service delivery models that related to PDS. However, the committee tasked with evaluating Kentucky waiver regulations was disbanded shortly after its inception and an outside contractor was hired in April 2017. The PDS committee has not received additional information on how this group will evaluate PDS services within regulations.

#### ***Initiative 5***

The PDS committee was tasked to examine the Direct Support Professional (DSP) workforce crisis that affects both participants and providers. In June 2017, the committee proposed and the commission accepted the below recommendation. The committee is hopeful that a registry system will create a network to establish a more pronounced pool of potential DSPs.

**Recommendation:** *Explore the possibilities and manner in which the cabinet can be involved in the development and ongoing maintenance of a Direct Support Professional (DSP) registry that meets regulatory requirements for participants and/or providers.*

#### ***Initiative 6***

The Community Integration committee met throughout FY 2017. Beginning in January 2017 the committee focused on Medicaid Waiver redesign, transportation, and access to services by individuals with medically complex needs.

**Activity:** The committee is conducting research related to defining medically fragile/medically complex and seeking information to recommend allocation of funding needed for accessible services in the community. No formal recommendations were made during FY 2017.

**Activity:** The committee reviewed the needs and issues surrounding transportation for individuals for community access. Representatives from the Transportation Cabinet presented a report card of transportation services. Committee members reached out to members of the Kentucky Association of Private Providers (KAPP) for feedback from participants in the waiver programs. The results were dramatically different than what was presented by Transportation. The providers indicated that transportation in the waivers through the Transportation Cabinet has many restrictions on the services such as availability of services limited to time of day. For example, transportation services are not available after 5:00 p.m. Monday through Friday and is not available after 1:00 p.m. on Saturday. Therefore, individuals do not have true community integration nor transportation for

employment that enables individuals to increase their independence. Results from the KAPP survey revealed 7 problematic areas identified by consumers:

1. Timeliness;
2. 72 hour notice;
3. Hours of operation;
4. Safety concerns;
5. Increased network;
6. Communication;
7. Training.

The committee continues to study alternative solutions for future recommendations to the commission.

**Goal 5: The primary focus for public intermediate care facilities (ICFs) will shift to expand networks providing a continuum of health care within the individual's community.**

The Department for Medicaid Services and DBHDID experienced a delay in the approval of waiver programs by the Center for Medicare and Medicaid Services (CMS). This delay resulted in a lack of slots available for a significant portion of the year. Therefore, the HB 144 Commission did not provide recommendations related to goal 5 to CHFS during FY 2017 although advocacy is ongoing.

## **STATISTICAL INFORMATION**

Following is the status of programs providing supports to individuals with intellectual and other developmental disabilities through FY 2017.

### **Community Mental Health Center (CMHC) Service Provision 2017**

- Based upon data reported by the CMHCs, 9,453 people with I/DD were supported by the 14 CMHCs in FY 2017.
- CMHC adult I/DD crisis services were utilized by 1,022 individuals during the calendar year 2016.

### **ICF Average Census FY 2009 through FY 2017**

The number of people who reside in state intermediate care facilities for individuals with intellectual disabilities (ICFs/IID) has decreased significantly with the implementation of a statewide transition process designed to transition individuals into the community.

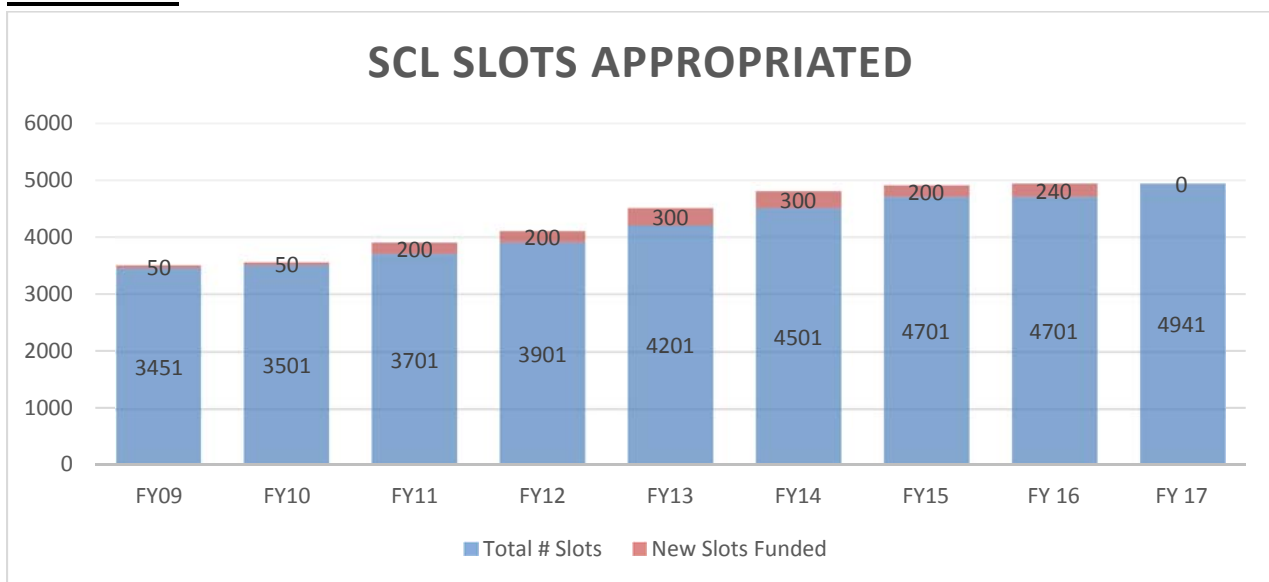
<b>Facility</b>	<b>FY09</b>	<b>FY10</b>	<b>FY11</b>	<b>FY12</b>	<b>FY13</b>	<b>FY14</b>	<b>FY15</b>	<b>FY16</b>	<b>FY17</b>
Oakwood	205	173	133	120	121	119	114	111	106
Hazelwood*	162	161	158	146	135	123	116	105	104
Bingham Gardens	34	32	28	24	23	21	21	24	24

Outwood	63	59	50	46	42	40	38	36	35
Total	464	425	369	336	321	303	289	276	269

\*Hazelwood Center census includes the three 8-bed ICF community homes.

As part of the settlement agreement with the US Department of Justice, each of the state-owned ICFs/IID continues transformation into a Center of Excellence. There are 3 specialty clinics in Kentucky. One located on the campus of Oakwood, one on the campus of Hazelwood, and one on the campus of Bingham Gardens. These centers serve as a resource to individuals, families, and community providers by offering specialized supports and services that otherwise are not accessible in the community.

### **SCL Waiver**



<b>SCL Slots</b>	<b>FY09</b>	<b>FY10</b>	<b>FY11</b>	<b>FY12</b>	<b>FY13</b>	<b>FY14</b>	<b>FY15</b>	<b>FY 16</b>	<b>FY17</b>
Total # Slots	3451	3501	3701	3901	4201	4501	4701	4701	4941
New Slots Funded	50	50	200	200	300	300	200	240*	0

\*240 slots were appropriated by the legislature for FY16; however, CMS approval of the SCL waiver renewal didn't occur until March, 2017.

### **Michelle P, Home and Community Based, and Acquired Brain Injury Waivers**

- **Michelle P Waiver Summary as of June 30, 2017**
  - 52.5% (5,268) of recipients are younger than 18 and 47.5% (4,775) of recipients are older than 18

- Individuals meeting level of care without requesting services = 144
- Individuals prior authorized for “blended services” (traditional and participant directed) = 2,426
- Individuals prior authorized for “traditional services” = 2,287
- Individuals prior authorized for participant directed services only = 5,186
- Total = 10,043

### **Acquired Brain Injury (ABI) Waivers as of June 30, 2017 (all over age 18)**

- **ABI Rehab Waiver**

- Individuals meeting level of care without requesting services = 11
- Individuals prior authorized for “blended services” (traditional and participant directed) = 8
- Individuals prior authorized for “traditional services” = 145
- Individuals prior authorized for participant directed services only = 22
- **Total = 186**

- **ABI Long Term Care Waiver**

- Individuals meeting level of care without requesting services = 2
- Individuals prior authorized for “blended services” (traditional and participant directed) = 21
- Individuals prior authorized for “traditional services” = 188
- Individuals prior authorized for participant directed services only = 42
- **Total = 253**

## **CLOSING THOUGHTS**

It has been a privilege for the Kentucky Commission on Services and Supports for Individuals with Intellectual and Other Developmental Disabilities to serve in an advisory capacity to the Governor and the General Assembly regarding the needs of persons with intellectual and other developmental disabilities. Commission members extend their gratitude to the Governor and the General Assembly for their continued support. Along with the Department for Behavior Health, Developmental, and Intellectual Disabilities, the commission looks forward to meeting their goals to improve the quality of supports for the citizens of Kentucky.

<sup>1</sup>Centers for Disease Control. (2015). *Disability impacts all of us: A snapshot of disability in Kentucky*. Author

## APPENDIX A – Kentucky Commission on Services and Supports for Individuals with Intellectual and Other Developmental Disabilities

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