

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 2016

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

Fiscal Year 2016

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 2016 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. The list of commission members and their term expirations as of June 30, 2016, are included in Appendix A of this report.

During FY 2012, the commission formed three 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 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 three priority areas and development of committees for each: (1) Health and Wellness; (2) Participant Directed Supports; and (3) Community Integration. These committees continued to meet throughout FY 2016.

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 2016.

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 (Centers for Disease Control and Prevention, 2015). The committee continued to work toward the goal to:

1. *Increase the overall percentage of Supports for Community Living 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 2013-2014 NCI data indicated that 19% of all Kentuckians with I/DD and 18% 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 22%. The 2014-2015 NCI data had not yet been released during the committee meeting cycle which ended on June 30, 2016.

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 goals and objectives for FY 2016:

1. *PDS participants will increase self-advocacy by self-directing their person-centered service plans (PCSP).*
2. *PDS families will increase their advocacy on behalf of participants by directing the participant's PCSP.*
3. *Participants and families should receive adequate training related to PDS programs across all waivers.*

- a. *Advocate for each appropriate CHFS agency to include participants and/or their families to participate in any training provided to provider agencies related to participant-directed services.*
 - b. *Ensure participants and/or their families without internet access are provided the same information in an alternative format.*
4. *Establish an Advocacy Coalition, including but not limited to the Arc of Kentucky, Autism Society of the Bluegrass, Kentucky Self-Advocates for Freedom (KSAFF), Down Syndrome Association of Central Kentucky (DSACK), and others to meet regularly with officials from DBHDID.*

Community Integration

The Community Integration Committee met on a quarterly basis throughout the reporting period. After reviewing goals established in 2012, the following priority issues were identified:

1. *Ensuring adequate funding and flexibility to support integrated community living. Areas of particular concern include:*
 - a. *1915c Medicaid Waivers and the Hart Supported Living Grant Program;*
 - b. *Minimizing employment costs for individuals who choose the PDS model;*
 - c. *Lack of appropriate services for the medically-fragile population; and*
 - d. *Lack of affordable and accessible transportation, especially in rural areas.*
2. *Understanding Alzheimer's within the I/DD population, especially among those with Down Syndrome.*
3. *Decreasing loneliness.*
4. *Decreasing the use of psychotropic drugs in the SCL program.*

The Community Integration Committee's activities primarily focused on priority issues 1 and 2.

FY 2016 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 2016 and agreed these goals are still applicable to its work. The following goals, updates, and committee reports reflect commission activities in FY 2016.

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

Aging and Down's Syndrome. Upon request of the Community Integration Committee, Roberta Davis and Dr. Frederick Schmitt presented information on this topic from a University of Kentucky study, currently underway, at the March 3, 2016, HB 144

Commission meeting. This study is the only one of its kind in the United States. The information presented concerned the prevalence of Alzheimer's disease in individuals who are also diagnosed with Down Syndrome. It was noted, however, that not everyone with Down Syndrome develops Alzheimer's disease. Individuals interested in learning more about this study were encouraged to contact Roberta Davis at the UK Sanders-Brown Center on Aging at (859) 218-3865 or rdavi3@uky.edu.

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 2016.

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

Initiative 1

The Community Integration and PDS Committees collaborated to develop the following recommendations to the commission.

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 SCL Medicaid waiver and then replicating it through the other waiver programs may allow for more flexibility in paying the pre-employment costs.

Current Status: The recommendation requires a statutory change and will be taken under advisement by CHFS.

Recommendation 2: *Reallocate existing funds to fund employment-related costs.* Since January 2014, there have been no SCL prior authorizations for "Natural Supports Training" and only approximately \$1,200 has been paid for "Family Training" through the Acquired Brain Injury Long-Term Care Waiver. Funds in these categories could potentially be reallocated for a new code to be used for "Employment Costs" or another new or modified code.

Current Status: There are no existing excess funds. This would be an increase in cost to the Department for Medicaid Services. The entire Medicaid benefits budget is used to pay for covered services for Medicaid recipients. Funds are not reserved or held back.

Recommendation 3: *Reduce employment-related costs.* Costs are substantially increased as waivers are updated. New requirements in SCL are expected to be incorporated into other waivers (as each is revised). Costs that could be eliminated include:

- First Aid and Cardiopulmonary Resuscitation training provided through American Red Cross or American Heart Association (cost \$70-\$125 per person trained).
- 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).

Current Status: The CHFS recognize these requirements may cause hardship to participants choosing PDS services. This recommendation will be taken under consideration.

Recommendation 4: *Kentucky Medicaid should request technical assistance and implement suggestions from the Centers for Medicare and Medicaid Services (CMS) regarding how to adapt the infrastructure for the self-directed model to ensure that participants are not responsible for employment related costs.*

Current Status: The department is aware of options related to self-direction; however, statutory language currently prohibits pursuit of moving costs to other aspects within the waiver(s).

Initiative 2

Expanding waiting lists for Medicaid 1915c Waivers. The Community Integration Committee identified the following concerns and suggestions for consideration:

- Waiting lists are growing for most of the disability-specific waivers, including the SCL, Michelle P, and Acquired Brain Injury waivers. The total count on waiting lists is approximately 8,000.
- Committee members recommended more funding be allocated to ensure that appropriate services and supports can be provided.
- Committee members noted that failure to do so could result in costly litigation, especially given the mandates of Olmstead and the fact that the Michelle P. Waiver was created as the result of a lawsuit brought by individuals who could not get waiver services in the community.
- Committee members suggested that the Michelle P. waiting list could be reduced by:
 - Pre-screening individuals prior to placing them on the waiting list (some screening is performed before individuals are placed on the SCL waiting

list, which is likely one reason there are fewer individuals on the SCL waiting list.

- Utilizing an assessment tool that has been validated for use across the lifespan of the individual.

Current Status: A pilot project has been launched to test an assessment tool. The results of the pilot project are pending.

Initiative 3

The PDS Committee made the following recommendations to the commission:

- Due to the number of individuals on the Medicaid SCL Waiver and Michelle P. Waiver waiting lists, the PDS Committee recommends funding for SCL and Michelle P. be included in the CHFS 2017-18 budget at a 20% increase each year. This funding would have a significant impact on the SCL and Michelle P. Waiver waiting lists.
- The spending reductions in the Governor's proposed budget were brought to the attention of the PDS Committee. While we understand the challenges facing our state, the committee is deeply concerned that the spending reductions of 4.5% would mean \$8.2 million of BHDID funded services would be impacted in this fiscal year and \$16.5 million in the next fiscal year. The PDS Committee opposes these cuts and recommends that no reductions occur to the dollars currently appropriated.
- Recipients of the Michelle P. Waiver that choose to self-direct their services are concerned about the lack of flexibility in the person-centered service plans and the 40-hour per week limit. Some recipients are currently receiving more than 40 hours, but there is no increase to their budgets. The PDS Committee encourages the Department for Medicaid Services to make a change in the Michelle P. Waiver regulation to allow for more than 40 hours as necessary according to the person-centered service plan.
- The committee discussed the number of placements in the Governor's proposed budget for the SCL and Michelle P. waivers. The waiting list for the SCL Waiver was 2,002 and for the Michelle P. Waiver was 4,900 (*as of the time of the recommendation on 3/3/2016*). The proposed budget reflects 41 new SCL waiver placements in FY 2016-2017 and an additional 130 in FY 2017-2018. The proposed budget reflects 83 Michelle P. Waiver slots in 2016-2017 and an additional 166 in 2017-2018. Due to the number on the waiting lists and approximately 12,400 aging caregivers caring for their family members, while not a formal recommendation, the committee asks that these numbers be increased.
- Eliminate the redundancy of multiple background checks for the same direct support professional that supports multiple individuals by amending regulations to

reflect that a background check conducted within 30 days of the date of employment may be used to fulfill regulatory requirements.

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 collaborated on a Centers for Disease Control and Prevention (CDC) grant proposal to improve health outcomes for people with intellectual disabilities and mobility impairments.

Activity: The Health and Wellness Committee reviewed NCI data around colorectal cancer screenings for people age 50 and older. It was found that in 2013-2014, 25% of Kentuckians receiving SCL supports had a screening in the past year. While this exceeded the NCI average of 19%, it was felt that this proportion is still far too low and that there is much room to make gains through collaboration and awareness.

Activity: The Health Risk Screening Tool (HRST) was updated to include alerts for raters to make them aware of the need for colon cancer screening for adults age 50 and older receiving SCL services.

Recommendation: The Health and Wellness Committee recommends the Health & Wellness Initiative at the University of Kentucky HDI explore collaborative opportunities with the Department for Public Health and BHDID to develop educational webinars and programming to be made available to self-advocates and their support providers, focused on colorectal cancer screening. (*Recommendation made at 6/2/2016 quarterly meeting*).

Initiative 2

The PDS Committee requested and received information regarding the number of individuals self-directing their supports and services accessed through the Medicaid waiver programs. At the time the statistics were gathered, approximately 11,000 individuals self-direct services across the Medicaid waiver programs. The committee continued its outreach efforts to ensure that participants are provided a user-friendly Participant Directed Program Manual. The committee also recommended that participants should be provided information on any new process as early as possible to avoid a misunderstanding or a lapse in services. Committee members attended

stakeholder meetings in March and April 2016 regarding revisions of the Michelle P. Waiver.

Initiative 3

The Community Integration Committee identified the lack of services for those who are medically-fragile as a priority item. Family members have expressed a variety of concerns to committee members about the lack of adequate services for the medically fragile in terms of available supports, lack of community integration because of prolonged dependence on specialized medical care, and individuals being released from medical facilities without appropriate support services or being required to remain in a hospital setting because there are no available community supports. A preliminary report prepared by the Martin School of Public Policy and Public Administration titled “*Report on States’ 1915c Waiver Programs for Medically Fragile Populations*” was distributed to the commission. The committee identified the following issues which need continued research and discussion:

- Current Kentucky Medicaid waivers are limited in terms of services provided. Skilled nursing care (offered through the State Plan) is limited to 16 hours daily;
- No specific waiver for the medically fragile;
- Residential providers (particularly SCL) lack the capacity to address complex medical needs;
- Lack of community-based agencies and staff to provide necessary care, especially pediatric skilled nursing;
- Hospitals are not evaluating waiver eligibility and other resource needs before discharging individuals;
- Caregivers who are aging alongside medically-fragile family members are losing the ability to provide the care needed; and
- Home and Community Based (HCB) waiver services often used by medically fragile individuals provide limited community access.

The committee continues to explore the feasibility of the following suggested resolutions:

- Modify the SCL/HCB Waivers to allow 24-hour care provided by professional caregivers (for example: nursing services, respiratory therapy, etc.); and/or
- Create a specific waiver for medically fragile individuals.

Initiative 4

The Community Integration Committee requested and received information regarding the Medicaid Waiver Management Application (MWMA). This system was designed to streamline processing of information required for eligibility determination for waivers and on-going services. It was initially made available to case managers with plans to

make it available to all waiver providers on each person's plan of care. That functionality was launched at the same time as the integrated application known as "benefind." Benefind allows Kentuckians the ability to apply for Medicaid, waivers, and other benefits (including Supplemental Nutrition Assistance Program (SNAP) and Kentucky Transitional Assistance Program (KTAP)) online, as well as manage their benefits through the same online account. Unfortunately, there were significant problems with the launch of benefind.

In addition to the technological challenges experienced, Community Integration Committee members continue to express concerns regarding moving to a paperless system, especially given that many waiver participants do not have easy access to computers or internet services.

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 HB 144 Commission did not provide recommendations related to Goal 5 to CHFS during FY 2016.

STATISTICAL INFORMATION

Following is the status of programs providing supports to individuals with intellectual and other developmental disabilities through FY 2016.

Community Mental Health Center (CMHC) Service Provision FY 2016

- Based upon data reported by the CMHCs, 9,291 people with I/DD were supported by the 14 CMHCs.
- CMHC adult I/DD crisis services were utilized by 497 individuals.

ICF Average Census FY 2008 through FY 2016

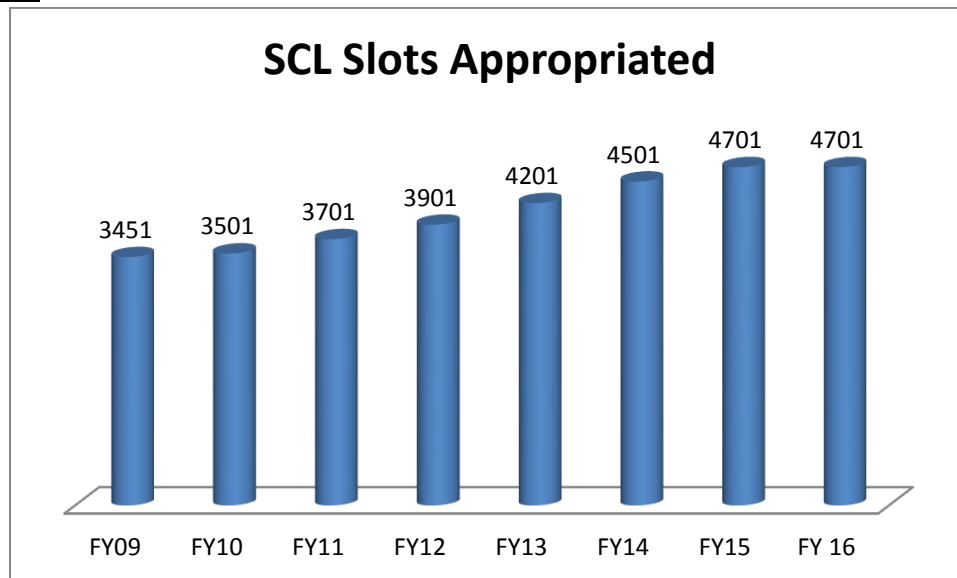
The number of people who reside in state Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) has decreased significantly with the implementation of a statewide transition process designed to transition individuals into the community.

Facility	FY08	FY09	FY10	FY11	FY12	FY13	FY14	FY15	FY16
Oakwood	226	205	173	133	120	121	119	114	111
Hazelwood*	168	162	161	158	146	135	123	116	105
Bingham Gardens	32	34	32	28	24	23	21	21	24
Outwood	65	63	59	50	46	42	40	38	36
Total	491	464	425	369	336	321	303	289	276

*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. 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



SCL Slots	FY09	FY10	FY11	FY12	FY13	FY14	FY15	FY 16
Total # Slots	3451	3501	3701	3901	4201	4501	4701	4701
New Slots Funded	50	50	200	200	300	300	200	240*

*240 slots were appropriated by the legislature for FY16; however, they are pending CMS approval of the SCL waiver renewal.

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

- **Michelle P Waiver Summary as of June 30, 2016**
 - 49.6% (4,980) of recipients are younger than 18 and 50.4% (5,068) of recipients are older than 18
 - Individuals meeting Level of Care without requesting services = 353
 - Individuals prior authorized for “Blended Services” (traditional and participant directed) = 2,431
 - Individuals prior authorized for “Traditional Services” = 2,374
 - Individuals prior authorized for participant directed services only = 4,890
 - Total = 10,048

Acquired Brain Injury (ABI) Waivers as of June 30, 2016 (all over age 18)

- **ABI Rehab Waiver**

- Individuals meeting Level of Care without requesting services = 38
- Individuals prior authorized for 'Blended Services' (traditional and participant directed) = 7
- Individuals prior authorized for 'Traditional Services' = 151
- Individuals prior authorized for participant directed services only = 13
- **Total = 209**

- **ABI Long Term Care Waiver**

- Individuals meeting Level of Care without requesting services = 14
- Individuals prior authorized for 'Blended Services' (traditional and participant directed) = 17
- Individuals prior authorized for 'Traditional Services' = 185
- Individuals prior authorized for participant directed services only = 41
- **Total = 257**

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 citizens of Kentucky.

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

Cabinet for Health and Family Services Secretary	Vickie Glisson 275 East Main St. Frankfort, KY 40621 (502) 564-7042 Vickie.glisson@ky.gov	Family Member TERM EXPIRES 7/15/2019 3RD DISTRICT	Missy R. McKiernan 3506 Saint Germaine Court Louisville, KY 40207 (502) 899-5130 missy0827@yahoo.com
Department for DBHDID Commissioner Acting Commissioner	Wendy Morris 275 East Main St 4WF Frankfort, KY 40621 (502) 564-4527 Wendy.Morris@ky.gov	Family Member TERM EXPIRES 7/15/2016 6TH DISTRICT ELIGIBLE FOR RE-APPOINTMENT	Donald B. Putnam 683 Elsmere Park Lexington, KY 40508 (859) 259-1685 donputnam@windstream.net
Department for Medicaid Services Commissioner	Steve P. Miller 275 East Main St. 6WD Frankfort, KY 40621 (502) 564-4321 Steve.Miller@ky.gov	Family Member TERM EXPIRES 7/15/2019	Julie Sweets 1342 Blue Level Providence Road Rockfield, KY 42274 (270) 782-2132 JulieBakerSweets@gmail.com
Office of Vocational Rehabilitation Executive Director	Buddy Hoskinson 275 East Main St. 2-EK Frankfort, KY 40621 (502) 782-3437 buddy.hoskinson@ky.gov	Self-Advocate TERM EXPIRES 7/15/2016 6TH DISTRICT NOT ELIGIBLE FOR RE-APPOINTMENT	Cathy Edwards 521 Burley Drive Mt. Sterling, KY 40353 (859) 497-0432 kybound99@yahoo.com
University Center for Excellence in Developmental Disabilities- Human Development Institute Director	Kathy Sheppard-Jones, PhD, CRC 126 Mineral Industries Bldg. University of KY Lexington, KY 40506-0051 (859) 257-3045 kathleen.sheppard-jones@uky.edu	Self-Advocate TERM EXPIRES 7/15/2019 6TH DISTRICT It is with regret we note Mr. Chesser's death on September 16, 2016.	James C. Chesser 1052 A Armstrong Mill Road Lexington, KY 40517 (859) 259-3954 jim.chesser@twc.com
Commonwealth Council on Developmental Disabilities Director	Mary Lee Underwood 32 Fountain Place Frankfort, KY 40601 (502) 564-7841 marylee.underwood@ky.gov	Self-Advocate TERM EXPIRES 7/15/2019 3RD DISTRICT	Andrew A. Venetianer 5601 Collington Court Louisville, KY 40241 (502) 713-8949 werdnav18@yahoo.com
Representative	Joni Jenkins State Capitol Room 309 Frankfort KY 40601 Joni.jenkins@lrc.ky.gov	Family Member TERM EXPIRES 7/15/2016 6TH DISTRICT ELIGIBLE FOR RE-APPOINTMENT	Peter A. Perry 3217 Mantilla Drive Lexington, KY 40513 (859) 296-9110 peteraperry@gmail.com
Representative	David Watkins Capitol Annex, Room 429B Frankfort KY 40601 David.Watkins.lrc.ky.gov	Family Member TERM EXPIRES 7/15/2016 1ST DISTRICT ELIGIBLE FOR RE-APPOINTMENT	Brenda R. Hosford 861 Squire Road Murray, KY 42071 (270) 293-9030 bhosford53@yahoo.com
Senator	Tom Buford 409 West Maple Street Nicholasville, KY 40356-1039 (502) 564-8100 tom.buford@lrc.ky.gov	Direct Service Provider- Representative of Kentucky Association of Regional Providers TERM EXPIRES 7/15/2019	Gayle J. DiCesare 5857 Horrell Road Owensboro, KY 42301 (270) 689-6702 gayledicesare@rvbh.com
Senator	Julie R. Adams Capitol Annex Frankfort, KY 40601 Julie.Adams@LRC.KY.GOV	Business Leader TERM EXPIRES 7/15/2016 4TH DISTRICT ELIGIBLE FOR RE-APPOINTMENT	Melissa L. David 5610 Cull Road Worthville, KY 41098 (502) 463-2895 melissa.david@itron.com

Direct Service Provider- KY Association of Private Provider Representative TERM EXPIRES 7/15/2016 5TH DISTRICT ELIGIBLE FOR RE-APPOINTMENT	Christopher D. George 196 Observation Pointe Drive Somerset, KY 42503 (606) 676-9530 chrisgeorge_bcba@mac.com	Business Leader TERM EXPIRES 7/15/2019	Lynn M. Braker 106 Golf Club Drive Nicholasville, KY 40356 (859) 948-8828 lynnb@rremedystaff.com
Direct Service Provider TERM EXPIRES 7/15/2019 6TH DISTRICT	Dennis Brandon Griffith 163 Jefferson Street Lexington, KY 40508 (859)553-5883 brandon.griffith@noboundariescm.com	Statewide Advocacy Group-Representative of Kentucky Arc TERM EXPIRES 7/15/2016 6TH DISTRICT NOT ELIGIBLE FOR RE-APPOINTMENT	Patty Dempsey 706 East Main Street Suite A Frankfort, KY 40601 (502)875-5225 arcofky@aol.com