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

March 3, 2016
Legislative Research Commission
131 Capitol Annex
Frankfort, Kentucky

MEMBERS PRESENT:

Deputy Secretary Tim Feeley
Acting Commissioner Wendy Morris
Tabitha Burkhart-Wilson
Leslie Hoffmann for Commissioner Steve P. Miller
Buddy Hoskinson
MaryLee Underwood
D. Brandon Griffith
Christopher George
Missy R. McKiernan
Julie Sweets
James C. Chesser
Andrew A. Venetianer
Brenda Hosford
Steve Shannon for Gayle J. DiCeasare
Marie Allison for Patty Dempsey

MEMBERS ABSENT:

Senator Tom Buford
Senator Julie R. Adams
Representative Joni Jenkins
Representative David Watkins
Dr. Kathy Sheppard-Jones
Lynn M. Braker
Cathy Edwards
Donald Putnam
Peter A. Perry
Melissa David

WELCOME
Deputy Secretary Feeley opened the meeting and welcomed Commission Members as well as members of the audience.

REVIEW OF THE MINUTES:
Minutes from the December 3, 2015 meeting were reviewed. Minutes were approved.

REVISE HB 144 GOALS AND RESTRUCTURE COMMITTEES Missy McKiernan

- HB 144 Committees met during the 1st quarter of 2016. Each committee reviewed goals and determined a change in goals or restructure of committees was not warranted at this time.
- Motion was made and seconded to remove this topic from consideration until a future time.

DMS UPDATES **Leslie Hoffmann and Lynne Flynn**

- Review of recommendations from the Participant Directed Services Committee from December 3, 2015 meeting was provided.
    - Include participants and/or their families in the construction of new waivers and regulations. The Committee encourages the appropriate CHFS agency to include participants and/or families in discussions that pertain to new waivers or waiver changes being considered, particularly when pertaining to self-directed services.
        - **Response:** The Department of Medicaid Services addressed this concern in the PowerPoint Presentation related to the Home and Community Based Services (HCBS) Waivers Update. Currently there are statewide advisory committees, public forums, work groups, and public comment periods which are available to participants and/or their families.
    - Notify participants whenever regulation changes are proposed that will impact their services and supports. (Currently participants do not receive regulation change information until after the proposed change(s) have taken place).
        - **Response:** There have been multiple opportunities for participants, families, and other advocates to provide public input related to waiver programs. Upcoming opportunities were listed in the PowerPoint Presentation related to the HCBS Waivers Update. In addition, if someone would like to be included on a regulation email distribution list, please contact: ronji.dearborn@ky.gov
    - Allow participants to change line items as need within their Plan of Care (budgets) across all waivers. Medicaid waivers through the Center on Medicaid Services are intended to give people with disabilities more opportunities to better community living and control of their lives. However, prohibiting changes in line items in the individual Plan of Care (budget) creates barriers to the flexibility intended in self-directing services. Also, when preparing a Plan of Care, it would be helpful if the participant could be provided a copy of the regulations by the Case manager as they may not have online service.
        - **Response:** It is the expectation that when a change in a budget is needed, the participant's case manager is contacted and the plan of care is reviewed and appropriate changes initiated. In addition, the participant should be able to receive a printed copy of regulations governing their services and supports from the Case Manager.
- MaryLee Underwood asked about the status of the MPW assessment
    - **Response:** Contract is in approval process and communication will be forthcoming. The intent is to get a baseline and determine the impact of a new assessment tool for children.
- Review of the Supports for Community Living Emergency Waiting List. The Department for Medicaid Services continues to work with the Centers for Medicare and Medicaid Services (CMS) to release additional slots
- Information related to allocation of slots across all Home and Community Based Waiver programs was reviewed.

COMMITTEE REPORTS:

Community Integration **MaryLee Underwood and Jim Chesser**

- Committee met on 2/19/16
- Committee received information on the Medicaid Waiver Management Application (MWMA) from Cathy Lerza
- Committee is excited about possibilities of better tracking; however, some members of the Committee expressed concern about the lack of a paper process for individuals who may need a paper alternative
- Jim Chesser requested that the CDO employer costs be revisited and that the Cabinet review the previous recommendations, and specifically the possibility of having participant-directed pre-employment costs be covered by the Hart Supported Living program.
- MaryLee Underwood clarified that the Community Integration and the Participant Directed Services Committees previously submitted recommendations related to pre-employment costs for individuals who choose to participant-direct their services. At the time the recommendations were submitted it was understood that the recommendations were not viable and that the only recommendation with potential for implementation requires legislative action.
- The Committee is scheduled to meet on May 10th from 1:30-3:30 at the Human Development Institute Coldstream Office in Lexington.

Health-Wellness **Dr. Kathy Sheppard-Jones**

Dr. Sheppard Jones was unavailable to provide an update for the Health Wellness Committee in person. However, Dr. Sheppard-Jones has provided a written summary that has been included at the end of the official minutes for Commission members review.

Participant Directed Services **Patty Dempsey and Cathy Edwards**

- Committee Co-Chairs Patty Dempsey and Cathy Edwards were not in attendance.
- Marie Allison, ad hoc member of the Participant Directed Services Committee represented the Committee and provided the update.
- The Committee met on 2/9/16
- The Committee has changed their committee name to Participant-Directed Services/Consumer Directed Option Committee to be reflective of the current terminology being used in different Medicaid waiver programs.
- The Committee submitted three (3) recommendations (contained in meeting materials) which were approved by the Commission for submission to the Department for Medicaid Services and appropriate Medicaid Waiver programs.
- Brandon Griffith requested an update on the use of KARES by individuals who participant direct services as an avenue to reduce pre-employment costs. He has not had to run any employees through the system yet, but it does not appear that an individual who chooses to participant direct supports has this resource available.

    - The Department for Medicaid Services will provide an update regarding the availability of this resource to individuals who self-direct services at the next scheduled Commission meeting.
- Marie Allison also requested that the Department for Medicaid Services provide a response to the following question:
    - "How can an individual get a copy of the budget that would be available utilizing traditional supports and a copy of the budget that would be available if they chose to self-direct all or part of their services prior to the submission of the Plan of Care so they can make informed decisions regarding their supports?"

COMMUNITY-BASED SUPPORTS FOR MEDICALLY-FRAGILE INDIVIDUALS – MaryLee Underwood and Diana Oliver

- Diana Oliver not able to attend
- MaryLee Underwood presented on the insufficient resources available to individuals who have special health care needs and their families.
- Family members often provide medical supports that are beyond their capability because there are no practitioners available
- There is not a specific waiver in Kentucky that addresses medical fragility and our current waivers offer limited medical support
- There are an insufficient number of community providers who have the capacity to provide the extended supports required by individuals and/or their families
- Many individuals with intellectual/developmental disabilities who are medically fragile are often forced to reside in nursing homes which are extremely restrictive for younger people
- Other examples:
    - Children who require Pediatric Skilled Nursing Care are living in hospitals (another form of institution) because services are not available or they are released home without appropriate services;
    - Children and young adults living with parents providing medical care far beyond their abilities, with levels of medical need advancing at the same time as parents age; and
    - Children living in Kentucky's only pediatric nursing facility (Home of the Innocents) age out with no place to go.
- Individuals with special health care needs are limited in community access and participation because of the lack of appropriately trained staff and adequate funding for the necessary supports.
- The Commonwealth Council on Developmental Disabilities has contracted with the University of Kentucky's Martin School of Public Policy to research and report on how other states are addressing this particular need.
- Goal is to start conversations on how Kentucky can address this area of concern for individuals with medical fragility and their families/caregivers across the lifespan..

AGING AND DOWN SYNDROME RESEARCH STUDY – University of Kentucky, Sanders-Brown Center on Aging

- Presenters were Dr. Frederick Schmitt, Project Investigator and Roberta Davis, Research Administrative Coordinator
- Study being conducted at UK is the only one of its kind in the United States
- Information presented about the prevalence of Alzheimer's disease in individuals who are also diagnosed with Down Syndrome; however, it was noted that not everyone with Down Syndrome develops Alzheimer's disease
- Individuals interested in learning more about the study are encouraged to contact Roberta Davis at the University of Kentucky's Sanders-Brown Center on Aging

COMMONWEALTH COUNCIL ON DEVELOPMENTAL DISABILITIES – MaryLee Underwood

- The CCDD has drafted its 5-year strategic plan and is seeking public comment
- An electronic copy of the plan will be forwarded to Commission members for their review and input

PUBLIC COMMENT

- No public comments

MEETING ADJOURNED **Deputy Secretary Feeley**

- Commission members were reminded that meeting dates for 2016 are located on the bottom of the agenda. Locations are yet to be determined.

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Supplemental Information for Health Wellness Committee

Dr. Kathy Sheppard-Jones, Chairperson of the Health Wellness Committee submitted the following written information for the record.

- Health & Wellness committee met on 2/3/16
- The Committee reviewed the work and goals from last year and decided to keep the physical activity goal based upon initiatives currently in progress. These include:
    - Health & Wellness Initiative activities that are currently underway, reflecting strong partnerships between DDID, Human Development Institute (HDI) and Commonwealth Council to impact change in health status.
    - Activities are taking place at an individual, organizational and systems level. There are 16 SCL provider agencies participating in the Health Matters 12-week evidence based program to improve health of people with developmental disabilities with over 250 individuals taking part.
    - HDI has also rolled out the Health Partners project, with the goal of providing holistic health and wellness training that is individualized to meet health goals, not only of a participant with a developmental disability, but also his or her chosen health partner. The curriculum was piloted in Oct for use with six (6) teams after an expert panel review provided input on how to make it most useful for diverse learners. There are now 13 pairs in Lexington, Richmond, and Louisville locations working on self-determined goals, ranging from physical to social health. The goal is to continue to offer this training and follow up support, and expand it to schools in central Kentucky as well. Anyone interested in finding out more, please contact Kathy Sheppard-Jones.
- Committee members reviewed health and wellness data for KY and discussed how improvements might be made in health screenings, decreasing the usage of psychotropic medications, and the lack of community based services for individuals who are medically fragile.
- The committee chose to address the need of individuals receiving screenings for colorectal cancer as an initiative to address in the upcoming quarter. Conversations are beginning with representatives from the Department of Public Health on how this might be accomplished.