Colleen Cicchetti, PhD
Child Psychologist
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Statement of Record on the Illinois Department of Healthcare and Family Services proposed Section 1115 Research and Demonstration Waiver

Friday, September 9, 2016
James R. Thompson Center
100 W. Randolph Street
Chicago, Illinois 60601
10:30 a.m.

Good morning. My name is Dr. Colleen Cicchetti. I am a Pediatric Psychologist at Ann & Robert H. Lurie Children's Hospital of Chicago where I lead the Center for Childhood Resilience. I am also an Assistant Professor at Northwestern University Feinberg School of Medicine. In addition to my role at Lurie Children's, I serve as Co-Chair of the School Age Practices and Policies Committee of the *Illinois* Children's *Mental Health Partnership (ICMHP)* and am the Clinical Director of the Illinois Childhood Trauma Coalition (ICTC).

Thank you for hosting this hearing on the Illinois Department of Healthcare and Family Services (HFS) proposed Section 1115 Demonstration and for the opportunity to offer testimony that represents the perspective of children. Children are not miniature adults and they have different mental health needs.

For almost 60 years, the Department of Child and Adolescent Psychiatry at Lurie Children's has provided psychiatric and psychological services to families and children of all ages, from every social and economic background. The need for this waiver and the timing of this waiver is evidenced by the situation at our hospital. Currently we have more than 800 children on a waiting list for outpatient child psychiatry services, double our typical waitlist. This year our specialists provided mental health evaluation and care in more than 28,000 outpatient visits; in 490 inpatient psychiatric admissions; 254 children served in the Partial Hospitalization Program; and more than 500 consultations each in the emergency department and the hospital inpatient pediatric and surgical services. The need for our services far exceeds our capacity and this situation is replicated throughout our state.

At Lurie Children's we believe that a critical component of addressing the mental health crisis facing Illinois and our country, is to invest in a public health approach. The Center for Childhood Resilience at Lurie Children's has been actively collaborating and consulting with Chicago Public Schools for over 10 years regarding model development and implementation support of a three-tier public health approach to addressing behavioral health issues of students (including primary prevention, secondary prevention and treatment). Much of this work and the work of Strengthening Chicago's Youth, Lurie Children's violence prevention collaborative, has focused on implementing strategies to address the impact of violence and trauma on students and interventions to prevent aggression in high risk youth. Our goal is to promote social, emotional, and behavioral health and the delivery of evidence-based interventions in schools and community settings to overcome treatment barriers and to build capacity of all child serving agencies to promote mental wellness and resilience. As noted in this week's court decision, the negative impact on youth and families that do not benefit from early assessment, prevention and community based intervention strategies is significant. Suicide has recently become the 2nd highest leading cause of death for teenagers in our country; and leaders from state and local agencies highlight the enormous drain of resources that addressing unmet mental health needs has on their programs from DCFS to DOJ. Extended stays in residential and inpatient facilities result from the shortage of community based treatment options. The proposed 1115 waiver's emphasis on early identification and treatment should result in significant cost savings across multiple public and private sectors and better outcomes for kids and families.

Earlier this year, Lurie Children's provided recommendations to HFS and DCFS on how to transform the behavioral health for Illinois children, all of which do not a require a waiver to implement. What follows are our specific comments on the draft 1115 waiver.

Delivery System Redesign

We commend HFS for the creation of integrated health homes focusing on behavioral health and their willingness to work cooperatively with managed care organizations to include them as means to control overall state costs. We urge the state to upwardly adjust the capitation rates to encourage the development of these homes in instances where the expected savings do not accrue to the HMO or the timing of savings is not within the contract period. We look forward to the more detailed explanations of these integrated health care homes and would urge the state to make these explanations public and available for comment before they are submitted to the federal government.

Work force Development

It is critically important for the state to expand workforce capacity for behavioral health. Under workforce strengthening initiatives in the waiver, there is mention of developing training and learning collaboratives for smaller community providers to support to their capacity to work effectively with Managed Care Organizations. This need is absolutely critical, but no details are provided on how this will be accomplished. Specifically, there is a significant shortage of child psychiatrists, nurses, and other mental health specialists trained to deliver early intervention strategies in educational and community settings and hospital-based services. It is critical that Professional Learning Collaborative and pediatric consultation model pilots developed by ICMHP and others be expanded to address this critical shortage and build evidence-based treatment options for children, youth and families. It is also imperative that we develop incentives to encourage the next generation of pediatric mental health specialists.

Relationship to Medicaid Managed Care

The 1115 waiver notes that the State is migrating Department of Children and Family Service (DCFS) children to a "specialized managed care product." There are no additional details about the timeframe or development of this specialized product. We applaud the effort and look forward to a more detailed explanation of the program and would appreciate any opportunity or forum to meet and discuss the complex issues surrounding the vulnerable population.

Inclusion of Children

Lurie Children's is pleased that so many of the demonstration benefits apply to children and youth, and that there are some much needed additional benefits for this unique population. The initiatives in the waiver around infant/early childhood mental health consultation and first episode psychosis are excellent.

Services to ensure successful transitions from Illinois Department of Corrections and Cook County Jail are included. We strongly urge that counterpart services be included for Illinois Department of Juvenile Justice, and the Cook County and other Juvenile Temporary Detention Centers. Supporting youth involved in the juvenile justice system in these transitional programs is essential given high rates of exposure to trauma and significant behavioral health needs. In addition, this meets key goal of rehabilitation and successful re-integration back into the community: the earlier these needs can be addressed, the less likely it is that the young person will later be involved in adult corrections.

Implications for Violence Prevention

Lurie Children's is very happy to see that crisis intervention training for police officers and mental health first aid training for volunteers and social service and health care professionals are included as part of initiatives to prepare the workforce for behavioral and physical health

integration activities. Lurie Children's expresses its strong support for this important provision in the waiver.

We understand that the waiver document contains only information necessary to obtain approval of the research and demonstration program. Since so much of the overall transformation will be included in State Plan Amendments and state rule changes, we encourage the administration to continue its public input process and stand ready to comment and assist on any design changes.

Thank you for your consideration.

HDA
Health & Disability Advocates

Statement: Illinois' Behavioral Health Transformation 1115 Waiver
September 9, 2016
Submitted by: Emily Gelber-Maturo, Health & Disability Advocates

HDA applauds the long-term vision the state has for the behavioral health system, and the commitment to addressing social determinants of health, such as housing and supportive employment, and expanding the Medicaid benefit package for people with serious mental illness and substance use disorders.

However, with any great system transformation, we need to contend with the realities of the short term. In order to implement many of the benefits and initiatives proposed in this waiver, we need to address systemic capacity, clarify roles of payers and providers, as well as improve infrastructure and accountability.

HDA urges Illinois to use the waiver to make much needed strategic investments in workforce and infrastructure in the short and long term. In order to enhance access to services and reduce unnecessary expenditures, we have to prioritize the assessment and diagnosis of mental illness and substance use disorders outside of the Emergency Department, the most expensive entry point to the health system. Assessment and diagnosis should happen in the community. Without adequately addressing our workforce challenges, we can't do that, and we can't take full advantage of services delivered through this waiver since eligibility for services is closely tied to diagnosis.

Further, while the services are critical to proposed cost savings; we will need enough providers, who are paid enough to cover their costs. That's not the current reality. We need rate reform. Loan forgiveness and training are not enough. Though the waiver does reference expanding telehealth which will likely help increase access to care, we will still need adequate rates to pay a provider on the other end of the screen.

HDA recommends that the state incorporate Medicaid infrastructure dollars to allow providers to keep pace, build capacity to bill, contract, and hire to provide services. We need to make sure that we are arming them to do what is expected and best within their roles by investing in our infrastructure.

In addition, HDA believes the waiver needs greater clarity on the roles of Managed Care Organizations vs. the roles of providers.

With how the waiver is crafted, it appears the State is outsourcing a good deal of responsibility to MCOs. It looks like Managed Care Organizations will be expected to implement service delivery. But the problem is that MCOs are payers, not providers. When the waiver addresses implementation of health homes and subsequent creation of a state plan amendment, we need to make sure that providers and other stakeholders are at the forefront of designing these. We don't call our MCO when we need care, we call our doctor.

HDA
Health&
Disability Advocates

In line with providing greater clarity of roles, HDA strongly urges the State to retain the role of accountability for service delivery. HDA encourages the State to establish an Illinois Behavioral Health Transformation Team, comprised of stakeholders representing providers, advocates, and consumers, to advise on the implementation of the waiver. With our state at a crossroads, operating with limited resources, we should take advantage of resources that are free, the time and expertise of smart, dedicated, caring providers, advocates, and consumers that can help to shape the long term transformation envisioned within this demonstration waiver. We stand ready to help.

HDA supports this waiver proposal and feels it contains several promising elements, but more is needed. The State must have a commitment to:

- increase capacity in the short term with Medicaid infrastructure investments and rate reform
- clarify roles - to make sure the right people are doing what they are best suited to do,
- and create responsive mechanisms for accountability,

Without this, all the good ideas within this proposal will lack the critical support necessary to transform our behavioral health system for the better.

ACCESS LIVING

ORAL TESTIMONY FOR ACCESS LIVING ON 1115 WAIVER APPLICATION

September 9, 2016

Thank you for the opportunity to provide testimony today on the HFS 1115 waiver application. Our comments today stem from our core values of consumer control and self-direction, which in the area of mental health prioritize consumer-centered care and consumer-engaged goal setting.

We have long been in favor of rebalancing Illinois' Medicaid long term care dollars, which to us means moving the needle on this area of spending so that we spend more on home and community based supports, as opposed to institutional settings. We are pleased that the State recognizes that investing in home and community based services can actually result in cost savings to the State. We believe that actuarial analysis for the *Williams* consent decree will demonstrate those cost savings, as it has for the *Colbert* consent decree. It remains, however, extremely important to do rebalancing well and by centering consumer-centered care and consumer-engaged goal-setting.

We believe that in order to provide real, fully-informed integrated care for persons with both behavioral health needs and other health needs, it is vital to develop a trained physician workforce that understands how to interpret possible linkages between mental health and symptoms of other health issues. Currently we are not confident that most physicians in Illinois have secured this training.

Access Living agrees that the State badly needs supportive housing services for individuals with serious mental illness. We encourage the State to fund, at the very least, a pilot project utilizing the "Housing First" concept in supportive housing for this target group. Housing First provides housing without mandating treatment for addiction or the receipt of services in financial literacy and basic self-care. We would urge the State to exercise some caution where Housing First has been linked with Assertive Community Treatment (ACT). ACT is team-based and multidisciplinary, providing individualized treatment and support to people with mental illness. This can often be very good for people with mental illness, but it can sometimes lead to a coercive setting that strips away the person's self-determination.

Access Living commends the proposal to fund supported employment services. Research has clearly shown that people with mental illness or substance use disorders fare well when provided this service. We further commend the State's choice of Individual Placement and Support (IPS) services as its model program. The client-centered approach of this model allows people to play an active role in defining the type of work they want and strategies in job-seeking, consistent with Access Living's philosophy that places primacy on consumer engagement and choice.

We urge the State to exercise caution about the maintenance of community supports for people with mental illness who are placed in IMDs, since they need to be able to keep what housing supports are already in place. It is critical to have a mechanism to ensure their housing is not lost.

Illinois also seeks Medicaid funds for individuals in need of stabilization due to crisis but without needs acute enough to require inpatient hospitalization. We encourage the State to

consider as "first responders" such centers as "The Living Room" in Skokie, Illinois. The Living Room, which opened in September 2011, is a residential room staffed by a trained peer counselor and with a psychologist and nurse available if needed. People in crisis can simply walk in, be evaluated by a psychiatric nurse to rule out a medical emergency, and talk about what is troubling them or just rest and relax in a nonthreatening environment. In its first year of operation, the Living Room handled 228 visits that resulted in only 15 emergency room referrals – a deflection rate of 93% that saved Illinois an estimated $550,000 in Medicaid costs. The great majority (84%) of deflections resulted in a return to the community.

For workforce-strengthening initiatives, Access Living recommends inclusion of certified recovery support specialists (CRSSs) in strengthening the workforce. Medicaid has recognized peer support services as evidenced-based practices since at least 2007. Illinois has created a CRSS credential for persons who have experienced their own personal recovery. These professionals offer a unique contribution, the insights that come from personal experience and personal recovery, and the message to others that recovery and personal empowerment are real and possible

The credential is earned in a rigorous and extensive educational program requiring 100 hours of training, a lengthy period of supervised practical and work experience, and a successful score on a CRSS written examination. Maintaining certification thereafter requires completion of 40 continuing education units every two years.

We recommend not only inclusion of CRSS professionals as an enhancement to the workforce but the same financial assistance to these individuals as that given other professionals. Obtaining a CRSS credential is a costly endeavor and considerable financial investment. We recommend that the expansion of the Illinois workforce include a tuition reimbursement mechanism for CRSS professionals who commit to serving Medicaid populations similar to loan forgiveness or other incentives provided other mental health and alcohol and drug use professionals.

In the area of first episode psychosis (FEP) programs, Access Living strongly supports the goal to develop a workforce and infrastructure sufficient to fund 13 teams statewide. Access Living recommends that the FEP team be expanded to include peer support specialists who have the lived experience of psychosis and can add unique value to the recovery-oriented program.[1]

Thank you for the opportunity to provide comments at today's hearing.

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[1] This approach is recommended by the National Institute of Mental Health in a 2014 white paper. http://www.nimh.nih.gov/health/topics/schizophrenia/raise/nimh-white-paper-csc-for-fep_147096.pdf

Health & Medicine
POLICY RESEARCH GROUP

September 9, 2016

Thank you for the opportunity to comment on the Illinois Behavioral Health Transformation Section 1115 Demonstration Waiver. The Center for Long-Term Care Reform at Health & Medicine Policy Research Group launched a Behavioral Health-Primary Care Integration Learning Collaborative in 2015 and we are beginning our second year working with 12 providers, consumers, and payers to operationalize goals that are very similar to those of the 1115 waiver.

The Learning Collaborative has identified Health Homes as a major source of lessons for current practices and an opportunity for Illinois to move toward high quality, financially sustainable, integrated health services. We, therefore, welcome the central role that Integrated Health Homes occupy in the Administration's 1115 Waiver and its broader plan for the behavioral health sector in Illinois. As a policy organization that deliberately sought out the expertise of people who provide and receive services in the existing, highly dysfunctional behavioral health system, Health & Medicine would like to share the following comments regarding the 1115 waiver and Integrated Health Homes.

The waiver refers to an "evolution of Illinois' payment and delivery system" and also an intention to "allow for flexibility for multiple models to emerge" that address diverse needs and create space for continuing innovation. If Illinois' behavioral health system is to evolve into a thriving ecosystem rather than sinking into "Darwin's nightmare" of predatory lionfish and life choking algae, we note two barriers that must be overcome: (1) data systems and business models that align with value-based payment and health home models are costly to develop and to effectively deploy, and (2) measuring quality in behavioral healthcare has been a historical and trending challenge for the state. In addition, we note that community-based integrated care with enhanced access to short-term residential treatment would be a major step forward, but that an integrated service plan can fall apart when a person is admitted to an inpatient hospital.

1) Data and business systems infrastructure
   Infrastructure investment and baseline interoperability is necessary, along with training to prepare providers to implement data exchange and analysis that coordinates care and shifts to value-based payment. Contract rate development, financial oversight of per-member-per-month payments, and coordinating workflows in a team-based, outcomes-oriented payment and delivery model requires more significant changes to data systems and business operations than can be achieved through training alone. In the development of the IHH SPA and other waivers and rule changes, as well as the initiatives that could be funded by the Integration Funds described in the 1115 waiver, we urge you to consult with providers in Illinois and health homes in other states about the infrastructural and operational needs to adapt to value-based designs.

For example, outreach and engagement in particular are the biggest challenges cited by health home programs with many years of experience in Missouri and those in Washington State, and managing the PMPM payments that allow for expanding and improving outreach is an operational challenge. The providers that can perform the difficult work of identifying and engaging people at-risk or people experiencing serious mental illness (SMI) or substance use disorders (SUD) also take on the added challenge of coordinating new benefits such as supported housing and employment. Those providers may not necessarily be the same providers that can adapt quickly to incentives for new business models.

Developing nimble business models that can maximize the benefits of value-based payment is an important component of health system transformation that we do not want to minimize or vilify. However, supporting the providers who excel at the *core work* of person-centered engagement and recovery to create financially-sustainable business models is a far better investment than attempting to teach providers that have savvy business models for new financial incentives, but do not have the skill set or inclination to provide person-centered care, which moves the dial on both prevention and recovery. The risk of incentives going awry and rewarding entities that are more revenue-savvy than person-centered appears to be acknowledged in the waiver when it calls for a third party pre-authorization and audits for SUD treatment in IMDs.

2) **Acknowledging deficiencies in quality measurement**
Gaps in quality measurement for SMI and SUD are a challenge for developing outcomes- or value-based payments and identifying those providers most likely to leverage integration funds to create innovative, effective health homes. The preliminary evaluation plan included in the waiver demonstrates this problem. Most of the proposed measures are for utilization, consumer self-reports of satisfaction with services, and costs. These are all important metrics, but the fact that it is difficult to identify validated and reliable quality measures that have been shown to be associated with improved health outcomes for people with serious mental illness[1,2], should be acknowledged as a challenge that will require creative and adaptable solutions. Measures of success in reaching members assigned to a health home and conducting assessments, as well as utilization measures that indicate engagement in community-based services and reduction in avoidable hospitalizations may serve as intermediary indicators of quality practice until more robust outcome measures are available.

3) **Hospital transitional care as part of integrated care**
One final lesson to share from the Learning Collaborative is that integration needs to address transitions between settings, including hospital discharge to the community and transitions

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[1] Gaynes, Bradley et al. "Relationship Between Use of Quality Measures and Improved Outcomes in Serious Mental Illness," Agency for Healthcare Research and Quality Technical Brief Number 18, January 2015.
[2] Pincus, Harold Alan et al. "Quality Measures for Mental Health And Substance Use: Gaps, Opportunities, And Challenges," *Health Affairs* 35, no. 6 (2016): 1000 – 1008 doi:10.1377/hlthaff.2016.0027

between residential care, hospitals, and community-based care. The waiver cites statistics on hospital readmissions and over-utilization of inpatient care, but does not specifically address a major stress point for patients and providers—hospital admission and discharge. Post-hospital discharge transitions arose as a particular concern in the Learning Collaborative, and we plan to work more to identify practical, effective solutions in the coming year of our work together. Health & Medicine is also a partner with hospitals and community-based organizations across the country in a hospital transitional care program, The Bridge Model. The Bridge Model is a person-centered, social work-led, interdisciplinary transitional care intervention that helps older adults and high utilizers safely transition from the hospital back to their homes and communities.

We would be happy to share more of our experience with the Learning Collaborative and the Bridge Model as the Administration continues its efforts to transform the behavioral health system in Illinois.

Sincerely,

Sharon Post
Director, Center for Long-Term Care Reform
Health & Medicine Policy Research Group

Illinois Health and Hospital Association

Statement of the
ILLINOIS HEALTH AND HOSPITAL ASSOCIATION

Friday, September 9, 2016

Patrick Gallagher
Group Vice President
Health Policy and Finance
Illinois Health and Hospital Association

State of Illinois
Public Hearing on Proposed Section 1115 Demonstration

James R. Thompson Center
Chicago, IL

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Illinois Health and Hospital Association

Testimony of Patrick Gallagher
Group Vice President, Health Policy and Finance
Illinois Health and Hospital Association

State of Illinois
Public Hearing on Proposed Section 1115 Demonstration

James R. Thompson Center
Chicago, IL

Friday, September 9, 2016

Good Morning, Directors Baldwin, Norwood and Sheldon and Secretary Dimas, I am Patrick Gallagher, Group Vice President of Health Policy and Finance at the Illinois Health and Hospital Association (IHA). On behalf of the over 200 hospitals and over 50 health systems that are members of IHA, I would like to thank you for your focus on transforming the behavioral healthcare delivery system in Illinois. With your leadership, the state has outlined an ambitious plan to address the numerous issues surrounding behavioral health. IHA looks forward to learning more of the details of the proposal and working with you to improve the lives of individuals living with mental illness and addiction. There are a several components of the waiver I would like to highlight as important to the hospital community as well as point out several questions and comments.

IHA has been examining priority behavioral health interventions that can improve access to care and we are pleased to see many of these included in the waiver. IHA's Behavioral Health Advisory Forum, made up of a diverse group of administrators and providers from across the state, developed recommendations with specific emphasis on evidence-based interventions that can be replicated across Illinois and that can improve the delivery of and payment for behavioral healthcare. We feel these are meaningful recommendations that will make a significant improvement across the state. Many of these align with the primary waiver initiatives of greater integration and workforce development.

In particular, IHA supports:

(1) Enhancing emergency and community-based crisis stabilization services. We want to stress that these services can be provided in a variety of settings, not just in an IMD. Colocation within or near a hospital's emergency department is an optimal setting, as it meets the patient where they often present in crisis for intervention and de-escalation;

(2) Using behavioral health homes to integrate behavioral and physical health, which is key to meeting all the health care needs of individuals with behavioral health conditions;

(3) Expanding telehealth capacity to serve individuals in both rural and urban communities. Currently, the primary impediments appears to be the low reimbursement that does not make the service a sustainable model to deliver care; and

(4) Enhancing the behavioral health workforce, including enabling providers to practice at the tops of their license.

All of these are important provisions of the waiver. There are other proposals in the waiver that hold significant promise, including those related to addressing homelessness, providing employment supports and enhancing the capacity of community behavioral health services.

While the details of the waiver implementation will be necessary to provide a final evaluation of the proposal, there are several issues we would like to raise at this time. Since health homes will play a foundational role in coordinating care, we would like to point out that providers are in the best position to provide services like patient and family support, comprehensive care management, health promotion and wellness. The role of the MCOs in coordinating care needs to be clearly articulated so the health homes achieve true outreach and coordination, rather than acting as a gatekeeper. As providers are challenged with complying with numerous new MCO policies and procedures, it will be important to strike a balance between achieving innovation and uniformity in designing the criteria for the medical homes. We request the state develop appropriate criteria with significant provider input to better inform future strategies. Similarly, the role of MCOs in the wavier needs to be clarified not only in terms of care coordination, but also in terms of achieving the goal of value based reimbursements. Value based contracts need to be mutually agreeable between providers and the MCOs, where incentives are aligned around realistic savings expectations. Therefore, continued oversight of the MCOs will be necessary to not only gain provider participation, but also to inspire confidence in the process.

The financial component of the waiver is critical, especially obtaining a better understanding of the distribution of funding as well as the expected savings. While achieving budget neutrality is central to a waiver, a meaningful transformation of services for persons with behavioral health conditions will require an increase in funding. Illinois' average spending per Medicaid enrollee ranks 49th in the nation – substantially lower than every surrounding state in the Midwest and lower than our peer states of California, New York, Texas and Florida. In some cases this will

mean increasing rates for services in order to provide adequate access to care, such as those for telehealth.

Enhancing access to behavioral health in Illinois and addressing workforce shortages are necessary components to ensure there is sufficient care to coordinate. Every day patients arrive in hospital emergency departments where compassionate care is delivered but all too often there is inadequate capacity to place the patient in an inpatient or community setting where ongoing treatment can occur. Developing the integrated health homes will also require funding to build capacity and the reimbursement model will need to provide sufficient incentives for providers to make the necessary investments for care coordination infrastructure.

Enhanced capacity, incentives to coordinate care, and an increased and fully utilized workforce will have positive repercussions throughout the health care system. I would like to leave you with just one example. More timely placement from the ED in the most appropriate level of care would occur with effective care coordination and use of crisis stabilization. We continue to hear from our members that patients are presenting in the ED at a higher level of acuity than in recent years and this not only has implications for the unmet health care needs of the patient, but also safety concerns for staff providing the treatment.

The time has come for a comprehensive plan to address these numerous behavioral health issues. We look forward to our continued dialogue on these important issues, and we appreciate your leadership on this initiative.

Proposed Section 1115 Demonstration Public Hearing

Illinois Department of Healthcare and Family Services

September 9, 2016

Testimony Submitted by Christina LePage, Managing Director of the Illinois Children's Mental Health Partnership

Thank you for the opportunity to speak before you today as Illinois prepares to submit its 1115 Demonstration Waiver application. The Illinois Children's Mental Health Partnership (Partnership) applauds the leadership and efforts of the Administration to transform children's mental health services, recognizing the urgency for Illinois to prioritize this critical public health issue.

The Illinois Children's Mental Health Partnership is the only statewide, public/private partnership in Illinois comprised of representatives from families, policymakers, legislators, advocates and child-serving systems that is committed to improving the scope, quality, and access of mental health programs, services, and supports for children and their families.

Illinois leaders took bold steps when they passed the Children's Mental Health (CMH) Act in 2003 and created the Partnership. For over twelve years, the Partnership has worked closely with its partners to address the need for a more comprehensive continuum of care for children and families. The Partnership is encouraged by Illinois' Waiver application, as it continues to move Illinois in the direction of system integration and delivery of services in natural settings. Targeted efforts to accelerate Illinois' integration of physical and behavioral health services will help increase prevention, early identification and intervention, and treatment for children before mental health concerns become more severe, and more costly to the State. An integrated approach will also help address the stigma that is often associated with mental health services, as it will promote the understanding that mental health is equally as important as physical health.

Additionally, the Partnership supports Illinois' shift to outcome-based reimbursement practices, clearly prioritizing quality over quantity. As Illinois makes this shift in practice, the Partnership strongly cautions the State to remain mindful of the complexities involved with defining and measuring mental health outcomes, especially among children. We remind the State of the importance of adopting a child developmental approach when establishing outcome measures; an approach that takes into account the changing needs of children and adolescents, and their families, as youth age. It is also critical that families and consumers are involved in the creation of outcome measurements to ensure that their individual characteristics, needs, preferences, and circumstances are accurately represented. In addition, to further support providers with the transition to outcome-based reimbursement models,

funding for behavioral health services needs to be consistent and sustainable in order to prevent service disruptions, staff turnover, and program cuts that negatively impact child and family outcomes.

We are also pleased to see the inclusion of crisis beds, respite care and intensive home-based services in the Waiver, which align with previous recommendations made by the Partnership's Children's Behavioral Health Integration Initiative (CBHII). Through CBHII, the Partnership worked with the Department of Healthcare and Family Services (HFS), the Division of Mental Health, and the Department of Children and Family Services to develop recommendations and service descriptors for HFS regarding additional services that should be included in the array of behavioral health services available to children.

Lastly, the Partnership enthusiastically supports the inclusion of infant/early childhood mental health consultation (mental health consultation) in the Waiver as a cost-effective strategy to support young children and their families. Mental health consultation is not a new concept for the State of Illinois; Illinois has been a leader in the nation for the work we have done across systems to support infant/early childhood mental health.

The Partnership is currently leading a Mental Health Consultation Initiative in close collaboration with the Irving Harris Foundation and numerous public and private stakeholders, to create a comprehensive framework and infrastructure to embed mental health consultation in all child-serving systems in Illinois. The inclusion of mental health consultation in the Waiver is a major step forward in the expansion and sustainability of this valuable support. Moreover, the Waiver will allow the State to further demonstrate the evidence-base for the use of mental health consultation to improve outcomes for systems, programs, providers, and most importantly, children and families in Illinois.

There is an urgency and necessity to respond to the mental health needs of Illinois' children in ways that challenge the status quo and maximize Illinois' very limited resources. The Partnership commends the Administration's leadership and clear commitment to improve the mental health system for Illinois children and their families. By working together, we can support children's mental health so that all Illinois children can live healthier, happier lives and contribute positively to the social and economic fabric of Illinois. Thank you for your time.

For more information about the Illinois Children's Mental Health Partnership contact Christina LePage, Managing Director, at clepage@voices4kids.org or 312-516-5569.

Testimony on Illinois' Behavioral Health Transformation
(Section 1115 Demonstration Waiver)
September 9, 2016

Good Morning. My name is Fred Berkovits and I am the Regional Director and Corporate Compliance Officer for Bria Health Services. I am also a member of HCCI and speak on behalf of all of our members serving the population covered under the 1115 waiver proposal. Like Dr. Stelter, I work with residents that have demonstrated an inability to function effectively in the community.

I have identified a number of cases where individuals have been returned to the community as part of the Money Follows the Person program without positive outcomes.

RESIDENT #1 (J.C.)

This resident was a brittle diabetic who was non compliant with his medications. We explained this to the MFP folks but they insisted that they would manage his diabetes. During the time he was out of the facility (9 months) he was hospitalized 5 times for uncontrolled diabetes. The resident called us to ask if he could come back because he was not doing well in the community. Since being back his diabetes is under control.

RESIDENT #2 (V.S.)

This resident had a history of substance abuse. This was explained to the MFP folks but they discharged her into the community. She was in the community for less than 5 months when she was found by the police wandering the streets and back using drugs.

RESIDENT #3 (E.P.)

This resident had a history of mental illness and medical issues. She was discharged into an apartment and during that time had multiple hospitalizations. She was referred back to the facility by the hospital.

RESIDENT #4 (A.J.)

This resident was discharged with MFP and within 5 days we received a call from an ICU because the resident was there and they needed medical history information.

Current residents: (A.B. and N.T.)

We have 2 current residents who are being pursued by MFP who have told MFP that they are afraid to live in the community because they like the structure that the facility provides and both have said that they consider this their home. However, the group is still pursuing them when they are in the facility.

Again, we request your consideration of preserving the current program for residents unable to return to the community.

Thank you for the opportunity to share our experiences.

Testimony on Illinois' Behavioral Health Transformation

(Section 1115 Demonstration Waiver)

September 9, 2016

Good Morning. My name is Dr. Jennifer Stelter. I'm the Operations Director of Clinical Programs for Alden Management Services. I'll be speaking today on behalf of the 300 skilled facility members of the Health Care Council of Illinois.

Although Illinois' Behavioral Health Transformation (Section 1115 Demonstration Waiver) plan is pertinent for people suffering with mental illness who can function independently in the community, it fails to detail plans for those who either aren't ready to function independently or aren't able to, long-term.

The plan discusses de-institutionalizing all patients and, in essence, discharging patients from hospital settings right to the community, which sets the patient up for failure when shortcutting a step-down approach to care that we all know works the best for long-term recovery. We believe this will lead to more relapses and an increased need for crisis level of care causing further use of hospital settings or jail to provide services for those suffering with mental illness.

This is the problem that the Demonstration Waiver claims to resolve but will actually heighten.

Alden's Behavioral Health Program is a residential rehabilitation program for those suffering with mental illness. Our program resides in skilled long-term care settings that allow not only the patient to engage in therapeutic mental health rehabilitation but also to care for often prevalent, comorbid medical problems (e.g., Diabetes, Type II, COPD, Hypertension, etc.). We offer short-term and long-terms stays, depending on where the patient is at in their recovery and ability to keep themselves safe. We provide 24-7 monitoring, as the patients learn coping skills and medication management needed to sustain stability out in the community.

Additionally, to fund the Waiver program, the plan is to take away $200 million dollars away from Medicaid Programs, i.e., taking money away from

residential care needed for patients that require this level of care. Taking this money away and closing programs like Alden's Behavioral Health Program can lead to this...one of our programs had 6 residents that were discharged to the community through Money Follows the Person, the state's latest quick fix to take patients out of long-term care settings and support them in the community. These patients required our level of care – now, 2 are in jail, 1 died, and 4 returned to the facility.

There are numerous examples of patients that are with us or were with us and have returned to our setting because they did not sustain stability in the community and needed a higher level of care. I have detailed some of those examples below and will review a few as part of my comments.

Examples:

1. Male, Caucasian, 41 years of age with Paranoid Schizophrenia. His voices give him strong commands and he is genuinely afraid of the repercussions if he doesn't do just as the voices tell him. The voices tell him at times to wash his hands, over and over, as people are dying from his germs. He will then scrub his hands with soap till they are raw and bleeding. The voices will also tell him not to eat and if he does, people will die and it will be his fault. So he will go days or longer without eating. It has gotten so bad that he now has to receive ECT every few months. He requires constant supervision to prevent serious self-harm from the commands. His family has been very pleased with how stable he has been since coming to us and starting ECT. They have said they believe it is because we are able to provide constant supervision and interventions that his family was not capable of doing and this keeps him much safer and healthier. He has been with us for two years.

2. Male, Caucasian, 68 years of age with Schizoaffective Disorder. He came to us after an ICU stay due to being found unresponsive in his apartment having not eaten or taken any medications for a few weeks. He seemed to do well with us and after a while insisted on going home again. We had him show us, for a 6 month period, that he could shower every day, keep his room clean, do his laundry, keep his bedding clean, take all his meds as prescribed, etc., all the things he would have to do to live on his own. He did very well over those 6 months and went home again to live on his own with outpatient psych and medical care all set up. Within a few weeks, we got a call from a local hospital saying he was back in the ICU

and was not expected to live after having not taken any medication since his discharge, including meds for hypertension as well as psych meds, and having not drank or eaten since his discharge. Miraculously he did survive and returned to us. He has acknowledged that this happens every time he tries to live on his own and he now states he does not believe he can ever live on his own and is afraid he will die if he tries this again. He takes all his meds when he is with us and is generally stable overall while at our facility. He has been with us for a total of seven years.

3. Female, Caucasian, 53 years of age, with Paranoid Schizophrenia. This resident came to us after she was arrested for assault. She was living with family but would often times believe that her meds, including the insulin for her very difficult to manage Diabetes, were poison and she would not take the meds. Her family had little if any success at getting her to take her meds when her paranoia was present. She had not been taking her psychotropic meds when she was in line to pay at a store and thought a customer in line behind her was talking bad about her (the other customer was not talking about her at all). She hit the other customer. The court allowed her to come to us as they felt she needed treatment instead of jail. She has very severe auditory hallucinations as well as very serious political and religiously themed delusions, and these only ramp up her paranoia even further. With constant staff interventions we can generally get her to take all of her meds, even her insulin. Her family was frightened of her when she lived with them, but they feel very comfortable to visit her at the facility and will take her out for short passes no longer than a couple hours. Her family, especially her mother who now is becoming pretty elderly, has said that they were not able to manage her when she lived with them before and don't believe they could manage her at any point in the future. But they feel that, due to the constant staff supervision and interventions, she is managed well at our facility and they would like her to remain with us. She has been with us now for eight years and is doing well. She has shown no physical aggression in those eight years.

4. Female admitted to us on May 27, 2016. Diagnoses include: Schizophrenia, unspecified, Major Depression Disorder, Recurrent, and Hypertension. Patient is 63 y/o AA and has been married once, but is currently divorced. She stated that she has been receiving mental health services for years. When she left another residential placement, she moved to an apartment near the city through the program called Money Follows the Person. She lived there for four years; and received services

through MFP. MFP provided her with assistance in managing her funds, taking classes which she attended two days a week plus field trips, and regular appointments with a physician and psychiatrist. Per the patient, living independently became stressful. She stated she had mental relapses, frequently. She says stress was the culprit. Stressful matters included: memory setbacks, reduced contact with family (afraid to be involved with family), being left alone often, and many medication adjustments. After one hospitalization and her stay with us thereafter, the new medication has her stabilized, less anxious, and she has built a network of friendships on the unit. She states she prefers living in a supervised environment. It appears that having a routine is the key to stabilization. She further stated that she does not want to return to the community to live independently at this time.

5. Female is currently 59 y/o AA with a diagnosis of Schizoaffective d/o, Major Depressive d/o, Single episode, Heart Failure, DM, HTN and Glaucoma. She was admitted to us in November of 2014 from another long-term care setting. She was married in her teens to her husband who passed away in 1979. To this union was born four children from 1975 to 1978. After this tragedy, she felt alone, and had little contact with her family. She expressed that she prefers to be in rehabilitation because, "it's so lonely out there." She went on to say, "I don't want to move from here." She said, she was afraid to make friends in the community, and to go to the laundromat because she might get robbed or hurt. She further stated that people would take advantage of her by asking for money or to borrow the TV, etc. She felt like no one valued her. She expresses that she loves living in this environment because she says no one here is trying to take advantage of her. "I have a place to be, with people I see every day, and I can tolerate people better."

6. Female is a 64 y/o AA with dx of Schizophrenia, Depressive episodes, DM type 2, Anemia, Chronic Embolism and Thrombosis of unspecified vein. She reports living in a one-bedroom apartment in the past (dates she cannot recall at this time). From what we've been told, twin daughters have taken advantage of her financially. What brought the patient back to living on a specialized behavior health unit was "...getting up depressed and talking to myself." She has lived with us since July 2010. She often inquires about living independently, but does not meet the requirements of the Money Follows the Person housing program. She needs assistance with medication administration, reminder to shower, and managing her

anger. She has been advised by the MFP that she would be in need of a supervised setting versus independent living.

7. 52 yr. old AA male with a diagnosis of Schizoaffective and HTN. He was moved out of our SNF by Thresholds into the community in May 2015 and was in and out of the hospital over seven times due to medication noncompliance during the time he lived in the community. In early 2016, Thresholds moved him into an ICF where he did not do well and in April 2016 Thresholds asked that he be readmitted to our SNF. When he returned to our SNF he was off his baseline and is still not back to the level of functioning he was at before he moved into the community.

8. 60 year old Caucasian male with a diagnosis of Bipolar D/O, Chronic pain syndrome, and osteoarthritis. He was living in the community working with Thresholds and he was unable to function, could not manage his medication and was in and out of the hospital. Thresholds moved him into an ICF where he did not do well and then moved him into our SNF.

9. 63 year old AA male with a diagnosis of Schizophrenia and HTN. He states that he does not want to move out into the community; he feels he would be taken advantage of and would not stay on his medication.

In conclusion, the examples I have presented demonstrate that not all individuals with mental illness with comorbid issues are able to function independently in the community. It is our recommendation that the 1115 waiver plan include accommodations for individuals who either aren't ready to function independently or aren't able to, long-term.

Thanks you for the opportunity to speak today. I am available to answer any questions you may have.

ILLINOIS DEPARTMENT OF Healthcare and Family Services

Bruce Rauner, Governor
Felicia F. Norwood, Director

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October 4, 2016

Christine Norrick
934 Oakwood Ave
Wilmette, IL 60091
cwnorrick@aol.com

RE: FOIA #16-665

Dear Ms. Norrick:

Thank you for writing to the Illinois Department of Healthcare and Family Services with your request for information pursuant to the Illinois Freedom of Information Act (FOIA), 5 ILCS 140/1 et seq.

Our Office received your FOIA request on September 27, 2016 for the following information:

Request complaints and annual reviews for 2016 for 2 senior supportive living facilities:

1. **Prairie Winds in Urbana, and**
2. **Victory Centre in Vernon Hills.**

The responsive records contain some redactions pursuant to Section 7(1)(a) and 7(1)(b) of FOIA. Section 7(1)(b) provides that "private information" is exempt from disclosure. "Private information" is defined in FOIA as "unique identifiers" which includes signatures. Therefore, these have been redacted from the responsive records.

Section 7(1)(a) provides in pertinent part:

Section 7. Exemptions

> (1) When a request is made to inspect or copy a public record that contains information that is exempt from disclosure under this Section, but also contains information that is not exempt from disclosure, the public body may elect to redact the information that is exempt. The public body shall make the remaining information available for inspection and copying. Subject to this requirement, the following shall be exempt from inspection and copying:
>
> > (a) Information specifically prohibited from disclosure by federal or State law or rules and regulations implementing federal or State law.

Federal regulations at 45 CFR 160.103, 45 CFR 164.502 and 45 CFR 164.514, promulgated under the Health Insurance Portability and Accountability Act (HIPAA), do not allow the Department to release a client's Medicaid records, eligibility status or participation status in the program. HIPAA protects all "individually identifiable health information" held or transmitted by the Department, in any form or media, whether electronic, paper, or oral.

"Individually identifiable health information" is information, including demographic data, that relates to:

- the individual's past, present or future physical or mental health or condition,
- the provision of health care to the individual, or
- the past, present, or future payment for the provision of health care to the individual,

and that identifies the individual or for which there is a reasonable basis to believe it can be used to identify the individual.

Further, 45 CFR 164.502 allows the Department to release what would be individually identifiable health information, if the information is de-identified. De-identification requires redaction of any information that could be used on its own, or in combination with other public records, to identify an individual. This includes, but is not limited to: names, addresses, dates that relate to an individual, phone numbers, email addresses, social security numbers, account numbers, certificate/license numbers, or any other unique identifying number. For this reason, the response to your request contains redactions to ensure all individually identifying information is removed.

In addition to HIPAA confidentiality requirements, federal regulations at 42 CFR 43 1.300-307 (Medicaid) require that state statutes prohibit the use or disclosure of information concerning applicants and recipients of Medicaid services, except for uses that are directly connected with administering the assistance programs. Illinois law satisfies this federal requirement, as well as, protecting the confidentiality of client information in all Department assistance programs, at Section 11-9 of the Illinois Public Aid Code (305 /LCS 5/11-9) and at 89 Illinois Administrative Code 102.30.

Section 11-9 of the Illinois Public Aid Code provides in pertinent part:

> Section 11-9 Protection of Records - - Exceptions. For the protection of applicants and recipients, the Illinois Department of Healthcare and Family Services, the county departments and local governmental units and their respective officers, and employees are prohibited, except as hereinafter provided, from disclosing the contents of any records, files, papers and communications, except for purposes directly connected with the administration of public aid under this Code.

Section 102.30 of the Illinois Administrative Code provides in pertinent part:

> Section 102.30 Confidentiality of Case Information
>
> (a) For the protection of clients, any information about a client or case is confidential and shall be used only for purpose directly related to the administration of the assistance programs.
>
> 1) The establishment of a client's initial or continuing eligibility for public assistance;
>
> 2) The establishment or the extent of an individual's need for financial assistance, medical assistance or other services; and
>
> 3) The establishment of procedure assuring the health and safety of the client.
>
> (b) Use of information for commercial, personal; or political purposes is specifically prohibited.

The information you seek encompasses confidential program participation status. The purpose of your request is not directly connected with the administration of the public assistance programs (e.g. establishing eligibility; determining amount of assistance; providing services). None of the statutory exceptions, referenced herein, apply to your request. Under Federal and State law and regulation, as cited above, HFS cannot release information about clients if there is a reasonable basis to believe it can be used to identify specific individuals and thus, the response to your request contains redactions to ensure all individually identifying information is removed.

To the extent you consider this response to be a denial of your FOIA request, you have the right to submit a request for review by the Public Access Counselor (the "PAC") in the Office of the Illinois Attorney General to:

Public Access Counselor
Office of the Attorney General
500 South 2nd Street

Springfield, Illinois 62706
Fax: 217-782-1396
E-mail: publicaccess@atg.state.il.us

If you choose to submit a request for review to the PAC, you must do so within 60 days after the date of this letter. Your request for review must be in writing, signed by you, and include a copy of your FOIA request and this response. 5 ILCS 140/9.5(a). You also have the right to seek judicial review of this response. *See* 5 ILCS 140/11(a),(b).

Sincerely,

//s//

Kiran Mehta
Freedom of Information Officer