# Statement to Milwaukee County Board on Proposed Closure of Hilltop and Rehab Central Robin Pedersen - March 12, 2013

My name is Robin Pedersen, and I reside in Milwaukee County. I'm a member of the Milwaukee Mental Health Task Force. I am the guardian of my brother who has a developmental disability and also mental illness. I believe it is in the best interest of the residents of Hilltop and their families and guardians to close these units over the next three years and relocate these residents into the community in a more integrated setting! As an advocate and guardian having lived experience with my brother since I was very young, I remember what it was like for our family and him when he lived at home. When he was seven years old, he became a ward of the State and went to live at Southern Wisconsin Center in Union Grove. This was very difficult especially for me because my buddy went to live far away from our family. As a result of this I had many behavioral issues at school and home.

At the time it was the best thing for my brother going to live at the institution because there were not services in the community to support his special needs. In the early 1980s, the State sent many of the residents at Southern Wisconsin Center, Northern Center, and Central Center back to the counties where they previously lived. I can tell you how the quality of his life has positively changed. There were struggles for him with his first two placements. He then went to live at a nursing home where a lot of his friends from Southern went to live. He attended a day program owned by Bell Therapy. They were really dedicated to him and their other clients to ensure that he had a much better quality of life! When they opened their first group home several years later, they asked me if my family and I would consider moving him to their group home. I agreed, and it was the best thing that happened for him and also our family! I am so grateful to the staff of Bell Therapy for providing him with an increased quality of life. He has a lot of opportunities to live and actively participate in the community just like you and I have! I don't believe anyone here would prefer to live in an institution! I am so grateful that he has a chance for a better quality of life and is doing very well! In fact, he has been going to a residential camp every summer for many years!

I believe it is in the best interests of the residents of Hilltop and their families and guardians to relocate them in the community. In order for the successful relocation of these residents into the community, it will be essential for the Family Care and Partnership Managed Care Organizations to develop the resources and capacity to meet these specialized needs of the residents. It is critical that an adequate Family Care capitated rate be provided to serve these residents who have complex needs and challenging behaviors in the community. The closure of the Hilltop units will require significant development of new resources. This will require ensuring provider rates that will support experienced and high quality providers.

The staff working at Hilltop are very dedicated to working with these residents. BHD staff will continue to support these residents during their relocation in the community as well as help the residents and their families during this transition process. They are will provide training to the providers and be available to help the providers with specific plans and needs of each individual to ensure they have a successful, quality of life. Due to the specialized and complex needs of these residents, appropriate, quality housing needs to be developed to ensure the best quality of life for them. For some residents they might do well in small group home (4 beds or less), an Adult Family Home, or a supported apartment with two residents and one on one care.

I am excited that the residents of Hilltop will have an increased quality of life and realizing that they can participate as active and meaningful residents of the communities in which they live!



The Milwaukee Mental Health Task Force is committed to being a leader in identifying issues faced by all people affected by mental illness, facilitating improvements in mental health services, giving consumers and families a strong voice, reducing stigma, and implementing recovery principles.

## Statement from the Milwaukee Mental Health Task Force on Proposed Closing of Long Term Care Facilities at the Milwaukee Mental Health Complex March 11, 2013

In the recent State of the County Address, County Executive Abele introduced a plan to close the long term care facilities at the Mental Health Complex over the next three years and develop person centered plans to serve each resident in the community. This includes Hilltop, the 70 bed long term care center (ICF-MR) for people with co-occurring mental health and intellectual and developmental disabilities and Rehab Central, which serves people who need skilled nursing home care and also have a mental illness. Most residents will be eligible for services from Family Care, which provides community based services and supports to three target groups: frail elderly, people with developmental disabilities and people with physical disabilities.

The proposal to close the long term care facilities and development community placements over the next three years, is in line with state and national trends to support people with disabilities in the community in a more integrated setting. Wisconsin's ICF/MR population has dropped by 2/3 in the last 8 years as more people have been served in community settings. Milwaukee has lagged behind and continues to maintain an institutional capacity that most other counties have largely stopped using. Developing a comprehensive person centered plan to downsize Hilltop and Rehab Central is also in line with the recommendations in the report from the Human Services Research Institute and Public Policy Forum, as well as the Mental Health Redesign and Implementation Task Force.

Furthermore, this direction is also in line with the Supreme Court decision in *Olmstead v. L.C.*, a ruling that requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs. The Department of Justice under President Obama has taken aggressive action to enforce the Olmstead decision and to ensure the right of people with disabilities to live in the community in the least restrictive environment.

As advocates, we support the right of residents at the Mental Health Complex to have the opportunity to live in the community because we believe this can provide an increased quality of life and offer additional opportunities for community engagement and to be near friends and family. To realize the potential of a better life in the community, it is vital that the community setting includes quality services, supports, including adequate staffing levels, carefully developed to meet the residents' needs and with the input of each resident and their guardian or family.

#### **FAMILY CARE HAS A KEY ROLE TO PLAY**

The vast majority of residents of the Mental Health Complex Long Term Care facilities are eligible for Wisconsin's Family Care program which is a Medicaid waiver that provides community based long term care services. Family Care is an entitlement in Milwaukee County which means that we no longer have waiting lists and any county resident who is functionally and financially eligible must be served. Individuals in Milwaukee County residents who are eligible for Family Care receive options counseling regarding their choices for long term care. Residents who are eligible for Family Care, and their guardians, will have a choice of two Family Care Managed Care Organizations (MCOs), two Partnership programs, and IRIS which support self-direction of community long term care services. These programs will oversee the community based services that residents will receive.

To be successful in relocating Hilltop and Rehab Central residents to the community, it will be essential for the Family Care and Partnership Managed Care Organizations to develop the resources and capacity to meet these important and specialized needs and to provide the level of funding needed to support appropriate staffing and needed supports, and adequate rates to secure experienced proven providers. As a managed care program, Family Care uses a capitated rate set by the state which pays a "per-member-per-month" rate, regardless of the number or nature of services provided. Advocates have long been concerned that the capitated rate may be a disincentive to service people with complex and costly needs - and we strongly believe that an adequate Family Care capitated rate is essential to serving residents of Hilltop and Rehab Central in the community.

#### RECOMMENDATIONS FOR MOVING FORWARD

The Milwaukee Mental Health Task Force has long supported the right of people with disabilities to live in the community in the least restrictive setting. We support the proposed concept of developing a plan to close Hilltop and Rehab Central in three years while concurrently developing quality community based placements for each resident. However, our support is contingent on the following safeguards:

 It is essential that all stakeholders proceed slowly and carefully to ensure that effective and appropriate supports and services are developed to provide residents with the best possible chance to have a good life in the community. This should include a careful review of best practices and lessons learned from previous institutional downsizings, and an examination of how these can be incorporated into the current closure given the relatively new role of Family Care.

We recommend that a forum be held within the next three months to highlight lessons learned from past institution closings and share best practices, so that these can be used to benefit residents as we move forward with the Hilltop and Rehab Central closures. This should include strategies for supporting and educating guardians, who have a very important role to play in this transition.

- The state mandated team for institutions closings, which includes representatives of advocacy groups (Disability Rights Wisconsin and the Board on Aging and Long term Care) must be front and center as an essential watchdog, ensuring the integrity of this effort. We support their efforts and critically important oversight role.
- Although there have been large institution closings in the past in Milwaukee County, this is the first closing of this size
  and complexity since Family Care has been in place. It will be important to determine how Milwaukee County and the
  Family Care MCOs can work collaboratively to develop and support the essential resources needed to successfully
  serve Hilltop and Rehab Central residents in the community.

This should include development of a robust continuum of community services including housing, specialized behavioral health services, crisis services including the Mobile team and respite beds. The planned closure will require significant development of new resources and that will require ensuring provider rates that will support experienced and high quality providers. Mobile crisis teams, should be available 24/7, with specific expertise in meeting the needs of three target groups of people, those with psychiatric disabilities, those with intellectual disabilities, and those with Alzheimer's/dementia.

• Funds saved from downsizing must be invested in developing community services and supports. This is in line with county board resolution (RES 11-516) signed by the County Executive which states in part: "The county must commit to continued funding of mental health care services at current levels with any savings produced as a result of the transition to a community-based service delivery model reinvested into the program to allow for expanded community services". Similar language was in the adopted 2012 budget.

This is especially critical for the minority of residents who are not eligible for Family Care. Milwaukee County must be the safety net for these residents and for others moving forward who have a mental health disability and are not eligible for Family Care. This will require a commitment for a long term increased investment in community services and supports including residential services. For the closure to move forward, Milwaukee County must make a commitment to develop and support community housing and services for residents who do not qualify for Family Care, and for other community members moving forward.

The vast majority of residents of Hilltop and Rehab Central have multiple disabilities and complex needs. For Family Care to be successful in serving individuals with complex needs, an adequate capitated rate is essential. We urge Milwaukee County to advocate with the Dept. of Health Services (DHS) regarding the need to provide an enhanced capitated rate to ensure the success of this institution closure. Advocates stand ready to work with Milwaukee County leadership to make the case to DHS for an enhanced rate for residents which will cover the actual cost of relocating residents to the community and developing specialized residential settings. We welcome the DHS decision to use Money Follows the Person funds to supplement the capitated rate, with a \$1000 per member payment to the MCOs to assist with relocation. However, in many cases, this supplement to the capitated rate will not be sufficient.

Note: Until 2011, a special "first year" enhanced rate was provided for Wisconsinites relocating from an institution. This recognized that one-time investments were needed to develop specialized resources, provide environmental modifications, develop behavior plans, and recruit and train staff with specialized skills. The enhanced rate for Year 1 is a good investment because it supports development of capacity and placements for people with complex needs — we should develop a strategy to make the case to DHS to reinstate the enhanced rate for a minimum of one year.

- Ensuring a comprehensive community based continuum of services. This would provide technical assistance and crisis back-up in the community and reduce the "revolving door" where the only option in a crisis is to re-admit people to an institutional setting. This "Community Ties" model is used by Dane County Human Services in partnership with the Waisman Center to support people with developmental disabilities and challenging behaviors. It includes development of person centered behavior support plans, training providers on crisis response strategies, use of environmental adaptations and modifications, a mobile team, and a Safe House and robust quality assurance.
- Independent external advocacy resources must be available for guardians and residents.
- Vulnerable adults with disabilities of all ages rely on the Chapter 55 protective placement and guardianship systems guaranteed under state law to protect their rights at the time of crisis and to ensure their safety. This is especially true today for persons with Alzheimer's and related dementias in the aftermath of the Helen EF Supreme Court decision. Over the years Hilltop and Rehab Central have served in part as the County's Chapter 55 placement and treatment facilities. The plan for closure must address Milwaukee County's continuing statutory responsibility under Chapter 55 to either directly provide or ensure that there is capacity within the system for both emergency and non-emergency protective placements and services.
- The closure plan should assess the County's responsibility to ensure and fund an adequate supply of volunteer and paid guardians to protect the rights of people in Chapter 55.
- We urge Milwaukee County to fund and operationalize increased oversight and quality assurance given this major expansion of community services.

The Milwaukee Mental Health Task Force was formed in 2004, in response to a crisis in inpatient psychiatric services that exposed major gaps in Milwaukee's system of mental health care. It includes over 40 organizations who work collaboratively to identify issues faced by people affected by mental illness, facilitate improvements in services, give consumers and families a strong voice, reduce stigma, and implement recovery principles.

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### RICMAR GUARDIANS

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### RICCI C. HADDIX: SOCIAL CASE HISTORY IN BRIEF

#### Background

RICCI C. HADDIX is a Thirty (30) year old, African American, male, currently residing at 6000 S. Buckhorn Av., Cudahy, Wisconsin 53110, and Apt. # 214. Ricci lives with, MARQUES R. CRUMP (age 37), Stepbrother and co-owner of the condominium where they reside.

Ricci was born September 22, 1982. His birth and early development were normal. Developmental milestones were achieved age appropriately. Ricci experienced common childhood diseases (Chicken Pox, measles) with no lasting impact.

Ricci entered K-4 at Wilson Elementary School in Wauwatosa, Wisconsin. Ricci demonstrated above average social and academic readiness skills K-4 through grade four (4). Ricci was able to make and maintain friends both at school and in his Sherman Park neighborhood. He enjoyed and looked forward to having his classmates and neighborhood friends attend his annual birthday parties.

Ricci enjoyed participating and watching a variety of sports as a child. He played soccer, football and basketball with classmates and friends year round. His elementary soccer coach described Ricci as "one of the hardest working players on the team". Ricci also enjoyed attending Green Bay Packer home games and having selected GB Players visit his home and school during his cousin's (Michael Haddix) stint as a member of the team.

Ricci experienced a life changing bike accident on July 22,1993, at age ten (10), while riding with three (3) of his friends in the neighborhood.

#### Medical

Ricci was rushed to nearby St Josephs Hospital's emergency room, where he was treated focused on presenting seizure activity and suspected head trauma. Ricci was later transferred to Children's Hospital of Wisconsin (CHW) for further examination and treatment.

After three (3) days of tests and examinations, Ricci was diagnosis with Traumatic Brain Injury (TBI), as a result of his bike accident and transferred from ICU to a regular room to complete the hospital discharge and outpatient treatment planning process.

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On day number four (4), Ricci experienced Status Epilepticus and was returned to ICU for further testing, close monitoring and treatment, focused primarily on stopping the presenting cycle or series of seizures. Further testing revealed Encephalitis, which then became the primary focus of treatment for the remaining period of hospitalization. After almost a month of hospital based treatment, Ricci was discharged with a dual diagnosis of TBI and Epilepsy/Intractable Seizure Disorder.

#### Education

Ricci demonstrated increased difficulty in learning when he returned to school to start grade five (5). He received additional help for reading while at school. He received informal help with math and other subjects from parents, peers and relatives at home and in the community.

Ricci received the majority of his education while at home and under the supervision of a home based teacher, utilizing an Individualized Educational Plan (IEP) developed and implemented via his IEP team.

Ricci graduated from Wauwatosa West High School, via his IEP, June 8, 2002.

#### Treatment

Extensive Drug Therapy, coupled with a variety of talk therapies has been the primary treatment interventions tried to date. Ricci has historically demonstrated various levels of benefit, as well as, substantial, concurrent, bothersome side effects from both forms of treatment.

Ricci's Physician Ordered Treatment Plans, over time, have included the use of multiple anti-convulsion medications, used alone, and at other times, with a variety of anti-psychotic drugs. A troubling on-going feature of Ricci's medical condition is his persistent resistance to all forms of treatment to date. Ricci has demonstrated historic resistance involving the administration of approximately thirty (30) different drugs. He has also demonstrated resistance for talk – based treatment provided by Social Workers, Psychologist, Psychiatrist, and others.

Some of the most bothersome side effects from traditional drug therapy include, but are not limited to:

- Increased seizure frequency and intensity;
- > Increased anxiety, irritability and agitation;
- > Vivid dreams and hallucination;
- > Mood changes, paranoia and panic response;
- Exaggerated compliance, rejection and/or resistance;
- > Restlessness and excessive episodes (walking, talking, standing, fatigue, sleeping, drooling).

The most predictable and optimally effective drug treatment for the control and management of seizures for Ricci has been the drug Lorazepam. This medication has proven effective in preventing seizure breakthrough, as well as, reducing the frequency and impact of typical post ictal episodes and events.

The most effective anti-convulsion drug treatment for the control and management of seizures for Ricci has been the drug Felbatol. Despite treatment, Ricci has experienced several thousand seizures since his initial seizure (7/22/93) following his bike accident at age ten (10).

RICCI C. HADDIX Social Case History Page Number Three (3) 10/21/12

#### **Brain Surgery**

Ricci underwent brain surgery July 18, 2003 at St Luke's Medical Center. The decision to try surgery came after it became clear that Ricci's condition was not improving under Drug Therapy \_\_\_\_ and, after obtaining the opinions of Physicians, working in the field, from around the country, including but not limited to, The Children's Hospital of Wisconsin (CHW), The Medical College of Wisconsin, Mayo Clinic and Cleveland Clinic.

#### Major Gain:

- a. Decrease in seizure frequency and seizure intensity;
- b. Decreased post ictal bounce back time;
- c. Decreased risk and improved response to preventive/ proactive treatment plan to manage and control observable symptoms leading to a series or cycle of seizures (Status Epilepticus).

#### Major Loss:

- a. Speech and Language;
- b. Decreased cognitive ability and over all learning capacity;
- c. Decrease in the ability to recognize and demonstrate age level socializations skills;
- d. Increased resistance to treatment;
- e. Increase in bothersome pre-seizure and post-seizure related episodes/events;
- f. Decrease in self-recognition of seizure auras and the ability to use his personal aura awareness to avoid injury and stay safe during, and after, a seizure occurrence.

#### Community Based Residential Treatment Facility (CBRF)

Ricci received his initial CBRF placement away from his birth home on August 4, 2004, after a period of hospital based rehabilitation. His placement was considered "God sent" at the time because of the lack of appropriate, comprehensive and effective treatment during the rehabilitation period at two (2) separate rehabilitation facilities. CBRF placement was also consider invaluable because it promised to provided the close monitoring demanded by Ricci's complex medical condition and related needs.

Instead of receiving the above expected God send, the actual CBRF services provided were "services from hell", in the expressed view of Parent and Legal Guardian. Ricci experienced a very troubling and dangerous CBRF placement at two (2) separately owned and operated facilities. These services included, but were not limited to:

- a. Extensive Medication errors;
- b. Extensive and routine client rights violations;
- c. Unreported physical and emotional abuse;
- d. Illegal discharge;
- "In your face disrespect" and routine disregard for the Legal Authority of Parent and Legal Guardian.

RICCI C. HADDIX Social Case History Page Number Four (4) 10/21/12

#### IRIS Enrollment

Ricci enrolled in Wisconsin's Self-Directed Supports Program June 1, 2010.

#### Major Strength

Philosophy and concept

#### **Major Limitation**

> Micro management, inherently contrary to program philosophy, concept and intent

#### **Property Ownership**

Ricci became a first time co-owner of a condominium on August 24, 2012, with his stepbrother, Marques R. Crump. Their home is located at 6000 S. Buckhorn Av., Cudahy, Wisconsin 53110, #214. Thanks to Milwaukee County, Wisconsin's Self-Directed Supports Program (IRIS), The Movin Out Program, Circuit Court of Milwaukee County, Attending Physicians, Pharmacists, Care givers, and the masterful work of a local "disability friendly" legal team, Ricci (and Marques) took great pride in taking occupancy in their new home on September 12, 2012.

#### RicMar

RicMar - is - not - a - business;

RicMar is simply our sons and wards, Ricci C. Haddix and Marques R. Crump;

RicMar Guardians are Phil Haddix and Rosemary Crump, biological Parents and Legal Guardians of Ricci C. Haddix and Marques R. Crump, respectively;

RicMar Interventions are the unique, individualized, carefully self-selected and self-directed resources and strategies employed to satisfy the assessed, long term support and healthcare needs of our sons/wards;

These person-specific interventions, resources and strategies combine, and flow from a comprehensive annual plan, designed to foster greater independence \_\_\_\_\_ while assisting our sons/wards with the daily living skills needed to sustain a safe, affordable, least restrictive living environment \_\_\_\_\_ and provide a nurturing catalyst for a continuously improving, personally satisfying, and thriving quality of life.

Respectfully Submitted,

PHIL HADDIX, Father

Legal Guardian, Omnipresent

Date: 10/21/12

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#### Short Biography of Marques Crump

Marques is thirty-six years old and lives in an apartment with his step-brother Ricci. Marques has a diagnosis of Intractable Epilepsy which simply means he has seizures that are not controlled by medication. He has been dealing with multiple seizures since he was ten years old as residual of his illness .Before his illness Marques was a bight, happy and energetic little boy. He was quite active at school and was beginning to be quite an athlete and student.

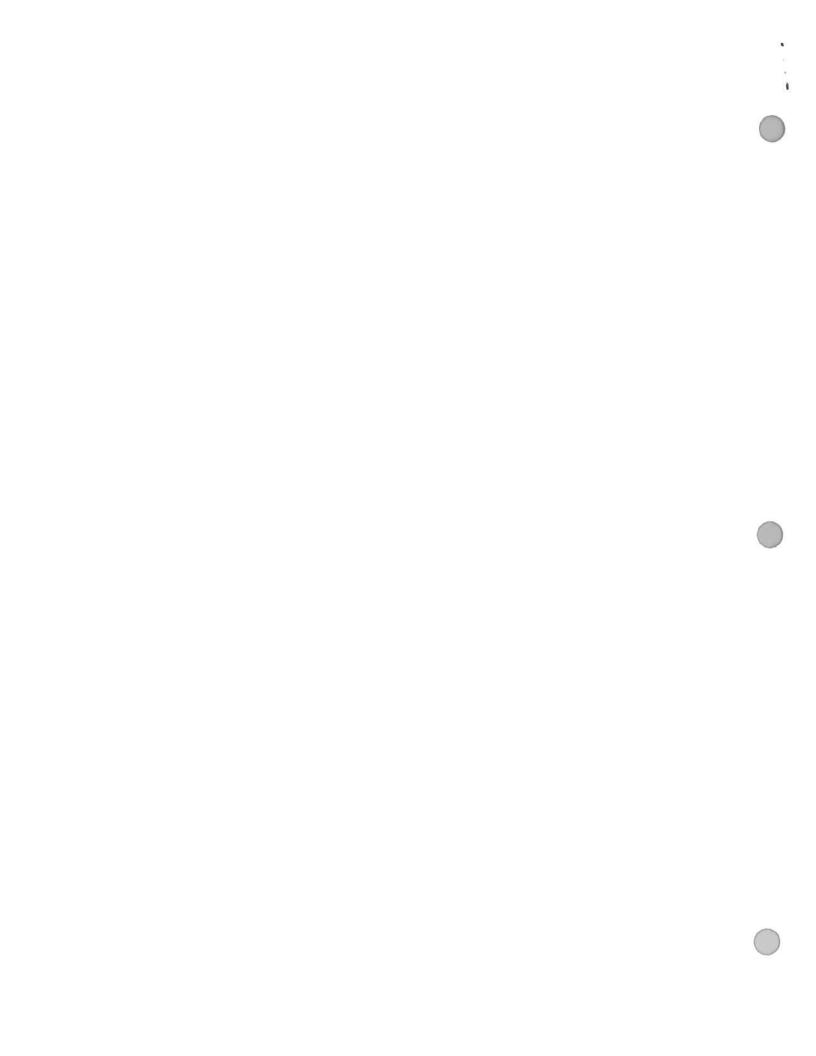
After his battle to stay alive at ten he was had endured thousands of seizures and was left unable to walk, talk, eat on his own, red, write, basically everything one needs to be independent in this life. His road back has been fought with many relapses and start-over. He has had two brain surgeries in an attempt to stop or reduce the number of seizures he has. He currently has on the average 2 seizures a day and as a result of the last surgery he is in a wheelchair because of right side parenthesis, and is partially blind.

He was enrolled in IRIS in 2010 because I felt this was an opportunity for him to have better care and access to more of his funds needed for his recuperation and recovery. Unfortunately we stayed with a healthcare agency that absorbed most of his funding and left us with only the basics to cover his costs. In 2011 I was convinced by IRIS I could move away from this agency and supervise the apartment myself.. I was told that I could act as his support broker and be paid for this service, which I had been providing for over twenty years without payment. Now not only would I supervise his medical care and supervise his care, I would manage a staff of eight people, do their payroll, train them recruit them, supervise them, provide guidelines of care and manage Marques and Ricci's (my step-son's) medical programs. This sounded ideal. They would have extra funds available for their needs, work, school, activities, etc.

Since we have been in IRIS we have had many battles to get reimbursement for out-of-pocket expenses, and changes in services that we were not informed of, the very services we entered the program to obtain.

Marques is a wonderful young man who has struggled for years to obtain normalcy. He has worked his way back from two brain surgeries, hundreds of hospitalizations, a stroke and residual complications from that and many more obstacles that have come along his path. He has not forgotten what he has been taught; "I can do all things through Christ who strengthens me."

Today our son's are thriving in their environment (Marques and Ricci) and we will continue to advocate for a self-directed, supportive program.





#### Statement from Disability Rights Wisconsin on Proposed Closure of Hilltop and Rehab Central Barbara Beckert, Milwaukee Office Director March 12, 2013

Thank you for the opportunity to speak with you regarding the proposed closure of the long term care facilities at the Milwaukee County Mental Health Complex: Hilltop and Rehab Central.

I am speaking you on behalf of Disability Rights Wisconsin, the protection and advocacy agency for people with disabilities in our state. DRW is part of a national network of protections and advocacy agencies established by Congress as part of the Developmental Disabilities (DD) Act in 1975 in response to deplorable conditions at Willowbrook, a large institution for people with developmental disabilities. Congress charged the Protection and Advocacy agencies with serving as the watchdog for people with disabilities with the top priority of addressing abuse and neglect of people with disabilities in institutions.

The DD Act focuses on the estimated 4.5 million children and adults in the U.S. who have developmental disabilities. The purpose of the Act is to assure that individuals with developmental disabilities and their families have the opportunity to actively participate in the design of community based programs and have access to <u>community</u> services, individualized supports, and other forms of assistance that promote and create opportunities for independence, productivity, and self-determination.

This is important background for your agenda item because it reinforces the right of people with disabilities to live in the community – rather than in institutional settings – as one of the core reasons that Congress established the P and A system. This was further affirmed by Supreme Court decision in Olmstead v. L.C., a ruling that requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs. The Department of Justice under President Obama has taken aggressive action to enforce the Olmstead decision and to ensure the right of people with disabilities to live in the community in the least restrictive environment.

It is also in line with the mandates of Chapter 55 of the Wisconsin Statutes and the Wisconsin Supreme Court decision in *In the matter of Judy K*. Chapter 55 requires that protective services and placement "shall be provided in the least restrictive environment and in the least restrictive manner consistent with the needs of the individual and with the resources of the county department." 55.12(3) Wis. Stats. The Supreme Court has interpreted the Chapter 55 mandates as requiring counties to "make a good faith, reasonable effort to find and fund" placements that meet the least restrictive standard.

Under Wisconsin law, facilities relocating 5 or more residents must file a Resident Relocation Plan with the Division of Long Term Care. This includes Nursing Homes, Facilities Serving People with Developmental Disabilities (FDD) or Community Based Residential Facilities (CBRF) considering relocation of 5 or more residents. This process is in place to protect the rights of vulnerable people and ensure that appropriate quality services and supports are in place.

DRW is mandated as one of the members of the State Relocation Team when residents to be relocated are identified as having mental, developmental, or physical disabilities. Our responsibilities include the following:

- Be available to residents and families during the relocation process to provide technical
  assistance and information as needed, regarding the legal framework, requirements of discharge
  planning and community placement options for residents with disabilities in the relocation
  process.
- Provide advocacy services as agreed upon to individual residents with disabilities to assist them
  to assert their rights and preferences during discharge planning and help them obtain proper
  discharge planning and appropriate amounts of quality community services.

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Protection and advocacy for people with disabilities.

 Advocate within the team process to ensure that the facility, governmental agency or managed care organization meet the community long-term support or other disability-related needs of the residents.

DRW and the Protection and Advocacy system support the right of residents at the Mental Health Complex and other institutions to have the opportunity to live in the community because we believe this can provide a better quality of life, offer additional opportunities for community integration and to have closer relationships with friends and family. This perspective is informed by the many people we have advocated for who have experienced neglect and abuse in institutional settings. However, to fulfill the promise of a better life in the community, it is essential that the community setting includes quality services, supports, including adequate staffing levels, carefully developed to meet the residents' needs and with the input of each resident and their guardian or family. DRW will vigorously advocate at both the individual and system level to ensure these services and supports are in place and adequately funded.

#### **FAMILY CARE HAS A KEY ROLE TO PLAY**

The vast majority of residents of the Mental Health Complex Long Term Care facilities are eligible for Wisconsin's Family Care program which is a Medicaid waiver that provides community based long term care services. Family Care is an entitlement in Milwaukee County which means that we no longer have waiting lists and any county resident who is functionally and financially eligible must be served. Individuals in Milwaukee County residents who are eligible for Family Care receive options counseling regarding their choices for long term care. Residents who are eligible for Family Care, and their guardians, will have a choice of two Family Care Managed Care Organizations (MCOs), two Partnership programs, and IRIS which support self-direction of community long term care services. These programs will oversee the community based services that residents will receive.

To be successful in relocating Hilltop and Rehab Central residents to the community, it will be essential for the Family Care and Partnership Managed Care Organizations to develop the resources and capacity to meet these important and specialized needs and to provide the level of funding needed to support appropriate staffing and needed supports, and adequate rates to secure experienced proven providers. As a managed care program, Family Care uses a capitated rate set by the state which pays a "permember-per-month" rate, regardless of the number or nature of services provided. Advocates have long been concerned that the capitated rate may be a disincentive to service people with complex and costly needs - and we strongly believe that an adequate Family Care capitated rate is essential to serving residents of Hilltop and Rehab Central in the community.

#### RECOMMENDATIONS FOR MOVING FORWARD

DRW supports the right of people with disabilities to live in the community in the least restrictive setting. We support the proposed concept of developing a plan to close Hilltop and Rehab Central in three years while concurrently developing quality community based placements for each resident. However, our support is contingent on the following safeguards:

It is essential that all stakeholders proceed slowly and carefully to ensure that effective and appropriate supports and services are developed to provide residents with the best possible chance to have a good life in the community. This should include a careful review of best practices and lessons learned from previous institutional downsizings, and an examination of how these can be incorporated into the current closure given the relatively new role of Family Care.

We recommend that a forum or strategy session be held within the next three months to highlight lessons learned from past institution closings and share best practices, so that these can be used to benefit residents as we move forward with the Hilltop and Rehab Central closures. This should include strategies for supporting and educating guardians, who have a very important role to play in this transition.

- As noted earlier in this paper, we believe the state mandated team for institutions closings, provides a
  proven process and protections for residents and must be in place.
- Although there have been large institution closings in the past in Milwaukee County, this is the first
  closing of this size and complexity since Family Care has been in place. It will be important to
  determine how Milwaukee County and the Family Care MCOs can work collaboratively to develop
  and support the essential resources needed to successfully serve Hilltop and Rehab Central
  residents in the community.

This should include development of a robust continuum of community services including housing, specialized behavioral health services, crisis services including the Mobile team and respite beds. Access to quality mental health services will be critically important. Although having a mental illness alone does not provide eligibility for Family Care, all of the residents of Hilltop and Rehab Central also have a mental health diagnosis. The planned closure will require significant development of new resources and that will require ensuring provider rates that will support experienced and high quality providers. Mobile crisis teams, should be available 24/7, with specific expertise in meeting the needs of three target groups of people, those with psychiatric disabilities, those with intellectual disabilities, and those with Alzheimer's/dementia.

 Funds saved from downsizing must be invested in developing community services and supports. This is in line with county board resolution (RES 11-516) signed by the County Executive which states in part: "The county must commit to continued funding of mental health care services at current levels with any savings produced as a result of the transition to a community-based service delivery model reinvested into the program to allow for expanded community services". Similar language was in the adopted 2012 budget.

This is especially critical for the minority of residents who are not eligible for Family Care. Milwaukee County must be the safety net for these residents and for others moving forward who have a mental health disability and are not eligible for Family Care. This will require a commitment for a long term increased investment in community services and supports including residential services. For the closure to move forward, Milwaukee County must make a commitment to develop and support community housing and services for residents who do not qualify for Family Care, and for other community members moving forward.

• The vast majority of residents of Hilltop and Rehab Central have multiple disabilities and complex needs. For Family Care to be successful in serving individuals with complex needs, an adequate capitated rate is essential. We urge Milwaukee County to advocate with the Dept. of Health Services (DHS) regarding the need to provide an enhanced capitated rate to ensure the success of this institution closure. Advocates stand ready to work with Milwaukee County leadership to make the case to DHS for an enhanced rate for residents which will cover the actual cost of relocating residents to the community and developing specialized residential settings. We welcome the DHS decision to use Money Follows the Person funds to supplement the capitated rate, with a \$1000 per member payment to the MCOs to assist with relocation. However, in many cases, this supplement to the capitated rate will not be sufficient.

Note: Until 2011, a special "first year" enhanced rate was provided for Wisconsinites relocating from an institution. This recognized that one-time investments were needed to develop specialized resources, provide environmental modifications, develop behavior plans, and recruit and train staff with specialized skills. The enhanced rate for Year 1 is a good investment because it supports development of capacity and placements for people with complex needs – we should develop a strategy to make the case to DHS to reinstate the enhanced rate for a minimum of one year.

- Ensuring a comprehensive community based continuum of services. This would provide technical assistance and crisis back-up in the community and reduce the "revolving door" where the only option in a crisis is to re-admit people to an institutional setting. This "Community Ties" model is used by Dane County Human Services in partnership with the Waisman Center to support people with developmental disabilities and challenging behaviors. It includes development of person centered behavior support plans, training providers on crisis response strategies, use of environmental adaptations and modifications, a mobile team, and a Safe House and robust quality assurance.
- Independent external advocacy resources must be available for guardians and residents.
- Vulnerable adults with disabilities of all ages rely on the Chapter 55 protective placement
  and guardianship systems guaranteed under state law to protect their rights at the time of crisis and
  to ensure their safety. This is especially true today for persons with Alzheimer's and related
  dementias in the aftermath of the Helen EF Supreme Court decision. Over the years Hilltop
  and Rehab Central have served in part as the County's Chapter 55 placement and treatment facilities.
  The plan for closure must address Milwaukee County's continuing statutory responsibility under
  Chapter 55 to either directly provide or ensure that there is capacity within the system for both
  emergency and non-emergency protective placements and services.
- The closure plan should assess the County's responsibility to ensure and fund an adequate supply of volunteer and paid guardians to protect the rights of people in Chapter 55.
- We urge Milwaukee County to fund and operationalize increased oversight and quality assurance given this major expansion of community services.