

## MINNESOTA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES

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February 18, 2014

The Honorable Donovan W. Frank
United States District Court – District of Minnesota
Warren E. Burger Federal Building
316 North Robert Street
St. Paul, Minnesota 55101

RE: Comments Regarding the Olmstead Plan

Dear Judge Frank:

Thank you for this opportunity to comment on the Olmstead Plan that was filed with the Federal District Court on November 1, 2013. Pursuant to your Court Order issued on January 22, 2014 permitting comments or objections to the Plan, the following are attached:

- 1 My comments and feedback as Executive Director, Minnesota Governor's Council on Developmental Disabilities.
- Comments and feedback provided by Council members at a regular Council meeting on February 5, 2014.

Respectfully,
Calleen Weekle

Colleen Wieck Executive Director

# Minnesota Governor's Council on Developmental Disabilities Executive Director Feedback February 18, 2014

For the past several years, the Minnesota Governor's Council on Developmental Disabilities (Council) has been advocating for the existence of a State Olmstead Plan and, most recently, we have been involved in helping to develop the Plan that is currently being reviewed. We are now providing a set of comments to the Court in accordance with the Court Order issued on January 22, 2014 permitting comments or objections to the Plan.<sup>1</sup>

We first want to recognize the work that many individuals have contributed to this effort and the time invested to create a Plan that can serve as a vehicle for significant systemwide changes in the services and supports that are made available and delivered to individuals with disabilities.

## **Acknowledgements:**

At every opportunity, our Council would like to express appreciation to all those who provided input and feedback for the Plan. Great credit must be given to Judy Plante and Beth Bibus, Minnesota Management and Budget, for their facilitation of meetings and for offering the Results Based Accountability outlines they provided for the final Plan. It is also important to thank all state employees who worked tirelessly for months on several versions of the Plan. Tony Records and several subject matter experts provided advice and counsel throughout the process.

#### Subcabinet:

One of the last times a group of State Department Commissioners came together to discuss disability issues was in 1984 when the Legislature created the "Institutional Care and Economic Impact Planning Board" to plan the future of state hospitals. At that time, the Commissioners from the State Planning Agency, Health, Economic Security, Finance, Veterans Affairs, Housing Finance, Administration, Human Services, Corrections, Energy and Economic Development and the Department of Employee Relations met from May 1984 until January 1985 to prepare policy papers and make recommendations.

<sup>&</sup>lt;sup>1</sup> Within 30 days of the date of this Order, the Executive Director of the Minnesota Governor's Council on Developmental Disabilities and the Ombudsman for Mental Health and Developmental Disabilities may file any comments or objections to the Olmstead Plan as currently submitted. (Paragraph 3).

The current Subcabinet represents a significant commitment of this Administration to collective problem solving. We must thank the Governor and Lt Governor respectively for their leadership in creating and chairing the Subcabinet.

In the upcoming years, additional state agencies must become involved in the work of the Olmstead Subcabinet including MnSCU, Department of Commerce, Department of Labor and Industry, Veteran's Administration, Minnesota Management and Budget (MMB), Administration, and others.

#### The Role of the Jensen Settlement Agreement:

At a hearing on November 25, 2013, the Court expressed concern about the lack of communication within the Department on issues pertaining to the Settlement Agreement and the Olmstead Plan, including the fact that, four days following a meeting with the parties in Court, the *Star Tribune* carried an article about the Governor's Executive Order creating the Olmstead Subcabinet.

Without the Jensen settlement agreement there would be no Olmstead Plan. Credit must be given to the plaintiffs and their families for bringing forth action.

Following is a **Section by Section Review** of the Plan:

crisis?

## 1. Demographics:

a. Our Council believes that the demographic section is important because the State needs to know:

Who are we talking about?

Are demographic and population trends, such as aging issues, being recognized?

Are we preparing for changes rather than acting in response to a

- b. This section of the Plan depends upon the American Community Services (ACS) as a primary source of data. The ACS definition of disability differs from other definitions of disability used by other groups as well as definitions under federal and state laws.
- c. There is a concern raised by groups that work with individuals with low incident disabilities (deaf, deaf/blind, and hard of hearing) that the estimates are not accurate. There is also a concern that the employment numbers of people with disabilities seem higher than other studies. Part of that can be explained when numbers are disaggregated and reveal very low employment numbers by type of disability.

d. Certain groups, such as individuals with Autism Spectrum Disorder (ASD) and their families, believe that no planning has been done to address their issues especially when considering that thousands of students with ASD will become adults in the next decade.

## 2. Input:

Some people may read this section and believe there was not enough input from those individuals and/or groups directly affected by the Plan. This section needs clarification.

Current state law requires that a state agency release the names of anyone who posts comments or input online.<sup>2</sup> In order to gather input from individuals with disabilities or family members and provide data privacy protection, advocacy groups collected direct statements, analyzed and summarized those statements, and then submitted comments. At least three advocacy groups collected 50 statements directly from people with disabilities.

Another part of the process that is not explicit is the conversion of input into goal statements, where the goals are vetted through the direct experiences of people with disabilities. Any and all input received online was forwarded to the state agency lead agency representatives. In addition, two individuals systematically reviewed and sorted all of the input at the end of August. As the Plan was written, the input was reviewed concurrently as an extra step to reflect the voices of those individuals affected. The themes were summarized and appear in Appendix C., pages 99 - 114 of the Plan.

#### Input for Future Revisions:

For future revisions of the Plan, state agencies can begin to coordinate efforts when needs assessments are done. Some needs assessments are required by state law and others by federal law. If needs assessments are underway, the results can be shared with the Subcabinet as a means of saving public funds, being more efficient, and capturing a broader range of perspectives leading to better questions.

There are many reports produced in Minnesota; however, there may not be much analytical work performed that will answer key questions.

It should also be noted that there has not been a summary report of all disability expenditures since 2002. That type of analysis and budget tracking on an annual basis would be helpful as an adjunct to the Olmstead Plan.

<sup>&</sup>lt;sup>2</sup> Minn. Stat.§13.03, Subd. 1 and Subd.3 (e)

## 3. Most Integrated Setting vs. Least Restrictive Environment:

One of many outgrowths of <u>Wyatt v. Stickney</u><sup>3</sup> and its progeny was triggered in 1971 when Judge Frank M. Johnson, Jr. issued the first order in this deinstitutionalization case. At that time, there were thousands of people hospitalized in Alabama, ostensibly for treatment. Most of them were "involuntarily committed through non-criminal procedures and without the constitutional protections that are afforded defendants in criminal proceedings.<sup>4</sup>

Many, if not most, of these people received no treatment whatsoever.<sup>5</sup> They were housed in inhumane conditions in "barn-like" dormitories plagued by overcrowding, extreme ventilation problems, and fire and other emergency hazards.<sup>6</sup>

The staff at the hospitals was under-qualified and stretched much too thin, and the people did not have individualized treatment plans.<sup>7</sup>

"Also contributing to the poor psychological environment [were] the shoddy wearing apparel furnished the patients, the non-therapeutic work assigned the patients ... and the degrading and humiliating admissions procedure which create[d] in the patient an impression of the hospital as a prison or as a 'crazy house.' "8

The *Wyatt* standards have had a reverberating impact on state and national law, and, perhaps even more importantly, on public consciousness. The standards have been incorporated into state and federal codes and regulations. The concept of treatment in the "least restrictive setting" contained in the *Wyatt* standards was later converted to "most integrated setting" in the Americans with Disabilities Act of  $1990^9$  and as the Supreme Court affirmed in 1999 in *Olmstead v. L.C.*  $\frac{10}{10}$ 

<sup>&</sup>lt;sup>3</sup> 344 F.Supp. 373 (M.D. Ala. 1972)

<sup>&</sup>lt;sup>4</sup> 325 F. Supp.781,784 (M.D. Ala. 1971)

<sup>&</sup>lt;sup>5</sup> *Id* at 784.

<sup>&</sup>lt;sup>6</sup> 334 F. Supp. 1341, 1343 (M.D. Ala. 1971)

<sup>&</sup>lt;sup>7</sup> Id at 1343-1344

<sup>&</sup>lt;sup>8</sup> *Id* at 1343

<sup>&</sup>lt;sup>9</sup> P..L. No. 101-336, 104 Stat. 328 (codified as amended at 42 U.S.C.A. §§ 12101-12213 and 47 U.S.C.A. § 225),

<sup>&</sup>lt;sup>10</sup> 527 U.S. 581, 119 S.Ct. 2176, 144 L.Ed.2d 540 (1999).

There is a 40 year difference in using terms such as "least restrictive environment" (LRE) vs. "most integrated setting." The LRE concept began with the existence of state institution systems and moving people out of these facilities to community settings that were less restrictive. The state institution represented control over a person in every sense of the word—regimentation, 24 hour control, fixed schedules, enforcement of idleness, lack of treatment, etc.

After passage of the Americans with Disabilities Act, the term "most integrated setting" came into the lexicon to represent a person who spends his/her life in typical homes, typical schools, and using typical community amenities. The individual is a member of the family, a neighbor, and a community member. Supports can enter and leave a person's life depending upon the needs of the person. A person does not need to move from one setting to the next to receive services. The Department of Justice defines most integrated setting as time spent with persons without disabilities.

This is a shift in thinking for Minnesota since "least restrictive environment" is still embedded in state statute and "most integrated setting" was only recently added in 2012.

## 4. Overarching Strategy #1:

The overarching strategic action of beginning with the individual seems to be lost and needs greater emphasis in any revisions of the Plan

## 5. Overarching Strategy #2:

In order to complete the comprehensive analysis that is referenced on page 25, one needs to begin with the individual, then ask the question, "What is preventing the most integrated setting?" and then track back to whether it is a state law or rule, a federal law or regulation, or is it someone's interpretation (aka folklore).

In 2014, emphasis should be placed on getting rid of obsolete laws.

In 2015, emphasis should be placed on a comprehensive review of state statutes.

Rud Turnbull, director of the Beach Center, University of Kansas, came to Minnesota on February 5, 2014 and provided a conceptual framework for developing public policy affecting individuals with disabilities based upon years of studying United States Supreme Court decisions and federal laws. His policy framework could help in completing this analysis. For example, at a systems level, Rud offers the CIA dimensions – Capacity in the system, Individualization, and Accountability.

People with disabilities and families must be included in this comprehensive systems analysis. See Attachment #1 for how input can be organized using this framework.

## 6. Overarching Strategy #3:

- a. Design and implement opportunities for people with disabilities to be involved in leadership capacities in all government programs that affect them.
- b. Provide support, training, and technical assistance to people with disabilities to exercise leadership. This will lead to sustainability of the Olmstead Plan over time.

For more than 25 years, our Council has been actively engaged in leadership development through several grants including Partners in Policymaking®, cultural outreach programs, and self-advocacy. We welcome the opportunities that will be provided to individuals with disabilities through the Olmstead Plan and planning process. We also acknowledge the number of training opportunities available through local communities, foundations, and advocacy groups; and commit to working with others to achieve this overall strategy.

## 7. Overarching Strategy #4:

Why is assessment of Quality of Life important?

Assessment of Quality of Life is important because one hears directly from the person experiencing the system rather than assuming that everyone is experiencing the most integrated setting.

By listening and learning from these quality of life measures, decisionmakers are able to take the necessary actions that can lead to system improvements, which then feeds into the Overarching Strategy #2.

Assessing Quality of Life can help answer the question, "Has anyone's life improved?" This is a key question repeatedly posed by the Federal Court.

Decisionmaking is based upon results that are based on individualized feedback rather than someone believing they know what is best for the individual or the situation.

Quality of Life can also help to provide a cost-benefit analysis (Results Based Accountability). If Minnesota is spending billions of dollars on a service system, it

would be helpful to know what are the benefits? What are we purchasing (output) vs. what are the efficiencies vs. is anyone's life better?

Since 2000, our Council has studied the federally defined outcomes in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) - independence, productivity, self-determination, integration and inclusion (IPSII). In order to understand what those terms meant, the Council contracted with MarketResponse International, a customer research company, that interviewed people with developmental disabilities and family members who were asked for personal definitions and dimensions that constitute the IPSII outcomes. The IPSII surveys were repeated in 2005 and in 2010 in preparation for submission of the Council's federally required Five Year State Plans to the United States Department of Health and Human Services.

Our Council has learned several lessons from this sampling -

The more significant the disability, the less likely that people with developmental disabilities experience the outcomes of independence, productivity, self-determination, integration and inclusion.

In 2006, less than 50% of the 435 respondents answered the following questions:

- 1. I can decide how public funds are spent for my services and supports (25% responded).
- 2. I have control over who I live with (37% responded).
- 3. I choose the staff who work with me (39% responded).
- 4. I know what to do if my health or safety is in jeopardy (44% responded.
- 5. My future will be secure, even if something happens to my parents, current staff, friend or advocate (46% responded).
- 6. I choose the provider who assists me (47% responded).
- 7. I have enough money to live on (47% responded).
- 8. People without a disability treat me as an equal (48% responded).

What do these results tell us?

We must disaggregate any Quality of Life results to break out what is happening to individuals with the most significant disabilities.

We must recognize that the promise of the ADA has not reached all people.

People with developmental disabilities continue to be treated as less than equal.

People with developmental disabilities are under the control of others for basic decisions—where do I live and with whom, who are my staff, how is the money spent.

#### 8. Employment:

This area could be improved by looking at the actions underway in Rhode Island and Oregon where Settlement Agreements have been reached with the Department of Justice. In both instances, the Governor or the leadership of the state was involved, funding sources were identified, goals were set, and monitoring systems were created.

Updated information about Minnesota's Day Training and Habilitation system and work on developing positive relationships with local providers will be a key factor in amending the Plan.

Our Council has heard directly from providers. They have expressed concerns about the Plan not adequately addressing the conversion to integrated employment programs. An additional concern is whether non-integrated facility-based programs will or will not be permitted. In this regard, the Plan does not address changing policy directions that some states are taking nor settlement agreements with the United States Justice Department on this issue.

Employment providers are concerned that the term segregated is only used in the employment section and does not appear in the education section or the residential section where there are also examples of segregated education and segregated residential services.

The Council has received the suggestion that terminology such as segregated be replaced in the employment section or that segregated be applied across all goal areas.

The providers also pointed out that people with disabilities are in competitive and supported employment because providers are offering job support services. The court monitor has suggested that this area of the Olmstead plan be strengthened and we agree.

#### 9. Health:

Groups within the Minnesota Department of Health (MDH) have offices devoted to disparities of health outcomes, based on race for example. In an MDH report to the Legislature, health officials acknowledged that "...Minnesota must tackle deep-seated problems if it is to close what are some of the widest racial health disparities in the nation." 11

It may be helpful for the MDH to consider an office devoted to disparities of health outcomes based on disability.

It would help to gather data from other parts of the MDH and the Department of Human Services (DHS) to address the overall goal of the Jensen Settlement Agreement.

Paragraph 7, page 3, of the Stipulated Class Action Settlement Agreement, filed in Federal District Court on December 5, 2011 reads as follows:

"The State of Minnesota further declares, as a top concern, the safety and quality of life of the Residents of the Facility. The State agrees that its goal is to provide these residents with a safe and humane living environment free from abuse and neglect. The State also agrees that its goal is to utilize the Rule 40 Committee and Olmstead Committee process described in this Agreement to extend the application of the provisions in this Agreement to all state operated locations serving people with developmental disabilities with severe behavioral problems or other conditions that would qualify for admission to METO, its Cambridge, Minnesota successor, or the two new adult foster care transitional homes."

For example, the Office of Health Facility Complaints (OHFC) and the Office of Inspector General (IOG) can help provide answers along with supporting data to questions such as –

Is the rate of abuse, neglect, injuries, financial exploitation and deaths of people with disabilities going up or down?

What is the trend line?

Our Council supports any efforts to reduce the level of abuse, neglect, injuries, exploitation, and preventable deaths of people with disabilities.

<sup>&</sup>lt;sup>11</sup> Harrington, B. (2014, January 31) Wide health gaps tied to race. *Star Tribune*. Retrieved from http://www.startribune.com

## 10. Housing:

Our Council was able to obtain a handbook about Individualized Housing Options described on page 45 of the Plan (see Footnote). Fourteen counties participated in this effort as a response to the moratorium on adult corporate foster care homes. This section of the Plan must be updated.

## 11. Services and supports:

This topic can be expanded or other initiatives can be referenced.

Person centered planning needs a state definition, a comprehensive user's manual, and ongoing training with regular updates and refresher courses.

Person centered training must be deployed across all ages and disabilities unless individuals refuse to use this method.

## 12. Education and lifelong learning:

Education and lifelong learning should cover access to regular education environments and curriculum, and the concept of inclusion in terms of "most integrated setting."

According to MMB budget documents, the child count (birth -21) for special education programs is 128,430.

Our Council has worked extensively on this issue. In 2012, MarketResponse International conducted a general population survey of Minnesota households to track changes in attitudes about people with developmental disabilities over the past 50 years. A parallel survey was done with households with a family member with developmental disabilities.

Based on findings, the surveys showed a significantly more negative outlook about education services among households with a son or daughter with developmental disabilities. As a result, in 2013, education was selected for a qualitative K-12 education study using a relatively new approach and methodologies, referred to as Narrative Research.

Over 200 stories and anecdotes were collected from 100 individuals including students with developmental disabilities, parents, teachers, school administrators, and case managers. Seven themes emerged, and key actions and perceptions were identified that can influence future events. The results of the 2013 study are being used to design a quantitative survey that will be conducted in partnership with the Minnesota Department of Education in the next few months.

#### **Settlement Class Counsel recommendations:**

Beginning on January 10, 2012, settlement class counsel offered these recommendations about the Olmstead Plan.

- 1. Involvement of stakeholders
- A public process that follows the Open Meeting Law and is respectful of the public's right to know that meaningful actions are being taken and measurable goals reached
- 3. A comprehensive plan that covers housing, PCA, transportation, employment, education, and assistive technology
- 4. Measurable goals and target dates are in place and enforced, and all responsibilities carried out
- 5. Adequate funding secured
- 6. Restructuring of systems
- 7. Appropriate assessment tool(s) in place and applied in a uniform manner
- 8. Necessary services and supports available regardless of geographic location of the individuals in need of services and supports
- 9. Tracking system in place, meaningful reports generated, and results used to improve the quality of services and supports
- 10. Quality assurance and evaluation
- 11. Comprehensive description of the current system
- 12. All individuals, regardless of disability, will benefit
- 13. Active involvement of individual advocacy groups
- 14. Use recognized and experienced external experts to ensure best practices are at the core of Plan implementation all related training
- 15. Transition planning requirements in place and followed
- 16. Implementation and enforcement of all aspects of the Plan
- 17. Is it Strategic Measurable Attainable Realistic Timely?

In reviewing those recommendations in 2014, many have been achieved but the following are critical to ensuring that the overall goal set out in the Settlement Agreement is fully realized and the Olmstead Plan is implemented as envisioned in the Olmstead decision:

- 1. Waiting list moving at a reasonable pace
- 2. Employment
- 3. Assistive technology
- 4. Adequate funding secured
- 5. Restructuring of systems
- 6. Necessary services and supports available regardless of geographic location
- 7. A tracking system

## **Olmstead Implementation Office**

A fully staffed Olmstead Implementation Office is necessary for the following reasons:

- 1. The amount of effort necessary to prepare the Plan and the amount of effort needed to update the Plan.
- 2. The State will have to guard against reverting to business as usual by minimizing denial that a Plan exists, focusing attention so that diversionary tactics will not work and are not allowed to taint the process, fact finding so that all reports are verified, and bringing an attitude of can do and compliance.
- 3. The Office does not have any statutory authority and so the staff must use their influence and establish relationships with large numbers of people.
- 4. The number of goals is both comprehensive and complex. In order to track progress there must be analytical capacity/capability.
- 5. Prior to 2015, a process must be established to review all legislation, rules, and budget proposals in order to align to Olmstead.
- 6. The Office could become a model employer by hosting an Olmstead Fellowship program so that graduate students with disabilities can experience first hand cross agency programs and services.
- 7. The Olmstead Office must have an effective communications strategy, and provide relevant and quality training and technical assistance

The Subcabinet will need to discuss this issue thoroughly.

#### **Release from Judicial Oversight**

The Court Monitor mentioned release form judicial oversight but this topic was beyond the scope of the Subcabinet and the state agency personnel assigned to write the Plan. Based upon the experience of the past two years, there is concern about the length of time for judicial oversight. The Judge has signaled continued oversight in an Order issued on January 22, 2014, stating "The Court reserves the right to extend jurisdiction of this Court beyond December 2014."

The Court may want to establish key review points and parameters for assessing compliance.

If implementation begins on January 1, 2014, then the State should be able to answer the following key questions on a regular basis.

1. How many people have moved from segregated settings to more integrated settings?

This calculation must consider a dynamic movement of people into and out of segregated settings.

This calculation must consider admissions, readmissions, discharges and transfers in order to get to a net number.

All figures must be verified.

Currently, the Olmstead Plan has selected specific targets such as St Peter, Anoka, ICFs, nursing homes, etc. In 2015 other settings might be selected.

2. How many people have moved from the waiting list?

Is the movement a reasonable pace?

3. Quality of life measures: If there are multiple methods of gathering this data, then the information can be summarized and submitted to the Court on a regular basis. Gaps must be highlighted.

These questions are identical to the Results Based Accountability framework. However, the answers are not simple because of the diversity of individuals who will be affected and benefit as a result of the Olmstead Plan, factors that include type of disability, level of disability, age, location (type of housing and county), by gender and by race.

#### The Court Monitor's Report and Comments:

The Olmstead Subcabinet did not discuss legislative action and scenario planning, the "What if?" questions. If there are shortfalls, then modifications may be needed. However, modifications can also occur because of external events (changes in federal policy, sequestration, new caps or limits), a breakthrough in technology which can cause improvements in people's lives, new opportunities for cooperation or collaboration, or emergence of critical issues. The Plan as well as those individuals/agencies charged with the responsibility of Plan implementation must recognize the need for flexibility without jeopardizing the overall goal stated in the Settlement Agreement or the fundamental requirements of an Olmstead Plan.

The following should serve as guidelines:

Measurable goals—the best advice the Subcabinet received was not to set unrealistic goals. Take the time to establish baselines.

The Plan can be strengthened by describing what will happen once a baseline is established and what actions will follow.

Our Council agrees with the Court Monitor that specific items can be strengthened. We are ready to assist in any way to move the Plan to the next phase of implementation.

ATTACHMENT #1

## Minnesota Governor's Council on Developmental Disabilities Council Member Feedback February 5, 2014

CIA Framework – Capacity in the System, Individualization, Accountability 1

The CIA Framework is based on three ethical principles that help to shape public policy affecting individuals with disabilities and their families. Those three ethical principles are: 1) Family is the core of society, 2) Dignity, and 3) Being in and of community. The following comments and feedback regarding the Olmstead Plan, provided by members of the Public Policy Committee, fit within the CIA Framework.

## **Capacity in the System:**

- 1. To some extent, implementation of the Olmstead Plan is delayed because, while budget proposals may be developed, the real legislative and budget package will not be introduced until the 2015 Legislative Session.
- 2. Are there any new federal funds available, or are there existing funds that aren't being utilized or haven't been investigated to help with implementation?
- 3. It is exciting to see the integration of behavior/medical and long term care services in the Plan.
- 4. When individuals need assistance in navigating systems, and getting the services and supports they need and want to be more independent, initiatives may be necessary. For example, a structure was needed in order to access housing services. The Housing Access Services grant showed that costs can be reduced by as much as 50% when individuals are living in own homes. This raises a question about corporate foster care services and related expenditures that may be unnecessary; some individuals could be living more independently and still received needed services but at a reduced cost.
- 5. The new rate setting methodology could be problematic. For example, individuals who are working in the community but need job support services are at a 1-3 ratio (one support person for three individuals). If funding is reduced, then jobs in the community could be lost.

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<sup>&</sup>lt;sup>1</sup> Turnbull, H. Rutherford, Beegle, Gwen, and Stowe, Matthew, "The Core Concepts of Disability Policy Affecting Families Who Have Children with Disabilities," *Journal of Disability Policy Studies*, 12(3),133-143.

- 6. Direct employment may cost more money than what the current day programs cost.
- 7. Internet access and data plan funding are critical to individuals with disabilities as a way to be connected to the community, yet the State legislature restricted both.
- 8. Access to and funding of assistive technology should be a major part of each goal area, and should be promoted and encouraged. However, assistive technology is missing and there is no consistency across waivers regarding payment for assistive technology devices. For example, one waiver will pay for an adaptive bike and another waiver will not; iPads are important communication tools and can perform major functions for individuals with disabilities but their purpose is defeated and access restricted when certain functions are locked.
- 9. The case management system is broken; more people are needed to help others navigate this system.
- 10. When choices are limited, even if the individual controls the funding, there may not be any real choice. There are no new options and some facilities are still inaccessible, so choice is further limited.

#### Individualization:

- 1. Individualization is critical. Individualization means one individual at a time. Keep going back to one individual and meeting his/her needs in the most integrated setting unless the individual objects.
- 2. One individual might need a waiver and another individual may not; and services and service levels can vary from one individual to another. Funding may or may not be a factor; funding may be there but community capacity is not so we need to understand the gaps and barriers.
- 3. Funding must be under the control of the individual as much as possible. The best solutions are nearest to the people.
- 4. We also need to honor aging in place; some people may not want to move from settings such as ICFs/DD or other residential facilities.
- 5. Keep in mind the spectrum of needs. There is no one approach and there may not always be enough resources. The lack of resources can apply to both the individual as well as the delivery system. For example, individuals with limited incomes may not be able to afford rent or house payments.
- 6. Individuals change; no one can plan out someone else's life. It is a tragedy when special education funds are spent but the individual ends up on a couch and is not able to be a participating, contributing member of the community.

7. Person Centered Planning must be implemented and should begin early in a person's life.

#### **Accountability:**

 One question was asked about tracking implementation of the Plan. Council staff may spend a lot of time on the entire agreement, but what is most important might be what is submitted to the Court. The January 22, 2014 Court Order states:

"The State of Minnesota shall file its first update, including any amendment to the Olmstead Plan and a factual progress report that shall not exceed 20 pages, within 90 days of the date of this Order.

The Court expects the parties to address the progress toward moving individuals from segregated to integrated settings; the number of people who have moved from waiting lists; and the results of any and all quality of life assessments. The Court needs to be in a better position to evaluate whether the Settlement Agreement is indeed improving the lives of individuals with disabilities, as promised and contemplated by the Settlement Agreement itself."

- 2. We need to be proud of the Olmstead Plan but implementation will take lots of work. We have a long way to go and want to get this right.
- We need to be in touch with what is happening in the field by using our networks, reaching out through self advocacy groups, and using social media to collect real data about quality of life.
- 4. Tracking progress must include actually going out into the field and asking people directly about quality of life issues. People from the State need to get into the field; they need to observe as well as ask people directly about how their lives can be improved.
- 5. Any type of quality of life measurement must be consistently applied. We cannot have one agency report extraordinary results with one tool, and another agency using a different approach and reporting results that aren't measuring the same things.
  - We should also be using a network closest to the person to help with this process.
- 6. Biases and political /social pressures could lead to unintended consequences so we need to be cautious about measuring quality.

- 7. There may be may be fear in the system about quality of life issues and measuring quality of life, and what the results could show. There could be some "gaming" around these measures.
- 8. Definitions of quality can put people in boxes. Keep in mind that people should not be placed in bubbles in an attempt to protect them. You cannot protect people with disabilities from themselves. If they want to take risks, they should be allowed.
- 9. Keep conversations open and not accusatory.
- 10. The new CMS rules that define community services reinforce and support the Olmstead Plan.
- 11. Collecting and reporting data might help improve performance. For example, when schools became aware of the extent of restrictive procedures being used, at least one school decreased the use of these procedures.