

**Money Follows the Person Roundtable**  
**Meeting Notes – Raleigh, NC**  
 February 11, 2010

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**Participants:**

Beth Haywood, NC TASH	Vivian Leon, DHHS
Susan Johnston, DMA	Jill Rushing, DD Council
Bob Thompson, ENC CIL	Ed Walsh, ICF-MR
W.C. Mayo, ENC CIL	Andrea Scott-Beard, Home Care
Bernadette Thompson, VR-ILRP	Tara Larson, DMA
Kathy Diehls, Pathways CIL	Mary Bethel, AARP
Kim Johnson, LTC Ombudsman	Ed Davis, DHHS/DVRS
Judy Walton, DMA	Roy Burnette, Pathways CIL
Cindy Ehlers, ECBH	Ellen Perry, Consumer/Advocate
Karen Johnson, The ARC of Durham	Bob Rickleman, UMC Charlotte
Kelly Woodall, Self-Advocate	Kay Zwan, ENC CIL
Jennifer Helton, Ralph Scott Life Services	Fran Hildebrand, Family
Sally Abril, Advocate & Consultant	Michelle Roberson, Family
Melvin Ward, Consumer	Jeff McLeod, Kinston, Consumer
Karen Murphy, DRNC	Marian Hartman, Facilitator
Ronnie Marshall, Consumer; transitioned from facility	Linda Kendall Fields, Facilitator
Holly Riddle, DD Council	Kathy Smith, RHA
Rose Burnette, DMHDD-SAS	Jeff Holden, Murdoch Dev. Ctr.
Mike Mayer, CRA	Bailey Liipfert, LLP, Community
Janet Breeding, ICF-MR	Benita Williams, Shabazz Ctr. CIL
Natarsa Patillo, DMA	Sabrena Lea, DHHS/OLTS
Sarah (last name?), Intern, DD Council	Heather Burkhardt, DAAS
Fred Johnson, ADA-CIL	

**Why we're here: Greetings, Purpose and Mission**

Opening remarks included the intention of the roundtable: “To set a tone of fellowship, mutual commitment, mutual accountability and gentle honesty”

“Brian’s story” – Jill Rushing from the DD Council offered a story of this consumer’s journey.

Participants introduced themselves (both those attending in person and those attending via speaker phone). Marian Hartman & Linda Kendall Fields, both with significant experience within the disability communities, will serve as facilitators today.

### **Where we’ve been**

Tara Larson from the Department of Medical Assistance opened the meeting by commenting on how nice it was to talk about people being served without the “money conversation.” She went on to say that this is not about money, it’s about justice. We shouldn’t be making policy on money. If money wasn’t the issue, what would our system look like? We control barriers – rules, how we get there, implementation. We must know where we want to get to take incremental steps to get there. We make social change one person at a time. We can make this work and we will make a difference.

### **Lessons learned from our past and present:**

#### **A compilation of participant comments**

1. The petition (approximately 400 signatures) kind of worked – it was hard, though. Can’t do it by yourself. Ellie Kinnaird helped them get RAIN started.
2. There is a MFP petition with 5,000 names. That petition brought high level Division staff to table.
3. Don’t take No for an answer. Never give up! Know the MFP Operational Protocol when advocating for someone.
4. Count people transitioning from settings like family homes, too. People should be able to live completely independently if they choose.
5. You can provide community-based services for 3 individuals for the cost of institutionalizing one. Money isn’t really following the person. Money is tied to the bed.
6. Communicate to the public that the problem isn’t that the budget doesn’t allow for people to be in the community. Must do it properly, though.

7. Are people where they want to be and living the life they want to live?
8. Other community entities must accept and be involved with people's lives.
9. Also being a benevolent dictator if you try to talk people out of wanting to live in an institution.
10. Projections for number of older adults coming out of nursing homes have been low – they would like to live in community as well. Target outreach towards their caregivers.
11. Need to do all we can to support families during process. Informal supports.
12. Find a way to keep people out of nursing homes to start with. Hard to get them out once they are in there.
13. State's slow approach to participant-directed services has been a barrier. Division of Aging's approach has been quite progressive. Must commit ourselves to allow people to have a say-so over the funds available.
14. Loneliness is a problem for everyone. Give people tools to guard against that – informal supports.
15. Have to make sure decisions are real and not fear-based.
16. Everyone has something to contribute. Important to have buy-in from direct care staff.
17. Process is very hard – money barriers, fear issues, choice issues.  
NC Start – program in 3 regions across state. Clinical team and respite house for people w/ DD and significant behavioral challenges or M/I. Provide consultation, crisis intervention, education. Ultimate product is a cross-systems crisis plan helping people work through the system.

Officially, 31 people have been transitioned, most from DD community.

**Where We're Going – The Project Objectives – What do they mean to us?**

**Objective 1: “Increase the use of home and community-based, rather than institutional, long-term care services.”**

**A compilation of participant comments:**

- Increase use of home, community-based services: need to support people to have quality transitions and informed choice about where they want to live. Acknowledgement that informed choice may mean staying where they are. Strong collaboration – community collaboration.
- Suggest weight shift: outreach, awareness, overcoming fear, ensure services are there (not all communities have all services), put everything in self-advocate language.
- Makes you think about paid services. Need real connections for people in communities. Language should encompass more than paid supports.
- Assist providers providing institutional services transform to community. Deal with legacy issues (HUD mortgages on buildings, etc.). Maybe use buildings for independent living/social networking training. Still supports people in the community. There needs to be acknowledgement of the pragmatic necessities this will involve.
- MFP is best-kept secret – get the word out. Family members have never heard of it, even though they have worked with facilities and group homes for YEARS. It's up to agencies to let families know.
- Self advocates need to be educated about MFP (on their level).
- Services should be accessible – 2-year waiting lists don't help anyone.

**Objective 2: “Eliminate barriers or mechanisms, whether in the State law, the State Medicaid plan, the State budget, or otherwise, which prevent or restrict the flexible use of Medicaid funds to enable Medicaid-eligible individuals to receive support for appropriate and necessary long-term services in the settings of their choice.”**

**A compilation of participant comments:**

- Eliminate barriers or mechanisms that prevent/restrict flexible use of Medicaid funds. Until we eliminate the institutional bias, if you build it they will come will continue to be the way it works. People don't understand at a functional level what it means to help people have a life instead of a building. We're funding slots, not people.
- Goes back to issue of collaboration. How do we encourage providers to work together to figure out how to make this work? Educate provider community.
- Team Daniel – is a model for flexible funding. Kelly Woodall had flexible funding in college.
- Must overcome both physical & attitudinal barriers. Veterans are coming back with hidden wounds of war. VA will not be able to build facilities fast enough – maybe diversify to provide short-term and intermediate services to them.
- Tara – challenged us to hit on attitudinal differences. As long as we think that life means services or a label, we'll be in the same place 5 years from now.
- Greatest determining factor to a successful transition is will.

**Objective 3: “Increase the ability of the State Medicaid program to assure continued provision of home and community-based long-term care services to eligible individuals who choose to transition from an institution to a community setting.”**

**A compilation of participant comments:**

- Continued provision of supports & services: policy around case management for people w/ DD. People are held to poverty-level income. Without case management, they won't know about all the resources or benefits mgmt. – set up to fail. We don't have enough workforce to support people out in the community.
- Housing is major issue. Any system that requires continued poverty begins to defeat the premise of people becoming more self-sufficient. Catch 22 of employment & eligibility for services.

**Objective 4: “Ensure strategies and procedures are in place to provide quality assurance for eligible individuals receiving Medicaid home and community-based long-term care services and to provide for continuous quality improvement in such services.”**

**A compilation of participant comments:**

- Quality assurance/improvement for home/community-based services. Continuum of care is critical. One of the barriers for MFP is that the waiver only lasts a year. Include plan for undesirable outcome in continuum of care.
- Needs may increase/decrease over time. Wide range of support needs, but in N.C. it's all or none. Eligibility/levels of care/physician write-offs.
- Needs to be continuum of education as well and that should include the medical community. Medical community sets expectations and they don't know about other options. They are concerned about liability. Families need to be included, too. Ask them what they need.
- Remember that WE are THEM. Almost all of us will age into the system.
- Educate case managers – have independent case management network so they can learn.
- The IMD exclusion – people with psychiatric diagnoses were specifically excluded by the federal government.
- Employment – more focus on this. We need a more holistic approach.
- There's a perception that ICF/MR community doesn't support MFP. They are supportive – it's a matter of figuring it out.

**Update on Project**

Trish Farnham, Director of the MFP Project offered the following project update:

Three priorities for Trish: 1) Transitions, including transitions contract  
2) Keep the money coming and 3) Get people together. Avoid creating chaos from sense of urgency.

Decisions made in the last couple of months:

1. Benchmarks – Originally said we'd support 304 people over the course of the project among people > 65; people with physical disabilities or people with DD. Each year, we have a target. CMS told states in December that they would start holding states accountable for benchmark numbers and asked states to decide whether they could meet the original benchmarks or needed to revise. Benchmarks were revised as follows:
  - a. # of Senior Citizens – kept at 7
  - b. # of people w/ DD – kept at 30
  - c. # of people w/ physical disabilities – lowered from 58 to 49. Seemed to be prudent thing to do, given the reality. CAP/DA slots are still protected.
2. Opportunity to apply for additional resources:
  - a. Associate Director position
  - b. Data Analyst
  - c. Resources for continued facilitation of the Roundtable
  - d. Outreach resources
3. Betty Jones, DMA put in place the process of fronting the \$3,000 (get it before person transitions instead of reimbursed afterwards).
4. Fronting under CAP/MR-DD all the services needed to do a safe transition – home modifications, etc. Home modifications that can be moved can be funded for renters. CAP/DA is on a calendar-year budget – you can front it, but it has to come out of the same budget. State just cut more CAP/DA slots.

Outreach to IL people. A person with CAP/DA waiver and a physical disability, state IL program could be a resource for home modifications. CAP/DA does not provide enough services to get a person w/ a physical disability out – they need skilled nursing. We truly need to realign system to provide choice and safety. We need a higher match to support the services.

Acknowledge that some risk is okay, good even. Ellen wants state to stop thinking about risk and start thinking about people. People with disabilities are human beings who make good and bad decisions just like the rest of us. Attitudinal barriers are reflected in policy and barriers. Liability issue is a red herring.

5. What piece do we need to do in-house and which ones can only the community do? (i.e., the N&O(?) is not a state entity, but it guides some of our decisions.)

Ronnie wishes world would treat people with disabilities as humans, not just a body. It warms his heart to see an organization without many people with disabilities asking him how to be more accessible.

### **How We'll do our work: Discussion of Workgroup Structure**

Trish commented that she would like to create a long-term strategy workgroup and a transition group. Community building, including jobs, seems to be missing from structure.

#### **Current Workgroup Updates:**

1. Outreach/Marketing/Education: work on brochure, request for documentary funding, conference coming up, outreach to specific groups.
2. Housing: establish Kitchen committees – local rep, HUD rep., LME rep, landlord or realtor, State IL program, CILs, users, participants, TCM. They have different groups in different areas (Sylva, Asheville, Wilmington, etc.). Housing availability varies from location to location. Sylva needs renters, Asheville doesn't, for ex.

In Wilmington, next meeting will include people from Governor's office and congressional delegation. DHHS and HUD have set aside \$ to support community living – they want to capitalize on that. HUD is releasing 1000 slots nationally for MFP. Must get local Housing Authority's support.

3. Peer/Family Support: Reena is assisting. The group has been meeting for a few months. We are trying to write a definition. In

the eastern part of the state, the LME is partnering with The Arc to talk to families.

4. Advisory Committee (broadened now to the Roundtable) – Key now is on next steps. There is urgency now that wasn't there originally.

### **Next Steps and Closing**

In closing, participants were invited to indicate in writing how they would like to be involved in the MFP project. They were specifically asked to choose areas in which they had passion and energy.

All participants were invited to the next Roundtable meeting in Wilmington, North Carolina on May 14, 2010.