

# **“And Now They Need A Life”**

A Formative Evaluation of Wisconsin’s Money Follows The Person Grant  
As It Influenced Services For People With Developmental Disabilities

John O’Brien and Connie Lyle O’Brien

*Restructuring has gone well for almost everybody, but we’re not finished yet. The next phase has to focus on people having more fulfillment in their lives. They have nicer homes and their own bedrooms, and now they need a life.*

*–Community Integration Specialist*

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Wisconsin's Money Follows the Person Grant comprised two initiatives: Nursing Home Transition for Elderly and Physically Disabled People and the ICF-MR Restructuring Initiative for people with developmental disabilities. This report focuses on that part of the ICF-MR Restructuring Initiative concerned with building local capacity to provide person-centered supports to people with developmental disabilities.

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**Thanks** to the participants in the Project Learning Groups, whose insights inform this report. Thanks also to the people who gave us their time for interviews in July of 2006 and to Peter Leidy and Fil Clissa for outstanding logistical support. Thanks especially to Marcie Brost, whose relentless desire to learn better ways of assisting people with severe disabilities to live rich, full lives made the space for us to learn what we have written about here.

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## Levers for ICF-MR Restructuring

### State Level Implementation

#### Statutory Authority

*Act 33: ICF Restructuring Initiative*

- No ICF or NH admission without court finding that this is the *Most Integrated Setting (MIS)* when compared to a community plan developed by the responsible county.
- Annual court review for people with DD living in ICFs and nursing homes. If not *MIS*, then community placement must be ordered.
- MA payment disallowed without finding of *MIS* except for emergency or short-term respite for person living with guardian.

#### Policy Development

- Funding from decreased ICF utilization follows person to community.
- Freeze ICF spending at 2004 levels.
- Management responsibility assigned to Division of Disability & Elder Services (DDES), which is responsible for HCBW programs.
- Phase down funding available to cover extra costs of downsizing.
- Level of funding based on support needs, not a pre-established rate.
- DDES must ensure sufficient funding to operate remaining ICFs.-MR

### Aids to County Implementation

Regional Forums for  
County & ICF  
Administrators

Training for  
Guardians Ad Litem

Information for  
Guardians

#### Support to Develop Person-Centered Local Responses

- Large group training.
- Learning groups.
- Person-centered consultation.
- County system development.
- Provider development.

## Focus

From the point of view of people with developmental disabilities who move from ICFs-MR to community service settings, *what matters is the place to which money follows them*. In this new place, will they meet staff who have high expectations that they will live a good life and willingness to learn with them what works to assist them? Or will they meet staff who lack the time, confidence and understanding to build a relationship with them that will sustain discovery and delivery of effective supports to desirable outcomes?

Wisconsin's Money Follows the Person (MFP) Grant supports, among other things, The ICF-MR Restructuring Initiative. This initiative aims...

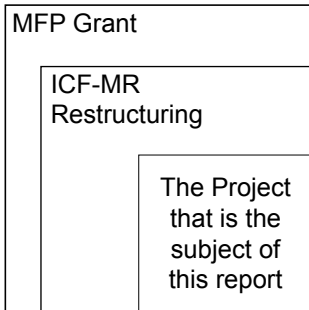
...to assist people with developmental disabilities to make a successful transition from an ICF-MR bed to a community setting that offers the least restrictive, most integrated supports at a cost justified by the person's needs.

...to reduce the number of ICF-MR beds.

...to increase capacity in community services.

In Wisconsin, responsibility for community services rests with the 72 counties. This decentralized system exhibits substantial variety in the ways services are delivered, the utilization and local operation of ICFs-MR, and the extent of local tax investment in DD services. As the diagram on the facing page summarizes, the initiative has a variety of levers to influence change. Admissions to ICFs-MR must meet a high standard if counties are to have access to medicaid funds. ICF-MR services must meet an annual test of being least restrictive and most integrated in comparison to an alternative community plan. County Human Service authorities gain access to funds previously used by ICFs-MR, and, at least to date, have had funding sufficient to meet the service needs identified in individual plans. There are funds to cover the additional costs of phasing out an ICF-MR. There are a variety of forums for people to learn about their changing responsibilities. And, there are a set of supports to

For a more extensive explanation of the ICF-MR Restructuring, see Appendix A, *Overview Bulletin for Guardians*, prepared with MFP Grant funds.



developing local capacity to provide person-centered services and supports. The learning from these support activities is the focus of this report. When we refer to “the Project” in this report we mean the set of MFP Grant efforts focused on developing local capacity to deliver most integrated services to people with developmental disabilities.

## Method

Since December 2004 we have facilitated a series of learning groups convened by the Grant Coordinator. These learning groups allow opportunities for reflection on issues the Project encounters while assisting local leaders to develop person-centered responses to the needs of people moving from ICFs-MR. They include consultants involved with the grant, county DD managers and case managers, state staff involved in the Restructuring Initiative, and staff and managers from service provider organizations. We kept notes from these meetings and prepared materials based on learning group work.\*

In July 2006, we interviewed people who have been involved with the MFP Grant in developing person-centered responses. We asked people who have developed new service organizations, service providers who have created new kinds of supports, case managers, nurse consultants, county and state staff and administrators, and MFP Grant consultants to tell us what they have learned through their involvement with the Project. The quotations in italics in this report are taken from these interviews.

We have compiled the work of the learning groups and what we have heard in our interviews into this account of what those involved in the Project have learned about the process of restructuring, how it can be influenced, and where it proves resistant to influence. Both the ongoing learning groups and this summary of learning serve the purpose of formative evaluation, which is “typically conducted, often more than once, during the development or improvement of a program ...for the program staff *with the intent to improve.*”\*\* By displaying the sense that those most involved in

\*These materials include minutes of meetings, memos and slides for the Grant Coordinator and Project consultants clarifying concepts of emerging importance –such as “capacity” and “crisis” (see Appendix B) and three more widely disseminated products to stimulate discussion of the “most integrated” criterion:

- “...to interact with non-disabled persons to the fullest extent possible”: *Perspective on “most integrated” services for people with DD.*
- *Reflecting on social roles*
- *Planning for community engagement*

\*\*Michael Scriven (1991) *Evaluation Thesaurus (4<sup>th</sup> Edition)*. Newbury Park, CA: Sage. PP. 168-169.

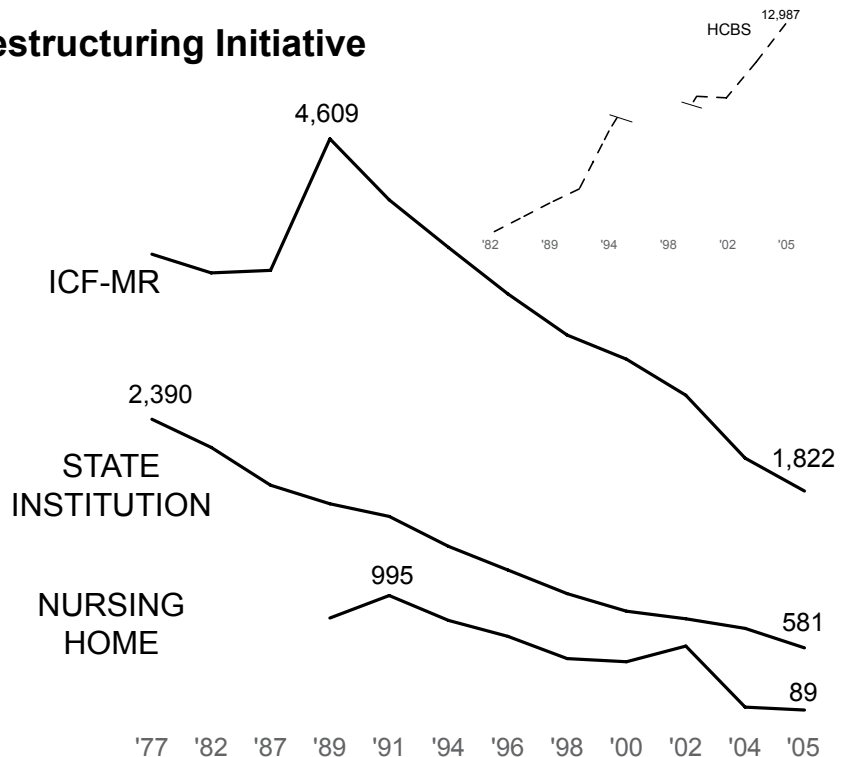
the MFP Grant make of their work and inviting comment by those with different perspectives on the restructuring process, we aim to further strengthen Wisconsin's effort to improve the lives of people who have lived in ICFs-MR.

## The Context of the ICF-MR Restructuring Initiative

The ICF-MR Restructuring Initiative is one of a series of efforts over more than 30 years to build Wisconsin's local capacity to assist all people with developmental disabilities in ways that make long term institutionalization unnecessary. By the beginning of FY2005 these efforts reduced the number of nursing home beds occupied by people with DD by 90%, decreased the number of state institution beds by 75%, and halved the number of ICF-MR beds while the number of people with DD served under HCB waivers grew to almost 13,000.

As the map on the next page shows, different responses to these initiatives by Counties over the past 30 years result in different patterns of local DD services and different levels of ICF-MR utilization. Though there are different local concerns, the whole state system faces a common set of issues, including these seven.

- Despite the growth in number of HCB waiver participants, waiting lists continue to grow in most counties. In addition to at least 3,700 people with DD, there are also significant numbers of elders and people with physical disabilities waiting for needed services.

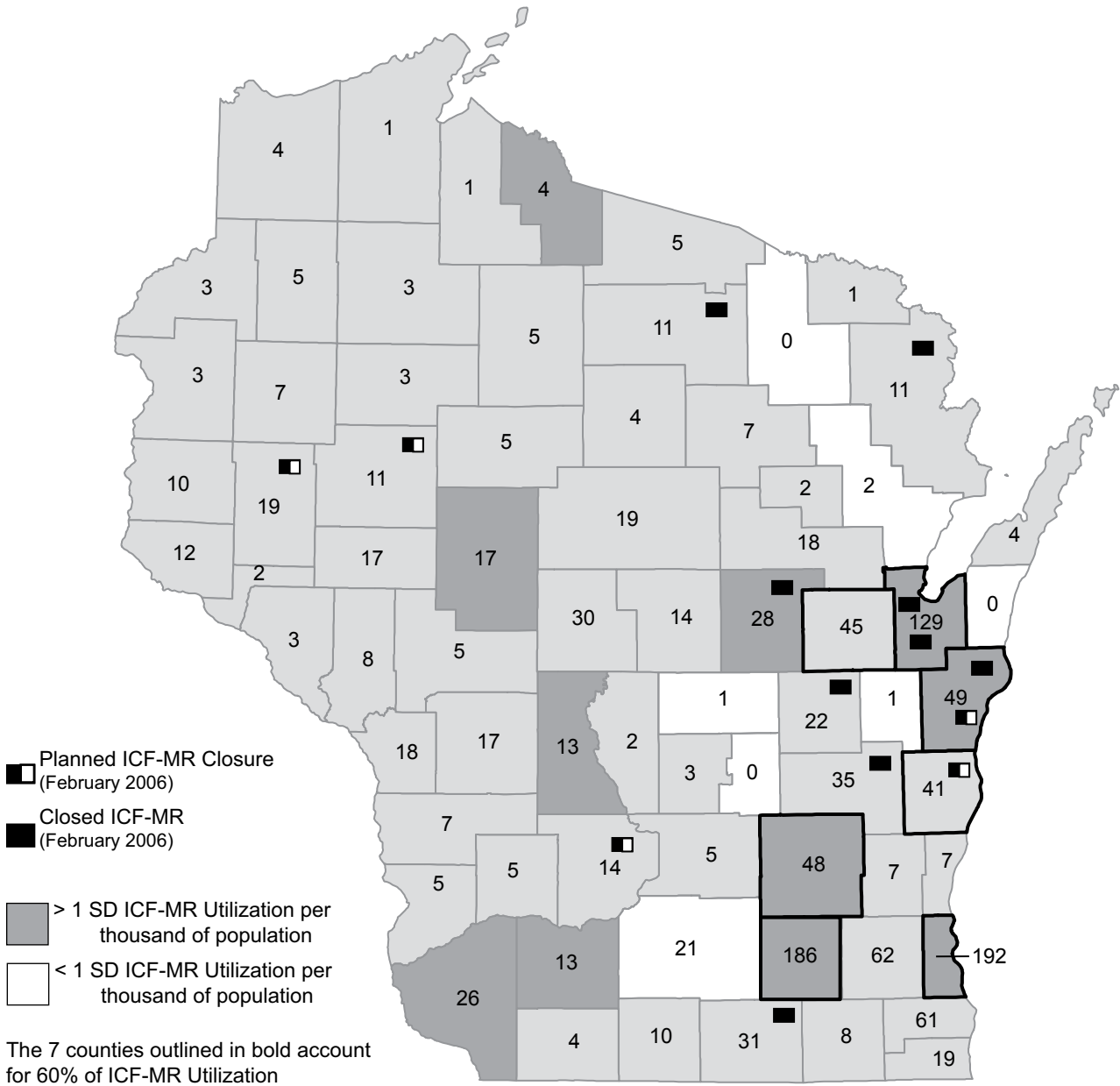


**Trend in Wisconsin Institutional Population FY 1977-FY2005**  
**Growth in HCB Waiver Participants FY1982-FY2005 (INSET)**

Note that time intervals vary so curves are not to scale.

From R.W. Prouty, G. Smith, & K.C. Lakin (2006) *Residential services for persons with DD: Status and trends through 2005*. Minneapolis: University of Minnesota, Research and Training Center on Community Living. P. 149.

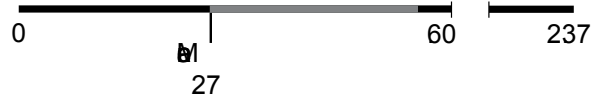




**ICF-MR Utilization by County**  
June 2005



**Variation in County Utilization of ICFs-MR by Number of Beds Used**  
June 2005 (SD = 35)



**Variation in County Utilization of ICFs-MR by Number of Beds Per Thousand Population**  
June 2005 (SD = .29)

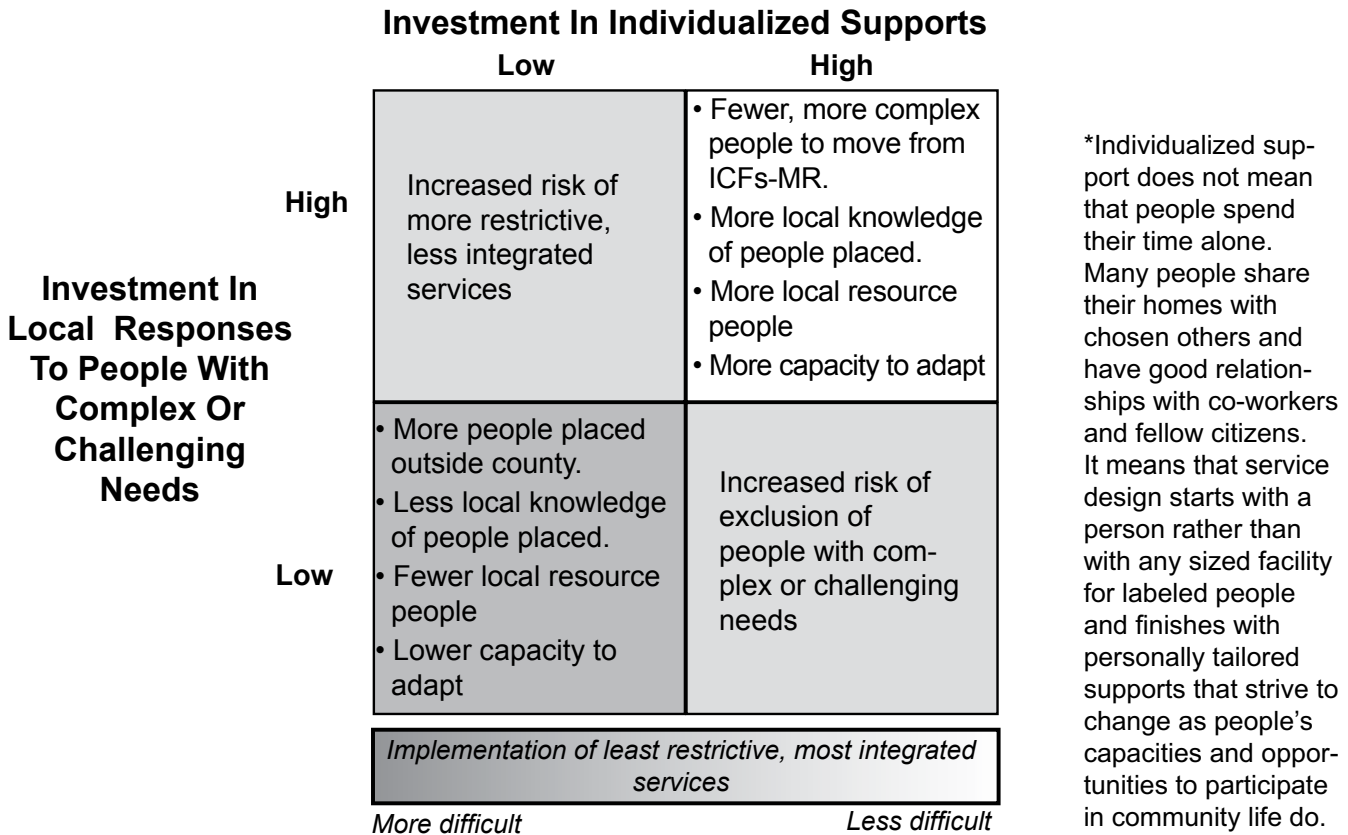
- Rates for HCB services have not grown in line with rising costs of labor, worker's compensation and other forms of insurance. In many counties, efforts to expand resources by utilizing such state plan services as personal care and efforts to maximize the proportion of available money that is matched by medicaid seem to be approaching their limit.
- The whole state medicaid budget is under very substantial pressure and major reforms in financing long term support are under consideration.
- Despite sustained opposition from some family members and some institution worker's unions, one state institution closed during the period of the ICF-MR Restructuring Initiative and relocations will continue from the remaining two centers on a person by person basis. This means that some counties must develop community services for people moving from state institutions at the same time as they move people from ICFs-MR.
- In most counties, case managers' and nurses' case loads are growing and so are requirements to assure compliance with a variety of regulations, including the requirement that protectively placed people be served in the least restrictive, most integrated environment.
- Many service providers have significant difficulty in recruiting and retaining capable support staff.
- Many service providers experience problems that they believe stem from an extended period of receiving insufficient rates for the services they provide.

Wisconsin law defines *most integrated setting* as the setting that enables the person with a developmental disability to interact, to the greatest extent possible, with persons without disabilities. [§46.299(1)(bm) Wis. Stats.]

Counties and service providers vary in their ways of adapting to these conditions, in the role that ICFs-MR play in their local system, and thus in the task of implementing institutional restructuring in line with the criteria of providing least restrictive, most integrated services.

The more a county has relied on out-of-county placement to deal with people with complex or challenging situations, the less it will have developed local ability to deal with those situations and the more likely it is that county staff and service providers will need to take extra time to get to know a person if they are to avoid planning for and moving strangers.

The more experience a county has in developing individualized supports for people, the less the risk that people with complex or challenging needs will be excluded from local services because they do not fit in to the pattern of service that suits groups of people congregated for service. Moreover, individualized supports\* provide the strongest platform for services that are least restrictive and most integrated.



## Project Logic

The purpose of the Project is to build local capacity. Capacity has two aspects: **growth**, an increase in the numbers of people who live in community settings, and **development**, increased local willingness and ability to improve the life chances of people with DD. The goal is both more and better supports so that people have better life chances.

Better life chances means that people with DD have as much personal freedom as possible and that they interact with other citizens without DD in positive ways. The services that assist people to live in this way will have staff who continually improve their understanding and ability to offer assistance in a way that is least restrictive and most integrated.

From the Project's point of view, the ICF-MR Restructuring Initiative offers county staff and managers an opportunity to lead by choosing to find a path of commitment rather than follow the path of compliance.

The **path of compliance** leads county staff and managers to react to the Restructuring Initiative as one more in a list of external demands. They focus attention on working efficiently within existing patterns of service to meet the requirements imposed by reviews of admissions and protective placements and the decisions of ICF-MR providers to close some or all of their beds. On the compliance path there is a strong emphasis on the difficulty or impossibility of adequately meeting individual needs outside of restrictive and separated service settings. There is vigilant attention to the qualifier "within the funding available" that the law applies to judges' decisions on the adequacy of placement. There may well be a demand for additional funding –perhaps in substantial amounts– to offer incentives for highly specialized facilities or very high staff ratios. There may well be an argument for "out of county placement", based on a judgment that the expertise necessary to meet individual need is only available if people are congregated on the basis of what is seen to

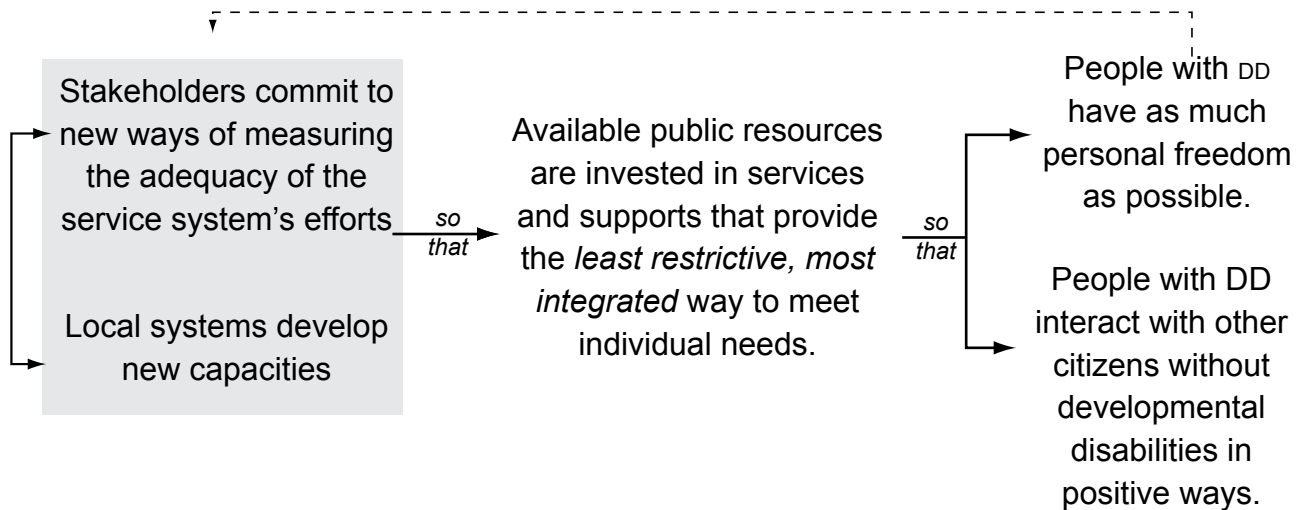
be wrong with them. On the path of compliance, restructuring is primarily a matter of re-location in conformity with a minimally disruptive interpretation of the “least restrictive, most integrated” standard.

The **path of commitment** leads local people to see the Restructuring Initiative as a means to improve the quality of available services and supports by offering transformed opportunities to people who have been disadvantaged by institutionalization, and sometimes by local failure to discover and deliver adequate community services. This commitment motivates a search for knowledge resources before fiscal resources. Framing budgets within limited resources will begin from a deeper knowledge of each person in light of the aims of maximizing personal freedom and opportunities for positive interactions with other citizens and an updated account of the person’s needs based on new understandings of disability and new ways to assist. Recognition of the central importance of individualized supports makes the search for specialized facilities obsolete and leads instead to seeking ways to bring capable, committed, well supported assistants into people’s lives. Assuring adequate supports may require higher than historically typical rates, but higher levels of investment go hand-in-hand with much higher expectations for quality of life.

The path of commitment begins when county staff and managers decide to adopt a new way of measuring the adequacy of the service systems efforts. This way of understanding quality frees them from institutional thinking patterns and allows them to develop individualized courses of action that give people with developmental disabilities better opportunities for personal freedom and social integration.

Pursuing the path of commitment calls on county staff to lead by doing three difficult but rewarding things. It asks people to set high expectations, to engage in honest and thoughtful self-evaluation, and to work with a growing number of people to create personally tailored supports. Higher expectations, thoughtful assessment of

practice, and development of better supports can't be imposed from outside. People need to embrace them as the right thing for themselves.



The Project invites county staff and managers and service provider staff and managers to choose the path of commitment and offers them resources and support as they develop local capacity to provide least restrictive, most integrated services.

The Grant Coordinator and Project consultants share three controversial assumptions, based not only on professional training but long personal experience.\*

One. Given adequate individualized support there is no one who requires long term placement in an institutional setting for reasons of developmental disability.\*\* On this understanding an ICF-MR or other institutional setting can never be the least restrictive, most integrated service.

Two. Respectful, caring personal relationships with people are the necessary foundation of adequate individual support. Technical knowledge and skill matters greatly, especially with people whose bodies are complicated or whose behavior is challenging,

\*To read about the perspectives of the most active project consultants, see:

Karen Green McGowan (2002). Getting Beyond Sick. In J. O'Brien & C. Lyle O'Brien (Eds.) *Implementing Person Centered Planning*. Toronto: Inclusion Press. Pp. 215-230.

David Pitonyak (2002) Opening the Door. In J. O'Brien & C. Lyle O'Brien (Eds.) *Implementing Person Centered Planning*. Toronto: Inclusion Press. Pp. 99-120.

Ruth Ryan and David Hingsberger (2001). *Real Eyes*. Richmond Hill, ON: Diverse City Press.

Peter Leidy (2004) Shoulder to Shoulder: Celebrating the Important Work of Direct Support Workers. *Mental Retardation*: 42, 4, 304-307

\*\* A small number of people, usually with mild intellectual disabilities, who commit violent crimes, present a significant danger to other people, and run the risk of victimization in the general prison population may be exceptions to this rule, but the exceptions need to be determined person by person.

but competent performance depends on seeing a whole person-in-relationship who has a positive future. Seeing and responding to a client-in-isolation-from-caring-others greatly reduces the chances that supports will increase personal freedom or positive relationships. Understanding and managing service as though it were simply an economic transaction that results in the performance of tasks (sometimes labeled “cares” or “programs” by those who adopt a medical model of service) shortchanges both the person receiving service and the person offering it.

Three. The positive relationships necessary to good support grow best when people with developmental disabilities have a secure home of their own and meaningful involvement with other people. These conditions are extremely difficult to meet in congregate settings, even small ones. The standards of least restrictive and most integrated entail individually tailored supports in typical community settings.

These assumptions are controversial in that many good people believe that small and medium sized congregate settings such as 4-8 person group homes or sheltered workshops can offer a high enough level of individualization to provide least restrictive, most integrated supports. Those closely associated with the Project disagree on pragmatic grounds. They have seen substantial positive outcomes for people who move from even small congregate settings into their own homes, with companions they or their allies choose and personalized supports for the performance of valued social roles.

Others contest these assumptions because they believe that it is impossible to afford them. Those closely associated with the project disagree because they refuse to discount the long term costs incurred by people with DD and their families and communities when people act from low expectations and compromise the level of personalization required to promote growth and development.

## **Project Leadership**

The Grant Coordinator, Marcie Brost, has played a primary role in those aspects of the MFP Grant that involve developing person-centered local responses. She has developed an extensive network among county and state administrators and staff through her previous roles as a lead state staff person in the workforce development initiative, in developing means for people and families with disabilities to own or rent their own homes, in organizing and managing *DD Network* (sponsor of three times a year training conferences), in developing flexible and effective ways to use HCB waiver funds, and in individual budgeting. In this broad and varied network, she has a reputation for clear values, competence, plain-spokenness, and fierce practicality in solving problems encountered in developing individualized services. In addition to long experience in services to people with DD, she is also the parent of an adult son with complex support needs who lives with the assistance of a highly individualized support system. His experience shapes her sense of what is possible and what is necessary in assuring least restrictive, most integrated services.

Advised by senior DDES staff, state and regional DD staff, and leaders from county systems and service providing organizations, the Grant Coordinator exercises leadership in six ways:

- Consulting with county staff and managers and service provider managers in her areas of expertise: person-centered planning; options for flexibly funding individualized services; workforce development; organizing individualized supports; housing; and mediating conflicts or developing positive relationships with family members and guardians.
- Identifying consultants and other resource people, some from Wisconsin and some from other places and managing their work.
- Matching local situations that she judges to have high leverage with skilled consultants and other learning opportunities.

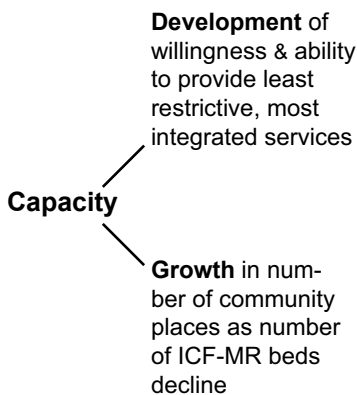


- Commissioning, designing, and implementing training sessions and learning materials for large and small groups.
- Listening to requests for assistance and policy and problem solving discussions to frame issues that will benefit from deeper exploration and bringing people together to explore them.
- Interpreting local experience with restructuring to state managers and advocating for refinements in state system policy and practice.

## Project Focus

Listening to conversations with members of a statewide network of county managers and service provider managers during the run-up to the implementation of the ICF-MR Restructuring Initiative, the Grant Coordinator and Project advisers decided to focus on capacity building, and especially on its development aspect, for the people seen as most difficult to serve.

In their understanding, those counties that utilize ICFs-MR the most have come to rely on the ICF-MR to manage people for whom no local service could be found, or delivered for a lower price. Many of these people were perceived as too difficult to serve locally because of the extent of their behavioral challenges, the difficulties arising from managing co-existing conditions such as psychiatric disability or addiction, or the nature and extent of their physical disabilities. Simply because they were willing to accept these difficult-to-serve people, some ICF's-MR were seen by guardians and perhaps by county staff as having highly specialized knowledge and skills. Some people have had multiple moves between available local services and ICFs-MR, state institutions, and mental health facilities, with each move back to a facility reinforcing the person's reputation as beyond the ability of local services. Moreover, as time passed, the people in ICFs-MR, especially the people placed out of county, were likely to have limited personal contact with county staff, thus decreasing the chances that their case manager would make it a priority to champion the development of local services to meet their needs, as long as no problems surface from the ICF-MR,



These difficult-to-serve people seemed to offer the greatest leverage for capacity building for seven reasons:

People in this group might **limit growth**

- Unless county staff develop and service providers can deliver effective supports to them, they will be left in an ICF-MR or transferred to a similarly restrictive facility.
- Counties might become hostages to a single provider who is only willing to take the difficult-to-serve person at a premium rate.
- Finding alternative places for these people might extend the time required for closure of a facility and increase phase-down costs.

People in this group offer a good opportunity for **development**

- Some of the people in this group have done poorly in enough group settings to justify an individualized approach to their living arrangements and supports (“This person has shown us that she can’t live with a group of people with disabilities.”).
- In some people’s minds, those in this group justify significant qualifications of the criteria of least restricted and most integrated. They cannot imagine these people living outside a specialized facility, much less thriving in their own home. If it is possible to serve those who attract such low expectations effectively in a community setting, expectations for community plans and protective placement reviews will rise.
- People in this group are likely to generate uncertainty and anxiety among staff. If it is possible to re-frame understanding and build confidence that staff can form productive relationships with them, there is great potential for improved quality of life. Improvements in quality of life will generate a positive cycle of expectations and performance.
- Because people in this group are seen as most difficult to serve, better outcomes for them will make the case for individualized supports for all people with DD. (“If we can serve this person through individualized supports, we can’t justify serving less difficult people in group settings.”)

See Appendix B for a Learning Group memo on capacity building that summarizes the Project’s initial understanding of capacity building.

The slides below, taken from the Grant Coordinator's initial presentations to county managers and state DD staff, summarize the Project's focus.

In context, the presentation made clear that "Impossible" does not refer to a person's characteristics but to a county staff member's judgement that institutionalization or out of county placement were the only feasible alternatives for a person.

### Wanted

Counties willing to develop the capacity to provide positive, individualized supports to people who seem "impossible" to serve with current knowledge & skills.

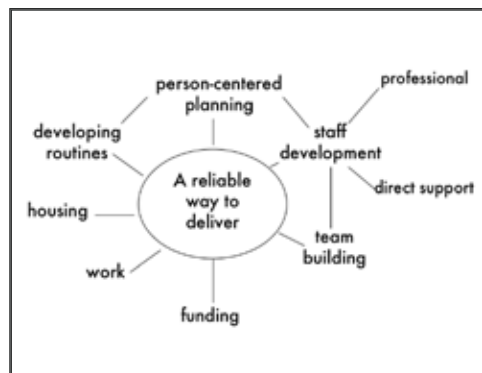
### "Impossible"

- We lack the money to establish and sustain effective assistance for this person
- No local service provider has or can develop the ability to assist this person effectively.
- We lack the knowledge & skill to plan & implement effective assistance

### Our Purpose

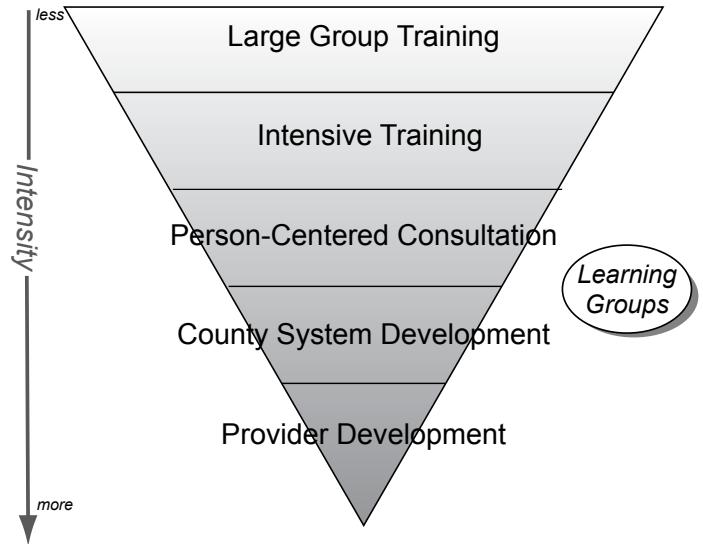
To work together to move...

...from...	...to...
"We don't know how to support this person & we are not confident that we can learn."	"We are responsible to learn how to support this person & capable of doing so."



## Project Interventions

The Project used approaches with different levels of intensity. First, **large group training** (summarized on the two pages following) to deliver useful information and clear value statements that inform and encourage as many people involved in the ICF-MR Restructuring Initiative as possible. Second, **intensive training**, focused on training and potential certification in the use of the *Health Risk Screening Tool (HRST)* for teams of nurses and case managers. Third, a set of more intensive interventions to increase the ability of counties that choose a partnership with the Project to create individualized supports. These include **person-centered consultations**, which support teams in planning implementing and delivering individualized services; **county system development**, which supports county staff and managers in developing local capacity to align their work and investments with the criteria of least restrictive and most integrated; and **provider development** which assists county staff and service providers to introduce a new level of individualization to a county's array of options. The whole Project is informed by the work of occasional learning groups.



The Grant Coordinator ensures the coherence of this diverse set of activities by selecting consultants whose values and expertise match the Project's focus, negotiating agreements for consultations and development activities, providing detailed briefings and follow-up interviews for workshop presenters and consultants, participating personally in at least one of each titled workshop and a cross section of consultations, and debriefing each consultation with those who received consultation and each workshop with a cross section of participants from her personal network.

## Large Group Training

15 workshops

3,193 participants

### January 2005 ••

- February •
- March •
- April •
- May ••
- June
- July
- August

September

October •

November •

December

### January 2006

February

March •••

April

May •

June •

July •

### Frequency of Large Group Training

County Staff	36%
Service Providers	56%
State Staff	7%
Person with DD or Guardian	2%

### Affiliations of Large Group Training Participants

Includes only participants who identified themselves in workshops between January 2005 and June 2006. 17% of participants did not identify themselves.

**We Can Do This!** Positive Approaches in Supporting People With Difficult Behaviors (2 days)

David Pitonyak, PhD

- You will gain practice skills that enable you to better assess and respond to people with difficult behaviors.
- You will learn sound methods of planning crisis response in support of people with difficult behaviors.
- You will go home from the training with a framework for understanding why some people need to exhibit difficult behaviors.
- You will learn practical and effective methods for planning individualized support for people with difficult behaviors.
- You will integrate terminology and concepts that will help you in your leadership to increase community capacity and commitment to support people with difficult behaviors.
- You will complete the training with a broader and deeper understanding of people who are notable for their difficult behavior.
- You will re-engage in your work with a renewed recognition of the value of your relationship and allegiance to people with difficult behavior.

5 Workshops

935 participants

January, February, April, May, November 2005

**Getting the Full Picture:** Success, good health, and quality lives for the people thought to be most complex (2 days)

Ruth Ryan, MD, Steven Meyer, PhD, and David Pitonyak, PhD

- You will learn principles of accurately diagnosing people who exhibit challenging behavior that will lead you to effective health promotion and support strategies.
- You will learn practical and effective interviewing skills that can be adapted to people with little or no verbal communication.
- You will examine the limitations in traditional behavior management approaches and learn effective methods to humanize behavioral support.
- You will learn specific strategies of behavioral support that feature non-aggressive, non-coercive approaches.
- You will learn practical steps in transitioning a person dependent on restraints or other coercive interventions and developing effective, non-aggressive behavioral supports.
- You will learn principles and strategies that will help you tailor effective supports to prevent and respond to crisis

4 workshops

549 participants

January, February 2005

**The Match Makes the Difference:** Building direct support relationships that result in continuity, competence, and commitment

Peter Leidy, Jennifer Felty, Linda Jorgenson, Ruth Ryan MD, Steven Meyers, PhD, Paul White

- Methods of recruitment and matching that foster the Good Match.
- Strategies that enable the Good Match to be sustained over the long run.
- Methods of supervising and mentoring direct service workers to increase their capacity to join in the reciprocal relationship essential in the Good Match.
- Methods of assisting people who rely on support so they develop capacity to contribute to building and sustaining the Good Match.
- System change strategies that foster organizational support to initiate, recognize, nurture, and sustain the Good Match.

1 workshop

115 Participants

March 2005

**The Beloved Community:**  
Nurturing the Role of Neighbor and Citizen (1 day)

Tom Kohler and Susan Earle

- You will have increased your capacity to look at your community and the people with disabilities who live there with a fresh, hopeful perspective.
- You will possess concrete strategies to link people and community—and the renewed motivation to do so.
- You will have options for helping people connect to the community that will not increase the cost of the service plan.
- You will have a framework for developing strategies that will improve the quality and satisfaction with direct support jobs.
- You will go home with a plan to get involved in at least one experiment in community connection.
- You will be inspired and renewed.

*1 workshop*

*225 participants*

*October 2005*

**Big Water and Solid Ground:** Helping people overwhelmed by anxiety find solid ground. (1 Day)

David Pitonyak, PhD

- Fear and anxiety affect our bodies and minds. What are the implications for care givers who are helping people in community settings?
- Medical problems and medication issues can be caused or worsened by anxiety. Learn ways to recognize anxiety symptoms triggered by a medical referral, as well as basic treatment options.
- Mental health conditions may be made worse by anxiety. Explore common mental health conditions, including panic attacks, post traumatic stress disorder, and obsessive compulsive disorder, that may result in extreme anxiety. Suggestions for their treatment.
- Low self-esteem and lack of self-confidence can be at the root of anxiety. Strategies for supporting the person to build a sense of confidence in ordinary community settings.
- Strategies for supporting a person's caregiver, including crisis preparation and paying attention to our own needs.

*3 workshops*

*873 participants*

*March, May, June 2006*

**Supporting Real Lives for People Whose Disabilities Include Complex Medical Puzzles**

(1 day)

Karen Green McGowan, RN CDDN

- How to identify, remove or reduce medical and health-related obstacles to community participation.
- How to enhance the reputations of people at risk of being discounted because they look so different.
- How to protect individual rights and personal interests in community health care settings
- How to understand the impact of health and physical limitations on achieving connection and membership in the community
- How to link the person's goal for community participation with the person's plan for medical management.

*2 workshops*

*355 participants*

*March 2006*

**Promoting Health Improvements for Children and Adults with Developmental Disabilities** (3 days)

Karen Green McGowan, RN CDDN

**Seizures**

How to recognize and document the more than 40 different types of seizures, recognize environmental stimulants and report these to the managing physician. This session covers old and new medications and the good news and bad news about drug regimes, particularly when there is more than one medication for seizure management.

**Drugs and Disabilities**

Children and adults with disabilities, along with elderly, often receive 7 or 8, if not more, drugs at a time. This can cause all sorts of new symptoms which often get treated as new diseases. This session addresses the major classes of drugs which are most often prescribed, how to recognize when things are not going well and what to do about it.

**Preventing Aspiration and Bowel Obstruction**

For individuals who move to the community after years in congregate settings, these issues are the two most common causes of preventable death. This session covers how to recognize, report and intervene with the most common causes for these potentially devastating problems. Additionally, this session addresses what happens before, during, and after food goes in. Does it go down, does it stay down and does it come out?

*1 3 day series of workshops*

*141 participants*

*July 2006*

Six themes tie together all of the Project's work:

- Build empathy and personal identification with those seen as difficult to serve as a foundation to respect for their ordinary human needs for security and meaningful engagement with activities and people of interest to them.
- Advocate strongly for the importance of commitment and continuity in relationships between people with DD and those who provide primary assistance.
- Raise awareness of knowledge and skills that offer positive ways to approach situations that are often managed in restrictive ways because they generate fear and uncertainty in the people they count on for support.
- Show the benefits of most integrated practices and individually tailored supports and encourage people to learn how to practice them.
- Identify the human and fiscal costs of exclusion from valued social roles and coercive controls.
- Actively recruit people to more intense commitment to the work of making services least restrictive and most integrated.

**Large group training** offers anyone involved in the ICF-MR Restructuring Initiative opportunities to consider issues of importance in providing least restrictive, most integrated services. There are two sources of workshop topics. Some workshops respond to direct requests from those involved in the ICF-MR Restructuring Project: "We need to understand the effects of the drugs people are taking." "We need better ways to assist people whose challenging behavior doesn't seem to improve." "We need to understand complex medical needs better." Some workshops developed based on the way the Grant Coordinator and Project advisers read the issues emerging in implementation: "The Project should underline the importance of the match between people and their support staff." "People need the opportunity to consider the importance of promoting people's involvement in citizen roles."

The Grant Coordinator's initial scan of her statewide network of contacts identified considerable concern about serving people placed in ICFs-MR with histories of difficult or dangerous behavior, especially people perceived to have co-occurring psychiatric disabilities. Accordingly, the Project began with three large group events aimed at providing a positive context for understanding and assisting people whose behavior and reputation generate great uncertainty and anxiety among service providers and county staff. As their titles –*We Can Do This* and *Getting the Full Picture*– reflect, these workshops intend to provide people with confidence that good lives are possible for people with difficult or frightening behavior, that people like themselves can play a leading role in providing the necessary assistance, and that they can study a growing body of relevant knowledge to improve their ability. Because of their large size and brevity, workshops could not teach people skills or offer in-depth knowledge. What they could and did do for many participants was encourage them to imagine better possibilities for people who had previously stumped and alienated them, described positive and practical ways to think about difficult situations, and reconnected people to the values that give meaning to their work.

The *We Can Do This* workshop and David Pitonyak, its presenter, had a special resonance for many people. People who came to the first two workshops wanted their co-workers and others from their home county to attend in order to build a common understanding and local momentum for the ICF-MR Resettlement Initiative and the Resettlement of people from State Centers. The workshop was repeated four times.

As 2005 passed, county staff encountered a growing number of people placed in ICFs-MR because their complex medical needs were understood as requiring continual access to professional nursing. In response, the Grant Coordinator engaged Karen Green McGowan, a nurse with long experience in health promotion for people whose disabilities include complex medical puzzles. She is a gifted

For a description of David Pitonyak's perspective and for workshop handouts, see <http://dimagine.com/>

See [www.mcgowanconsultants.com](http://www.mcgowanconsultants.com) for a description of Karen Green McGowan's work and her publications.



teacher who is able to connect simultaneously with most nurses and with other staff who have little or no medical training. Her workshops combine practical information about fundamental health care issues with profound respect for the humanness and developmental potential of people with complex medical needs.

A positive response to Karen Green McGowan’s workshops and her consultations increased interest in the *Health Risk Screening Tool (HRST)*. The *HRST* was initially developed to guide assessment of people moving from institutions into community settings to assure their safety and has evolved into a tool to support systematic health care decision making for all people with DD. It supports judgements about which people need intensive monitoring by a nurse. This decision is critical to health and safety for people with DD. It also has a significant impact on the best use of nurses’ time and thus on the feasibility and cost of appropriate community services.

Desire to test the usefulness of the *HRST* led to the Project’s only **intensive training**, two workshops in July 2006 for teams from counties, service providers, and state staff with the opportunity for certification in application of the *HRST* on successful completion of post-workshop requirements. Participant reaction to the workshops has been positive, but as of this writing, the systems the teams represent have made no decisions about widespread adoption of the *HRST*.

From January 2005 through the present, out-of-state consultants not only presented workshops, they also offered **person-centered consultation** to teams who wanted advice about individual situations. Ruth Ryan, MD, a psychiatrist who specializes in people with DD who experience difficult to treat behavioral or psychiatric disabilities collaborated with Steven Meyer, PhD, a psychologist. David Pitonyak, PhD specializes in helping people build and support positive relationships

County Teams	22
Provider Teams	13
State Staff Teams	2

**Participants In HRST Training**

Each team consists of two people, an RN and, typically, a case manager.

Consultant	Counties	People With DD
Ryan	6	17
Pitonyak	6	32
Green McGowan	4	21
Leidy	5	10

**Person Centered Consultations**

with people who can be very difficult to live with if they are not competently supported by people who are personally committed to them. Karen Green McGowan, RN, CDDN focuses on positive health promotion and planning for people with the most complex medical conditions. She involved two people with Kathy Bazata, OTR, ATP and Kerry Jones, ATP to demonstrate advanced methods to assess positioning and equipment needs. In addition to the three out-of-state experts, Peter Leidy, who has long experience in organizing and supporting individualized services, provided consultation on the practical aspects of designing supports that integrate committed relationships and clinical competence. Marcie Brost, the Grant Coordinator, also provides person-centered consultation around individualized service development, sometimes in collaboration with one of the other consultants.

These consultations model the Project's core belief: competent service depends on seeing a whole person-in-relationship who has a positive future. Consultants spend time with people that county staff were uncertain about serving adequately, review documentation, apply their expertise in suggesting both a productive way to understand the person and specific practices or interventions likely to be of help in supporting the person's growth and participation in community life, and sometimes facilitate team planning activities.

A few consultations focused on people who were not moving in a timely way from facilities scheduled to close because responsible counties were uncertain about how to define adequate service. Most consultations are part of a broader partnership between the Project and a county which is aimed at **county system development**. This level of Project intervention aims to extend a county's capacity to provide individualized supports. The Project Coordinator, the County DD services manager, and the state CIS staff person assigned to the county work together to encourage development through a combination of attendance at large group and intensive training, participation in learning groups, involvement in study tours, person-centered consultation, provider development, and consultation on a variety of issues such as housing, workforce

development, and funding options. These partnerships have been intentional, but not formalized into written plans. Instead, one step has built upon the others.

Each county system development effort is different but all share a common assumption: a county can leverage setting up individualized supports for people who are currently seen as very difficult to serve into higher quality supports for a growing number of people. People who have been placed from ICFs-MR benefit from more personalized services and generate learning throughout the county system.

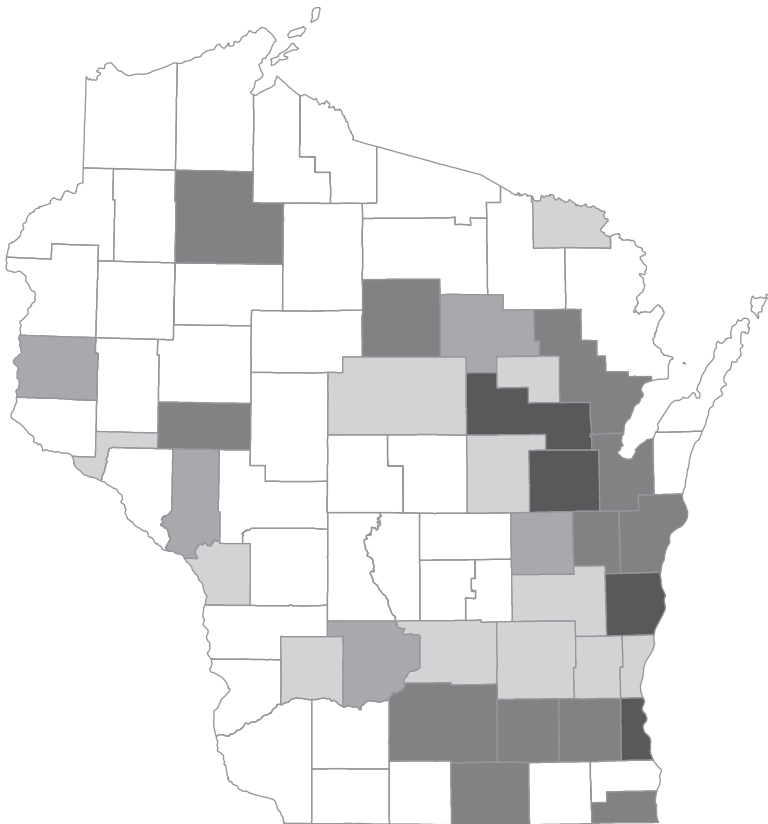
After participation in large group training and person-centered consultation, some county leaders decided to try an approach to service that was new for their county and its usual service providers. This led to **provider development** activities. Provider development includes consultation or staff development, arranging study tours of Wisconsin service providers who are already supporting people in individualized ways, continuing involvement in setting-up and implementing new support arrangements, and ongoing advice in the creation of new service providers.

As the map and the scatter plot on the next page show, Project investment in interventions other than large group training varied depending on both numbers of people that counties had placed

in ICFs-MR and county interest in developing more individualized supports.

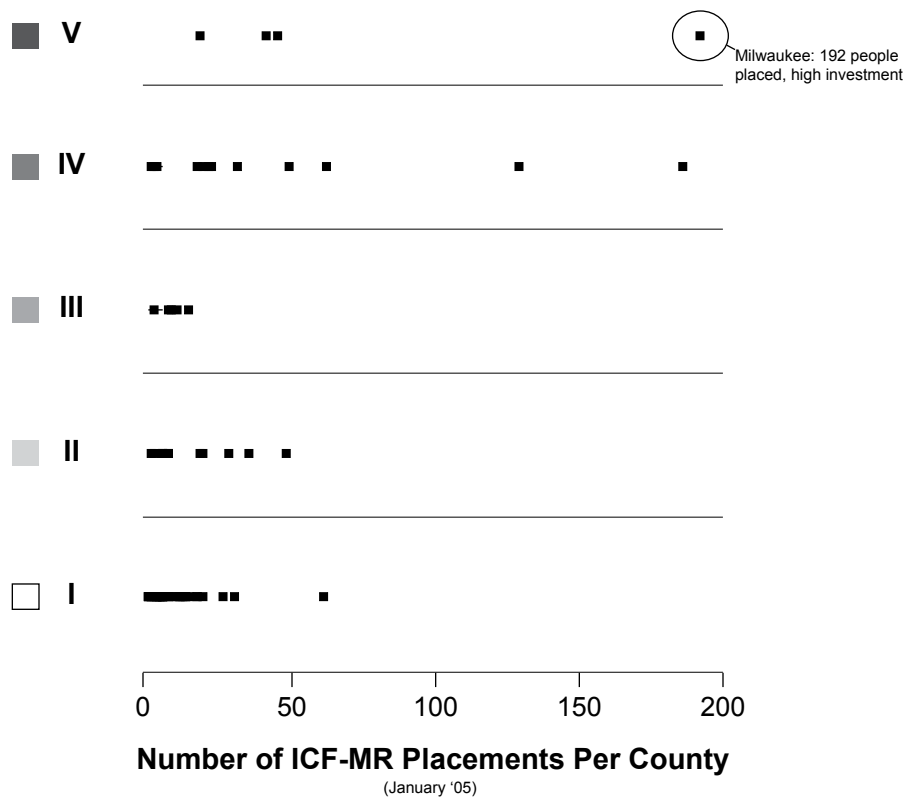
The diagram on the left summarizes the relationship between the current status of a county system and the mix and focus of Project activities. The return of people who have been placed in ICFs-MR surfaces important issues in counties with extensive experience in providing individualized supports just as they do in counties that have typically relied on

		Investment In Individualized Supports	
		Low	High
Investment In Local Responses To People With Complex Or Challenging Needs	High	<ul style="list-style-type: none"> <li>• Assist in demonstrating less restrictive, more integrated service designs.</li> <li>• Consultation focused on clinical issues &amp; organizational development</li> </ul>	<ul style="list-style-type: none"> <li>• Affirm values</li> <li>• Consultation focused on clinical issues</li> <li>• Link to others as model &amp; mentors</li> </ul>
	Low	<ul style="list-style-type: none"> <li>• Clarify values</li> <li>• Promote self-evaluation</li> <li>• Support to develop one or two individualized support arrangements as a way to learn through action.</li> </ul>	<ul style="list-style-type: none"> <li>• Clarify values</li> <li>• Promote self-evaluation</li> <li>• Consultation focused on clinical issues</li> </ul>



- Level of Project Investment**
- **V Intense Investment.**  
Training, multiple consultations, system development, provider development
  - **IV High Investment**
  - **III Moderate Investment**
  - **II Low Investment**
  - **I Access to training only**

Level of Project Investment in County

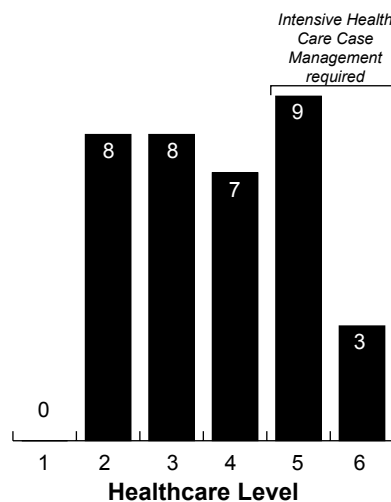


congregate services. The important difference is that counties that decide to learn how to better adapt to match the needs of a person who has posed a significant challenge to a well established pattern of individual supports face different issues than the issues that face counties with an established pattern of group placements that decide to learn how to tailor individualized supports in response to people the county has previously seen as too difficult to serve.

Throughout the period of the MFP Grant, the Grant Coordinator has convened a number of **Learning Groups**. Learning Groups are of two kinds. Some bring together Project Consultants to reflect on what they are learning and what the Project’s next steps should be in response to the changing situation. Others focus on a theme that the Grant Coordinator thinks is worth a deeper understanding. Learning Group themes included:

- The meaning of “most inclusive” service and how to communicate it.
  - Strategies for county system leadership.
  - Effective, systemic responses to crisis that will avoid the re-establishment of long term congregate facilities.
  - Developing capable providers for people with complex needs
  - Shifting the nurses role from oversight to active health promotion.
- (A summary of the record from a discussion of this theme is on the next page).

Summary of 35 Project consultations by Karen Green McGowan RN, CDDN. About  $\frac{1}{3}$  of the people referred for consultation because of perceived complex medical needs need intensive Health Care Case Management by an RN (see the following page for a description); at the time of assessment, only 3 require intensive, ongoing nursing supports



**Avoid:** Nurse as purveyor of "pills & procedures"

- Separate health care case management as a DO system nursing function from nursing services, purchased as part of a person's individual plan
- Consider engagement with nurse practitioners as part of primary care strategy
- Invest significantly in increasing nurses' specialist knowledge & capacity to act as consultant & teacher

**Remove Health Issues as a Barrier to Real Life**

**Purpose**

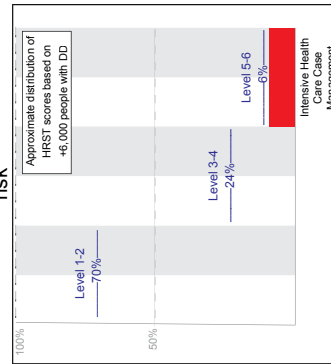
- Death rate similar to general population
- Excellent health-related supports to development contribute to growth & high expectations
- Significantly decreased utilization of restrictive or expensive health care because of prevention & early intervention

**Outcomes**

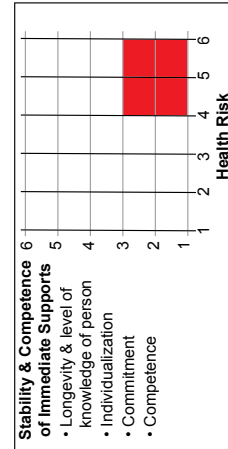


This is a **nursing specialty**, requiring specific training & supervised experience. **CC** certification is a good start. Specialist knowledge and commitment is especially important for people that other health care providers bve difficulty seeing with **igh** expectations for good health & development

**Focus Intensive Health Care Case Management on those at greatest risk**



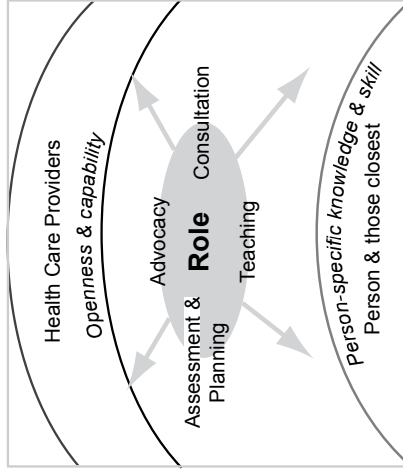
- 100% of people served screened annually or after major health event by broker or other capable person
- **eeners** trained & certified



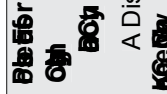
- **RK**, uncertainty, & difficulty of nurse del-egation decisions increase as the stability & competence of a person's immediate supports decrease
- Promoting continuity, competence, and health intelligence in direct support workers is essential.
- **iff** with people at **igh** risk require significant amounts of direct instruction from nurses

**Avoid:** Nurse as agent of compliance & control

- Focus on purpose rather than getting trapped in debates between medical vs rehab models
- Distinguish health care case management from monitoring paperwork compliance
- Practice in terms of principles...
  - ...nursing role is to reduce restrictive treatments & promote practice that increases people's options
- **igh** level of health risk is not, in itself, justification for con-gregate "placement"



**Growth Factors**  
Funding for MA match (may-be from RWJ) establishes cost benefit & justifies on-going funding as MA card service or waiver benefit. Growth will be the respon-sibility of a not-for-profit agency.



**A Discussion with**

24 May 2006

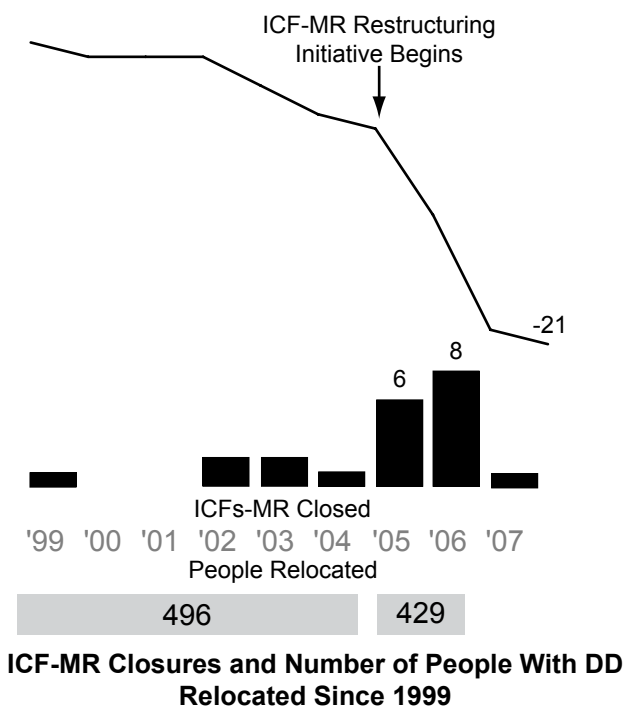
Connie Lyle O'Brien & John O'Brien, Recorders

## Larger Than Expected Numbers Move From ICFs-MR

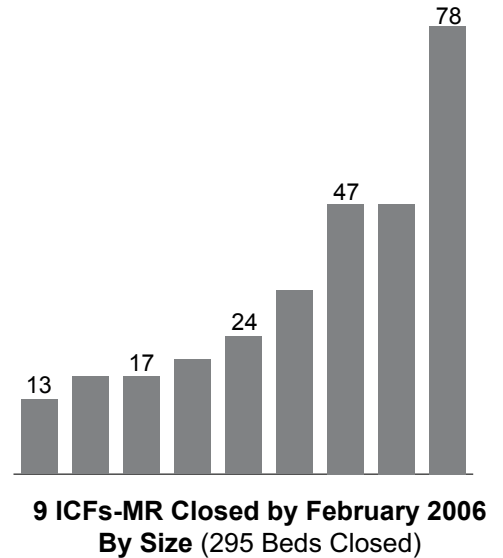
Based on the MFP Grant's assumptions, those guiding the Project initially thought that the main driver for decreasing the numbers placed in ICF's-MR would be the changing criteria for ICF-MR admission and a higher standard for annual review of people with DD placed. Well trained Guardians Ad Litem would use individual community placement plans to convince trained judges that a steadily growing number of people would be served in a less restrictive, more integrated way in community settings. In the early months of the grant, movement would be reasonably slow as counties caught on to planning in terms of the new criteria and, in later months of the grant, numbers would grow steadily toward the 200 moves identified as one of the desired outcomes of the MFP Grant. Under this assumption, Grant development activities would focus on partnership with counties that chose to invest in individualized supports for difficult to serve people.

The assumption of slow and steady growth to 200 people over the MFP Grant period did not hold. Nearly as many people have moved

in the first 20 months of the MFP Grant as moved in the 72 months before the MFP Grant began. In the environment created by scarcity of funds and uncertainty about the future shape of long term support, signals about rates for services have driven the change by giving a number of ICF-MR operators reason to close. Some were already seeing a steady decrease in placements and believed that rates were inadequate to meet rising costs. When the state agreed to fund the full cost of meeting service needs identified in community placement plans for as many people as possible, that gave counties good reason to move as many people as they reasonably can, in case the ability to fully fund plans runs out.



Not only did more people with DD than expected moved, most of them moved because the ICF-MR they lived in closed, either returning the beds to the state or converting them to skilled nursing beds. By February 2006, 9 ICFs-MR had closed, by August 2006 there were 14 closures. A person with DD whom the PASSAR process determines not to require active treatment can occupy a skilled nursing bed without imposing a cost penalty on the responsible county. As of August, 2006, 66 people (5% of the total number of people involved in the ICF-MR Restructuring Initiative) had been assigned a “no active treatment” status and moved into skilled nursing beds.



Moving substantial numbers of people introduced additional time pressure on counties. Closure plans include a closure date negotiated between the ICF-MR and the state Department of Health and Family Services, which creates a deadline for the responsible counties. Because the state agreed to pay phase-out costs, there will be more money to fund community alternatives if people are moved in a timely way. Greater time pressure means less opportunity to develop individualized supports in places that had no history of individualized services for difficult to serve people. People whose community supports cannot be developed by the time of closure are at risk of appearing to qualify for placement in an ICF-MR or even a Skilled Nursing Facility because no less restrictive alternative exists.

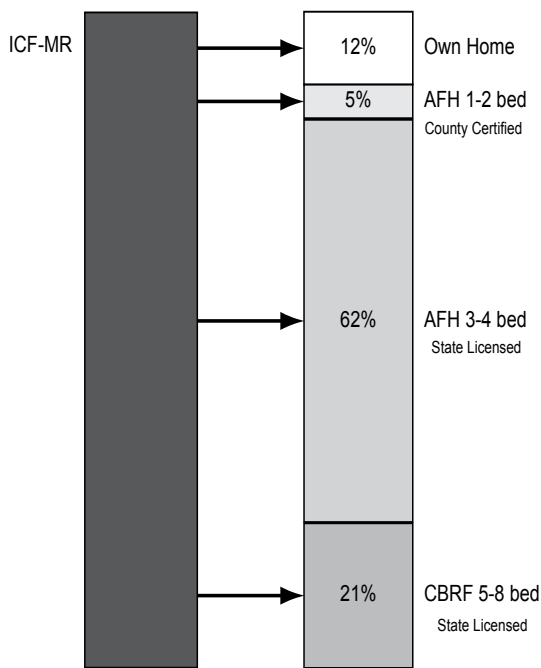
Counties that had placed large numbers of people in facilities that closed or downsized faced a significantly increased workload for case managers who were already heavily committed. Familiar service providers who were willing to expand to serve people from ICFs-MR reduced the burden of planning and developing services for a number of people.

In some counties, ICF-MR provider agencies became community group living providers, continuing to serve many of the same people



in new group homes. This approach reassured some guardians who had confidence in the ICF-MR and valued continuity. It also offered some county staff a continuing relationship with a known organization.

Existing providers and new providers from among ICF-MR operators reduced the numbers of places that counties needed to find. This left a smaller number of people who might slow or block closure because no adequate provider could be found at a justifiable price. Several of these people attracted Project investment and three have become the focus of provider development.



**Living Arrangements of People Resettled Under the ICFMR Restructuring Initiative**

(August 2006)

A majority (67%) of the people with DD who have moved into community services during the grant period have moved into Adult Family Homes (AFH), licensed or certified facilities where they live with 1 to 3 other adults. Some AFH's are operated as a business by families: others are operated as small group homes by agencies. About 1 in 5 people with DD have moved into a facility licensed as a Community Based Residential Facility (CBRF) where they live with 4 to 7 other people with DD. About 1 in 8 of the people who have moved so far have moved into their own home or apartment with individually tailored support.

Most people with DD who moved during the MFP Grant period moved into group living arrangements, regardless of assessed level of need. The number of others a person lives with is better predicted by

the way Counties responded to the demand to move people within tight deadlines than by the level of assessed need for support.

Some people at the highest levels of need for assistance moved into their own homes and the person with the lowest level of need for support moved to one of the largest facilities. Counties familiar with 4 bed AFHs and CBRFs tended to pattern growth on what they

Level of Care	Own Home	AFH (1-2)	AFH (3-4)	CBRF (5-8)
DD1A (12%)	1.19%	0.23%	7.00%	3.73%
DD1B (33%)	4.43%	2.33%	19.35%	7.69%
DD2 (54%)	6.29%	2.10%	36.60%	9.09%
DD3 (0.23%)				0.23%

**Living Arrangements of People Resettled Under the ICFMR  
Restructuring Initiative By Assessed Level of Care**  
(August 2006)

knew. Many county managers and case managers decided that they lacked the time to develop a new form of service.

### **Benefits Identified by Project Participants**

Most of the people who have attended large group training or have been involved in consultations and development activities have very positive things to say about the ways the people associated with the Project have helped them and improved their responses to the people they are moving. They identify four sorts of benefits from their involvement with the Project.

- Project consultants as a source of **practical support**.

*Because of Karen’s advice on positioning, people are breathing easier and eating better.*

*–Service Provider*

*Peter has played a key role in strengthening providers. He’s helped us think about who would be a good match for someone who cusses and throws things at people. And for a woman who is physically violent. His support has been of immediate benefit to particular people.*

*–County Manager*

*Marcie has helped us figure out a host of problems: how to find accessible housing, where to get funds for provider development and equipment, how to recruit and support staff, how to deal with guardian’s worries*

Quotes, with minimal editing for ease of reading, are from from July 2006 interviews. Each quote comes from a different person. County staff represent six counties.

*and objections. I can call her anytime and she always has a creative idea.*

*–County Case Manager*

*Marcie and Karen talking with the guardians was just as beneficial as the actual training. For three or four of the guardians, those conversations made the difference in their agreeing for the person to move*

*–County Manager*

*Working closely with Marcie and Pete has paid off in a new service provider who is committed to individualized supports.*

*–County Manager*

- **Project as a source of new ways to understand people.**

*We don't have what Karen brings. Without her people's situation would not be so good. Karen's work brings an absolutely exciting perspective. It was like a lightning bolt for me. She talks about health promotion, not maintenance. Her expectation is that people can be more than they already are; that everyone can develop and everyone can participate meaningfully in life.*

*–Nurse Consultant*

*The learning visit we made to New Horizons North showed us what individualized supports really are. Before the visit, I thought that individual supports were only for people who needed only a little bit of assistance. I learned that they can work well for anyone; especially people with complex needs.*

*–County Case Manager*

*David did a consult with M and got me thinking about her differently... He changed our attitude that negative behavior is always something under the person's control. It may not be the person trying to make me*

*mad, it may be the only way the person can express the pain they're in. Some issues are the system's issues and not M's. I've started to think about my job as peeling away some of the bureaucracy so we can say, "This is what the person needs, how can we get it?"*

*–County Case Manager*

*The trainings have given us new insights that we use everyday: Psychotropic meds can mask important problems and cause us to ignore them. Maybe he's not just hitting his head, maybe he's in pain. People might have PTSD.*

*–County Case Manager*

*Kathy and Kerry did a seating evaluation for G. I learned so much from that. And what I learned carries over to other people – it's like a domino effect.*

*–County Case Manager*

- Project as a reminder and **reinforcer of fundamental values.**

*We know there is a person there, but the person is easily hidden by procedures and paperwork. We go back for more of the trainings because they keep refocusing us on what we already know but can forget: we have a real choice to see and respond to the person or not.*

*–Service Manager*

*Being involved in working with T has made my job enjoyable. We have been getting farther and farther from what is really important. This work has brought us back to center.*

*–County Case Manager*

*David's consults really put the emphasis back on people, relationships and family. This has really been an eye opener. When the waivers first started, we had time for conversations, doing things together. Then*

*caseloads went up, time got tighter, and now it seems we just have meetings. We used to have a more hands on picture of the person. Now more people are on “programs”. We got too busy and pressured to find a provider. When David comes in and personalizes the individual and shows a true relationship, it reminds us of how it should be. What he says and does really made me realize what we’ve given up. There has to be time to keep people in focus and connections personal. Right now, mandates and policies rule. The job gets less and less personal and less and less meaningful. David gives us a chance to remember how it used to be when it was good.*

*–Community Integration Specialist*

*Most of what David says, we knew but have forgotten. The chaos of the job, higher case loads –you’re constantly putting out fires. You get so caught up in what’s going on with long term care and redesign that you forget what you know is most important. David brings us back to this.*

*– County Manager*

- Project as **confidence builder**.

*What I’ve learned from Karen will help me in my job with other people. I have better questions to ask and more confidence to raise them because she has shown me that improvement is possible for people that I wasn’t sure about before.*

*– County Case Manager*

*David models the relationship and the interactions that have the best chance to work with a person.*

*–State Manager*

*It’s amazing to see Karen actually work with people. Families participated in the consults and were amazed*

*too. It was priceless to see a person become more alert and breath better. The person felt better and you could see it instantly. Once you have seen the change, you want to do what you can to make sure that people don't slide backward.\**

*–Community Integration Specialist*

*Ruth's training influenced the case managers to look deeper at medical issues and to raise questions with the doctors. Some doctors have not responded too well to this, but it's resulted in better health care for some people and we'll keep on questioning.*

*–County Manager*

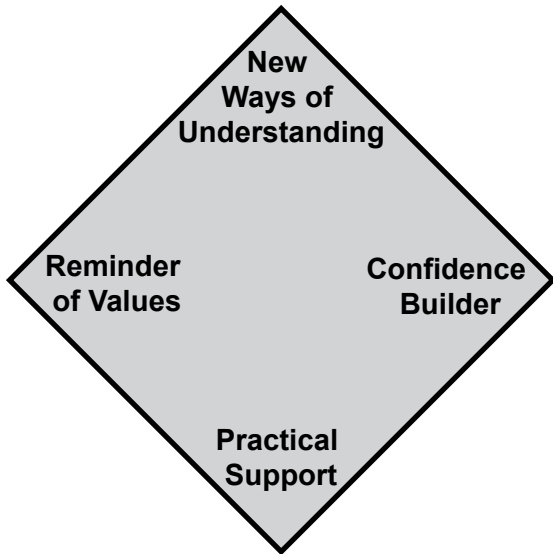
*The HRST [Health Risk Screening Tool] makes objective a lot of stuff that's usually visceral. It helps people see and react to the facts about people who sometimes scare us because their bodies are so different.*

*–State Manager*

*A man who had lived [in a facility] for 41 years was moving out and we didn't know how to address his needs and his family was deeply worried about his moving out. We went to a training and thought David would be great to work with. We liked his philosophy and approach. So Marcie coordinated a consultation with David. He spent four days with all the different people involved in R.'s life. He helped us imagine what life could be like for R. in the community. The consult gave us increased confidence to make a plan and determine the steps to community. David helped people develop a common understanding of what makes R. tick*

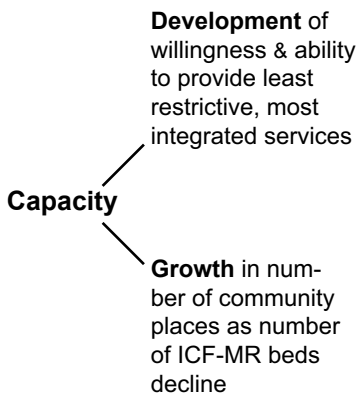
*–County Case Manager*

*\*Immediate changes are possible because people have been poorly positioned; knowledgeable adjustment simply (and sometimes dramatically) demonstrates a possibility which can only be sustained with informed daily work and often with new equipment.*



Though these benefits can be broken down into a list for ease of understanding, they are more closely connected than the list shows. Each influences the others and all arise from personal contacts with people connected to the Project. The more Project activities people chose, the more benefit they experience. People do gather information about challenging behavior or complex physical needs and connect with additional sources of information, but even more important is their sense of a better understanding and a clearer responsibility to take action to improve people's relationships and wellness and thus their lives.

### Influencing the Trade-Off Between Growth and Development



Forces for growth have dominated opportunities for development in the ICF-MR Restructuring Initiative. More than double the planned numbers of people moving from ICFs-MR into community settings offers reason for celebration: all reports that we know of indicate that most people are better off and enjoying their new living arrangements. The fact that nearly 80% of the people have moved as the result of an ICF-MR closure plan indicates success in meeting the MFP Grant's goal of re-balancing the service system.

From the Project's perspective, these successes involve an opportunity cost. The requirements of moving large numbers of people on tight timelines created a pull away from the process of development that could have resulted if there were time for Counties to learn to implement more individualized supports.

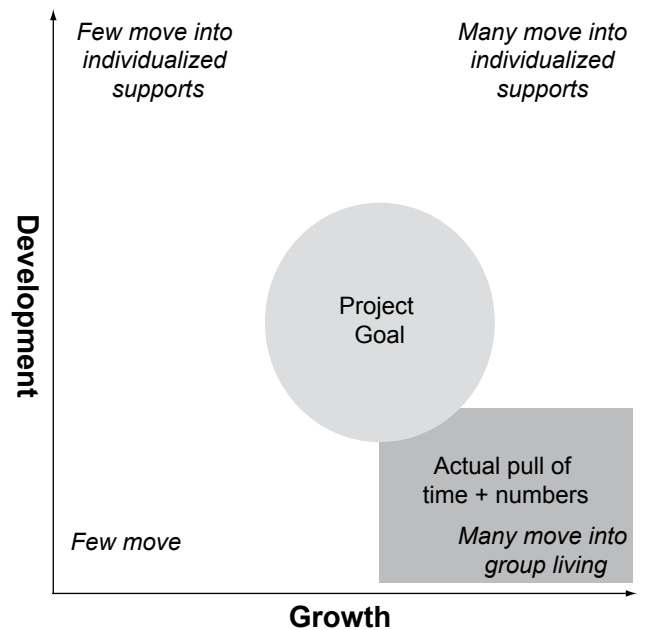
Note that we are **not** saying that people are poorly served in their current living arrangements. We did not visit more than a few people and have no information on the quality of life for most of the people placed. Moreover, in common with others close to the Proj-

ect, we believe that individualized supports represent the best vehicle for realizing the standards of least restrictive and most integrated services. While we have evidence and much practical experience to support our belief, we recognize that many people disagree and would not count the opportunity costs that we do from inability to invest in developing individualized supports.

From this perspective, the 20 months of Project activity have produced significantly less developmental change than the Project itself aimed to generate. Though the goals of the MFP Grant have been met or exceeded, the Project has not fulfilled its ambitious, self-imposed goal of positioning a substantial number of the people moving from ICFs-MR as occasions for change in their county system.

This is not to say that the Project has had no developmental impact. Each of the perceived benefits outlined in the previous section influences the way people who chose involvement with the Project manage the trade-off between meeting growth targets and investing in development. Most of the shifts in understanding and practice that they report are consistent with two of the Project’s three themes: higher expectations for people’s potential to develop and the foundational importance of relationships. These shifts have influenced individual plans, the way individual plans were made, the choice of service providers, and the choice of group living arrangements. However, for most people who moved during the MFP Grant period, the third theme, providing personally tailored supports, remains beyond reach.

Four Counties did accept the Project’s invitation to develop new capacity by creating individualized supports around a person with complex or challenging needs, a person that they would not have





imagined successfully living in his or her own home. Developing these opportunities has proven a rich source of meaning for the staff involved and those situations that have been fully implemented have, so far, greatly benefited the people involved (though, of course, they have not “cured” the person’s impairments, eliminated challenges, or yet reduced the costs of support).

Despite the success and satisfaction that these efforts at individualized supports have brought, the Project assumption that success with those seen as most difficult would set a new benchmark and drive county efforts to move from smaller group settings to more individualized settings has yet to be validated. In fact, the system seems to some people to be moving to a very different implicit benchmark which can be baldly stated like this, “A person should live in the largest group he or she will tolerate without exhibiting symptoms that can only be abated by more individualized supports.”

### **Beyond Technical Assistance: A Learning Process**

The process of growth in numbers of community placements can be understood and managed as a technical process: funds secured; objectives negotiated, reviewed, and revised; individual plans made, approved, and monitored; rates set and budgets managed; placements solicited, selected, and made. This process is formalized and governed by policy and procedure. It’s principal criteria are uniformity, efficiency, and economy. To learn is to be briefed on policy objectives and trained in correct procedures. In technical assistance, an expert teaches a person with a problem a solution to that problem.

Doing this technical level of management well is vital to the success of the ICF-MR Restructuring Initiative, and the initiative has successfully moved more than twice its targeted number of people because of capable, hard working state and county managers.

In addition to supporting these managers in making moves, the Project has had an additional focus –development of new opportunities for personal freedom and social inclusion in a period of growth

in community placements— and thus engages different issues with a different process. This difference shows at the point that the process meets a person who is difficult to place.

The technical process for growth management has a legitimate response to people who are difficult to move to a community setting. The court accepts a plan that specifies an ICF-MR as the least restrictive, most integrated setting that is affordable for this person or the PASSAR process certifies that this person no longer requires active treatment and can be placed in a Skilled Nursing care bed. This may mean that a person has to move from a closing ICF-MR to another facility, but it allows the growth process to proceed.

The Project positioned itself exactly at the point of stuckness, where responsible people were uncertain about the possibility of serving a person effectively in a community setting. Correctly understood, this uncertainty is not so much about procedures or techniques as it is about ability to respond effectively to a situation that gives people good reason to be anxious because of violence, powerful emotion, or bodily complexity. Those involved with the Project have seen two ways of coping with the uncertainty and anxiety carried by people who are difficult to serve.

#### **Less Effective**

Avoid uncertainty and anxiety through a pattern of “place the person at a distance, pay a premium price if necessary, monitor and move on to someone with better possibilities.”

Group the person with others based on similarity of symptoms

Put priority on control of symptoms through medications and compliance oriented behavior programs.

Assume that a straightforward fix for problems exists; blame the person’s non-compliance or complexity for failure

#### **More Effective**

Own uncertainty and anxiety as a motivation to learn better ways. Invest in getting to know the person and learning about support alternatives.

Tailor supports to individual needs to access opportunities.

Put priority on building and supporting committed relationships with capable people.

Invest in increasing self-efficacy - a sense that “We can learn how to make a positive difference and we can be resilient to mistakes- by building knowledge and skills through action.

If technical management is a matter of laying out and following the shortest line between two points, the Project's work is like picking apart knots. Because those responsible for the management of growth can cut through the knots by legally identifying an institution as the least restrictive, most integrated setting, there have been a number of respectful and informative conflicts between the Grant Coordinator and those responsible for managing growth. The point of these conflicts has been to make time for the people directly involved to learn their way out of stuckness through the Project's process of practical support to problem solving, remembering key values, discovering new ways to understand the person, and building confidence. It is a mark of the quality and commitment of those whose responsibility is to manage growth that they have accepted these conflicts, responded to them within the constraints of their responsibilities, and been informed by what has resulted.

An example: Extensive consultation revealed an opportunity for a very substantial health improvement for a person with complex needs. Supporting that improvement required not only major (and costly) changes in equipment, personally tailored supports, and extensive environmental modifications, but also time past the closing date of the ICF-MR. This left the person facing either an interim move or additional time in the facility he has lived in for years or re-classification as a person who does not need active treatment. The Grant Coordinator challenged and supported county and state managers to deal with this outlying situation in a way that makes improvements for the person most likely.

The stuckness that interests the Project shows when county staff cannot imagine what an effective community service setting would look like for a person, or when no available service provider will respond to a person, or when a person's guardian refuses repeated efforts to demonstrate that a move into a community setting will be beneficial.

Each situation is unique, but reflection suggests four common features of stuck situations and four aims of the learning process that defines the Project's work when it has functioned at its best.

One. Key people are disengaged from the person. The case manager reads reports and attends meetings but does not know the person as a person. The guardian has had little or no personal contact for a long time. More than this, features of the person's situation put people off from encountering the person as a person, whether these are individual characteristics –apparent non-responsiveness, violent reactions to another person's approach, angry or passive rejection of contact, unkempt or disturbing appearance– or characteristics of the setting –noise, smell, security features, medical paraphernalia, routines. The Project's aim is to help key people (re-)connect with the person, choose a (renewed) respectful relationship with them, and look for others who know and care about the person and ally with them.

**From disengagement to relationship**

Two. Key people lack a sense of what would work to support the person and so they are trapped by an unrealistic pessimism. The Project invites people to make an important distinction: a person can thrive and require assistance with complex health needs; a person can thrive and experience occasional periods of mental illness; a person can thrive and experience compulsions or significant difficulties in self-control. This distinction puts interventions aimed at controlling or remedying difficulties in the context of efforts to create and support positive relationships and accommodating environments. The Project also provides people with the opportunity to learn from a person with relevant expertise and experience whose message will include not only insight into possibilities but also confidence in the ability of people in committed relationships to develop necessary skills given adequate support.

**From pessimism to a sense of possibility**

Three. Key people don't trust one another. The person's reputation and history tempt people to blame him or her for the apparent intractability of the situation. County staff and service providers are

**From blame to trust**

uncertain of the other's commitment to the person when trouble arises and each imagines being abandoned by the other. Guardians blame professionals for disrupting the stability of their situation and staff blame guardians as obstructionist. The Project invites people to invest their trust in the person's capacity to respond to the opportunities available when people who care get adequate support for problem solving.

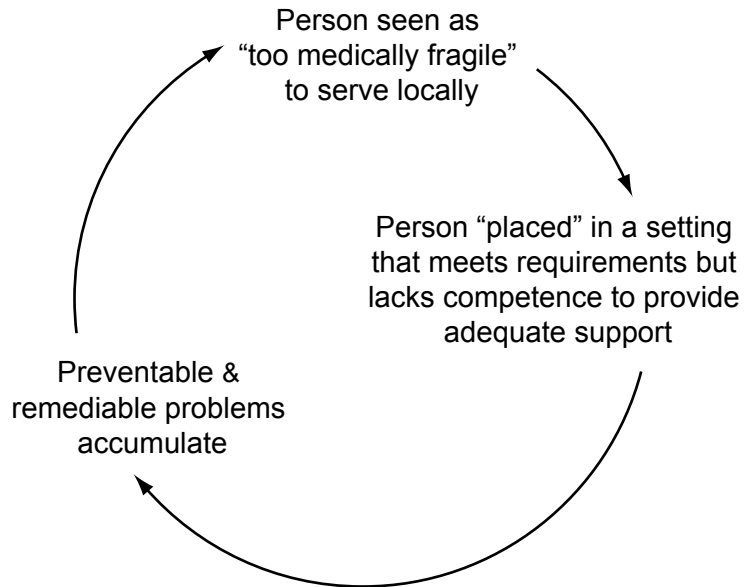
**From scarcity to a sense of capacity**

Four. Key people are ridden by a sense of scarcity. The human service system is overcommitted, case loads are large, many people are waiting for needed services, budgets are under pressure, capable staff are difficult to recruit and retain under current rates, capable physicians are not easy to find, and community acceptance is limited. Each of these issues deserves address. In the face of all this, the Project invites people to search for and mobilize the capacities that surround participants in the ICF-MR Restructuring Project: people who already have a caring relationship with the person, current priority in the system, access to improved rates for demonstrated need, housing assistance, service providers interested in building their competence, nurses interested in becoming advocates for health promotion, opportunities to contribute to community life, and the knowledge and support of Project consultants and activities. Scarcity exists simultaneously with possibility. A sense of scarcity pushes key people to settle for institutionalization. A sense of capacity pulls key people into searching for the edges of what is least restrictive and most integrated.

These moves to stronger relationship, a sense of possibility, trust, and identified capacities trace a learning process that proceeds as people work together to make positive changes for individuals.

Failure to embrace stuckness as a motivation for learning accumulates costs. Some of these costs accumulate in people's bodies or in people's histories of missed opportunity and trauma. Some of these costs raise the rates or remedies the service system has to pay in order to meet people's needs for assistance. The Project has encountered two patterns through which people incur these costs.

One pattern noted in a Project Learning Group incurs costs through a vicious circle. A person with disabilities that include complex medical puzzles is seen as impossible to serve locally. Their county system locates a placement in a facility licensed and willing to provide care for such people, places the person, monitors the placement, and annually affirms that this is the least restrictive setting appropriate to the person's needs. The person stays as long as the facility chooses to continue to provide services. If the facility is highly competent at supporting the person's physical complexities, the person pays only the costs of restriction and isolation that the least restrictive, most integrated standard is intended to remedy. If the facility is less competent, costs accumulate in the person's body as the person struggles to adapt to low developmental expectations, poor positioning, poorly informed mealtime routines, and poly-pharmacy. These costs can go unnoticed, perhaps until the person's death, normalized by a story that defines these additional acquired disabilities as the inevitable consequence of the person's disability. But the moves occasioned by the ICF-MR Restructuring can result in knowledgeable assessments that identify the need for remedial action and specify what will be necessary to support the person, a money cost increased by the needs created by acquired and preventable impairments. In these circumstances, competent assessment converts the consequences of inadequate support into a cash claim against the human service system.



It is important to recognize that this pattern is neither exclusive to ICFs-MR nor a necessary feature of ICFs-MR. It need not occur in an ICF-MR and it could occur in community settings and in situations where people live with their families. It does occur in set-

tings that pass inspection and it can happen even when a person is assisted by credentialed people who feel affection for him or her. While it takes knowledge, skill, and sometimes creativity to prevent or reverse this negative spiral, what's required is not so esoteric or so highly specialized as to be beyond the reach of ordinary practitioners.

Simply transferring a person from an ICF-MR where this pattern operates to a community setting does not interrupt or reverse this pattern. The pattern can move with the person in the form of a story (a plan of care) that specifies what must be done to cope with the symptoms of missed opportunities for positive health. This story misdirects by leading people to think that they know all they need to know about looking after the person's body. The pattern can only be left behind when a person's move includes competent assessment that specifies positive possibilities for the person's future and definite strategies for adequate support to get there.

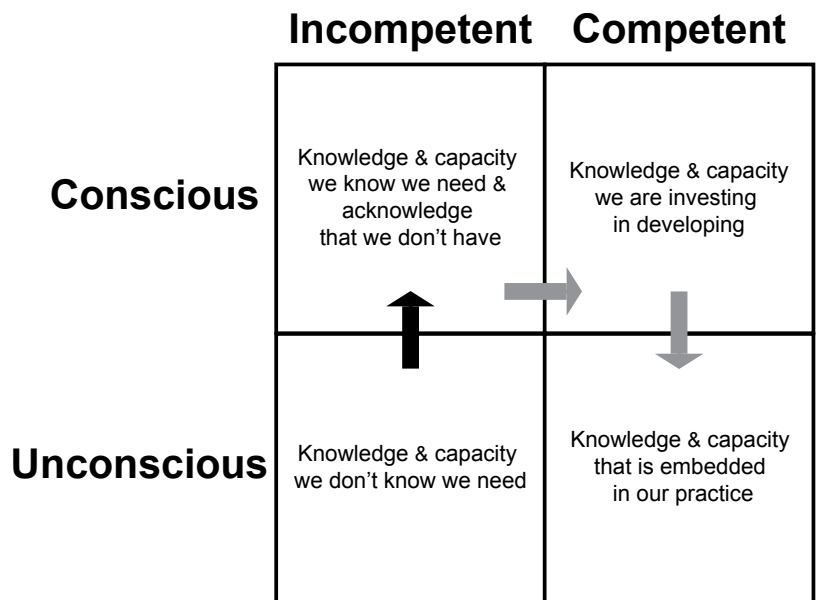
Any capable manager would want to eradicate this costly pattern. But typical bureaucratic tools are not sufficient to change it. The Project Learning Group that discussed this pattern endorses the insights into quality improvement taught by W. Edwards Deming and his associates: quality cannot be inspected in, it results from systematically applying a deep understanding of cause; attempts at quick fixes amount to tampering and ultimately degrade quality. We believe that costly patterns like this one can be undone, but that exhortation to do better, or more rules, or tougher enforcement amount to little more than tampering. What's needed is sustained action based on a good understanding of the causes of the pattern.

This pattern results from what people do not see because they assume that debilitating conditions (for example GERD or constipation or depressed breathing) are "normal" for a person whose body is uniquely complex or that typical functions (such as communication or coughing) are "impossible for a person in that condition to achieve." This assumption blocks a straightforward inquiry into what

might be done to promote health and well-being: people don't see the opportunity for improvement because they do not look for it. They do not look for it because they are sure it is not there.

Furthermore, this pattern is part of organizational culture. It is not just one or two poor performers who do not see opportunities to promote people's health, it is, in a sense, the whole organization that fails to see. In these circumstances, a staff person who questions the pattern –perhaps after attending a training or reading a journal paper- will seem “unrealistic” to her colleagues, who will encourage her to rejoin “the real world”. This process is reinforced by the fact that a physician or a nurse can be well trained but never have encountered a teacher with deep knowledge of positive possibilities for people whose disabilities include complex medical puzzles.

The Project Learning Group found this simple diagram\* useful as a pointer to the causes of negative patterns that keep people from living lives that are least restricted by services and most integrated through the way services assist them. On this understanding, many missed opportunities follow from “unconscious Incompetence”, possibilities not seen because not only is knowledge and skill missing, its existence is unknown. In this state, there is something important that we don't know that we don't know.



Project consultants noted these signs of “unconscious incompetence” affecting the lives of people they assessed.

- People receiving multiple drugs (up to 16 different drugs), each targeting a discrete symptom, with no evidence of root cause analysis.

\*There are many versions of this diagram, but we don't know a definitive reference for it. We learned of it from Denny Rogers, a senior manager at GE and a member of the Butler County, OH Board of MRDD.



- Positions, movement routines, and feeding procedures that degrade health and mobility.
- Lack of support for communication.
- Intensive staffing or “behavior programs” that have been in force for long periods despite lack of evidence of developmental growth.
- Continuing approval, or at least unquestioning acceptance, of these enduring conditions both by licensing authorities and by responsible county staff and Guardians Ad-litem involved in Watts reviews.

The diagram expresses an important aspect of the Project’s strategy: provide people with large and small group connections to consultants who have the gift of moving people over the boundary from not knowing that there is something important to the people they support to knowing that there is something worth their working to learn. Then assist people to develop ways to learn what they now acknowledge they need to know by changing the way they respond to at least one of the people who is moving. This change defines knowing. Knowing is not just being able to recite or write information into plans, it is being with other people in a way that produces valuable results.

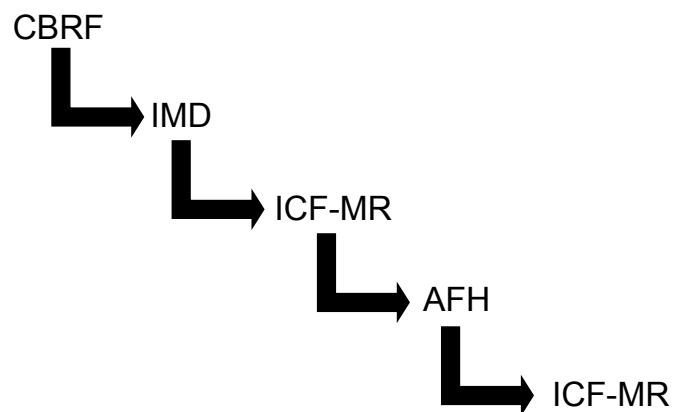
This kind of knowledge seldom comes cheap. The stage of conscious competence requires the investment of time and the means to plan, try, and reflect on new things, resources which are scarce and made scarcer by deadlines. There are good reasons to avoid acknowledging unconscious incompetence, including these....

- The costs of remedy may be high.
- People may want to avoid feeling remorse for the effects of what they have done or failed to do
- Knowledge of better ways may lead to higher expectations for other people and these expectations may be disruptive of settled ways of working.
- Taking account of better ways will take too much time and interfere with deadlines

- Myths to justify current conditions are easily available...
  - ...The person lacks awareness so it doesn't really hurt
  - ...The person is at fault for whatever has happened; it is either an inevitable consequence of his or her impairments or a result of willful non-compliance
  - ...No better ways exist
  - ...Better ways are unaffordable and expecting them is an unreasonably greedy claim on public resources

Appreciation of the strong pull back toward unconscious incompetence partly explains the Project's practice of offering repeated consultations to some of the Counties willing to make a matching investment of effort to learn new ways.

The vicious circle of accumulating cost is one pattern of unnecessary costs. The Project Learning Group identified a second pattern, more typical of the history of a number of people with challenging behavior or intractable psychiatric disability. Most people move from time to time, and some people spend occasional periods in psychiatric facilities, but this pattern looks and feels like falling down stairs. Moves are involuntary and, apart from psychiatric hospitalizations, likely to be terminated by the facility giving up on the person and excluding him or her. Each "placement" is likely to be more restrictive than the last, because, after several failures, responsible county staff may look for a place that offer a regimen that will effectively contain the person, and because with each bounce the person's reputation for difficulty increases, and because the accumulating costs to the person may make him or her increasingly challenging to support. Costs born in the person's body accumulate: long term effects of increasing doses of multiple drugs prescribed for behavior control are common; so are conditions such as un-



diagnosed dental problems, undiagnosed depression, undiagnosed seizure disorders, malnourishment and a variety of other medical conditions missed because they are assumed to be “normal” given the person’s impairments or because they are so infrequent that only some one who specializes in complex situations is likely to notice them; so is psychological trauma, which may grow into an unrecognized Post-Traumatic Stress Disorder. Costs to the system and the person accumulate when money and staff time are wasted on perfunctory functional analysis and undisciplined data analysis that leads to long term imposition of ineffective and often coercive “behavior plans”. Failure to establish and support relationships that build a sense of security and trust can result in high-cost low-benefit staffing patterns, where the system may pay for one or sometimes even more staff people whose assignment amounts to no more than guarding and restraining the person or engaging the person in the most rudimentary of routines. As the person’s reputation for difficulty grows, the cost of the next “placement” can grow proportionately.

Like the vicious circle, the pattern of bouncing from program to program can continue until the person dies or becomes exhausted. To interrupt it requires a compassionate and knowledgeable effort to understand the person’s current situation in light of their history. To be effective, this effort must see a person-in-relationship, even though (or especially because) many of the person’s relationships may have been broken for a long time. It will disclose a person who has capacities and desires for a positive future and find practical ways to acknowledge and build on them. The central question in defining a new way to be with the person will be “Who cares about this person as the person he or she is and what will it take to support and build on these relationships?” The next question will be. “How can the people who care about this person assist him or her to develop their capacities in the context of community life?”

As with the first pattern, this pattern can only be interrupted when people notice and take account of what they have not previously

seen. Through training, and especially through individual consultations, the Project has assisted a number of people involved in the ICF-MR Transition Initiative to move toward greater competence.

## **The Future**

The term of the MFP Grant has expired, and with it Federal funding. The work of the ICF-MR Restructuring Initiative continues. Additional ICFs-MR are scheduled to close and to downsize. People continue to move into community settings. The revised placement review process remains an important topic for training and improving practice.

The Project's agenda for developing Counties' ability and willingness to deliver services based on the best possible understanding of the standard of least restrictive and most integrated is far from completion. Many people who have moved have services that are based on a better understanding of their possibilities and needs. And many of these services are offered by a staff who have had strong invitations to be in a committed and well informed relationship to the person or to support those who are. This work is not done.

The Project has surfaced and the Grant Coordinator has advocated for improvements in the management of the Restructuring process, including these:

- Negotiate more assertively with facilities that choose to close to allow sufficient time for good planning and service development.
- Reconsider the required process for meeting with guardians and family members as a group when a facility is closing or downsizing. Meeting guardians and family members individually would prove a more effective way to understand and address their concerns that would probably consume only a bit more time than dealing with the resistance that group meetings typically generate.

- Continue to provide rates and make other individualized expenditures sufficient to remedy the costs incurred by ineffective services.
- Continue to support county staff, Guardians Ad Litem and Judges to come to a better understanding of the meaning of the least restrictive, most integrated standard and a better practical appreciation of the developmental potential of people with significant disabilities, given appropriate support.
- Support nurses to develop their role as health care advocates. Adopt the Health Risk Screening Tool on at least a pilot basis to support health care decision making.
- Assure that the implementation of Family Care preserves and improves local ability to provide competent supports to people with substantial needs. Competent supports do not compromise the least restrictive, most integrated standard by reducing the capacity to provide individually tailored assistance.
- Continue to offer a variety of supports to county and service provider staff.

The Project adopted a very ambitious goal for itself: to facilitate the ICF-MR transition Initiative in a way that promoted the creation of individualized supports for people moving out of ICFs-MR and thereby to influence a cascading shift in local services away from services based on small groups and toward people living in their own homes and participating in a variety of socially valued community roles with competent support. Except for a few people, the Project did not meet the first condition of this goal for people moving from ICFs'-MR and there is no concrete progress toward the second condition, the transformation of local services.

There are multiple reasons for this failure:

- Twenty months is too short a time to see much progress toward major system change.
- The numbers of people who moved and the timelines imposed by ICF-MR closures added enough to the workload of already

overcommitted county staff, these requirements came to some counties in addition to the need to move people from closing or downsizing State Centers.

- Family Care –a fundamental, state-wide re-structuring of Wisconsin’s long term care system– is in the offing. The future management of county systems is uncertain and these uncertainties raise important questions about the timing of efforts to transform systems.
- Individualized supports for people with significant support needs are as new to most provider organizations as to many counties. For the most part, counties could not find individualized supports simply by soliciting a different service provider.
- The Project was the main source of demand for individualized supports. Guardians and people with disabilities themselves choose in terms of what they know, and in most counties individualized supports for people with significant disabilities are not visible.
- The Project’s understanding of the meaning of least restrictive and most integrated in terms of individual experience of personal freedom and participation in valued community roles is an unusual one. County staff and service providers are accustomed to understanding these standards as describing the match between an account of a person’s deficiencies and a type of service program. This habitual and common understanding meant that people associated with the Project needed time to communicate the differences in practice and purposes that they advocate.
- The Project’s choice of focus on people who caused county staff and service providers uncertainty made the associated training and consultations relevant and influential. But the messages most people got from the Project have concerned understanding individuals, supporting good relationships with the people who assist them, and promoting health. Project consultants believe strongly in individualized supports, but these beliefs and their

reasons for them have not been the main focus of their training and questioning the design of services has not been the primary reason for most consultations.

The Project's inability to move very far toward this goal does not diminish the commitment of the people most closely involved. They will continue to build on the many relationships formed and strengthened and the knowledge generated by the MFP Grant. The improved quality of life for the small number of people who receive newly developed individualized supports justify the very hard work of the county staff who created these situations.

*INFORMATION*

*BULLETIN #2*

ICF-MR

Restructuring Initiative

Questions Answered

1. How does the Restructuring Initiative Work?
2. What has changed?
3. Why does a community plan have to be developed?

**FOR GUARDIANS**

OF INDIVIDUALS WITH  
DEVELOPMENTAL DISABILITIES

***CURRENTLY LIVING IN***

***AN INTERMEDIATE CARE FACILITY (ICF)***

***OR NURSING HOME***

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## How does the Restructuring Initiative work?

### What has changed?

### Why is this Restructuring Initiative being done?

#### 1. What is the Restructuring Initiative?

You'll recall from Information Bulletin #1 that Wisconsin's Restructuring Initiative is an initiative of the State Department of Health and Family Services.

The Initiative affects all individuals with developmental disabilities who:

- a) Currently reside in a Wisconsin ICF, except the three State Centers for the Developmentally Disabled;
- OR
- Currently reside in a Wisconsin nursing home and are receiving active treatment;
- AND
- b) Have court-ordered protective placements.

The Initiative also affects all individuals with developmental disabilities who are applying for admission to a Wisconsin Intermediate Care Facility (ICF) or nursing home, except the three State Centers for the Developmentally Disabled.

The Initiative is intended to "restructure" the way that Wisconsin's state and county governments provide residential services to people with developmental disabilities, and to help these governments and the courts that protectively place people, to better meet their obligations under state and federal law.

**The most important thing to remember is that the Restructuring Initiative changes the way the courts conduct annual Watts reviews for people with developmental disabilities who are protectively placed.** Read on to find out more about these changes.

#### 2. When did the Restructuring Initiative start?

May 1, 2005

For people with developmental disabilities currently living in an ICF or a nursing home.

January 1, 2005

For people with developmental disabilities applying for admission to an ICF or nursing home.

#### 3. What is meant by "annual Watts reviews"?

Everyone who is protectively placed has been protectively placed by a court or court commissioner. {When we refer to a court in these Information Bulletins, this could also mean a court commissioner.} The court has the power to determine where the person will live, and to order that appropriate services be provided to the person in the place where the court determines that s/he will live. Since 1985, the court has been required to review the person's living arrangement on an annual basis and do one of two things:

- Approve the continuation of that arrangement for another year; or
- Order that a different living arrangement be provided for the person.

These reviews are often called Watts reviews because of the 1985 Wisconsin Supreme Court case that resulted in annual reviews being required by state law. The court case is *Watts v. Combined Community Services*, 122 Wis. 2d 65 (1985).

You may recall being involved in previous Watts reviews for your ward. Typically, you would be contacted by an attorney who has been appointed by the court to act as the Guardian Ad Litem for the person. This attorney is responsible for preparing a report about the person's current living arrangement. The report is then submitted to the court and the court considers the report during the annual Watts review.

If your ward previously lived at one of the State Centers for the Developmentally Disabled, you may remember a Watts review where the court approved a plan for the person to move out and live in an ICF, nursing home, or community living arrangement. It's important to remember that protective placements and annual Watts reviews continue, even if a person moves from one type of living arrangement to another.

#### **4. What is a Guardian Ad Litem and how is this person's role different from my role as legal guardian?**

State law also requires that the Guardian Ad Litem be an attorney. The Guardian Ad Litem is appointed by the court, to represent the best interests of the person who is protectively placed, and to assure that the person is living in the least restrictive and most integrated living arrangement necessary to meet his/her needs. State law requires that every protectively placed individual have a court-appointed Guardian Ad Litem [§880.331(1) Wis. Stats.]. The Guardian's Ad Litem job is to consider a person's living arrangement and talk to the person and others involved in his/her life about the living arrangement, including the legal guardian and those providing residential support to the person. The Guardian Ad Litem must also be knowledgeable about alternative living arrangements that are available and could meet the person's needs. Ultimately, the Guardian Ad Litem is required to make a recommendation to the court at each annual Watts review regarding whether the current living arrangement is the least restrictive and most integrated placement where the person's needs can be met.

An individual's legal guardian cannot also be appointed to serve as his/her Guardian Ad Litem. These two roles must be filled by different people. As legal guardian you may consider your responsibility to represent the best interests of your ward and may wonder why a Guardian Ad Litem is needed to do virtually the same thing that you are doing. Here's why:

First, the Guardian Ad Litem is legally responsible for ensuring that all of the legal requirements for protective placements, included in State statutes, are followed. To this end, Guardians Ad Litem must attend continuing education training to keep abreast of changes in the statutes.

Second, it is assumed that in determining what is in someone's best interest, the court needs input from many sources, including an objective legal opinion from a qualified attorney, who can:

- Understand the complex requirements for protective placements in State law;

- Consider the living arrangement, and compare that arrangement to the available alternatives;

- Take account of the opinions of everyone involved;

- Make a well-reasoned recommendation to the court, based on all of the information considered.

Third, in some instances the protectively placed individual, and people closely involved in his/her life, may disagree on the "best interests of the person." For example, what the protectively placed person wants may not be what is in his/her best interests. She or he may want to take more risks than someone looking objectively at the situation would consider being in his/her best interest. Or, the person may be resistant to change, even if someone looking objectively at the situation would consider the change to be in his/her best interests. Likewise, what the ICF or nursing home wants for the person may be influenced by what would most benefit the facility. And you, as the guardian, may also find it hard to be objective. You may feel a tremendous responsibility, as the guardian of another person, to protect that person. In some cases, that might mean you would understandably oppose changes that involve risk, even if someone looking objectively at the situation would consider the change to be in the best interest of the person, and the benefits would outweigh the risk.

The Guardian Ad Litem is responsible for providing an objective opinion to the court at the annual Watts reviews. The Guardian Ad Litem must consider both the current placement and the available alternatives in reaching a conclusion about whether the current placement is the least restrictive and most integrated living arrangement where the person's needs can be met. (The meaning of "least restrictive" and "most integrated" is addressed on page 7 of this Information Bulletin.)

#### **5. How will the annual Watts reviews change under the Restructuring Initiative?**

The annual Watts reviews will change in two ways:

Change ONE:

As of May 1, 2005, annual Watts reviews have involved the court taking a new look at whether an individual's current living arrangement is the **most integrated setting** where the person's needs can be met. This is a new requirement for the courts.

This means that for annual Watts reviews that occurred on or after May 1, 2005, the plan submitted by the individual's county of responsibility, which addresses how a person could live in a less restrictive setting, had to also address how the person could live in a more integrated setting.

**Wisconsin law now states that a court cannot approve the continuation of an individual's placement in an ICF or nursing home unless the court concludes that this placement is the most integrated setting where that person could live and get their needs met.**

This change in the State law means that the court must make a specific finding, after reviewing the plan submitted by the county of responsibility, that an individual's placement in an ICF or nursing home is the most integrated. If the evidence does not support this finding, the court cannot approve the continuation of the individual's placement in the ICF or nursing home.

Note: The individual's county of responsibility is the county that the State determines is responsible for paying for his/her residential services, whether that care is provided in an ICF, nursing home, or community living arrangement.

Change TWO:

As of May 1, 2005, Watts reviews involve the court taking a closer look at whether an individual's current living arrangement is the **least restrictive living arrangement** where the person's needs can be met, given the funding available. The court has always been required to consider whether a person is living in the least restrictive environment where the person's needs can be met with the funding that is available.

In order for the courts to take a closer look at an individual's current living arrangement, the Restructuring Initiative requires the court be given additional information, beyond the Guardian Ad Litem report, to help the court make a decision about whether a person is living in the least restrictive environment. This means the court must receive and consider a plan from the individual's county of responsibility, which describes how the person could live in a less restrictive living arrangement (often called a "non-institutional" or "community" setting) and have his/her needs met with the funding that is available to pay for the person's supports needs.

## **6. How does the court decide which living arrangement is the least restrictive and most integrated?**

The court considers all of the information presented to it as part of the annual Watts review. This information has always included a summary provided by the Guardian Ad Litem of the current living arrangement (the ICF or nursing home). This information will now also include a plan, submitted by the county of responsibility, which explains how the individual could live in a less restrictive and more integrated setting than the ICF or nursing home where she or he currently resides. Having all of this information allows the court to compare the available living options for the individual who is protectively placed. The Guardian Ad Litem will also consider the plan submitted by the county of responsibility in determining what placement recommendation she or he will make to the court.

The court and Guardian Ad Litem must adhere to the following definitions in determining where a person should live:

**Least Restrictive Environment** [§55.06(9)(a)] has no exact definition written into the law. Generally, the courts have drawn the definition from the Federal Rehabilitation Act of 1973 which requires providing each individual with the least restrictive treatment and conditions which will allow the maximum amount of personal and physical freedom.

**Most Integrated Setting** is defined in State law as "a setting that enables an individual to interact with persons without developmental disabilities to the fullest extent possible." [§46.279(1)(bm)] This definition in Wisconsin law was drawn from Federal regulations interpreting the Americans with Disabilities Act, passed by Congress in 1990. [28 CFR pt. 35 App. A. pp. 525-526]

To summarize, the least restrictive living arrangement is the living arrangement that provides the person with the most personal and physical freedom. Personal and physical freedom is really about how many choices a person has in his/her daily life. For example, can a person choose what time to go to bed, what to wear, what and when to eat, how to spend free time, whether to go outside or stay inside, and whether to spend his/her free time at home in the bedroom or in the living room.

The most integrated living arrangement is the living arrangement which provides the greatest opportunities for a person to

interact with people who don't have developmental disabilities. This generally means interaction with non-disabled people who are not paid providers of support or services.

**7. Why does the court have to consider least restrictive environment and most integrated setting in deciding where a person who is protectively placed will live?**

State law that governs protective placements and annual Watts reviews contains language that requires protective placements to be in the least restrictive and most integrated setting where an individual can get his/her needs met. [§55.06(9)(a)] The courts must follow this law. Ultimately, as a result of the Restructuring Initiative, the "most integrated setting" standard is the predominant standard that the court must use in rendering a decision about placement.

Federal regulations interpreting the Americans with Disabilities Act of 1990 require that "public entities," including state and county governments, administer their programs and services in the "most integrated setting" that can meet the needs of the individual with a disability. [28 CFR §35.130(d)]

**8. Why is the state Department of Health and Family Services (DHFS or The Department) doing this Restructuring Initiative? Aren't Watts reviews already working the way they are supposed to?**

As mentioned earlier, Federal laws like the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990 require that people with disabilities receive services in the least restrictive environment and most integrated setting. States and counties, such as Wisconsin and its counties, that utilize Federal money to provide services to people with disabilities must follow these laws.

Wisconsin law now requires the State and counties to ensure that protectively placed individuals with developmental disabilities are living in the least restrictive and most integrated settings where their needs can be met. DHFS recognizes that the combination of State and Federal laws creates an obligation on the part of State and county governments and that the State and counties must do more to ensure they are meeting this obligation. That is why they created this Restructuring Initiative. DHFS recognizes that, in the past, the courts have not been required to request information at Watts reviews regarding the potential for protectively placed individuals to live in less restrictive living arrangements. In addition, the Department also recognizes that prior to 2005, the most integrated setting standard was not something that the courts were required to consider. In addition, prior to May of 2005, there was never a requirement for a county of responsibility to provide the court with a specific plan addressing how a protectively placed individual could be effectively supported to live in a less restrictive and more integrated setting than the ICF or nursing home.

As a result of all of these realities, DHFS believes that the courts frequently had inadequate information about whether a placement in a less restrictive and more integrated living arrangement was possible. The Department believes this is likely to have led to some court orders to continue a placement in a more restrictive and less integrated arrangement than was truly necessary for a person. Where this occurred, the requirements of State and Federal laws were not being followed. Therefore, DHFS has introduced the Restructuring Initiative, to better ensure individuals with developmental disabilities are living in the least restrictive and most integrated living arrangement where their support needs can be met.

**9. Can the State or County force my ward to move out of the place where s/he currently lives, as a result of the Restructuring Initiative?**

No. The Restructuring Initiative does not give the State or counties any power to move people out of their current living arrangement, without a court order from the court. At the annual Watts review the court will decide each individual's case after carefully reviewing information about the person, his/her unique support needs, and proposed living arrangements. The impact of the new State law is that the court cannot approve the continuation of an individual's placement in an ICF or nursing home unless the court concludes that this placement is the most integrated setting where that person could live and get their needs met.

This change in the State law means that the court must make a specific finding, after reviewing the plan submitted by the county of responsibility, that an individual's placement in an ICF or nursing home is the most integrated. If the evidence does not support this finding, the court cannot approve the continuation of the individual's placement in the ICF or nursing home.

[The final section, omitted here, directs readers to contacts and information.]

## Learning Group Memo #1 - Developing Capacity

Some people currently placed in ICFs-MR offer Counties and service providers the opportunity to develop new capacities. Developing these capacities requires learning and change on four levels:

- Finding a way to understand the person that leads to accurate assistance which preserves the values of inclusion and choice that the system is committed to uphold.
- Implementing necessary assistance in a highly reliable way.
- Creating and sustaining individualized opportunities for the person to live, work, learn, and play in their community.
- Managing all available resources in ways that support the learning and change necessary to do the preceding three things.

Expert consultation and training contribute to the development of capacity, but they are not sufficient. Capacity grows when local leaders take responsibility for learning by engaging in new ways with people who give them good reason to question their local system's ability to offer them good support. Available information about these people's condition or their history leads decision makers to conclude that they pose an unmanageable threat to the reliability of local services. Decision makers do not see a way to sustain effective relationships with direct support and specialist personnel that will protect the person and other people from harm and offer the person opportunities for a reasonable quality of life. Three perceived scarcities influence this judgment:

- We lack the money to establish and sustain effective assistance for this person (and, perhaps, we have other priorities).
- We know what is needed, but no service provider available to us locally has or can develop the ability to sustain effective assistance for this person. (And a provider elsewhere has this ability at a cost that is less than our estimate of what it would cost to develop it locally.)
- We lack the knowledge and skill necessary to plan and implement effective assistance with this person. (And a provider elsewhere has this knowledge and skill at a cost that is less than our estimate of what it would cost to develop it locally.)

An effective strategy to develop County and provider capacities around people that are currently defined as too difficult to serve will give decision makers reason to change all three of these perceptions, so that they conclude that...

- Sufficient money is available.
- There are positive reasons to develop the ability to support people locally and that these reasons outweigh the advantages of placing people out of county or advocating that people remain in ICFs-MR.
- Local people are able and willing to learn what is necessary to plan and implement effective assistance.

Experience in Wisconsin and elsewhere clearly demonstrates the importance of this last judgment. Since the move to local services began, counties and service providers who are confident in their ability to figure out how to support a person who is difficult to serve have been able to greatly expand their capacity to cope adequately with the risks and difficulties that accompany service to people who live with profound disability, difficult and dangerous behavior, or psychiatric disabilities in addition to their developmental disabilities. Counties and providers who lack this confidence do not grow because they invest in avoiding difficult people or they adopt over-controlling and counterproductive strategies to manage the risks they assume that these people present.

This project cannot substitute for the effective use of authority within the system. State and regional managers need a variety of ways to make the case that Counties should avoid exporting people who are difficult to serve to other localities and, instead, develop individualized ways to support them in their county of origin. State and regional managers need to be helpful to Counties in identifying practical ways to deal with questions of sufficient funds. CIP staff need to strongly question and assist in the revision of individual plans that are inadequate either because they dodge local responsibility for learning to provide support or because they do not apply best practice

principles. State staff with specialist knowledge need to be available to provide effective back-up to local efforts. Given these contributions from those with line authority and specialist state roles, this project focuses on assisting willing Counties and service providers to make a fundamental shift:

From	To
"We don't know how to support this person and we are not confident that we can learn"	"We are responsible to learn how to support this person and capable of doing so."

The chances of making this shift increase when local people have access to several different kinds of learning activities.

- Finding productive ways to understand the impairments or symptoms or difficult behaviors that can reduce the motivation to develop an effective relationship – e.g. understanding the role that Post-traumatic Stress Disorder may play in people's lives.
- Developing knowledge and skills that are relevant to people's particular needs –e.g. becoming an effective communication partner.
- Practicing ways to plan with people that support...
  - good judgments about balancing necessary protections for the person or for other people with choices and opportunities that are meaningful to the person
  - collaboration among those who matter to the quality of the person's life
  - the integration of effective interventions into the pattern of everyday life
  - identification of a person's capacities and practical ways to develop them
  - problem-solving to deal with changes in circumstances
  - learning to improve the effectiveness of the assistance available to a person
- Making good use of people with specialized knowledge or authority –e.g. the contributions of mental health services or working well with the courts and the police
- Managing the details of implementing an effective system of assistance –e.g. recruiting, training and sustaining staff who will build positive relationships

Some of the knowledge that supports the shift to responsible relationships can be gained through participation in large group learning events; some learning calls for intensive, person-centered coaching and supervision; some requires the support of a community of practice (a group of people who share a strong interest and willingness to assist each other to develop their knowledge and skill).

This project is different from other necessary approaches to capacity building. As the table suggests, it aims to develop capacity by increasing willingness and ability to learn new ways to deal with people who challenge current levels of understanding and competence. Because individual circumstances and local conditions matter, some parts of the project center on particular people in particular localities. These learning activities need to be designed in collaboration with responsible county, state, and provider representatives. These local designs will be based on the way involved people answer the question, "What will it take for us to learn how to assist the people we currently do not believe we can serve?" –after they have the opportunity to consider expert descriptions of best practice.

	Maintain capacity	Develop capacity
<b>Targeted &amp; Time Limited</b>	<ul style="list-style-type: none"> <li>• <i>Training on specific conditions or procedures within current perceived competence.</i></li> <li>• <i>Adjusting to changes in waivers, procedures, etc.</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>Designing county/provider development plans</i></li> <li>• <i>Learning about new approaches to assisting people seen as too difficult to serve.</i></li> </ul>
<b>Ongoing</b>	<ul style="list-style-type: none"> <li>• <i>Required staff training</i></li> <li>• <i>Maintaining MA compliance</i></li> <li>• <i>Making &amp; revising CIP plans</i></li> </ul>	<ul style="list-style-type: none"> <li>• <i>Communities of practice around specific issues</i></li> </ul>

The learning process will unfold as County and local provider leaders pass through two decision points.

1. Orienting themselves to current best practice through team attendance at large group leadership workshops. These workshops will be conducted by nationally recognized experts who will draw on their experience to answer the question, “What do County leaders and provider leaders need to know about effective supports for people who are challenging to serve?” Teams will include county managers, provider managers, and local leaders among family members and people with disabilities.

2. Choosing to authorize a local implementation team whose task is to engage with specific people now in ICFs-MR for whom the current level of local knowledge, skill, and supports is insufficient, develop in-depth understanding of their individual needs for assistance, and design and support the implementation of the kind of housing, work, learning, and leisure opportunities that have the best chance of responding to their needs. The local implementation team is not a planning-about-people-in-general group, it is a learning-with-particular-people-by-making-changes team. In making it’s contribution, local implementation teams can draw on the expertise of CIP staff, state staff with specialist knowledge, and a variety of project resources including:

- In depth learning events that bring people from different localities together on a state wide or regional basis.
- Involvement in cross-county learning groups, study tours, etc.
- External facilitation, team-building, planning and problem solving assistance.
- Assistance in reviewing local services and system practices.
- Expert consultation from specialist state staff.
- Expert consultation from national experts.

This table suggests some of the specific learning activities that the project can arrange. The mix and timing of activities will depend on how many Counties choose to authorize implementation teams and the issues those teams identify as most important.

<b>Orientation to Developing Capacity</b>	<b>Achieving Deeper Understanding</b>	<b>Building Person-Specific Knowledge, Skills, and Effective Local Collaboration</b>	<b>Developing Organizational Capacity</b>
Overview Seminar for County and Provider Leaders: “What do we know about effective supports for people who are challenging to serve?”	Intensive Seminar on Mental Health Care for Persons with Developmental Disabilities	Person-focused consultation Collaborating effectively with mental health providers workshop	High-reliability Services Workshop and Consultation
County Learning Plan Facilitation	The Importance of belonging	Person-centered Planning practice Workshop	Good-Work with Challenging People Workshop and agency consultation
	Dealing with crisis		Stretching Supported Employment Opportunities Intensive Workshop and Consultation
	Power and Control Training		Creative Housing and Support Options Consultation
	Humanizing and Understanding Behaviors and Situations that are Hard to Understand		Leadership for Capacity Building Seminar

