

---

# **Massachusetts Long-Term Supports System Transformation**

---

## **Appendix I:**

### **Collaborative Model and Presentations**

## **Real Choice Decision-Making Model**

### ***Background***

The Real Choice (RC) Systems Change Grant is a \$1.3 million grant over 3 years funded by the Centers for Medicare and Medicaid Services (CMS) in 2001. The purpose of the Real Choice Grant is to enhance the quality and accessibility of available home and community services and supports for individuals of all ages with disabilities and long-term needs. One major component of the grant is to create mechanisms for meaningful involvement of consumers in the planning, implementation, and evaluation of the Real Choice grant and its projects. Real Choice also focuses on addressing gaps in services, specifically for historically un-served and under-served populations within the Commonwealth<sup>1</sup>.

### ***Real Choice Partners***

There are currently three groups working on the Real Choice Grant. These groups include:

***UMASS Medical School's Center for Health Policy and Research (UMMS/CHPR)*** UMMS/CHPR applied for and received the Real Choice Systems Change Grant on behalf of the Executive Office of Health and Human Services (EOHHS), Division of Medical Assistance (DMA), Massachusetts Rehabilitation Commission (MRC), and the Office of Elder Affairs (OEA). UMMS/CHPR is responsible for the overall coordination of the grant.

### ***Real Choice State Partners***

The State Partners are a team of representatives from various state agencies (Executive Office of Health and Human Services (EOHHS), Division of Medical Assistance (DMA), Massachusetts Rehabilitation Commission (MRC), Office of Elder Affairs (OEA), Department of Mental Health (DMH), Department of Public Health (DPH), and the Department of Mental Retardation (DMR)) that provide direction on the Real Choice Grant. Many of these representatives work collaboratively on other systems change projects to enhance community-based services.

### ***Consumer Planning and Implementation Group (CPIG)***

The Real Choice Planning and Implementation Group (CPIG) represents consumers across disability, age, ethnicity, geographic location, and includes community advocates and providers. The group was developed after a Real Choice Public Forum (January 2003) at which time consumers voiced their anger that consumers were not “meaningfully involved” in the Real Choice Grant. A

---

<sup>1</sup> This includes individuals who are not able to get all the services they need due to funding or service limitations, as well as individuals who are not served by any state agency due to diagnosis or level of need.

Consumer Nominating Committee was formed at the Forum, and the CPIG began meeting in February of 2003. Since the Forum, the CPIG has had two full-day retreats as well as three additional meetings within a five month span to “catch up” on the grant and provide recommendations about the Real Choice grant.

### ***Groundbreaking Meeting: June 26, 2003***

On June 26, 2003, the entire Consumer Planning and Implementation Group (CPIG) met with Real Choice State Partners for the first time to collectively and collaboratively discuss and plan for the Real Choice Grant and the potential pilot. It was at this meeting that both parties recognized that sitting at the table and working collaboratively was itself, systems change.

### ***Why is this Systems Change?***

#### ***Consumer group that cuts across disability and age.***

Consumer groups are often formed as project and population-specific advisory groups in response to multiple agencies, which more often than not results in competition among disability groups over limited resources. More recently, the consumer community leveled the playing field by assertively engaging themselves as equal partners in the Real Choice grant through the work of the CPIG. The existence of a consumer planning and implementation group with representatives across disability, age, ethnicity, and geographic location allows for meaningful involvement in systems change and provides consumer groups with an opportunity to work for the common goal of “Real Choice” in community living.

#### ***Collaborative planning, implementation, and evaluation of disability services and supports.***

Although consumers and state agency representatives have worked in the past to enhance disability policy, such efforts have been small in scale and/or have focused on single disability issues. Some efforts have also maintained separate consumer and state groups, thus supporting a “them” and “us” mentality that is counter-productive. There is a need for a more systematic approach that allows for consumer and state agency collaboration across disability, age, and programs. Providing such a mechanism for communication, collaboration, and planning will allow Massachusetts to enhance the current community service delivery system in a systematic and holistic way, which in turn will synchronize efforts and create effective and efficient practices to planning and implementing disability policy<sup>2</sup>.

---

<sup>2</sup> The Real Choice grant will build on the coordination initiated by the Individual and Family Support legislation signed into law on July 26, 2002. The purpose of the legislation is to increase consumer involvement in the planning and evaluation of supports, increase flexibility of supports

### ***Real Choice Systems Change Grant: Pilot Idea***

After meeting extensively over the past five months to meld as a group and to identify areas of need for systems change in disability policy, the CPIG identified a need to provide personal assistance supports and services to people with disabilities based on functional need, not disability or diagnosis.

The CPIG acknowledges that there are promising practices for providing such services in Massachusetts, but such practices are limited to small groups based on their agency affiliation, diagnosis, and/or type of disability. In order to truly assist people to transition from institutions or remain in the community and promote informed choices, CPIG feels that the system of personal assistance and support services must be redesigned to support the growing need for community supports to people of all ages with disabilities. The CPIG and the state partners jointly recognize that such an idea will need extensive discussion and collaboration in order to identify a feasible project that can be embraced by both consumer and state partners. The two groups agreed that the formation of a Real Choice Collaborative Team comprised of consumers and state partners would provide a good model to further develop, design, and implement the pilot project. The meeting between CPIG and the RC State Partners on June 26, 2003 was an excellent start to state and consumer collaboration. During this meeting, the two groups recognized the importance of sustaining such a mechanism for communication and collaboration.

Regardless of how the Real Choice pilot is designed, the Real Choice Collaborative Team will look to the CPIG, the State Partners, and the UMMS/CHPR project staff to provide input from the community, state, and grant coordinator's perspective to ensure a truly inclusive decision-making process that will hopefully create lasting systems change in Massachusetts.

### ***Sustainable Systems Change***

If this system is proven to be an effective mechanism for disability policy design and implementation, it is recommended that the Executive Office of Health and Human Services, the Office of Disability and Community Services, and the Office of Elder Affairs, and the Office of Health Services adopt a similar structure for meaningful consumer involvement in the planning and implementation of other disability policies and grants in Massachusetts. If found effective, adopting this structure will emphasize the Administration's commitment to cross-disability coordination and meaningful consumer involvement in the planning, implementation, and improvement of community-based services for people of all ages with disabilities and/or long term needs. To make this structure truly effective, parties involved will need to continually assess the groups' membership to ensure accurate representation of disability populations and state agencies that provide disability services and supports.

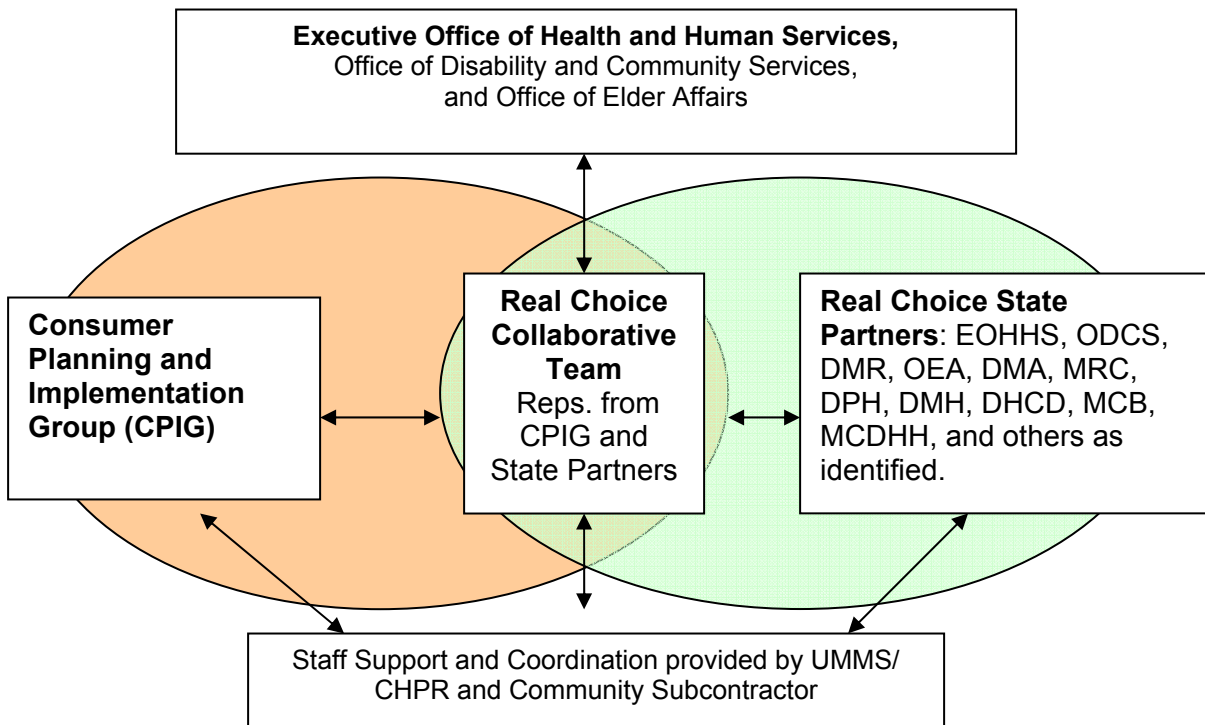
---

and services to meet unique needs, and ensure coordination among funding sources (<http://www.communitygateway.org/mfofc/legislation.htm>).

## ***Collaborative Decision-Making for Real Choice and Future Systems Change Initiatives***

### ***Real Choice Collaborative Team***

The CPIG and the RC State Partners are proposing that representatives from both groups sit as members of one decision-making group for the Real Choice Grant and its pilot project (see chart below). It is proposed that the Executive Office of Health and Human Services, including the Office of Disability and Community Services (ODCS) and the Office of Elder Affairs, recognize this as the decision-making entity for the Real Choice Grant and its pilot project, as well as support the inclusion of this model in the Independence Plus Grant.



## **Regional and National Presentations**

**O'Connor D, Barisano D, Keilson J, Sypniewski K. "Innovations in Web-based Recruitment of Direct Support Workers." 20<sup>th</sup> National HCBS Waiver Conference. Milwaukee, WI. October 27, 2003.**

**O'Connor D. "Recruiting Direct Support Workers through the Web." CMS Systems Change Conference. Baltimore, MD., March 2, 2004.**

**Barrett E, Jones K. "Massachusetts Real Choice: A Collaborative Process to Consumer Involvement." Presented at the Centers for Medicare and Medicaid Services (CMS) Systems Change Conference, March 2, 2004.**

**Barrett, E., Kamen, D., and K. Jones. Real Choice and Independence Plus Systems Change Grants. Massachusetts Rehabilitation Commission Consumer Conference. Worcester, MA. December 1, 2004.**

**Barrett. E., and K. Jones., A Breif Overview: Real Choice and Independence Plus Systems Change Grants. Connect the Dots Meeting. Boston, MA. December 20, 2004.**

**Barrett, E. Overview of the Real Choice and Independence Plus grants. National Association of Social Workers Annual Advocacy and Policy Day. February 25, 2005.**

**Wamback, K. and E. Barrett. Poster presentation: Overview of Real Choice grant, collaborative decision-making model, and pilot project. CMS Annual Systems Change Conference. February 28-March 1, 2005.**

**Cabral L. Massachusetts Mental Health System Transformation Grant: How Medicaid Can Support the Mental Health Recovery Model. New Freedom Initiatives: Building Sustainable Systems for Independence. Baltimore, MD. Feb 29-Mar 2, 2005.**

# A Brief Overview: Real Choice and Independence Plus Systems Change Grants

---

Connect the Dots Meeting  
December 20, 2004



# Real Choice Grant Partners

---

Real Choice is funded by the Centers for Medicare and Medicaid Services (CMS) and administered by UMASS Medical School, Center for Health Policy and Research (UMMS/CHPR).

## State Partners

- Executive Office of Health & Human Services
- Executive Office of Elder Affairs, including MassHealth Long-Term Care
- Department of Mental Retardation
- Massachusetts Rehabilitation Commission
- Department of Mental Health

## Community Partners

- Older people and people with disabilities
- Advocates and advocacy organizations
- Families and caregivers
- Service providers



# 2001 Real Choice Grant

---

- \$1.3 million administered by UMMS/CHPR in collaboration with state and community partners.
- Goal of the grant is to enhance the quality and accessibility of the present array of community-based long-term supports.
- Implemented a cross-disability Consumer Planning and Implementation Group.
- Implemented a Collaborative Team of consumer and state partners.
- Developing a uniform functional assessment process through an integrated workgroup of state and community partners (building off of MDS-Home Care).
- Developing and implementing a pilot project to test the use of flexible supports and individual budgets (Cash and Counseling Model).



# Real Choice Pilot Overview

---

- Based on RWJF's Cash and Counseling Demonstration and Evaluation Project (now in results phase).
- Individuals will participate in the Real Choice functional assessment process to identify their level of need.
- Individuals will receive an individual budget based on their needs.
- Individuals will design a spending plan through support from a fiscal intermediary and a community liaison.
- Budgets will be up to \$36,000 a year or less (special circumstances may be approved by the Collaborative Team).
- Services and supports will be provided in a cost-effective method that best meets the individual's needs.

# Pilot Target Population

---

- Adults diverse in disability, age, ethnicity, and level of need who are Medicaid eligible (but not eligible for the MassHealth PCA Program).
- Individuals will reside in southeastern or central Massachusetts.
- Individuals will require assistance with two or more unmet needs relating to activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs).

# Pilot Specifics

---

- Goals are to increase the quality of life and independence of participants through flexible funding.
- Systems are designed to be applicable across disability and ages.
- Pilot components:
  - ❖ uniform functional assessment process;
  - ❖ individualized budgets & spending plans;
  - ❖ fiscal intermediary support;
  - ❖ community liaison support (support in designing & monitoring spending plans);
  - ❖ representative (also known as surrogate) option; and
  - ❖ consumer-driven quality component in addition to a traditional quality system.

# Why is this Pilot Important?

---

- Only Medicaid eligible individuals who require “hands-on” assistance with 2 or more unmet ADL needs can participate in the MassHealth PCA Program.
- The current PCA Program allows consumers to hire workers, but not use funds to modify homes, purchase transportation, etc.
- Other flexible programs are available in pockets across the system, but are restricted to particular populations.
- For some individuals, funds are available, but flexible providers and workers are difficult to find.
- As more individuals live in the community, services need to be more flexible and individually-based.

# Independence Plus Grant Partners

---

Independence Plus is funded by the Centers for Medicare and Medicaid Services (CMS) and administered by UMASS Medical School, Center for Health Policy and Research (UMMS/CHPR).

## State Partners

- Executive Office of Health & Human Services
- Executive Office of Elder Affairs, including MassHealth Long-Term Care
- Department of Mental Retardation
- Massachusetts Rehabilitation Commission
- Department of Mental Health

## Community Partners

- Older people and people with disabilities
- Advocates and advocacy organizations
- Families and caregivers
- Service providers



# 2003 Independence Plus Grant

---

- \$500 thousand grant administered by UMASS Medical School Center for Health Policy and Research (UMMS/CHPR) in collaboration with state and community partners.
- Goal of the grant is to develop a Medicaid waiver that will allow individuals with disabilities to direct their own individual budget and choose the services and supports that best meet their needs in the community.



# Independence Plus: Waiver Design

---

UMMS/CHPR will work with consumer and state partners to ensure the following CMS requirements are met:

- Person-centered planning approach;
- Enhanced fiscal support system to assist consumers with the employer responsibilities and flexible budgets;
- Support brokerage and peer mentoring system to assist consumers to create spending plan;
- Participant protections to ensure safety procedures and back-up systems; and
- Quality system to ensure consumer-driven outcomes.

# Independence Plus Quality Work Group

---

- Integrated workgroup with cross-disability and cross-state agency representation.
- Will develop and refine continuous quality improvement system for Independence Plus Waiver while watching the progress of the Real Choice pilot project.
- Sample projects: Development of quality indicators, a participant survey tool/process, quality of life measurement tool, grievance procedures, appeals procedures...

# Real Choice and the Strategic Plan

<u>Strategic Plan</u>	<u>Focus</u>	<u>Relationship</u>
LTC/Community First I.1e	Flexible Self-Determination Models	The Real Choice grant is piloting flexible consumer-directed support services.
LTC/Community First I.3a	Critical Services to Maintain Independence	The Real Choice grant is providing opportunities to increase personal care and workforce options by allowing participants to decide how their budget is spent and to hire friends, neighbors, and family.
LTC/Community First I.4a	Shared Destiny with Stakeholders	A systematic process for involving consumers in grant activities was developed by Real Choice through the creation of a cross-disability Consumer Planning and Implementation Group and Collaborative Team.

# Real Choice and the Strategic Plan

<u>Strategic Plan</u>	<u>Focus</u>	<u>Relationship</u>
LTC/Streamline Access II.1a	Streamlining Intake and Assessment	The Real Choice Functional Assessment Tool was developed after reviewing assessment tools used across settings (in MA and other states). The tool has three levels: intake, assessment, and specific modules.
LTC/Community First III.2d	Workforce Development	As noted in I.3.a, the Real Choice pilot allows more flexibility pertaining to worker options, potentially increasing the worker pool.
Mental Health/ Goal One	Consumer-Centered, Recovery-Oriented Services	Real Choice is providing an opportunity for people with mental health disabilities to direct their own individual support services while having the support needed to make informed decisions.

# Independence Plus and the Strategic Plan

<u>Strategic Plan</u>	<u>Focus</u>	<u>Relationship</u>
LTC/Community First I.1e	Flexible Self-Determination Models	Independence Plus will develop the infrastructure to sustain a Cash and Counseling Model through a Medicaid waiver.
LTC/Community First I.3a	Critical Services to Maintain Independence	The waiver will allow participants to use individual budgets to purchase flexible supports and services needed to live in the community.
LTC/Community First I.4a	Shared Destiny with Stakeholders	Independence Plus work is driven by the Collaborative Team with involvement of the Consumer Planning and Implementation Group (developed through the Real Choice grant).
LTC/Community First III.2D	Workforce Development	Waiver participants will be able to choose and manage their own workers, including friends, neighbors, and family members.

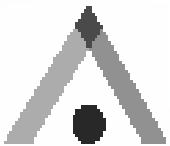
# **Massachusetts Real Choice: A Collaborative Process to Consumer Involvement**

---

**CMS Systems Change Conference  
March 2, 2004**

***Center for Health Policy & Research (chpr)***

***University of Massachusetts Medical School***



# Presentation Goals

---

- ❖ **Provide a brief overview of the Massachusetts Real Choice Grant**
- ❖ **Describe the systems created for consumer involvement in the design, planning, and implementation of Real Choice activities**
- ❖ **Provide suggestions for how to involve consumers in a collaborative process**

# Massachusetts 2001 Real Choice Grant

---

- ❖ **\$1.3 million grant administered by UMASS Medical School Center for Health Policy and Research (UMMS/CHPR) in collaboration with State and Community Partners**
- ❖ **Goal of the grant is to enhance the quality and accessibility of the present array of home and community-based long-term supports available to individuals with disabilities and long-term illnesses**

# Grant Partners

---

## State Partners

- ❖ Executive Office of Health & Human Services
- ❖ Executive Office of Elder Affairs
- ❖ Department of Mental Retardation
- ❖ Massachusetts Rehabilitation Commission
- ❖ Department of Mental Health
- ❖ Department of Public Health

## Community Partners

- ❖ Older people and people with disabilities
- ❖ Advocates and advocacy organizations
- ❖ Families and caregivers
- ❖ Service providers

# Three Phases to Our Grant

---

- ❖ **Phase One: Information gathering and relationship building**
- ❖ **Phase Two: Pilot design and implementation**
- ❖ **Phase Three: Evaluation and recommendations for long-term sustainability**

# Steps Toward Collaboration

---

January 2003

- ❖ **Community Living Forum held to seek consumer input on the Real Choice Grant**
- ❖ **Consumers and advocates voiced frustration about their lack of involvement**
- ❖ **Consumer Nominating Committee appointed**
- ❖ **The direction of the grant was changed based on community input**

# Steps Toward Collaboration

---

February 2003

- ❖ **Real Choice Consumer Planning and Implementation Group met for the first time**
- ❖ **The Group chose a name to reflect their desired level of involvement**
- ❖ **The Group identified issues important to the disability community**

# RC Consumer Planning and Implementation Group

---

- ❖ **Representation across age, disability, ethnicity, and geographic location**
- ❖ **Includes consumers, self-advocates, caregivers, and providers**
- ❖ **Time needed to build trust within the group and with Grant and State partners**
- ❖ **Met intensely over 6 months to learn about the needs of members and gain consensus on desired Real Choice pilot project**

# Steps Toward Collaboration

---

## May 2003

- ❖ **Real Choice Consumer Planning and Implementation Group hosted the second Community Living Forum to update the community on their involvement and their pilot idea**

## June/July 2003

- ❖ **Consumer and State Partners met as a full group (25 people) to develop a collaborative decision-making model**
- ❖ **Consensus was reached on the pilot idea and goal**
- ❖ **The Collaborative Team was appointed to design the pilot**

# RC Collaborative Team

---

- ❖ **5 representatives from the Real Choice Consumer Planning and Implementation Group**
- ❖ **5 representatives from the State Partners Group**
- ❖ **Decision-making entity for the Real Choice Grant**
- ❖ **Designing and implementing the Real Choice pilot**
- ❖ **Testing the effectiveness of “real” collaboration among state policy-makers and people with disabilities**

# Picture: Decision-Making Model

*Description of picture:* Two circles overlap each other. In the left circle, there is the “Real Choice Consumer Planning and Implementation Group”. In the right circle, there is the “State Partners”. Where the two circles overlap in the center, there is the “Real Choice Collaborative Team”. Above the circles, there is the “Executive Office of Health and Human Services, Office of Disability and Community Services, and Office of Elder Affairs” as the oversight agencies. Below the circles, there is “Staff Support and Coordination provided by UMASS Medical School”.

# Steps Toward Collaboration

---

## August 2003

- ❖ **First meeting of the Collaborative Team**
- ❖ **Collaborative Team committed to a consensus decision-making process**

## December/January 2004

- ❖ **Collaborative Team completed the design of the pilot methods and a Review Committee was formed to assist with the “Request for Proposals” (RFP)**
- ❖ **RFP released January 27, 2004 and proposals are due March 27, 2004**

# Real Choice Pilot

---

- ❖ **Goals are to increase the quality of life and independence of participants through cost-effective flexible funding**
- ❖ **Systems to be applicable across disability and ages**
- ❖ **Pilot components:**
  - ✓ **uniform functional assessment process**
  - ✓ **individualized budgets & spending plans**
  - ✓ **fiscal intermediary support**
  - ✓ **community liaison support**
  - ✓ **consumer-defined quality system**

# Larger Community Outreach

---

- ❖ **Public forums**
- ❖ **Articles in community newsletters**
- ❖ **Accessible website and advertising materials**
- ❖ **Presentations during advocacy and provider meetings**
- ❖ **Consumer group members educate their own disability communities**

# “ABCs of Collaboration”

---

- ❖ Found in “Stakeholder Involvement in Home and Community-Based Services”
- ❖ Written by Bergman, A., Ludlum, C., O’Connor, D., Starr, J., and Terrill, C. (March 2002)
- ❖ Provides information on how to involve stakeholders in planning, program development, and quality improvement related to home and community-based services
- ❖ Developed for the Home and Community-Based Resource Network, [www.hcbs.org](http://www.hcbs.org)

# A: Anticipate Concerns

---

- ❖ **Identify and involve stakeholders early on**
  - ✓ **Create an open process for planning in the early design stages**
  - ✓ **Seek new voices, but don't forget established advocacy leaders**
  - ✓ **Allow time for consumers to identify their goals for the project**
  
- ❖ **Be okay with not knowing everything**
  - ✓ **Be okay with others knowing this as well**
  - ✓ **Be pro-active**
  - ✓ **Be willing to learn from mistakes**
  - ✓ **Create systems to address mistakes**

# A: Anticipate Concerns

---

- ❖ **Get to know who you will be working with**
  - ✓ **Learn the history, values, and concerns for each group**
  - ✓ **Learn the history between various groups**
- ❖ **Know that advocacy groups will be in different stages of their own group development**
  - ✓ **Find ways to work with even the smallest and newest groups**
- ❖ **Show that you are serious about involvement**
  - ✓ **Allocate appropriate time and resources for meetings, accommodations, stipends, and transportation**

# B: Build Trust

---

- ❖ **Be pro-active, consistent, and transparent**
  - ✓ **Customer service is essential**
  - ✓ **Follow-up, follow-up, follow-up**
  - ✓ **Provide materials and information in a consistent manner over time**
  - ✓ **Be honest about the challenges you face**
  - ✓ **Trust the process yourself and allow time for the trust-building process**

# B: Build Trust

---

- ❖ **Allow time for a new cross-disability group to build relationships and trust within the group**
  - ✓ **This may be the first time the different groups have worked together since groups often work against each other to fight for limited funding resources**
  - ✓ **Encourage a consumer-controlled process to leadership and decision-making within the group**
  - ✓ **Allow time for group members to learn the needs and vision of other group members**

# C: Communicate Effectively

---

- ❖ **Ensure accessibility of meetings and all communication**
  - ✓ **Create easy to read charts and short summaries**
  - ✓ **Ask people what their needs are; do not assume**
  - ✓ **Create systems that people can rely on**
  - ✓ **Plan early to ensure accessibility of location and documents**
  - ✓ **Document meetings and next steps**

# C: Communicate Effectively

---

- ❖ **If there is a challenge, put it out on the table**
  - ✓ **People probably already know it exists**
  - ✓ **Identify a solution during meetings, not after meetings**
  - ✓ **Ensure all voices are heard**
  - ✓ **Push for consensus**
  - ✓ **Take time after meetings to talk with people**
  - ✓ **State agency representatives and stakeholders can forge agreement even during difficult times**

# Conclusion: Why Collaboration?

---

- ❖ **Collaboration creates a better product and buy-in**
- ❖ **Those that use the services and supports are the experts**
- ❖ **Viewing consumers as “collaborators” instead of “advisors” can begin to address a “them and us” mentality**

# Conclusion: Why Collaboration?

---

- ❖ **Getting consumers involved on all levels, from the leadership team to task-specific work groups, provides consumers with a better understanding of the planning process and will ensure the end product meets the needs of consumers**
- ❖ **Although collaboration may take more upfront time and resources, the end-result is a more efficient and cost-effective process**

# For More Information...

---

[Visit www.massrealchoices.org](http://www.massrealchoices.org)

- ❖ Meeting summaries from RC Consumer Group & Collaborative Team meetings
- ❖ Decision-making model
- ❖ Project updates
- ❖ “Request for Proposals” document

Contact information: Erin Barrett, Project Director  
508-856-8496 or [erin.barrett@umassmed.edu](mailto:erin.barrett@umassmed.edu)