



REAL CHOICE SYSTEMS CHANGE

EVALUATION REPORT

on the

THE INSTITUTE ON DISABILITY/UCED

Project Advisory Council

NH's Real Choice Systems Change Project

May 19, 2005

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In the fall of 2001, New Hampshire was awarded one of the nation's largest Real Choice System Change Grants. Part of President Bush's New Freedom Initiative, these grants were intended "to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life." The Real Choice grants were awarded to help states design and implement improved ways of providing community supports and services to children and adults who have a disability or long-term illness. New Hampshire's Department of Health and Human Services (DHHS) was awarded this Real Choice System Change Grant and contracted with the Institute on Disability at the University of New Hampshire to lead this work.

To guide the Real Choice Project the Institute on Disability brought together a broad cross-disability coalition of people with disabilities, family members, and representatives from DHHS and other organizations serving individuals who need long-term care. In addition to working with the Real Choice System Change grant, this Advisory Council also worked closely with other system change efforts in the state, including the Nursing Facility Transition Grant (NFT), Community Integrated Personal Assistance Services and Supports (CPASS), and the Medicaid Infrastructure Grant (MIG). Staff representatives from the Real Choice System Change, CPASS, NFT, and MIG initiatives are active members of the Real Choice Advisory Council.

Over the course of the four-year grant, New Hampshire's Real Choice System Change Project recorded an impressive list of accomplishments; these included:

- Creating and supporting a cross-disability Advisory Council;
- Establishing a model community project in Littleton to create an inclusive and accessible community and to improve community-based, long-term care services and supports;
- Creating the Policy Resource Center to identify and analyze barriers to consumer-directed services and to make recommendations to eliminate these barriers;
- Issuing, through the Policy Resource Center, policy briefs on topics related to long-term care and community-based supports;
- Supporting an outreach van to bring assistive technology and durable medical equipment to residents in all communities throughout the state;
- Piloting an alternative to guardianship for individuals with disabilities;
- Promoting consumer direction and choice through the mental health peer support agencies;

- Offering an educational series for legislators on long-term care issues;
- Developing a web site to share information, at www.realchoicenh.org;
- Conducting two annual conferences on best practices in community-based services in New Hampshire; and
- Developing strong cross-disability coalitions to advocate for the needs of all individuals with a need for long-term supports and services.

Evaluations of many of these initiatives already have been conducted in the course of the Real Choice Grant. The purpose of this evaluation is to assess the work of the Real Choice Advisory Council in setting direction and guiding system change efforts in New Hampshire.

Methodology

The evaluator attended four Real Choice Advisory Council meetings, including the council's meeting with the DHHS Commissioner John Stephen and the January 2005 meeting to consider the Advisory Council's future now that the Real Choice grant is drawing to an end. The evaluator also accompanied the council on the site visit and meeting with Littleton's Model Community council. The primary methodology for evaluating the Advisory council was extensive telephone interviews with Advisory Council members (only one council member was unavailable to be interviewed). A standard survey instrument was used for the interviews (the survey is included as an addendum to this evaluation). Interviews were conducted in February and March of 2005; completion of the survey typically took a half an hour, but many interviews went longer. Council members were asked about their participation on the council, the composition of the council, the ability of the council to influence system change, the success of system change initiatives, and lessons learned along the way. Finally, members were asked about the continuing role of the Advisory Council.

Advisory Council Membership

Twenty-six Advisory Council members, 17 women and nine men, were interviewed for this evaluation. As is often the case in the field of disabilities, members on the council wore more than one hat. Eleven people were staff members of either the Real Choice Project or one of New Hampshire's other system change initiatives; of this group, two people have disabilities and four have family members with disabilities. Ten individuals are employed either by DHHS, Granite State Independent Living, or other organizations supporting individuals with disabilities; half of these council members have a disability. Of the council's four community members, one has a disability and three have family members who have disabilities.

More than half those interviewed (15) considered themselves active council members, eight members described themselves as fairly active, and three reported that they were no longer active on the council. Those not active include a community member whose personal obligations limited her involvement during the past year; she now has more time and plans to continue with the council. A worker at the DHHS said while she no longer

attends council meetings, another staff person now represents her bureau on the council. Asked, if they felt their voices were heard on the council, 23 members answered yes. A recent member to the council said that he is still finding his place in the group. A council member who has a disability reported that her voice was *sometimes* heard by the group, stating, “They didn’t have my experience and therefore they would block it out. There were so many agency type people and everyone wanted to say their piece.”

Members were asked if the Advisory Council was representative of project stakeholders including elders, individuals with mental illness, and people with other disabilities. Nearly all those interviewed stated that the council needed to do a better job recruiting and supporting community members with disabilities. Council members acknowledged that individuals with physical disabilities and those who have family members with disabilities are well represented on the council, but other constituencies are missing. Eight of those interviewed wanted to see better representation from the mental health community, seven members noted the lack of elders on the council, and five people felt community members with cognitive disabilities, including traumatic brain injury, should be represented. Other recommendations included inviting a teenager with disabilities to join the council; having better geographic representation; and bringing in educators, business people, and town administrators. One council member felt the Advisory Council would be more effective if it included top decision makers, including: representatives from the Governor’s office; leadership at DHHS; and administrators from New Hampshire’s community developmental services, mental health, and aging systems.

Several individuals noted that when an agency representative leaves the council, his or her organization sends another staff member, but when a community member leaves that individual is not replaced. Members wanted to see a formal process for identifying, recruiting, and maintaining community members with disabilities. Several council members suggested working with New Hampshire’s active advocacy community – NAMI-NH, AARP-NH, Area councils on Aging, People First – to identify effective new council members.

The council member who has recently come on board stated, “As a new member I could have benefited from an orientation.” Several others interviewed also commented that an orientation process and connection with a mentor was needed to help new members feel welcome and better informed.

Members’ Expectations of the Advisory Council

Members were asked what expectations they had of the Advisory Council and whether these were met. Council members differed on what they expected coming onto the council. Some thought they primarily would hear reports from the different projects and were pleased that they have been able to take a more active role. Two council members shared the following thoughts:

“My involvement far exceeded my expectations in term of helpfulness of the individual members, the information that they made available to me, and the

support the council has provided to my project, and the weight that has been given to my input on issues outside of my project's scope.”

“I thought this would be a typical report out format with no active role for members. Early on members made it clear that they didn't have enough time in their day with that kind of format. They wanted to play a key role in defining the program.”

Ten of those interviewed expected the council would help shape the system change projects; half of this group felt that the council fell short in this area, while the other half believed that the council had a significant say in projects. All of those who participated in the work group that developed the Model Community request for proposals (RFP) and helped select Littleton for this grant were enthusiastic about their contribution.

“I think that the council as a whole is listened to. ... We do have a role in the way things work. I was part of the original team that did the RFP for the model community grant and I was thrilled to be part of that process. That doesn't happen on most Advisory Councils.”

A community member who worked actively on the Littleton project expressed regret that the council did not have a stronger voice in the other system change projects.

“We got our updates, but what we didn't do, that was really important to us in the beginning, was to be involved where there were decision making points ... where we might be able to serve in an advisory capacity. The grants did run off without us. We did stay connected to Littleton and I would like to have seen that a lot more.”

Those who were disappointed that the council did not have a greater decision-making role with the projects included four project staff members who wished that the council had provided more input on their projects. One staff member noted, “In the work on my grant, there was minimal attention given to it in meetings. There was not enough time to get it on the agenda.” Another project director said that she had hoped that, “We (Real Choice and the Medicaid Infrastructure Grant) could have dovetailed a bit more in the area of the ECI (Elderly and Chronically Ill) Medicaid Waiver.”

Two of these project directors accepted responsibility for not being more assertive in seeking the council's involvement.

“I was hoping the council was going to assist me and other staff people in how to sustain these projects after funding ended. ... I don't think we spent any time really talking about sustainability as a group. Maybe I was being unrealistic to expect that would happen. ... I take responsibility; I needed to say more and to follow up.”

“I expected advice from the council about my project. I’m hoping that the next grant that I’m working on that I will get that. I didn’t ask for advice for the first grant and I take responsibility for that.”

A member who was initially discouraged that major decisions were made without council input, has seen that change with the director on the new housing grant asking the Advisory Council to help with her project.

To ensure that projects have the benefit of the expertise and experience of the council membership, the agenda for council meetings should include time for members not only to hear from projects, but also to provide feedback, share information, and engage in problem solving. In addition, smaller work groups should be formed to provide support to these projects outside of council meetings. Most council members are more than willing to help if asked. Members who were active in work groups for the Legislative Series and the Model Community Projects were the most enthusiastic about their experience with the council.

Other expectations for the Advisory Council included the hope that the council would work closely with DHHS and state government on long-term care issues. However, DHHS Commissioner Don Shumway, an early champion of the Real Choice System Change Project, resigned shortly after Craig Benson was elected Governor. Benson appointed Nick Vailas to replace Shumway and when Vailas resigned the Governor appointed John Stephen to the post. The change in leadership at DHHS had significant impact on the Advisory Council’s role in state government; the council has not been able to establish the close working relationship with the Commissioner’s office that it had enjoyed when Shumway was heading the department.

Support for Advisory Council Members

Nearly all of those surveyed (21 of 26 respondents) reported that the project’s communication with the Advisory Council members was adequate. People appreciated getting information prior to meetings and being informed about state and national issues. Five individuals said that the amount of e-mail from the project chair was at times overwhelming. “We are all overloaded with information, sometimes it’s too much.” Another council member observed, “One thing that was confusing - I’m on Chris Collier’s (council Chair) e-mail list and I get a lot of stuff. I’m not sure if it’s Chris the advocate sharing information or is it Real Choice?”

Two council members reported that communication was not adequate. One noted:

“It could have been improved if there had been a clearer form of milestones to be reached, a checklist where we are at this point. We don’t have this and it would be good if we could have a better idea of what had been accomplished and who is responsible for the work put into it.”

When asked, ‘Were you adequately supported in your role as a council member,’ only one person felt support was inadequate and two stated they did not require any supports. A council member who wanted additional support from the council said she wished the group had given more input on the state project she heads up. All other council members felt they were given adequate support. A council member who has mobility problems commented, “They went out of their way to time it so people could get there and it (the meeting space) was accessible to me.” A community member who cares for her sister said that she felt welcome, stating: “People really appreciated us for what we did.” A council member with cognitive difficulties said she got a lot of help from Janet Williamson, a staff member with the Real Choice project. Another community member was enthusiastic about his involvement, saying that the council provided “absolutely tremendous support and it was meaningful. It was not just words, it was meaningful support.”

The Advisory Council’s Role in System Change

Those surveyed were asked what the Advisory Council’s role was in responding to changes in community-based care in New Hampshire and if the council was effective in this role. Half of those interviewed (13) believed that the Educational Series for Legislators was the most effective vehicle for addressing issues around long-term care and hoped that a forum on some aspect of long-term care could be an annual event for legislators. An advocate reported on his experiences during the legislative session, saying, “I believe that we changed a little bit how people think about community-based care. I would hear arguments that were made by Braddock and Bobby Silverstein (both presenters in the series) being used in committee hearings by legislators.” Another health care advocate observed:

“The Policy Resource Center and the legislative education piece were effective. We opened minds, opened discussion. We are in a position now where we could carry on and keep the PRC going and keep the legislative sessions going. We could be tremendously effective. We have a reputation now and that’s good.”

Council members recognized the value of having a cross-disability coalition to share information with one another and to address systemic barriers to community-based care. With one member stating:

“Communication to stakeholders within the system was key. Being able to organize a response to legislative changes and to get the word out about best practices, that statewide coordination role is a tremendous strength of the council. There are so many silos of operation that cover adults with disabilities and elders that coordination is crucial.”

Several members noted that the AARP Forum for Presidential Candidates and the Real Choice Annual Best Practices Conferences helped highlight issues around long-term care. Another council member credited the Medicaid 101 series with helping families and providers better understand changes being proposed to the state’s Medicaid program.

Seven people mentioned specific system change grants – NFT, CPASS, Mentorship, Model Community – and their impact on different aspects of community-based care.

Again, many members expressed disappointment that the Commissioner of New Hampshire’s Department of Health and Human Services did not take more advantage of the expertise and resources that the council has to offer.

“The system change piece was sidetracked with political culture. We did not get as much done as far as influencing the department heads.”

“If the environment we are in hadn’t changed, we could have done so much more. We just don’t have the support.”

“It was hard to move forward on initiatives that were not grant related. We never got to the bigger systemic issues. Being realistic, the political climate changed and we lost the support of the DHHS Commissioner and the Governor.”

A council member who had once lived at the Laconia State School had this to say: “I would like to see something different from the home care system. Move a little faster so people ain’t so confused about what they want for themselves. The council might be able to sit down and talk with them and sort it out a little more.”

New Hampshire’s System Change Initiatives

Advisory Council members were asked to reflect on the work of the Real Choice Project and other system change efforts. They were asked whom the project had helped, was the project successful, and what lessons were learned in the course of the project.

Beneficiaries of System Change Efforts

Questioned about who benefited from the Real Choice project and other system change work, more than half of those surveyed (14) cited the success of the Littleton Model Community; other initiatives mentioned included the Educational Series for Legislators (9), the Nursing Facility Transition project (7), Mentorship (4), and CPASS (4).

Those working directly with the projects were incredibly moved by the changes they witnessed in the people who participated in the programs.

“The first person to leave the nursing home and move to the community - that was extremely rewarding. All the time it took and then – wow – it was *worth* it all. Now nine people have left; that’s the most significant thing that I got out of that. People made this choice and they are very happy they are out of the nursing home. The first guy to go out got tears in his eyes when he opened up his own refrigerator. Now he can eat whenever he wants to.”

“One of the women we serve here (in Littleton) held a meeting in her house; she was head of the committee distributing accessibility funds to businesses. She was

in a place of power, which is very rare for people with disabilities. She has grown so much from this; her neighbors now know her. She still has trouble with sidewalks and snow removal and the town manager now knows her. It's been neat to see her grow as a person and this is true of others we see who have been working with this project. The whole thing of being treated like a child, you don't see that very much any more."

"Seven people are off guardianship and wouldn't have been if this (Mentorship project) wasn't there. Nine people were threatened with guardianship and avoided it. A number of people actually transitioned off mentorship and went on to a greater level of independence and I think they appreciated that."

Inspired by individual examples of what happens when people are able to have real choices in their lives, council members recognized the importance of sharing this information. Many identified the work of the legislative series and the Policy Briefs developed by the Policy Resource Center as being critical. A council member noted, "To change over time we need to continue to educate people in decision making positions in our state. In the long run that will help everyone in New Hampshire."

Was the Real Choice Project Successful?

Asked if they believed the Real Choice Project was successful, six were unsure and 20 members answered with a qualified yes. Members reported that many programs, especially the Model Community, were extremely successful; however, nearly everyone recognized that it is too early to judge whether the Real Choice Project has been successful in bringing about system change. A community member believed that the Real Choice Project could be considered successful *if* the work of the project continues beyond the grant. Another council member observed that:

"The expectations of a system change project are unreachably high at the outset. It is an incredibly slow process; in order to change systems you have to get people within the system to rebel and bite the hand that feeds them to say, 'We aren't going to do it that way any more.' It has been effective in bringing people together to hope and dream. I think we have been effective in changing the minds of individuals about personal dignity and choice. ... When you actually look at how this effort allowed people to live in their own community in a way that honors their dignity, that's happened for only a handful of folks, but it is an important step"

Asked if their input as a council member was important to the overall success of the project, 13 believed that it was. In response to this question one member laughed, saying "It damn well better have been." Six council members said they felt Real Choice would have been successful with or without them and five people didn't know if they contributed to the success or not. A number of those interviewed attributed the success of the Real Choice initiative to Project Director Sue Fox. People appreciated the extraordinary level of commitment and competence that she brought to this work and considered her leadership invaluable. One council member exclaimed, "Sue is incredible.

... If legislators needed to know something they would call Sue. If that isn't success, I don't know what is." Another council member commented:

"It goes without saying that Sue Fox is exceptional; she is a wonderful choice. She has all the practical experience at the Department and from being a provider. She's savvy and a good listener. The program wouldn't have done one half as well if she hadn't been there."

When asked what they perceived as the most significant change that has occurred as a result of the Real Choice Project, council members talked about the importance of educating legislators, the power of creating a cross-disability coalition, the ability to demonstrate that with supports people can leave nursing homes and return to their communities, and that there are less-restrictive alternatives to guardianship. The majority of council members attributed the most significant change to the Littleton Model Community project. People recognized the valuable role this project has played in changing people's attitudes.

"Some real systemic changes took place, especially in Littleton. Because of that experience, a lot of changes are taking place in the professionals who worked with the project. It's altered their perception of what is possible."

"I think the most significant change at the local level (in Littleton) is that there is a forum now of an amazing mixed group of people - professionals and citizens who are very well educated about disabilities, disabilities rights, disability law, and who can respond effectively to opportunities to make changes in the community based on a sound set of principles and philosophy about choice, dignity and universal design. The mere presence of that group, as a forum for discussion and a springboard for action, has been an incredible outcome. These are people who would not be leaders in the community without this process."

"It's (Model Community Project) brought together a lot of people who have not thought about people who are isolated and have challenges. It's opened people's minds to looking at accessibility and how to include people with disabilities. The respect piece of it has gone up - respecting the voice of people with disabilities. That has been significant, we were going in that direction already and this helped us move forward."

While most council members believed the project had made a positive difference in New Hampshire, there were others who were worried about the sustainability of the Real Choice work. One member wondered, "Did we change the system? I don't think so." A director of one of the Real Choice programs commented, "If the goal was to help these projects get up and running for two years, yes it was successful. If the goal was to do more and maintain these projects, well the jury is still out." A longtime advocate shared his concerns, stating:

“I’m fairly discouraged about what these projects accomplish long term given all the other systems issues that are going on (New Hampshire’s budget crisis, Medicaid restructuring). Three years from now will there be any artifacts left of this project? Littleton obviously will remain, I don’t know about the other projects. Hopefully the Advisory Council will continue. I was pleased at the last meeting that people saw a need to keep going. It does work and people get it; you want to keep it alive.”

Lessons Learned

Council members reported on the lessons they have learned in their work with the Real Choice Project as well as with the state’s other system change efforts.

The Littleton Model Community Project,

Again, council members most frequently cited Littleton when they were asked what lessons have been learned in their work with the council. People were excited about the opportunities that happen when a committed community works together to make its town welcoming and accessible for all its citizens. In reflecting on the Littleton experience, several people underlined the importance of not trying to make a specific model fit every community, but rather letting the community develop its own agenda and find what will work best for its town. The coordinator for the Littleton project observed that there was a “tremendous value added” in working with local leadership and bringing the issues of accessibility and access for people with disabilities to existing community projects. Another council member from Littleton who has worked with the project commented, “The fact that the grant – the money for this - went through the town and that the town manager was very involved was critical. The town manager will never forget people with disabilities now when the town is making decisions.”

As a whole, the council expressed a strong commitment to expanding the work begun in Littleton to other towns in New Hampshire and beyond.

“Their (Littleton) council has hospitals, schools, businesses, and town administrators all coming together to say ‘How do we think about the people who live in our town?’ In Littleton we helped a number of people dramatically – if it were done on a statewide basis the result would be phenomenal. We have Commissioners of roads and schools, why don’t we have a commissioner for people? This may sound farfetched, but I don’t think that is far away.”

“The work we are doing in Littleton is significant and I hope will provide a pilot that can be replicated in other places. I think we have created something that will be sustainable and will create system change for how people are supported to live in the community. ... I have come to believe that if we really want to make life better for people we need to work at the community level. We focus too much on the individual person in our system and if you are successful you make a difference for one person. If we work at the community level we can make life better for everyone.”

“The Littleton project was the biggest contributor. They are now a resource and model and mentor. We actually picked up some of the theories of that and are putting that in recommendations to the Governor. It is a community coming together and being responsible for each other – making it accessible, available, and something everyone can participate in.”

The Educational Series for Legislators

Educating policymakers was seen as a vital component in moving forward with system change. One council member stated, “We learned that legislators are open to ideas as long as you feed them (educational forums included a free lunch). They are a lot more sympathetic to what we are trying to do than I would have thought.” A member who is a former state representative talked about the work of organizing the series and stated: “The process for preparing for them and doing them made us think through the whole aspect of how you can change people’s minds and change the system.”

The council’s work in educating the legislature also included providing New Hampshire lawmakers with regular Policy Briefs from the Policy Resource Center (PRC) at Franklin Pierce Law Center. The Policy Briefs, each focusing on a specific issue, have been very favorably received. A council member who works with the PRC shared her experience following the publication of the Policy Brief on Transportation.

“I had any number of phone calls that said this is so helpful and had moved our discussions along. It helped to inform discussions and even opened up discussions. I had legislators call, people in transportation, the transportation agency all called around this issue. Anytime you open up and educate people and get rid of bias by laying the facts on the line, you have to have some success. It is always a slow process, but it has helped to have created a resource for people.”

With at least a third of the legislature turning over every two years, council members strongly recommended pursuing funds to ensure the Legislative Educational Series and Policy Briefs continue to be a resource in New Hampshire.

The Nursing Facility Transition Grant

The NFT grant demonstrated that, with support, elders with mental illness living in nursing facilities are able to return to their communities. Living in the community not only offers dramatic improvements in the quality of the individual’s life, but also saves the state substantial money. Two council members commented that an important outgrowth of the NFT grant was the development of a community wrap around approach to working with elders who need intensive supports. This model, adapted from children’s mental health services, has been an effective means for planning and monitoring supports for elders. The council member working with NFT said, “Because of this grant the wrap around momentum is still going. ... I just got a call from Portsmouth to come and help them set up a wrap around for elders.”

The Real Choice Advisory Council

For many of those interviewed, their participation on the Advisory Council taught members powerful lessons about collaboration and perseverance. Council members reported that creating a cross-disability coalition with a shared vision has resulted in a stronger voice for system change.

“At the state level the council provided the opportunity to link systems and community networks. Its ability to provide information to the legislature and the community at large is a tremendous advantage. The council, in its commitment to continuing, is acting as that springboard for action. We are a group who are already assembled and who trust each other and come from the same philosophy - that is powerful. That is the first step in system change process. We are creating a different way to organize ourselves in response to need and opportunity that is not driven by paternalism or an eligibility-based system, but is independent.”

As with most new entities, it took several meetings for the Advisory Council to figure out its role. The chairperson of the council said in retrospect it would have been helpful to begin the council with a one-day workshop that laid out the full scope of the Real Choice Project. Several council members observed that the Advisory Council began to move forward after they participated in planning sessions conducted by Patty Cotton from the Institute on Disability. People felt this work helped them focus their efforts and come together as a group. The chairperson of the council later used this same planning model with the Littleton Model Community Council to help members think about how they would work together to make a difference in their community.

When asked if they had changed as a result of their involvement with the council, 14 members answered yes. Nearly everyone, including those who said they had not changed, said that serving on the Advisory Council gave them a greater understanding of the issues associated with long-term care. A member who is also the director of a state agency was surprised by how much he benefited from his participation on the council. “It gave me a better grasp of the issues. I learned a lot in terms of the transition to community-based care and how it works. I feel better armed, which is odd since I’ve been dealing with these issues for years.” A community member found her work with the council made a difference in being able to get the services she needed. “I knew about stuff before my Medicaid case workers and I was educating them. That helped; I let them know that they can’t snowball me. I know more than they do.” A council member who works with the state observed:

“I got a better appreciation of the impact that different actions that the government takes has on people with disabilities. Something that impacted me most in dealing with the Littleton Model Community Project was hearing about all the different aspects of community life and the role that communities play in people’s lives and how different kinds of barriers get in the way of someone with disabilities being able to participate in that community life. I was struck by that on an emotional level, intellectually I knew it, but it hit home at a different level.”

The council helped many members feel that they had allies in their work. A community member who has a son with disabilities explained, “I don’t feel so alone. I don’t feel like I am the only person who feels that it isn’t right.” A council member who described herself as a loner said she learned that collaboration is powerful. Nearly everyone said they appreciated the value of working with a diverse group; the director of the Real Choice Project summed it up, saying:

“I came into this having an appreciation of inclusiveness. Working with the council I feel even more strongly about how important it is to have every voice at the table and to listen to what they have to say. This group has given me a sense of the importance of what we do and how important it is that we work together to do it. The cross-disability representation of the group is unique and really valuable.”

For a few members, joining the council had profound personal implications. The coordinator of the Littleton Model Community, a former public health worker, talked about her experience, saying, “Kathryn Wallenstein (a fellow council member) calls me a convert – I now will never escape from the field of disability. Kathryn is absolutely right, and that change had more to do with my involvement with the statewide council than my engagement with my job.” With the funds from the Real Choice Grant ending, the work begun with Littleton’s Model Community Project will continue through a Transition Grant from the New Hampshire Developmental Disabilities Council. The coordinator for the Model Community Project will head up this Transition project. Another council member, a former realtor, changed careers as a result of joining the council; through her new job working in the disability field she met the man who later became her husband.

The Future of the Advisory Council

On January 26, 2005 the Real Choice Advisory Council held a half-day planning meeting to decide on the council’s future. At this meeting people talked about the importance of having a strong cross-disability coalition to address issues that impact community-based, long-term care in New Hampshire. Members believed the Real Choice Advisory Council is in a unique position to help guide system change efforts in the state. Most of the council members have been with the project since its inception and have a shared history of effective collaboration. In addition, the council collectively possesses tremendous knowledge and expertise in the area of community-based care. All those at the planning meeting recognized the resources the council has to offer and saw the value of continuing their work beyond the grant project. Everyone in attendance made a personal commitment to continue serving on the council.

As the Real Choice Advisory Council moves forward, members saw their mission as two-fold: 1) to identify and help remove barriers that prevent people from being active participants in their communities; and 2) to educate and support communities to be inclusive and welcoming to all people. The council identified several areas where they could play a significant role. These areas included: advising newly elected Governor John Lynch; responding to GraniteCare (DHHS’s plan to reform Medicaid); educating the

legislature about long-term care issues; and working with the new Real Choice grantees and other community-based initiatives including the Under One Roof Project in Peterborough and the Transition Projects recently funded by the New Hampshire Developmental Disabilities Council.

New Hampshire has received grants for four new Real Choice Projects in the areas of housing, evidence-based mental health practices, quality assurance within the ECI Waiver, and a feasibility study around developing LIFE accounts. While each of these projects may want to establish an advisory committee focused on their specific initiative, all the grantees could benefit from joining the Real Choice Advisory Council with its statewide, cross-disability focus on promoting quality, community-based, long-term care options. Members felt that the council could be invaluable in helping those working on new projects make connections, find resources, and learn from their experiences. In return, new grantees can help the council expand its consumer membership and provide support for the council's work. Representatives from the new Real Choice grants, as well as the director of Under One Roof, attended the council's March meeting and have joined the Advisory Council.

Governor John Lynch is asking for ideas to address the state's crisis in long-term care; the Advisory Council has offered to be a resource to his administration. On behalf of the council, Real Choice Project Director Sue Fox has met with Caroline McCarley, the Governor's advisor for Health and Human Services. Ms. McCarley has agreed to attend an upcoming Real Choice planning meeting.

During the telephone interviews, which took place after the January planning meeting, council members talked about how pleased they were that the council has made a commitment to continue with the work that was started with the Real Choice grant.

“That the folks who are engaged in this are interested in continuing, that is indicative of success right there. We have had the same experience at the local level. The (Littleton Model Community) Advisory Council is committed to one another and to the group.”

“We have a history. We need to develop that reputation and have the Governor and others look to us a resource for expertise, direction, and next steps.”

In the arena of long-term care we have all the players around the table and beyond long-term care – Mentorship and the Littleton project – we would know how to address whatever issue is out there facing people with disabilities.

Sustaining the Council

The Real Choice Advisory Council offers a wealth of expertise, resources, and personal connections. The council has a historical perspective that is invaluable. Having the council disband at the end of the project would be a huge loss to New Hampshire. Resources are needed to continue with council initiatives including: the education of legislators, annual Best Practices Conferences, and the expansion of the Model

Community effort to support other New Hampshire towns in learning how to include and support *all* their members. Council members are in the process of meeting with AARP New Hampshire, the New Hampshire Charitable Fund, and the Carsey Foundation at UNH to secure resources to continue various aspects of this work.

With the Real Choice Grant extension ending in July, other support for the Advisory Council needs to be in place. Members representing four different system change projects have each agreed to host a regular council meeting, ensuring that the council will continue to meet over the next year.

Summary and Recommendations

For the past four years members of the Real Choice Advisory Council have come together to guide the work of the Real Choice System Change project and other community-based care initiatives in New Hampshire. The council played a pivotal role in the creation of the Model Community Project, the selection of Littleton for this grant, and providing ongoing support for this pilot program. Council members also planned and oversaw the Educational Series for Legislators, the annual Best Practices Conferences, and the Medicaid 101 Series that focused on proposed changes in the state's Medicaid program. With the New Hampshire chapter of the AARP, the council hosted a Presidential Candidates' Forum on Long-Term Care. While the Advisory Council had hoped to have a more influential role with the Commissioner at DHHS, this cross-disability coalition has been a valued resource for programs within the department and for other statewide organizations.

Even though the original grant that brought the Advisory Council together is ending, members of the council are committed to continuing the system change work that they have begun. Inspired by the work with the Littleton Model Community Project, the council is pursuing opportunities to help other communities to be welcoming and inclusive of all citizens. In addition, the council will continue to identify and work to remove the barriers that prevent people with disabilities and frail elders from being supported in their homes and communities.

The following recommendations are offered to the Real Choice Advisory council as it moves forward with its work.

Council Membership

The Real Choice Advisory Council has an active membership with good representation from state and private agencies providing or overseeing long-term care. The fact that many council members either have a disability or have a close family member with a disability makes this body particularly sensitive to the need for quality community-based supports and services. While council members with physical disabilities are well represented, the council could benefit from the addition of members who experience other disabilities, including mental illness, traumatic brain injury, or developmental disabilities. In addition, if the council hopes to be influential in guiding New Hampshire's long-term care policies, its membership should be expanded to include

representatives from the public and private sector who have decision making authority. Finally, as the council expands its work with communities, civic and business leaders should be invited to join the Advisory Council.

The Real Choice Advisory Council should be strengthened to include:

- Generational diversity; there should be increased representation of elders and families who have children with disabilities;
- Disability diversity including individuals with brain injury, mental health issues, developmental disabilities, and physical disabilities;
- Geographic diversity with all regions of New Hampshire represented;
- More decision makers, with representatives from the Governor's office, Community Support Network Inc., and the Department of Health and Human Services; and
- Representation from community members, including business people, town administrators, and educators.

To help in its recruitment of new community members the council should look to the state's advocacy community. NAMI - New Hampshire, Area Councils on Aging, the New Hampshire Mental Health and Aging Consumer Advisory Council, AARP New Hampshire, and People First are all in a position to recommend individuals who would be assets to the council.

Advisory Council Structure

With the council making the transition from being an advisory group overseeing a time-limited grant to being an ongoing coalition working to improve long-term care, a more formal organizational structure is needed. Council members must decide how they want to operate and how they will govern themselves. Decisions will need to be made on the responsibilities for the council's leadership, and how leadership is passed on. The council also will need to consider whether there should be criteria for membership and if there should be term limits for members. There should be an established process for replacing members who leave the council. When a member representing an agency leaves, the agency generally assigns someone else to serve on the council; however, there is no process for replacing community members who leave.

Those most enthusiastic about their experience with the Real Choice Advisory Council were members who participated in the work to develop the Model Community Project or who helped plan the legislative training or annual Best Practices Conferences. The council's capacity to be a vital, creative resource will be significantly expanded if every member believes he or she is contributing to its accomplishments. The council should establish small, focused committees to do time-limited work on specific issues or to advise discrete projects. These committees should report back to the full council.

Supporting Council Members

As a cross-disability coalition, working on a number of fronts, understanding the scope of the Real Choice Advisory Council can be a challenge for new members. Providing all

members with a standard information packet that includes historical background, a synopsis of the different system change initiatives, and a directory of council members would be helpful. An orientation process should be developed to help newcomers understand the Advisory Council's mission, its role in New Hampshire, and the responsibilities of its membership. Mentors should be assigned to new council members to ensure that they feel welcome, are able to make connections, and have someone they can turn to if they have questions or concerns.

The only significant complaint voiced during the telephone interviews was the disappointment of some members that the council did not play a more active role with some of the system change projects. The council should be a resource for all its members; it can serve as a clearinghouse for information and ideas and help to brainstorm and problem solve around issues confronting members' organizations or the community they serve. Meeting agendas should include the opportunity for members to bring their issues before the council. Having breakout groups during council meetings would help ensure that there was time for individual projects to get feedback and would encourage the participation of members who may be uncomfortable speaking in a larger group setting.

With representatives from new system change initiatives – Under One Roof, the four new Real Choice Grants, and the Developmental Disabilities Council's Transition Projects - joining the Advisory Council it is important that the council's membership understand both the scope of these new projects and how the council can support this work. The agenda for an upcoming Advisory Council meeting should be devoted to welcoming new members and exploring the ways the council can be a resource to these system change efforts.

The council should continue to provide support to its members with cognitive or physical disabilities. A mentor should be assigned to help members with cognitive or other disabilities who may need support to participate. Communication support should be available – CART captioning, for example – at meetings, trainings, and other events for those who need it. People should be able to request communication support prior to an event.

Continued Support of Model Communities

The Littleton Model Community Project has successfully demonstrated what can happen when a committed community works together to support all its members. The Real Choice Advisory Council should seek to expand the work begun in Littleton to other communities. The lessons being learned in Littleton and with the Under One Roof project can help guide other caring communities to be inclusive and supportive of all residents, including frail elders and people with disabilities. In taking on this work, the council should link with existing community efforts to help them expand their initiatives to include access for people with disabilities. For example, the Advisory Council could collaborate with the Main Street New Hampshire project to include the issue of accessibility in their work with communities around the state.

Playing an Influential Role in System Change

With its experienced leadership in community-based care, the Real Choice Advisory Council is uniquely qualified to provide valuable input on policy decisions affecting long-term care in New Hampshire. Additional efforts are needed to ensure that the council is recognized as critical player in this arena. The Advisory Council should formally offer to share its expertise and experiences with state agencies that are applying for or recently have been awarded system change grants. When possible, the council should help shape grants and provide input prior to their being submitted. In addition, the Advisory Council should dovetail with existing efforts in the state around long-term care, including Medicaid reform and changes in New Hampshire's Home and Community Based Care Waiver. The council has established effective collaborative relationships within DHHS, but further work is needed to develop a good working relationship with the Commissioner's office.

The Real Choice Advisory Council has played an active role in providing policymakers with valuable information and education on long-term care issues. The Educational Series for Legislators, Policy Briefs issued by the Policy Resource Center at Franklin Pierce Law Center, the Medicaid 101 Series, and annual Best Practice Conferences all have proven to be effective means for influencing long-term care policies in New Hampshire. Continuation of these efforts should be a priority; with grant support for these ending, council members will need to seek partners to help sustain this work. In addition to working with legislators, the council should reach out to the Lynch administration and invite a member of the Governor's staff to join the council.

Next Steps

As the Real Choice Advisory Council begins a new chapter it should engage in a strategic planning process. This process can help the council reaffirm its mission, identify goals, and create a roadmap to move forward. Developing a strategic plan also provides a team-building opportunity for old and new members, and ensures that the entire membership has a voice in setting the direction for the future.

Questions for Real Choice Advisory Council Member and Project Staff

1. Male _____ Female _____
2. What is your role with the Advisory Council? Check all that are appropriate.
Consumer ____ Professional ____ Community member ____
Staff ____ Other _____
3. Do you consider yourself an active member of the Advisory Council? If no, why not?
4. What expectations did you have of the Advisory Council? Were these met?
5. Do you feel that your voice was heard on the Advisory Council?
6. Was the Advisory Council representative of project stakeholders including: elders, individuals with mental illness, and people with disabilities? How would you recommend improving diverse representation?
7. Was the project's communication to Advisory Council members adequate? If not, how could it have been improved?
8. Were you adequately supported in your role as a Council member? If not, what could have been done to improve this?
9. What was the Advisory Council's role in responding to changes in community based care in NH? Was the council effective in this role? Why or why not?
10. Have you changed as a result of your involvement on the Advisory Council? In what ways?
11. Who did this Real Choice Project help and in what ways?
12. Do you believe that the Real Choice Project was successful? Why or why not?
13. Do you feel that your input as an Advisory Council member was important to the overall success of the project? Why or why not?
14. In the course of the Real Choice Project what lessons were learned?
15. What do you perceive as the most significant change that has occurred as a result of the Real Choice project?
16. What do you see as the continuing role of the Advisory Council?
17. Is there anything that hasn't been asked that you feel is important to know?