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Support Brokerage in the Real Choice Pilot: An Analysis of Experiences and Perceptions of Consumer-Directed Agencies' Staff

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Introduction

This paper focuses on the experiences and perceptions of community liaisons and the managers of Consumer-Directed Agencies (managers) who participated in the Massachusetts Real Choice Pilot. The experiences of the Real Choice community liaisons and managers provide insight relevant for the larger implementation of the support brokerage component for an Independence Plus option that will be available within the Massachusetts Community First waiver.

Pilot community liaisons and Consumer-Directed Agencies resemble 'support brokers' and 'support broker agencies' as defined and implemented by the Cash and Counseling Model funded by the Robert Wood Johnson Foundation and the Independence Plus Model adopted by many states through CMS waivers. This paper draws upon a total of 20 meetings (staff meetings) that Ken Schlosser, LICSW and consumer advocate, facilitated among three separate consumer-directed agencies and their respective staff members selected to provide community support for the Real Choice Pilot. Sessions included both community-directed agency community liaisons and managers, and occurred from June of 2005 to July of 2006. The subjects in sessions included consumer updates, problems in working with individual participants, procedural difficulties, involvement of family members, and coordination with traditional providers. The sessions also included discussion about the mission and efficacy of the Pilot model as they applied to participating consumers (or participants) and to community liaisons and managers.

It is important to note that this paper is drawn solely upon meetings with Real Choice staff (or managers and community liaisons), and that perceptions about Real Choice consumers are not those of the participants themselves, but rather Pilot community liaisons and managers. Along with delineating reported experiences and perceptions of Real Choice staff, this paper provides also some analysis of that material. While this analysis draws from clinical and consumer-advocate expertise related to empowerment-based work, this paper seeks to remain grounded in the data offered by Real Choice community liaisons and managers.

The 20 2-hour staff meetings consisted of 12 sessions with Elder Services of Worcester Area (ESWA, consumer-directed agency for the Worcester pilot area), 6 sessions with the Southeast Center for Independent Living (SCIL, consumer-directed agency for the Southeast Area), and 2 sessions with Options (consumer-directed agency for Southeast Area upon reassignment from SCIL to Options). At ESWA, community liaisons were drawn primarily from employees of another Worcester-based agency, Community Health Link (CHL). Both SCIL and Options recruited community liaisons primarily from within their own respective agency staff. In this paper, a separate section is devoted to the perceptions and qualities of the Real Choice staff at Options, the 3rd sub-contracting agency. This group displayed some characteristics distinct from staff members at ESWA and SCIL, which are relevant for considerations of agency readiness and receptivity

to an empowerment-based model such as Independence Plus. Because of their late entry into the Pilot, Options met with this consultant for only two sessions. Accordingly, separate from the section devoted to Options, this paper predominantly draws its reporting and analysis from meetings with Real Choice staff members at ESWA and SCIL.

An Understanding of the Pilot's Goals

a) Two project goals

The Mission of the Real Choice pilot had two interrelated goals. The first Pilot goal was to establish opportunities for consumer control, specifically in selecting and purchasing resources and in employing and managing direct workers (workers hired by consumers as homemakers, drivers, etc.) The second Pilot goal was to help consumers strengthen skills and confidence to be self-determining and autonomous.

The first goal was to be achieved structurally, by departing from a traditional human service model to reshape the role of staff to be consultants instead of directive case managers, and to redefine consumer rights and responsibilities so that consumers, rather than staff, were central to decision-making.. This goal was rooted in a framework designed for staff and participants that identified when consumers were to take the lead, the procedures they would utilize to implement their choices, and the support available from staff. Correct implementation of and adherence to the Pilot guidelines about roles, boundaries, and differentiated responsibilities were essential in targeting this first goal. If the first goal was achieved, it ensured that consumers would be in a position to make real choices on their own. While creating opportunity, the first goal did not ensure that consumers would be able to effectively take advantage of the expanded control that the Pilot offered.

Accordingly, the Pilot also recognized a second goal: to provide consumers the means and support to become empowered, gain practical knowledge, and strengthen abilities in decision-making. This second goal did not hinge on correct implementation of policies, procedures, and roles differentiation, but rather required that Real Choice staff help consumers to develop the commitment and skills that fostered self-direction. The second Pilot goal was also contingent on staff mastery of the attitudes and supportive techniques that fostered participant independence.

b) Correct implementation guided by roles, policies, and procedures

In staff sessions, community liaisons and their supervisors focused most of their attention on the structural shift required by Real Choice model. They believed that the differentiated roles and responsibilities for community liaisons and participants guided community liaisons to stay within role as consultants to a consumer-driven process and, at the same time, highlighted for Real Choice participants that they were to take the lead in selecting expenditures and managing their Real Choice funds. In staff meetings, community liaisons often focused on programmatic guidelines, particularly

when a consumer wavered from assuming a designated responsibility or argued that a community liaison should instead perform the task in question. Community liaisons were gratified that they and many participants gained over time greater familiarity with Real Choice guidelines.

c) Facilitating consumer skills in self-direction and empowerment

The Real Choice model departs from traditional paradigms in its support of significant expansion of consumer choice and autonomy. An emphasis on consumer self-direction is not prioritized in the predominant paradigm of human service delivery in which the locus of control remains firmly with provider agencies and staff. In the current provider community, agencies such as SCIL (and perhaps CHL) place relatively more emphasis than the norm on consumer involvement and input. However, an agency's interest in consumer empowerment does not necessarily bring with it a staff that has been provided a full understanding of the underpinnings of this goal or been trained in skills to foster it. In staff sessions, community liaisons and managers paid far less attention to the second goal of the Pilot strengthening consumer empowerment. When cases were reviewed, there were rarely descriptions of skills being taught that would enhance a participant's ability to make spending choices or to shop with more confidence or to effectively conduct an interview with a direct worker. Community liaisons were not able to identify and demonstrate understanding of the full range of techniques that were particularly useful in supporting consumer independence. Further, SCIL and ESWA community liaisons both conveyed a narrow understanding of how people gained greater independence. Their shared view was that cumulative experience with making Real Choices would, by itself, enable numbers of Real Choice participants to become more self-directed.

d) Qualified acceptance of the goal of consumer self-direction

Some Real Choice staff members expressed – directly or indirectly – skepticism that a number of participants could attain effective self-direction. This view was reflected in several ways. They considered these consumers as a poor 'fit' for the Pilot – too unskilled for designated Real Choice participant responsibilities. Here, staff implicitly faulted the Pilot model for unrealistic expectations about its applicability for all or most consumers. In practice, they significantly expanded community liaison control for those participants who they felt were ill-matched for the Pilot. In some cases, they regarded their interventions as departures from the model. In other instances, they believed that the model sanctioned 'flexibility' so that staff could be more directive with participants who faltered in fulfilling tasks.

An example of skepticism about consumer self-direction occurred when the author questioned whether a community liaison had lapsed by making a decision for a participant. A manager responded by noting, "They are all disabled, after all." In another expression of skepticism, a Real Choice manager noted that she was an adherent of a traditional approach which regards active case management and respectful staff direction as the appropriate response to a range of difficulties that consumers experience.

She was concerned that the Real Choice and Independence Plus models were overly optimistic about how many and to what extent consumers could achieve autonomy. In her view, this excessive optimism could lead to participants who were set up for failure, including exploitation by direct workers. This manager was clear and forthcoming about the challenge, given her past training, of working within the Real Choice model and about her rationale for skepticism about the model's applicability.

Although there was a widespread undercurrent of skepticism about the universal applicability of the Real Choice model, all community liaisons, unlike the manager cited above, asserted that the approach to consumers in Real Choice was quite consistent with the perspective and style of work that they utilized in their respective ongoing work settings (Community Health Link support workers and SCIL skills trainers.)

e) An appreciation of increased resources and supports for participants:

Community liaisons and managers believed that the Pilot enabled the vast majority of consumers to attain resources and services for unmet needs that would otherwise be inaccessible (due to limits on insurance and state departments' funding). In contrast, staff believed that Real Choice had far more limited success in enabling consumers to develop skills in self-direction. For example, in an informal poll at an ESWA staff session, community liaisons and managers concurred that 7 out of 8 participants had secured resources/services that improved their quality of life, but that only 2 consumers had demonstrated gains in self-direction.

It is important to note that the Pilot's mission did not specify as a target goal to address gaps in funding and services available to consumers. Proponents of a Cash and Counseling approach – like Real Choice – believe that one by-product of consumer control is that it results in more effective and individualized resource/service expenditure. Nevertheless, the Real Choice mission is not fiscal efficiency, but rather expanded opportunity for consumers to control their own lives and to enhance abilities to be self-directed. Given this, in order to be consistent with Real Choice, gains in participants' resources/services could not be viewed as a success unless they have been driven by consumer decision-making.

Staff Orientation and Training

As support broker agencies became oriented to the program, they were charged with recruiting, training, and supervising community liaisons. There were situational difficulties. At SCIL, the project coordinator who was most grounded in the Pilot's policies and procedures ended her employment. At ESWA, training for community liaisons was conducted by managers who were not yet fully familiar with the Pilot.

Further, the Pilot had created a comprehensive, handbook (48pp.) of Real Choice Guidelines that was primarily focused on policies and procedures. It included some specific material directed at participants. The Pilot Director had conveyed the expectation that the two-subcontracting agencies – ESWA and

SCIL – would each simplify and reorganize this material into a curriculum to train community liaisons and into informational material for Real Choice participants. This did not occur.

Given the focus of the Guidelines on policy, procedures, and role descriptions, there were gaps in written material provided to Real Choice staff. The Guidelines did not expound upon Real Choice Pilot's philosophy of expanded consumer control. It did not identify staff skills essential to facilitate increased consumer autonomy or the types of interventions that could inadvertently undermine consumer empowerment. There was no instructional material on the process by which self-empowerment occurs or on the challenges and setbacks that one could expect Real Choice consumers to encounter.

Finally, community liaisons were expected to educate consumers in how to interview/hire/ oversee workers. However, community liaisons were not trained in this area or given accessible instructional handouts for participants on the various components of acting an employer. It was widely acknowledged by community liaisons that preparing participants in this area was insufficient.

Consumer Recruitment/Orientation Process

According to staff, due to the time pressures of start-up, the Pilot's consumer recruitment process did not achieve adequate outreach to consumer populations. Consequently, ESWA, SCIL and CHL consumers predominated in the Real Choice participant group. Nevertheless, the consumers recruited for Real Choice were diverse across a range of parameters. While several participants were encouraged by Real Choice staff to join the Pilot, it seemed apparent that selected consumers were genuinely interested in participating in Real Choice.

Consumers were oriented and trained by their respective community liaisons. Without a standard training manual or group instruction, it is likely that the extent and quality of a participants' orientation and training varied, determined by the individual skill of and time devoted by respective community liaisons. It appeared that community liaisons did put effort into explaining policies, procedures, paperwork, and differentiated responsibilities. This process was ongoing as experience with aspects of the Pilot often required reviewing or strengthening consumers' familiarity with relevant policies and procedures.

Accepting a Wide Variability in Participant Skill and Levels of Commitment.

It is likely and understandable that the compelling appeal of the Pilot for consumers was the prospect of gaining additional funds for needed services and resources. If candidates for enrollment into the Pilot were drawn by the opportunity for additional funds and resources, they may have hesitated – out of fear of disqualification – to share uncertainty about their willingness/ability to fulfill all designated participant responsibilities.

The Pilot did not set a standard around capability or motivation that a consumer had to attain to be accepted into Real Choice. This rejection of a provider-determined standardized measure of consumer competence was consistent with a program that was seeking to be consumer-directed. As such, the Pilot was accepting that consumers would initially display a broad range in levels of commitment and skill as they took up the required tasks of a participant. The broad accessibility of Real Choice to consumers was, later, questioned by some staff that came to regard a number of consumers as ill-matched to the Pilot. The concern about admissions criteria can become a focus when managers and staff are struggling to implement a challenging and innovative program model. Nevertheless, given these doubts, Real Choice staff would have benefited from a clear Pilot rationale for an admissions process that was broadly accessible to most applicants and that did not attempt to 'measure' an applicant's capability to make choices. One aspect of that rationale is that a Pilot model focused on empowerment cannot include an admission process that imposes an undue amount of staff, control, scrutiny and judgment of applicants -- a traditional dynamic which is at odds with the consumer-driven partnership between Real Choice participants and community liaisons

Assessment of Consumer Need/Spending Plans/Budgets

The assessment tool itself was a wide-ranging functional assessment to establish unmet needs. The choices of resources or services a consumer made in a spending plan had to conform to the needs identified in one's assessment. The information provided in the assessment was primarily or, at a participant's request, solely based on self-report (unless s/he had a legal guardian). This approach was supportive of the Pilot model's mission of consumer control.

Staff expressed concern with several aspects of the Real Choice planning and spending process. SCIL staff worried that there were consumers whose personality or interpersonal style had led them to understate their needs in the assessment process and, as a result, were penalized by low individual budget allotments. Community liaisons and managers were concerned when unanticipated delays in planned expenditures occurred, for example, when a participant deferred on shopping, when a consumer suffered a lengthy institutionalization, or when stores refused Real Choice payments for purchases. Staff worried that these delays could result in lost funds or termination from the Pilot.

A SCIL staff person (who has a physical disability) observed that many Real Choice consumers would initially be timid about including on spending plans items or services that are not traditionally covered by insurance or provided by human service agencies. It could be inferred from this observation that once participants gained experience with the Pilot and Real Choice staff, some would gain confidence to include expenditures that were less conventional. In one such example, a SCIL participant with an identified need for increased recreational and social activity itemized a well-researched and thrifty vacation with neighbors that was within the letter and spirit of the Pilot.

Working with Real Choice Consumers: Sustaining Hope

Literature on facilitating consumer empowerment demonstrates the importance of staff remaining hopeful about an individual's capacity to take control, of 'believing' in the consumer and in the prospect for change. Staff's ability to maintain such hope was inconsistent. Real Choice consumers who were relatively confident in their choices, able in pursuing direct workers, and adept at paperwork seemed to receive ample positive reinforcement and were genuinely admired by the staff involved. When participants suffered from unanticipated hardships during the course of the year, staff members were compassionate and aware that this temporarily affected a consumer's participation.

However, when staff became disheartened about a consumer's capabilities or commitment, it was often expressed in staff meetings as skepticism about a consumer's 'appropriateness' for the program. Staff's diminished hope also revealed itself when staff characterized a consumer's difficulties with Real Choice as determined by an attributed fixed deficit or character flaw. For example, one consumer's repeated requests for new funding or new types of expenditures was persistently perceived as a product of his tendency 'to hustle' and manipulate staff to relax procedures around spending plans. Another consumer was perceived as chronically passive, and left to her own devices, likely to underutilize opportunities afforded by Real Choice funding. Staff expressed a lack of confidence that a number of participants could effectively manage direct workers.

These expressions of pessimism took place in staff meetings. They were not directly communicated to participants. They can be characterized as a form of staff venting about frustrations and concerns. Nevertheless, the frequency of this pessimism also reflected to staff's own disempowerment, and its lack of confidence or clarity in how to facilitate a consumer's development and growth in self-direction.

Working with Real Choice Consumers: Perceiving Strengths

Real Choice asserts that consumers have capabilities for self-direction in an extremely vital arena: choices around resources and services. In many

mainstream systems of care, consumers have not been regarded as unable to exercise autonomy and control. The emphasis focuses on diagnosing consumers' deficits and attending to them. Real Choice requires that staff members move to a strengths-based approach. They must become more adept at discerning consumer capability or – since empowerment is an incremental process – spotting some part of an ineffectual behavior that is positive (“finding the nugget of gold”)

Generally, staff members appreciated the effect of disabilities on consumers and understood the hardships they faced. With this in mind, they genuinely admired participants who energetically engaged Real Choice and who were resilient in the face of setbacks. The SCIL team marveled at a participant who had suffered from depression, the breaking up of a relationship, and a heart attack, and went on to utilize Real Choice to take a computer class and skillfully employ homemakers. They admired the fortitude of a Real Choice participant who effectively mobilized her team to win release from a nursing home despite the discouragement of that facility's psychiatrist. ESWA appreciated the pluck of a participant who, after a fire destroyed his apartment, reached out not only to Real Choice, but to other agencies, as well to support him through the transition to a new residence.

At the same time, staff often overemphasized a consumer's weaknesses and missed seeing elements of relevant strength. For example, a young woman who chose few items in her first spending plan was viewed as too 'passive'. She decided to purchase a power wheelchair months after it had been encouraged for consideration by staff. Her determination to not be swayed by others could have been regarded – from a strength-based perspective – as a feisty insistence on working herself into the Pilot at her own speed.

A participant diagnosed with mental illness, who transitioned from a nursing home, was adamant about purchasing silk sheets. Focusing on weaknesses, staff regarded this request as impulsive, faulty decision-making, and a demonstration of an unappealing snobbishness. However, they did not consider that this consumer's pursuit of a longing (even if extravagant) could also be viewed as a reality-based attempt to shake off the demoralization and deprivation of confinement and the passivity of institutionalization. Participants' efforts at autonomy and self-direction can often evoke resistance, rather than understanding, if staff is trained in a deficit-focused, rather than strengths-based approach.

Working with Real Choice Consumers: Supporting Expanded Participant Choice

a) Seeking to support consumer choice

The key element of the Pilot is that it offers consumers genuine opportunities to make choices regarding resources, direct workers, and services that they believe meet real needs. Compared with the traditional

human service model in which providers and staff ultimately guide and make fundamental decisions regarding consumers, Real Choice represented a radical departure and shift in power and control.

Staff members did work earnestly to uphold the Pilot's mandate to expand and support consumer choice. In many instances, they respected the participants' lead role in making decisions and did not try to shape a consumer's choice or take on tasks for which a consumer was responsible. Generally, it did seem that consumers freely made decisions around spending plans and revisions to them – without a guiding or controlling hand from community liaisons. In consequence, consumers experienced ownership around plans. For example, some expressed impatience with delays, advocated for a better system to make shopping accessible, and felt free to reshape plans over time.

b) Working with consumers whose choices were regarded by staff as unwise

While Real Choice staff was broadly accepting of the Pilot's paradigm shift to expand opportunities for consumer choice, they faced a critical test when consumers made decisions that they considered unwise, imprudent, or self-defeating. When the decisions that participants made seemed effective or without negative consequence, staff understandably demonstrated acceptance of consumer control. However, 'bad choices,' as perceived by staff, challenged the staff's comfort and skill.

In Real Choice, consumers' right to choose needs to be supported, even when it leads to unwise or even self-defeating choices. The "right to fail" is an essential ingredient in a process of self-empowerment. If one has been disempowered and offered little control over one's life, learning to make choices is a struggle. One necessary skill is to not be immobilized by the prospect of making an unwise decision (many people feel anxious around spending choices). Another skill is having faith that one gets better over time at making choices. One needs to assume a hopeful attitude that if you make a less-than-satisfactory choice, you can use it as an opportunity for new learning (many of us learn from 'shopper's remorse').

Nevertheless, Real Choice community liaisons and managers faced a substantial challenge when participants pondered or made choices that staff considered unwise. In traditional human service settings, staff often evaluate their own effectiveness by the number of their consumers' "successes" and are trained to redirect consumers away from choices that will lead to setbacks and heightened vulnerability. In addition, human services settings have suffered significant budget cutbacks. In that environment, Real Choice staff was aware of shrinking resources to meet participants multiple needs and was understandably apprehensive about "bad choices" that did not respond effectively to meet those needs. So, letting go of staff control and protectiveness required a significant shift for community liaisons and managers.

Community liaisons were inconsistent in their acceptance of participant choices that they considered unwise. Successful attempts at honoring "the right to fail" included: 1) Supporting a consumer's wish to purchase a scooter when staff believed a powered wheel chair would suit him better; 2) Accepting a consumer's decision to purchase a costly kitchen set, even though staff felt this would limit his funds for other needs; 3) Giving space to a consumer who regularly delayed completion of Real Choice paperwork, even as it complicated access to spending; 4) Supporting a consumer's wish to get bids for an accessible shower, even when her community liaison was certain that the bidding process would clearly prove this choice beyond her means.

While it had its successes, Real Choice staff lapsed numbers of times in supporting choice and the right to fail. For example, several staff met with a Real Choice participant whom they deemed "passive" to "brainstorm" collectively for items in her spending plan. They seemed unaware that this form of staff involvement was bound to be experienced as pressure and compromised this consumer's right and ability to be self-determining. A manager and community liaisons confronted a Real Choice consumer and told him "in no uncertain terms" to stop off-schedule calls to his hired driver. While staff were understandably concerned that these calls were aggravating the worker and might lead to her departure, this top-down intervention was nevertheless disempowering and compromised the participant's trust that he controlled decisions in Real Choice.

In fact, the most staff lapses in supporting consumer choice and the "right to fail" occurred in the area of Real Choice participants and direct workers. Although a number of consumers were effective in hiring and overseeing direct workers and others were clearly making improvements in this area after initial tentativeness, staff were often anxious that consumers were making unwise decisions either in their choice of direct workers or supervision of them. These apprehensions were expressed in meetings, but were rarely expressed directly to consumers – for fear of hurting or annoying consumers or interfering with self-direction. Staff concerns included: 1) A consumer who was not hiring a needed 2nd homemaker because she believed that her primary homemaker (her sister) disapproved; 2) A consumer who had hired a worker to clean her house, but the house seemed as untidy as usual; 3) Several terminations by participants of direct workers that staff considered impulsive.

Staff members were so concerned about some participants' ability to manage and make decisions about direct workers that in several instances they unilaterally intervened and seriously compromised participants' roles as employers. For example, when a participant's direct worker called to complain angrily that pay checks had been delayed and that she might quit, a Real Choice manager told her to suspend work until the payment snag was resolved. Upon being asked about the lack of involvement of the participant, the manager asserted that quick action was needed and the participant would not comprehend the problem. A Real Choice participant was struggling to

stabilize himself in the community after a placement at a nursing home. Without his permission, his community liaison contacted his new homemaker so she would “support the goals we’re working on”. While conceived as interventions to serve the interests of the participants, these staff actions clearly were in contradiction with the goal of consumer choice and control. In these and other instances, Real Choice staff were departing from the role of consultants to participants and assuming a traditional approach in which staff direct and decide.

Working With Consumers: Impasses

In numbers of instances, a staff person and a participant reached an impasse. Sometimes, consumers delayed making calls to find candidates for direct work or put off doing paperwork. In one instance, one consumer strongly believed that the community liaison should take care of the paperwork or make calls for interviews. The staff member firmly disagreed. Another impasse occurred when a consumer had been given some guidance on how to choose and purchase a computer, but was not following through. In two instances, consumers wanted more help with shopping than community liaisons felt was appropriate.

These impasses were stressful for staff. When purchasing or hiring was delayed, they worried that consumers would lose out on funding. They were concerned that trust was eroding when consumers’ expressed frustration or anger that community liaisons were not doing enough to help or resolve a difficulty. During impasses, community liaisons often felt frustrated with the Pilot Guidelines that mandated staff help without indicating the extent and methods of appropriate assistance. In some instances, staff resorted to a formula. The phrase, “I put the responsibility back on her (the consumer)” was stated several times while describing impasses. Impasses also elicited more negative or disparaging staff characterizations of consumers: “manipulative”, “she would just as soon have us do it for her”, “he needs to be case managed – just doesn’t fit for Real Choice”. Impasses also led to inconsistencies or compromises. For example, a community liaison, who had rejected doing paperwork for a consumer later decided to do so.

In two instances, Real Choice managers decided to assign a case manager to specifically try to resolve an impasse with a participant. The rationale was that the community liaisons time/ pay was too limited to work through the difficulty. Neither participant accepted the help from the additional staff person.

Working with Consumers: Choices Disallowed

On one occasion, a consumer was told a choice of a purchase would not be approved. This was the instance already mentioned when a participant wanted to buy silk sheets. There was concern that it left her too little for other

necessary purchases. The choice was eventually disallowed, with a staff explanation that the expensive sheets were ruled out as too decorative and unrelated to her identified needs. There is a probability that occasionally a consumer in a Real Choice-type program will wish to pursue a purchase that is 'luxurious' in that it significantly diminishes a participant's remaining budget funds for other spending priorities. It will be important to carefully think through in advance and to make available the categories and rationale for disallowed purchases. If the criteria for disallowed purchases is vague, they could become a vehicle for unwanted staff constraint of consumer choice.

On another occasion, a Real Choice manager insisted that a consumer modify his choice of a dining set to a less costly alternative (which the manager had researched by contacting the store directly). The manager noted that this participant had never firmly settled on a spending plan and made multiple spending requests. She believed that her intervention beneficially set a limit on a participant who tended to push and pressure around standard spending procedures.

Working with Real Choice Consumers: New/Prior/Co-existing Relationships

Most participants had worked, prior to Real Choice, with their community liaisons as counselors (CHL) or as skills workers (SCIL). Community Health Link personnel maintained their ongoing role and added to it the role of community liaison for Real Choice. At SCIL, when personnel became community liaisons, other staff replaced them as skills workers. It is probable that this expansion or switching of roles was somewhat confusing for both consumers and staff. However, when asked, community liaisons did not believe these transitions were problematic. This is consistent with their view that the approach to participants in Real Choice was not a departure from the kinds of relationships formed in their primary positions.

With consumers with whom they had already worked prior to the Pilot, community liaisons were more confident interpreting a consumer's behavior and knowledgeable about factors that might influence their participation in Real Choice. For example, a community liaison knew of a participant's habitual gambling and of the effects on him of his wife's erratic mental health. This knowledge was used to understand some ad hoc requests from him for funding and his hesitancy in seeking a homemaker (that his partner might angrily disapprove.) In another instance, a community liaison knew from prior work how a consumer's mood and memory shifted when she was without or took herself off a medication. A prior working relationship with a Real Choice participant was not in all instances an absolute plus. A community liaison who had worked with his Real Choice consumer as a skills worker explained a key intervention: "Often D. just talks and talks and doesn't listen. You just have to tell him to cut it out and insist that he be quiet." The contradictions between this way of intervening and the goals of Real Choice were not manifest to the community liaison or his team.

Community liaisons understandably demonstrated more anxiety in their work with consumers who were new to them. A community liaison struggled to understand why a participant was regularly withdrawn for the first half of a meeting and unwilling to focus on matters concerning Real Choice. A community liaison was tentative with a participant new to her, aware that the latter could become easily annoyed.

Working with Real Choice Consumers: Techniques and Skills Utilized

Staff focused often on clarification – returning to guidelines to try to explain consumer and community liaison responsibilities. They provided empathy to support consumer's frustrations with delays in budgets being approved, monthly reports being distributed, or checks arriving to stores. Staff engaged in advocacy. For example, along with participants, they argued that the task of shopping be made more accessible to participants. They prompted consumers to regroup and return to tasks that had been left undone. They tried to be firm and observe limits when consumers were insistent that community liaisons should pick up a task that the latter felt would compromise consumer autonomy.

The Role of Manager

a) Confusion about the parameters of the role

Managers believed the orientation and materials they received did not adequately describe the breadth of the role they exercised in Real Choice. One manager noted that her expectation was that the role entailed oversight and technical assistance to community liaisons. Both ESWA and SCIL managers reported that they and their respective agencies spent far more hours on the Pilot than they had anticipated.

In practice, managers actively supervised community liaisons, taking on or sharing some of their responsibilities, had numerous direct contacts with Real Choice participants, engaged in a range of case management activities, and coordinated with the Fiscal Intermediary. They believed that the challenges of the work and the limited time/pay allotted to community liaisons required that they provide supervision and, at times, expansive support. For example, a Real Choice manager arranged with community liaisons to establish herself as arbiter of unanticipated consumer requests for spending plan changes. Both the manager and community liaisons concurred that this division of labor enabled community liaisons to avoid appearing uninformed if uncertain how a request should be resolved and allowed community liaisons to 'not be the heavy' if a decision frustrated a participant's hopes.

In contrast, the view of the Pilot Director was that the Pilot Guidelines indicated that many of these activities resulted from managers overextending themselves and assuming the responsibilities of community liaisons. She

was concerned that the expansive activity by managers could weaken the effectiveness of community liaisons.

b) Managers' contacts with participants:

Real Choice participants initiated calls directly to managers at both ESWA and SCIL to advocate or express confusion around spending issues, to complain about perceived community liaison inadequacies, and to seek reassurance and support. Many Real Choice participants in the eastern region were active members at SCIL and were familiar with the managers involved with Real Choice. One manager who had defined an active role for herself saw phone contact with consumers as an opportunity to “back up” community liaisons by reinforcing limits and clarifying misunderstandings. At SCIL, managers had direct face-to-face contact with consumers. For example, a manager went to a meeting at a Real Choice consumer's house to convince a participant that he needed to stop requesting off-schedule transport from his direct service driver. He felt his presence reinforced the message to the participant.

c) Managers and Inter-Agency Coordination

Managers spent significant time on coordination and communication with other providers involved with Real Choice participants. They advocated when a consumer was stuck in an inappropriate institution waiting for residency in the community. They coordinated with relevant agencies when a fire resulted in temporary homelessness for another consumer. They conferred with other funders/insurers when there was a lack of clarity about funding streams. These tasks reflected managers belief that community liaisons time was limited (and best devoted directly with consumers) and/or that as agency management their status (relative to the direct service workers who were community liaisons) would elicit more timely and responsive responses from other involved providers. Managers' activity in inter-agency liaison was also affected by the fact that a number of participants, prior to entry to Real Choice, were not being served by an active case manager or provider team. Managers described the challenge of explaining the mission of the Pilot to other agencies, particularly the redefined roles of staff and consumers. For example, another provider seemed puzzled when an ESWA Real Choice manager was not taking control or making decisions in ways that she would in her regular position at Elder Affairs.

d) Managing community liaisons who were family members or friends of participants

There was a significant difference between manager's relationships with community liaisons drawn from human service workers and their relationships with community liaisons who were family members or friends. With the latter, managers had far less frequent phone or direct contact. These community liaisons also did not attend Real Choice staff meetings. The more tenuous connection with community liaisons who were family members/friends may have been a failure to orient them and set clear expectations. It may also have indicated that community liaisons, who were family members/friends,

were less willing to maintain regular contact and attend staff meetings. It is clear that the inclusion of family/ members/ friends/neighbors as community liaisons represents the preference of some participants and works best for them. (For example, a SCIL participant clearly indicated that to accept funds from outsiders evoked some shame and that she could only feel comfortable with Real Choice if her community liaison was a member of her own family,) However, Real Choice and Independence Plus need to find more effective ways to integrate community liaisons who are family members or friends so that they (and the consumers they serve) do not become marginal and under-supported.

Consumers Whose Primary Disability was Mental Illness

While numbers of Real Choice consumers had mental health as a secondary disability, four participants had a primary disability of mental illness. At the point of joining the Pilot, three of the four were in nursing facilities and one was in a rest home. Two of these consumers were new or relatively new to managers and community liaisons. Both experienced difficulties: one after she was discharged, the other before her transition occurred.

The Real Choice assessment instrument did not focus on a psycho-social history and respected consumer limitations on who else could provide information. An ESWA manager believed that lack of information seriously diminished Real Choice staff's understanding of the situation and capabilities of a Real Choice consumer diagnosed with mental illness whose rest home discharge was suspended. She worried that the Pilot had set the consumer up for an acute disappointment. (At the same time, she noted that consumer control over who participates in an assessment is consistent with self-direction and occurs also with consumers in Elders' Services.) A Real Choice participant, diagnosed with mental illness, became critical of and then blocked contact with her SCIL staff, some weeks after her transition to an apartment. Staff was anxious about her safety, but had no background information to assess her cut-off or whether this had been associated with past or evolving emergencies.

Generally, both ESWA and SCIL (and Options) seemed less confident about their understanding of and work with participants diagnosed with mental illness. Perhaps the most negative and disparaging comment about a Real Choice participant was made by a staff person regarding a consumer diagnosed with mental illness: "She hates everyone!" Staff members also felt insufficiently knowledgeable about the mental health system and/or frustrated by its inaccessibility.

The Options Real Choice Staff: A Strong Beginning

The author met with Options Real Choice staff twice. The first meeting with Options occurred as they began the Pilot and as most were meeting Real

Choice consumers for the first time. Given the limited number of sessions, impressions can be only tentative. However, several characteristics emerged. First, most staff were hopeful about their work and readily characterizing participants' gains and strengths. A coordinator described conducting a meeting with a consumer who was uncertain whether to participate in the program. Up until this meeting, the participant had had her nephew as her community liaison, and he was no longer able to continue in that role. The consumer was quite hesitant to have someone outside her family (a Real Choice staff person) take on this role and held the view that if help was needed, the family should be responsible.

The Options staff person described a very skillful interaction with this consumer. She was patient, non-directive, followed the consumer's lead and helped her weigh pros and cons. In the end, the participant decided to continue Real Choice and utilize an Options Real Choice community liaison. This vignette was notable in several ways: 1) it was the most detailed description of specific work offered by a Real Choice staff. It took the risk of exposure, provided opportunity for feedback, and an opportunity to learn from its effectiveness; 2) The staff person positioned herself so that the consumer could work through and be in charge of this decision; 3) She effectively used relevant skills to support that process; 4) She respected and saw the strength of the participant's position about help preferably coming from within the family. By validating it, she enabled the consumer to consider a shift.

This work had been done by a senior person in the Options group, but it certainly indicated the presence of leader who was versed in empowerment-based concepts and skills. In discussion about their ongoing work with consumers and Personal Care Attendants, Options staff articulated a view that a consumer often initially makes an ill-considered choice of a PCP worker and/or does not oversee effectively the PCA's work. Options staff regarded this as natural consequence of a consumer's inexperience and as an opportunity for learning and enhanced effectiveness. This perspective suggested again a comfort working with choice and also an expertise in the area of consumers and direct workers.

In the two meetings that occurred, the work of Options was just beginning. It may be that some of the group's sense of hopefulness and focus on consumer strengths were related to a "honeymoon phase". Nevertheless, the skills and attitudes demonstrated also suggested that some Real Choice staff are better matched than others to the consumer empowerment model of Real Choice. As such, an orientation and training program should be flexible, modulating its breadth and length to the varying levels of readiness and competency of different Real Choice teams.

Representatives

No Real Choice participant sought out a representative to provide additional support or to take charge of a designated participant responsibility.

ESWA made contact with a Worcester-based Genesis Clubhouse, which trains consumers to provide peer support, but after expressing interest, Genesis did not follow through. There is a legitimate question whether a Real Choice participant would choose as representative a peer with whom they had no acquaintance. Real Choice consumers could have chosen family members, friends, or neighbors as representatives, but perhaps did not because they believed an unpaid position would be unappealing or unfair. (Several consumers did choose family members/friends for the paid role of either community liaison or direct worker). Once having a community liaison, consumers may have considered it intrusive or redundant to add a representative who would be involved with decision-making or tasks

RECOMMENDATIONS

While I propose a number of recommendations to improve the pilot model, I want first to note its successes. Generally, both consumers and staffs were engaged by the Real Choice (RC) pilot's mission: to enhance participants' control over decisions about resources and services and to improve consumers' quality of life through **this** self-direction. As described by staff, RC participants seemed to be motivated to develop and pursue spending plans. The model proved applicable across a diverse range of consumer capability and across disabilities. The training of managers, Community Liaison (CLs) and participants--supplemented by the 'Guidelines' in the pilot manual established general clarity about roles, and policies/procedures.

Based on staff reports, consumers pursued a diverse range of items in their spending plans. geared to meet needs and/or improve quality of life. Staff meetings indicated that participants advocated for themselves on several occasions--reaching out to people at different levels of the pilot hierarchy to argue for the appropriateness of a spending request or for more assistance in securing qualified direct workers. Staff teams became cohesive and members were mutually supportive. During the course of my involvement, consumers suffered numbers of setbacks--including a death due to terminal illness, physical illnesses, emotional difficulties, and a fire that destroyed an apartment. Even with all this--consumers and RC staff remained resilient and connected.

The following specific recommendations emerged from this analysis of the experiences and perceptions of consumer-directed agencies' staff. These will be most helpful as Massachusetts moves to implement components of the pilot project on a larger scale. The recommendations are outlined below; detailed explanations and rationales are included in the appendix.

1. Selection of support brokerage agencies and staff within those agencies should include an assessment of:

- a. Their knowledge and utilization of perspectives focused on consumer empowerment and their familiarity with practices/ techniques that foster consumer self- direction.
 - b. The breadth of their experience with inter-agency liaison and coordination with Departments/providers relevant for Independence Plus participants. (This criterion only applies to selection of agencies and managers.)
2. Independence Plus trainers (or team of trainers) should be identified to provide new Independence Plus staff extensive training on the core elements of Independence Plus. There should be a major emphasis on concepts that are critical to understanding and working within a consumer empowerment model and on the staff skills that foster consumer control and choice. There should be significantly more training time allotted than was provided in the Real Choice pilot.
3. The training team should recommend and demonstrate shifts in staff culture that are consistent with and strengthen Independence Plus.
4. The program should develop a curriculum and training manual.
5. The program should redefine the role of manager to include supervisory and case management responsibilities and non-formal contact by participants.
6. The training curriculum and materials should include a module on ways to teach and support consumers to interview, hire, and oversee direct workers.
7. The training materials should clarify whether support brokers should be allowed to have dual roles with a consumer. If so, provide guidelines addressing potential role strain and confusion.
8. The program should ensure that Independence Plus support broker/consumer contact is flexible and should structure reimbursement so that support brokers are able to provide sufficient and flexible support.
9. Support brokers should make commitments.
10. The Independence Plus Assessment Form should highlight and explore more extensively key components of the program.
11. The program should expand and strengthen consumers' orientation and training.
12. The program should develop and provide a consumer handbook that focuses on goals for Independence Plus participants, challenges that they will encounter, and the skills that can be helpful.

13. Independence Plus consumers should make commitments.
14. Program materials should provide a clear rationale and guidelines for when purchase requests will be disallowed. Insure that the decision to deny a purchase request is transparent and promptly communicated to a participant.
15. There should be an outreach effort to describe and explain Independence Plus to other agencies/funders that may be involved with potential participants.

Conclusion

Individuals have various levels of ability to self-direct their services and supports. Individuals who cannot fully and independently direct all aspects of their care may be able to direct many aspects if they are provided with education, coaching, and other individualized levels of support. For this reason, many programs that offer consumer-directed services have included a “counseling” or “community liaison” role to offer assistance to consumers in learning to navigate the complex world of service delivery.

However, just as individuals have various levels of ability for self-direction, community liaisons have various levels of ability to provide assistance to consumers. For this reason, community liaisons also need support in order to provide effective assistance to the individuals with whom they are working. Potential community liaisons may be agency employees who bring very specific knowledge about a particular range of service options but know little about the person whom they are supporting; or they may be family members or friends of the prospective consumer who bring specific knowledge about the individual and their needs but may need to learn more about how to help the individual access services and supports. In either case, they may know very much or very little about how to offer support in a way that is empowering and reinforcing to the individual with whom they are working. Because of this diversity of consumers and community liaisons in any self-directed program, it is important for programs to build in appropriate support not only for the consumers but also for their community liaisons.

Community liaisons were generally successful in providing assistance in a non-directive, consultant role. However, they were less effective in helping consumers to become more empowered. Community liaisons and program managers were also inconsistent in their capacity to remain hopeful about a consumer’s capacity for self direction, particularly when participants made choices that the liaison or manager considered unwise.

Supportive group discussions with a trained social worker, who had expertise in programs focused on empowerment, helped to strengthen the capacities of community liaisons to focus on the strengths of the individual consumer and to assist the consumer in building upon those strengths. The influence of these training/support sessions was somewhat diminished by their late start. They were introduced after staff had been recruited and oriented to the Pilot's goals and their responsibilities, and after they had met with consumers to help them to develop their first Real Choice spending plans. Nevertheless, the support and reflection that occurred in these group staff meetings made an important contribution to the success of the Real Choice Pilot Project.

Appendix 1

Discussion of Recommendations for the Independence Plus Model

September 5, 2006

INTRODUCTION: Strengths of the Real Choice Model

While I propose a number of recommendations to improve the pilot model, I want first to note its successes. Generally, both consumers and staff were engaged by the Real Choice (RC) pilot's mission: to enhance participants' control over decisions about resources and services and to improve consumers' quality of life through this self-direction. As described by staff, RC participants seemed to be motivated to develop and pursue spending plans. The model proved applicable across a diverse range of consumer capability and across disabilities. The training of managers, Community Liaison (CLs) and participants – supplemented by the 'Guidelines' in the pilot manual established general clarity about roles, and policies/procedures. Based on staff reports, consumers pursued a diverse range of items in their spending plans, geared to meet needs and/or improve quality of life. Staff meetings indicated that participants advocated for themselves on several occasions – reaching out to people at different levels of the pilot hierarchy to argue for the appropriateness of a spending request or for more assistance in securing qualified direct workers. Staff teams became cohesive and members were mutually supportive. During the course of my involvement, consumers experienced a number of setbacks – including a death due to terminal illness, physical illnesses, emotional difficulties, and a fire that destroyed an apartment. Even with all this, consumers and RC staff remained resilient and connected.

RECOMMENDATIONS

1. Selection of Support Brokerage Agencies and staff within those agencies should include an assessment of:
 - A. *Their knowledge and utilization of perspectives focused on consumer empowerment and their familiarity with practices/ techniques that foster consumer self- direction.*

Agencies and staff have significant variability in their experience with both the theory and practices of self-empowerment. Some individuals who assisted in the implementation of Real Choice were highly skeptical that self-direction was as broadly applicable as the Pilot mandated. Other individuals who worked for the pilot were more confident about the viability of consumer empowerment and displayed more comfort in supporting it. A program focused rigorously on consumer control is quite different from programs that are based on a more traditional case management model. Even agencies that report themselves as consumer-focused in approach can find the mandates of Independence Plus intensely challenging. While

staffs may have had exposure to the argument for expanded consumer control, most have not received training in a repertoire of skills that are particularly geared to support consumer autonomy.

It will be helpful for Independence Plus administrators and training teams to assess this domain when identifying potential support brokerage providers. Clear upfront communication in the Request for Proposals about the need to adhere to and apply an empowerment-based approach, with specific expectations delineated, will alert potential support brokerage candidates in the application process that the Commonwealth prioritizes agencies' effectiveness in supporting and working with consumer choice. Support brokerage readiness assessments will provide the Commonwealth with an understanding of the weaknesses and strengths that eventual participating agencies and staff will have in this critical domain. These readiness assessments will help inform and target subsequent support brokerage training for effective implementation of this model.

B. The breadth of their experience with inter-agency liaison and coordination with Departments/providers relevant for Independence Plus participants. (For Agencies/Mgrs only)

Independence Plus participants may also be receiving traditional services and/or case management coordination from existing traditional state and provider agencies. Consumers may require that support brokerage agencies coordinate with involved providers or advocate for new services from relevant agencies. This coordination and communication must be consistently grounded in fully informed consumer consent. An assessment of a potential support brokerage agency's experience and ongoing inter-department/agency relationships can identify the strengths and opportunities for such coordination, as well as identify potential gaps and weaknesses.

More traditional and long established provider agencies are often charged with extensive case management responsibilities, inclusive of cross-service coordination, while more consumer-run programs play less of a role in case management. While the ability of potential candidates for Independence Plus to communicate across funding sources and agencies is important, this criterion should not be rigidly applied, so that it disqualifies agencies, with lesser experience in this area, that have other notable strengths as candidates for support brokerage services.

2. Independence Plus Trainers (or Team of Trainers) should be identified to provide new Independence Plus staff extensive training on the core elements of Independence Plus. There should be a major emphasis on concepts that are critical to understanding and working within a consumer empowerment model and on the staff skills that foster consumer control and choice. There

should be significantly more training time allotted than was provided in the Real Choice pilot.

Emphasis on Training Focused on Consumer Empowerment

Independence Plus has two interrelated dimensions. First, the model focuses on a structural shift in how services are distributed to consumers--with a clear set of protocols and procedures that put the consumer more directly in control of planning and purchasing of services and resources. Proper implementation of this shift requires policies and procedures, adherence to defined roles, boundaries, and differentiated responsibilities between the support broker and the consumer. The second dimension of the Independence Plus model is to create a program that nurtures and sustains consumer empowerment. This emphasis requires knowledge of the rationale for consumer-driven programs and of support brokerage skills and attitudes that promote consumer autonomy.

The Real Choice pilot training and manual predominantly focused on the structural shift through detailing policies, procedures, and defined roles, which then became the primary focus of support brokers. This first dimension is necessary, but not sufficient by itself to meet the goals of the Independence Plus model. Alone, it enables a level of program consistency and structures that provide an opportunity for consumer control. It delineates how support brokers must cede traditional responsibilities to allow participants to take the lead. However, empowerment is a process and a transfer of power, knowledge, and control. Consumer motivation and activity is not generated necessarily by a simple changing of the rules. The first experiences with new forms of independence are often filled with uncertainty and a lack of trust. Real Choice support brokers' singular concentration on the procedural and role responsibilities did not prepare them for a range of issues connected to the process of empowerment, itself, including how to interpret impasses, to teach participants skills around choice-making, to engage perceived 'unwise decisions', and to examine their own interactions with consumers.

Accordingly, the Independence Plus model should include a conceptual framework for a consumer empowerment-based approach and core tenets of its implementation. The training should include the concept of "learned helplessness" and how studies indicate that apathy and passivity are not a product of too much care-taking, but rather of repeated experiences where one cannot control decisions over one's life. The training should delineate the process by which people move from disempowerment to self-direction and the internal and external obstacles that they face

Along with a general framework focused on empowerment, the training should also target the particular challenges for consumers and support brokers. It should examine the consumer's' potential struggle with autonomy over finances--to make spending choices, to shop, and to be an

employer. The training should acknowledge the range in commitment and skills that consumers bring to the Independence Plus opportunity for self-direction. It should provide guidance and practice at analyzing impasses, frustrations and concerns that support brokers and consumers may encounter as participants seek to assume responsibility. Trainers should identify ways in which support brokers can be helpful and engaged without undermining consumer self-direction. It should also assert the importance in staff meetings and supervision for support brokers to examine openly their inevitable lapses in adhering to a new and challenging model. Training should demonstrate how support brokers can provide critical feedback to one another in a substantive, but non-judgmental manner.

Skills and attitudes particularly relevant for Independence Plus can be taught and practiced--using case vignettes, role plays, etc. These include: generating and sustaining hope; seeing strengths; supporting and working with choice; validating effectively a consumer's efforts and experience; engaging in open-ended, non-judgmental conversation; conducting behavioral analysis; helping shape adaptive behavior; and teaching problem-solving skills that can help a consumer move forward.

Although the support brokers' skills are important, it is not essential that support brokers participate in all aspects of the participant's involvement in Independence Plus. In the Real Choice Pilot, a number of participants used the space afforded to them by the support broker to work through challenges and to become more adept at the model. Consumer control involves giving participants that space to learn independently and to make decisions. However, there are times in which effective skills of support brokers can be employed to catalyze or solidify significant gains in participants' independence. Support brokers must be adept at determining when utilization of their skills is appropriate. Over-involvement by staff may crowd a participant or distract from her/his own efforts, while under-involvement may deprive participants of support and education that maximizes gains in consumer independence.

Independence Plus Training Team

Given the newness of this model as well as its complexities, an Independence Plus Training Team is recommended. The Independence Plus Training Team should consist of individuals who have extensive knowledge of theories of empowerment and experience and with actual efforts to enhance consumer control and independence. They should also have a background in training individuals to work within this paradigm shift.

Independence Plus training should be provided to both management and support brokers within agencies that intend to implement this model. All initial training should occur prior to implementation. Training leaders should be independent of the agency itself and should be available to

observe and participate in meetings, problem-solve, and provide feedback. Training should be interactive, with opportunities for new support brokers to demonstrate learning and practice skills. Trainers will encourage support brokers to articulate and explore apprehension they may experience about aspects of the model. A new staff culture that supports and is consistent with the model should be advocated for and demonstrated by the training team. This shift is inclusive of establishing an environment that requires risk-taking and self-examination, much like what is required of participants.

The Independence Plus Training Team should work with new support brokerage agencies and their staff to develop effective leadership strategies, to provide necessary ongoing training, and to provide opportunities for learning through consultation. To be most effective, the Training Team should be integrated in the Independence Plus model in ways that give it the stature and authority to fulfill its role and to insure responsiveness from support brokerage agencies. The extent of the Training Team's involvement should be flexible as different agencies will vary in their understanding and experiences related to consumer empowerment, their competence in skills that foster participant control, and their abilities to self-examine and self-monitor.

Almost all agencies and their staff subscribe to notions of respecting consumers, of individualized, client-centered work, and of the need for some consumer input into and collaboration with service plans. Many agency managers and staff will accordingly believe that their past practice fully prepares them for the Independence Plus model. As the Real Choice pilot indicates, this assumption can be invalid. Without a Training Team that is well versed in consumer control and approaches to foster it, there is a strong likelihood that new support brokerage agencies will not be adequately equipped to implement and sustain the model. There is a potential for lapses in the model implementation. Accordingly, agencies who are not adequately trained and supported may experience additional frustration with the model. Without a framework to analyze setbacks, there will be a tendency to view them as manifestations of a deficit of the individual consumer and/or the model. At the same time, insufficiently trained agencies and support brokers will be less likely to consider whether impasses are a temporary lull in a consumer's growth toward self-direction or reflections of inadequate, but correctable staff support.

3. The Training Team should recommend and demonstrate shifts in staff culture that are consistent with and that strengthen Independence Plus

Respectful communication

Human service providers advocate the need for respect for consumers. However, disrespectful communication about consumers in staff meetings and discussion periodically occur. They are either not perceived as

disrespectful or are allowed to go unchallenged. Examples of disrespect toward consumers include patronizing (even if affectionate) comments or jokes about consumers, repetitively associating consumer behavior with perceived chronic pathology or character-based flaws, and describing consumers in disparaging ways with terms claiming to be clinical ('manipulative', 'splitter',) or drawn from everyday language ('lazy', 'weird') Since this disrespectful communication is episodic, and not the norm, traditional providers may rationalize it as a way that a stressed staff vents among each other – a kind of 'shop talk'. In addition, the culture of human service providers is often conflict-averse, and often, when a staff person uses disrespectful language to depict a consumer, it goes unchallenged, for fear that to do so shames the offender or indicates others are smugly sitting in judgment

Given the philosophy behind the Independence Plus model, these aspects of staff culture in traditional settings has to be challenged. 'Shop talk' runs the risk of undermining core components of a consumer-directed program. Even when perceived as a gentle joke, disrespectful communication has the effect of corroding hope in participants' ability to change. It can deflect support brokers from essential self-review of skills, assumptions or beliefs. The loose and/or stigmatizing use of terms to account for consumer behavior often problematically unifies staff around their power to define and name, a power which could diminish in a consumer-directed approach.

Accordingly, trainers must advocate for and demonstrate that Independence Plus demands a higher standard and expectation for respectful communication about consumers among staff. It should indicate that there needs to be a collective effort to uphold this standard by individual risk-taking and effective interventions to challenge disrespectful language.

In order to guide this commitment, Independence Plus would benefit from a practice standard specific to respectful communication and stigmatizing language.

More specific and expansive descriptions by support brokers of their work

There is exposure and risk involved when a staff person describes with detail her work with a consumer. Staff can be tentative about doing so. Or, if they do, staff respond by focusing on the consumer--and do not share additional information about the consumer/staff interaction. In traditional settings, this reticence may be accepted, with the hope that over the years increased confidence will lead to more expansive reporting.

Trainers should articulate that in Independence Plus there needs to be an explicit value on sharing all aspects of one's work--even where one was uncertain or inept. The program requires that all staff grapple with new ways of conceptualizing and working. Learning to narrate one's work in

detail and from a variety of dimensions is important to the collective effort to adhere effectively to the Independence Plus model.

4. The program should develop a curriculum and training manual

Rationale

A curriculum and training manual will ensure that core Independence Plus concepts and skills will be identified and that a coherent, organized range of subjects will be explored. A curriculum and manual should construct training that includes didactic instruction with ample forms of interaction and practice, including group discussions and exercises. It should also provide trainers a sequence of topics to cover and time frames for how to move through the curriculum. The curriculum should also include concepts and skills that are generally applicable to all empowerment-based approaches. It should cover material specifically targeted to the challenges of and effective ways to work in the Independence Plus model.

5. The program should redefine the role of manager to include supervisory and case Management responsibilities and non-formal contact by participants

In the Real Choice pilot, managers felt they were not prepared for or given adequate guidelines for the supervisory role that they viewed as critical to support staff and the pilot's model. In Independence Plus, this supervisory responsibility should be acknowledged and amply described. Some of the tasks involved are generic: support, validation, and help clarify concepts, provide relevant information, and skills teaching. However, managers in their supervisory capacity will have to shift significantly as they turn from a traditional program to Independence Plus. They will not be helping the staff determine whether services are adequate or need to be amplified. There will not be a focus on strategizing to overcome a consumer's resistance to a plan or shaping an intervention to redirect a consumer from an ill-conceived choice. They will need to supervise relationships in which staff is far less in control and/or knowledgeable about a consumer's direction.

Given this shift, supervisors in Independence Plus may understandably first encounter confusion as to what kind of support they are offering. For some, there may be an assumption that less support brokerage supervision is required given the expanded control that consumers are provided. This assumption is certainly not the case given the challenge that staff face in working within a new model. Supervisors can play the role of upholding the model and helping support brokers who are struggling to stay within its spirit and mandates. Instead of determining or approving specific services, the supervisor may instead work closely with the support broker to brainstorm methods to help a consumer who is struggling to take charge--to design a spending plan, to proceed with interviewing, to shop, or to manage their services and/or expenditures.

Supervisors can model the importance of evaluating whether a proposed staff intervention supports or usurps consumer autonomy.

The experience of the Pilot indicates that managers become known to RC participants. Specific formal consumer appeal processes were delineated in the Real Choice guidelines. However, as was the case in Real Choice, consumers may contact managers (and the Pilot Director) in less formal ways – to advocate for specific expenditures or flexibility in their spending plans, to complain about the absence of candidates for direct service positions, or to say they do not get enough help. The role description of manager in Independence Plus should consider the probability of these non-formal consumer contacts and provide general guidelines on how to negotiate them

6. The training curriculum and materials should include a module on ways to teach and support consumers to interview, hire, and oversee direct workers.

As described in support brokers' reports, some Real Choice participants apparently experienced challenges with interviewing, hiring, and managing workers. Although preparing consumers to meet these responsibilities was delegated to Real Choice support brokers, some had not followed through. This seemed related to an absence of training material available to RC support brokers and/or participants in the area of direct workers. The consumer's guidebook provided some information, but it was dense, poorly organized, and inaccessible without a high level of reading proficiency. In Independence Plus, support brokers need more effective materials on how to orient and support consumers who take up the varied tasks associated with being an employer. During training, a curriculum should anticipate the range of ways in which consumers may be challenged when assuming this new role. It should also describe methods that support brokers can utilize to coach and assist participants as they hire and oversee workers. Support brokers need to appreciate that initial consumer efforts may be not fully efficacious but can serve as a foundation for eventual confidence and competence. While Real Choice support brokers expressed varied concerns about participants' perceived difficulties with employer responsibilities, they rarely engaged consumers in conversation about what they were experiencing. When questioned about this approach, staff expressed apprehension about appearing judgmental. Independence Plus Support brokers should be trained in how to promote non-directive dialogue, how to validate both the efforts and problems a consumer encounters as an employer and how to encourage problem-solving techniques that help a participant move forward.

7. The training materials should clarify whether Support Brokers should be allowed to have dual roles with a consumer. If so, provide guidelines addressing potential role strain and confusion.

Within the Real Choice Pilot, there were two instances in which support brokers continued in a pre-existing service relationship with consumers, while they assumed their roles as support broker in Real Choice. There were benefits in this arrangement. With a dual role, there is an established connection between the support broker and participant. Further, the support broker, with a dual role, may have a ready awareness of how the larger social context or provider relationships may impact a participant. Further, a dual role may reflect a participant's preference.

It is important to recognize that the Independence Plus model is a departure from more traditional models. It is likely that the pre-existing working relationship that a support broker has with a consumer is based on principles and practices different from those that guide the partnership between Independence Plus participant and support broker. Independence Plus requires support brokers' willingness to undertake new learning, skills, and support methods to foster consumer control. The challenge for support brokers is accentuated if they maintain an on-going role in which they exercise traditional provider guidance, direction and decision-making. This conflict can cause confusion for both the support broker and the consumer involved.

If the Independence Plus model allows for dual roles of support brokers, the model needs to provide guidelines and direction about how to evaluate whether a support broker can effectively manage both roles, and, if so, the methods that enable support broker and consumer to negotiate role differentiation.

8. The program should ensure that Independence Plus Support Broker/Consumer contact is flexible and should structure reimbursement so that Support Brokers are able to provide sufficient and flexible support.

The needs of Independence Plus participants for support brokerage are quite varied. In the beginning phase, most consumers clearly will require significant support broker involvement. However, as the program proceeds, participant skills and level of self-direction, specific challenges, impasses, and lapses in commitment can affect the amount of time a support broker provides. The recommendation that support brokers offer consumers training in learning and applying skills can be fulfilled only if ample support broker/participant contact is established and sustained.

9. Support Brokers should make commitments

During the recruitment and orientation process, it will be helpful for agencies that are interested in becoming a support brokerage agency as well as individuals interested in becoming support brokers to be offered a list of core commitments for participation in the Independence Plus model. The commitments should emphasize the required perspective, values, and need for a transformation in perspective and approach. The commitments

can be referenced, later on, as Independence Plus agencies and support brokers encounter difficulties. Independence Plus Support Broker/Agencies Commitments may include:

- A. Support brokers/agencies need to recognize that the program is a dramatic expansion of consumer control and self-direction.
- B. Support brokers/agencies need to learn and solidify a new perspective and skill set focused on fostering participant autonomy. They may need to 'unlearn' some prevailing views, attitudes and practice techniques that are not supportive of this model.
- C. Support brokers/agencies must identify their own lapses. (For example, a staff member may be unilateral or exercise too much power, make negative assumptions about participants' capabilities, disconnect in the face of an impasse, or characterize the participant in a patronizing way.). Given that Independence Plus is a new model, it is understood that we are all fallible and, thus, vulnerable to a lapse.
- D. Support brokers/agencies must examine lapses – what caused them, how to correct them. Feedback should be direct, but non-pejorative.
- E. Support brokers/agencies agree that intervening to address lapses is not an attack on a peer, but a contribution to enhance the collective practice of the group.

10. The Independence Plus Assessment Form should highlight and explore more extensively key components of the program.

In the Real Choice pilot, a participant was interviewed with an assessment tool geared to establish a consumer's functional status as it related to activities of daily living and instrumental activities of daily living, regardless of the individual's disability or reason for assessment. In addition to assessing ADL and IADL functioning, the tool included modules that assessed various needs related to transportation, caregiver stress, recreation and community involvement, memory and cognition, and mood and emotional well-being. This assessment instrument, while comprehensive, had deficiencies that should be addressed. The instrument worked as a vehicle to establish needs, but it did not highlight and adequately explore the major dimension of Real Choice-consumer autonomy and self-direction in the area of finances. Given the centrality of choice, the Independence Plus assessment should be more expansive in exploring experiences with autonomy. Accordingly, additional questions should include whether or not consumers believe they are or have been in control of specific areas in their lives. Further, consumers can be asked to describe obstacles – external or internal – they have had to overcome to attain autonomy. The assessment module should explore whether or not consumers are interested in expanding self-direction in their life and how

strong this interest is currently. The assessment should also focus on Independence Plus-specific tasks. Consumers can be asked if in the past or present, they been confident about or encountered difficulties when making shopping decisions and to what degree they enjoy shopping as an activity. Consumers can be asked whether they have experience being an interviewer or interviewee and how they regarded that experience. (Shopping and money management were included in the Real Choice assessment. However, these activities received no more weight than numbers of other functional activities relevant to need but not necessarily to participate in the pilot.) In addition to providing more extensive information about consumers' experiences with self-direction, an improved and more focused Independence Plus assessment instrument would also highlight for participants the priorities, goals and purposes of the program.

There was an inconsistency in the Real Choice pilot assessment instrument between functional, physical and psychological disabilities. The first two assessment areas always included a question about interest or ability in self-direction. This question is not asked in regards to a range of psychological difficulties explored in the modules on Mood and Emotional Well Being or Memory and Cognition. The Independence Plus assessment should correct this imbalance and disparity.

11. The program should expand and strengthen consumers' orientation and training.

Independence Plus would benefit by providing participants with more extensive orientation and training than was offered in the Real Choice pilot. Participant training should include the rationale and exploration of the mission to expand goal consumer autonomy and self-direction, the notion of empowerment as a process and the concept of learned helplessness, and the skills relevant to making choices, dealing with paperwork, and being an employer.

Orientation should convey the expectation that a participant's skill in self-direction will improve from practice and experience, and that setbacks are often learning opportunities. Participants will benefit from the identification of challenges that they may encounter. Some of these potential challenges include:

- Coming up with ideas for a spending plan--when being in charge of choices is not familiar.
- Making final decisions about spending plans when one needs to prioritize.
- Proposing an expenditure idea even if one worries that others may consider it unnecessary or wasteful.
- Keeping faith in Independence Plus when procedural problems delay finalizing plans or making purchases.

- Keeping up with tedious paperwork requirements.
- Calling candidates for a job or doing interviews.
- Setting clear hours and expectations for a worker.
- Providing feedback to an employee if s/he not performing as expected.

Training for consumers may include teaching a set of skills that are helpful to master these anticipated challenges. The orientation and training should be interactive and participatory.

In the participant training on serving as an employer, one issue that should be explored is the difference between hiring a family member, acquaintance or friend, and hiring someone new to the individual. The particular challenges of managing someone new, of establishing control with a family member, and of setting limits with a friend should be explored.

12. The program should develop and provide a consumer handbook that focuses on goals for Independence Plus participants, challenges that they will encounter, and the skills that can be helpful.

An up to date, user-friendly and accessible handbook should be provided and utilized to orient and train consumers. It will ensure consistency and quality control to the orientation and training process. The handbook will be a useful reference and resource as participants become more familiar with Independence Plus. The handbook should also use concrete scenarios to practice skills and to illustrate program challenges.

13. Independence Plus consumers should make commitments.

As with support brokers, consumers would benefit from making explicit commitments in order to participate in the Independence Plus model. Consumer commitments are focused on ways to pursue the goal of consumer self-direction and to sustain that pursuit in the face of internal or external stressors. Examples include:

- A. Taking control, with support, of my Independence Plus responsibilities: making choices to develop a spending plan, participating in the shopping for resources, completing paperwork, and interviewing, hiring, and overseeing direct workers.
- B. Recognizing that I will become more expert and confident at self-direction over time.
- C. Recognizing that I will learn and use skills over time that improve my ability at being in charge.

- D. Accepting that there will be frustrations. I may believe that Program procedures are causing a delay. I may lose confidence in my ability to do a participant task. I will use skills and support to move forward.
- E. Using my support broker, as needed, to assist in learning new skills.
- F. Recognizing that my commitment to the Program, itself may weaken. Use my skills and supports to re-commit.
- F. Advocating for myself if I believe my support broker and/or the program need to be more effective or more faithful to Independence Plus' mission and goals.

14. Program material should provide a clear rationale and guidelines for when purchase requests will be disallowed. Ensure that the decision to deny a purchase request is transparent and promptly communicated to a participant.

Within the Real Choice pilot, the consumer guidebook identified allowable and non-allowable services. Even so, there were times in which requested purchases/services were not listed in either category and, after some staff deliberation, were refused. Independence Plus participants should be clearly informed that, although Independence Plus is a consumer-directed model, the Commonwealth has the right to refuse purchase of services and supports if it does not feel such services fall within the boundaries of the program. This right to refuse purchases should be exercised thoughtfully. Items in consumers' spending plans may be unconventional and, in some instances, viewed by others as not the most effective purchase to meet a participant's needs. Nevertheless, many of these choices should be allowable- given the mandate for consumer control and the demonstrated success of the model. A decision that a requested purchase is non-allowable should be transparent and effectively and promptly communicated to the participant involved. This responsiveness is vital to communicate respect to participants who may have their trust in Independence Plus undermined by a purchase denial.

15. There should be an outreach effort to describe and explain Independence Plus to other agencies/funders that may be involved with potential participants.

The Independence Plus model is new and, thus, unfamiliar to many traditional providers and state agencies. To insure effective implementation of this model, it is essential to conduct extensive outreach to state agencies and their case managers at the local level, as well as to traditional provider agencies to insure that they understand the philosophy, purpose, and practices of Independence Plus. This will increase the likelihood that other agencies will appreciate the primacy of self-direction in the Independence Plus model. Outreach that support brokers engage in inter-agency liaison only with consumers' informed consent, and that participants, rather than staff, are the decision-makers. At the same time, an Independence Plus outreach effort should

emphasize that the model requires and will benefit from effective inter-agency collaboration and support.

Appendix 2

An Approach to a RC Staff Training Curriculum

Concepts

- Learned helplessness
- Empowerment Disempowerment
- Core tenets of a consumer empowerment approach
- Stages of change
- Staff's role in a consumer-empowerment model,
- *Apply all of the above to Real Choice*
- Airing/exploring doubts:
 - a) Aren't we expecting too much of some consumers?
 - b) Do staff become disempowered by this approach?
 - c) Isn't 'consumer self-direction' just the politically correct fad of the day?
 - d) Isn't RC only appropriate for 'high functioning' consumers?

Skills

- Seeing the strengths
- Generating hope: cheerleading
- Working with consumer choice, including impasses/ 'unwise' choice
- Ways to validate
- Engaging in non-directive, open-ended dialog
- Problem-solving techniques
- Behavioral analysis/ reinforcement of adaptive behavior
- Basics of skills teaching

Applying RC concepts and skills: A Case Vignette

Dina¹, a RC participant has put off for 2 months to make phone calls to candidates for a homemaker position, who can also help organize her paperwork. Her CL brings it up and encourages her to move forward. Dina responds defensively that she does not have time to get to it now. The CL points out, sympathetically, that Dina is stressed by accumulating paperwork. Dina changes the topic. In staff meeting, the CL notes that the Dina tends to be

¹ The names on these case studies are fictional to protect the identities of the Real Choice Pilot participants.

passive and may try to put the phone calling onto the CL. She's worried because Dina's apartment is increasingly messy and she isn't keeping up with RC paperwork.

Referencing RC concepts and skills, how might the CL think about and respond to this consumer?

- 1) With an understanding of disempowerment, the CL can appreciate that Dina's hesitancy makes sense and should not be surprising. She has been in a system of care that has never called upon her to make significant choices and has sent a nonverbal message that she is not capable of doing so. Empowerment is a process and an exchange. You don't unleash consumer motivation and activity simply by changing the rules. The first reaction to new access for increased power/control is often filled with uncertainty, lack of trust, etc.
- 2) Generate hope. The CL can point out that Dina did well in devising a spending plan and in ordering resources. She can express confidence that eventually Dina will get to this task.
- 3) Validate. It is important to validate her delay in taking up this task. Without any agenda or pressure, ask Dina to help the CL understand how delaying makes sense now. If Dina is anxious about doing an interview, the CL can note that she may be coping with this worry by putting it aside. The CL can remind Dina that she has never hired or been an employer before; this can add to concern that she won't ask the right questions or somehow offend the candidate or that she'll make a mistake and hire someone she doesn't like.
- 4) Normalize. Many people feel anxious before they interview someone. Even more so, if it is their first time.
- 5) See strengths. In bypassing the staff's prompts and not apologizing for her delay, Dina is demonstrating some independence and an understanding that she is in charge.
- 6) Problem-solving. 'What are the pros and cons of continuing to hold off on an interview?'
- 7) Draw on learned-experience. 'Have you ever been interviewed before? Did the person who interviewed you do a good enough job?'
- 8) Self-disclosure. The CL can share his/her experiences with interviewing.
- 9) Teach skills. Even if Dina wishes to continue to delay, she may be willing to allow the CL to review some basic interview skills. Role play- go back and forth on interviewing each other.

Appendix 3

Promoting Respectful Communication about Consumers by RC Staff

- 1) Do not speak in staff meetings about consumers in ways that are stigmatizing or pejorative.
- 2) Do not use a diagnosis or symptom to define a person. Use person-first language.
- 3) *A rule of thumb.* Imagine a consumer overhearing how you were discussing her/him in staff meeting:
 - a) The consumer may disagree--even sharply--with how s/he is characterized, as in “Jane is confused about the rules about the budget” or “Jose changes the topic when I bring up the subject of interviewing homemakers”).
 - b) **But** the consumer would not feel that you were putting them down, patronizing or making fun of her, as in, Jane is trying to get us to do all the work for her.” “Jose has a weird idea about what telling the truth means” or “He is a scam-artist”
- 4) Everyone may lapse into disrespectful communication. Use a non-threatening way to flag and explore such instances. (e.g., a small bell in staff meeting that anyone can ring when an instance of disrespect has occurred.)

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