Learning from Other Communities

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This paper reflects a synopsis of the work in person/family-centered planning representative of its implementation across a variety of disability service systems, including prisons, schools, community-based service agencies and institutional settings. The authors who have contributed to this paper have direct experience in the field working with individuals who have disability labels of severe and persistent mental illness, mental retardation and developmental disabilities, and learning disabilities. It is their hope that this paper will serve to guide the emerging best practice in the design and delivery of person-centered service delivery systems.

Lessons from the Field: The Use of Person/Family-Centered Planning Processes

Introduction:

There is national and international movement to include person/family-centered planning practices into the design and implementation of individualized services with individuals and their families. There is a growing body of research that points to person-centered planning as a best practice. In the case of children and youth, this movement has sometimes been reflected in policy, as in the case of the mandates of the Individuals with Disabilities Education Act (IDEA), which mandates rights for families and older youth. Similarly, it is supported by grant programs such as the Comprehensive Mental Health Services for Children and Their Families, which calls for and provides technical assistance to implement family-driven, child-guided, individualized plans of care.

There is a growing demand from people who use services and from the people who provide them for a system that is responsive to the unique needs and interests of the people it is designed to support. Across the country more service systems are focusing efforts on integrating person-centered planning for more people (O'Brien & Lyle O'Brien, 2002). This demand reflects both the development of consumer movements in different services systems (e.g. Mehan, Hertweck, & Meihis, 1986), critiques of what John McKnight (1995) characterized as "professionalized services and disabling help" and an understanding that consumer-driven efforts may help transform services (Osher & Osher, 2001) and create cost efficiencies (e.g. Institute of Medicine, 2001). Efforts to implement promising consumer-driven practices in long-term care system reform have been on the rise as have consumer-driven approaches to improving outcomes for children and youth with emotional and behavioral disorders and their families (Osher &Hanley, 1997). In England, there has been a change in national policy to increase choice and

inclusion of persons with disabilities into typical community experiences and a recent research study (2005) reports the efficacy of using person-centered approaches across areas of life, people and contexts.

In the United States the President's New Freedom Initiative called for national reform in mental health care resulting in the President's New Freedom Commission on Mental Health. The second goal of the Commission focuses on developing individualized consumer and family-driven mental health care (Final Report, 2003). New York State is in early stages of mental health system transformation to integrate scientifically-based practices that promote recovery-focused services and supports that are responsive to the unique interests and needs of the person (Carpinello, 2005). This reformation is further informed by the voices of some 6000 New Yorkers who have used or are currently using mental health services in a white paper, *Infusing Recovery-Based Principles into Mental Health Services*, (2004), in which person-centered practices were identified as a top priority for creating quality mental health services. Berwick (2001) highlights the need for service delivery to be more person-centered in order to meet the needs of "every single one."

Promising Practices:

Providers of service *want* to employ the technologies that best help the people they are committed to serve. Person-centered planning that is used to create individualized services yields significantly better outcomes and practitioners sincerely appreciate bearing witness to the positive impact to the fruit of their labor.

Times have changed. The mind-set of the Industrial Age (things, products, manual worker) is no longer effective. The advent of the Information/Knowledge Age (humanness, innovation, collaboration) challenges organizations to place a superior value on leveraging the interests, talents and capacity investments of its stakeholders as a means to achieving better results. People want to know that what they are doing in the world matters in some way, (Covey, 2004). *Beyond Disability: Tools for Building Person-Centered Relationships*, (Blessing, 2005) has supported providers of mental health services and/or developmental disability services within institutional and community-based settings to build upon the existing staff capacity to acquire new skill sets necessary for integrating more person-centered approaches to individualizing services and supports around topic specific issues or areas. Additionally, *A Framework for Planning,* (Blessing and Ferrell, 2004) provides a formal structure for methodically guiding individuals, and the people who support them, toward a customized plan for supports and services. Each has proven to be effective when working with any group of people, including in strategic planning with organizations and staff team building planning processes.

Similar developments have taken place for children with emotional disturbance and their families. Here professionals, families and youth have collaborated in implementing child and family-driven individualized planning to provide culturally competent strengths-based services and supports that enable youth to stay at home, in school, and participate

in community activities (Burns & Golman, 1999; Kendziora, Bruns, Osher, Pacchiano, & Mejia, 2001). These approaches are most successful when they are nested in a comprehensive approach to prevention and treatment which creates a healthy school and community foundation (Osher, Dwyer, & Jackson, 2004) that builds assets (and protective factors) and reduces risk factors for all children and youth. This approach addresses the ecological factors which often lead to the unnecessary removal of children and youth (particularly those of color) from school and community (Osher, Sims, & Woodruff, 2002; Osher, VanAker, Morrison, Gable, Dwyer, & Quinn 2004; Woodruff et al., 1999).

Person-centered practices capitalize on holistic system's designs which are proving to be highly effective. Early statistics gleaned from the New York State Western New York Care Coordination Program designed to integrate person-centered practices into a recovery-oriented system indicate positive results (increase in gainful activity; reduction in hospitalizations and a decrease in the overall cost for managing care) for individuals who are experiencing the impact of severe and persistent mental illness in their lives and for whom traditional services did not work, (2004). Similarly in New York State, data from the Inmate to Citizen project, (Cornell University, 2005) indicate a statistically significant impact on staff attitude and treatment planning for inmates with special needs (mental retardation and developmental disabilities/learning disabilities) after introducing person-centered training and technical assistance across the correctional and parole systems. The Career Development Initiative currently underway in New York utilizes person-centered approaches to identifying and implementing individualized evidence-based employment and career planning that has resulted in people obtaining and sustaining a greater number of jobs commanding higher strategies than traditional strategies had provided in the past (Cornell 2001). Consequently, recent program enhancements to the initiative, *Foundations in Recovery (2005),* have been embedded and secured a permanent place for state-wide training and technical assistance in person-centered practices as a primary vehicle for facilitating individualized recovery and employment planning.

Further, person/family-centered practices is being implemented for end-of-life planning (Kingsbury 2002) as well as serving as the basis for the development of advanced directives to be used when an individual is facing a critical time and is not capable of making needs and wishes clearly known, (ELP Learning Community 2002).

System infrastructures that are enhanced, reformed and/or designed with a commitment to long-term holistic strategic planning that pays attention to building and sustaining communities of learning across and beyond the service community are today's example of best practices.

Person/family-centered practice can only be effective when it is respected and embraced as a process rather than a project. There must be a plan for building an organizational platform for change.

Person/family-centered care often depends upon a facilitative infrastructure of support (Walker, Koroloff, Schutte, & Bruns, 2004). In the case of children and youth with emotional and behavioral disorders this is often facilitated by a family-driven and youth-guided system of care (Kendziora et al., 2001) Hallmarks of person-centered outcomes are used as benchmarks to chart progress and measure success in achieving individualized goals. A standard set of core values serve as the foundation upon which professional training and development, individualized planning and person-centered practice transpires. This set of core values are based upon the common humanity of all people, not upon those specifically invented for people who are living with the label of a given disability, (Kendrick, 2000). The original Western New York Person-Centered Planning training curriculum (Blessing, 2003) and its revised version *Foundations in Person-Centeredness* (Blessing, et al., 2005) have embedded these core values as the foundation for person-centered thinking and practice. This foundation has helped to provide a platform for practitioners who wish to make sense out of how to customize approaches to treatment that encourages the integration of tried and true approaches (such as psychiatric rehabilitation) with new technology (tools of person-centered planning) based on each the interests and needs for each individually unique plan. Similarly, Wraparound Milwaukee, which has achieved impressive outcomes through implementing a youth and family-driven approach to wraparound, provides extensive ongoing training to its contractor network to ensure that they implement individualized services in a strength-based, family and youth-driven manner (Kendziora, 2001).

Formal and informal learning communities are established to orchestrate and ensure cross-system collaboration and to expand beyond traditional providers to families and members from the community-at-large. There is active administrative support and involvement to mobilize existing and cultivate new resources. Attention to developing and sustaining influential implementation groups is given priority as these groups become largely responsible for providing leadership in staff development and training, coaching and mentoring and monitoring quality indicators, (in Holburn and Vietze, 2002).

Competency-based curriculum training with on-going mentor support provided to facilitators of person-centered planning is crucial to quality person/family-centered services.

Training in and of itself is not enough to secure system's impact and change toward developing and implementing person-centered planning and practice. Formal, on-going mentoring of newly trained facilitators has proven to be a successful approach to furthering professional development and in the establishment of statewide facilitator support networks in the South Carolina Training and Technical Assistance Project. Facilitators are evaluated on an on-going basis to ensure that they are consistently meeting competency standards required of skilled facilitators. The learning community established through the Western NY Care Coordination Project, designed around a philosophy of "learn-do-teach," reinforces the importance of on-going commitment to facilitator development, (Blessing 2003). Across the state psychiatric facilities in New York State, the importance of ongoing mentor support is seen as an essential ingredient to

the successful implementation of the Career Development Initiative; facility personnel are currently engaging in a statewide mentor planning process that is designed to align practitioners, regardless of program discipline, around delivering streamlined services in response to and support of an individualized plan for recovery.   International associations such as the Essential Lifestyles Planning (ELP) Learning Community, have long purported the importance of the need to sharpen skills and contribute new learning to the evolution of the field in culturally sensitive, individualized person/family-centered planning and practice. Standard field and train-the-trainer curriculum, such as the *Foundations to Person-Centeredness*, (Blessing, et al., 2005) provides a framework for ensuring that all trainers and facilitators are covering essential content areas that teach and reinforce person-centered thinking.

Person/family-centered practices are not seen as an "add-on" responsibility to existing work. Rather, they are seen as the way to be more creative and flexible with existing resources, and in fact, ultimately make the work more productive.

Plans that are developed as a result of person/family-centered planning processes have the tendency to write themselves. A comprehensive view of the person's vision for recovery leads practitioners and other supporters toward the activities that will specifically move the agenda forward. Each action leads to the next provided that the team is committed to assessing progress against the person's vision of recovery.

Recovery goals that are born of person-centered practices provide the context for people for whom real choice is limited. Inmates in the Special Needs Units of the *Inmate to Citizen* project (Cornell University) are finding the connection between attending mandatory groups, such as Anger Replacement Therapy, to achieving his release goal of being re-united with his family. Although still in its seminal stages, research on the application of person-centered planning to the delivery of health care supports to persons with disabilities suggests that it holds great promise (Person-Centered Health Care Project).

The role of health insurance is crucial in the delivery of responsive person/family-driven services.

It is crucial that person/family-centered practices become sustainable through the use of health insurance and specifically through Medicaid. Evidence-based and cost effective practices in mental health are beginning to be implemented and recognized by the Centers for Medicare and Medicaid Services (CMS).

Medicaid and Medicare are playing an increasingly important role in the reimbursement of mental health services. In 2003, the New Freedom Commission Report cites statistics that Medcaid and Medicare combined programs spent nearly $24 billion on mental health care (Lutterman, Hirad and Poindexter). At the present time, Medicaid funds more than half of the public mental health services administered by States and could account for two-thirds of the spending by 2017 (Buck). Given this data and the fact that Medicaid

has more flexibility to reimburse for person/family-centered services, the emphasis of this section is on Medicaid. In combination with the various mental health and substance abuse block grants, there are opportunities for increasing access to person-centered care.

It is important to note that Medicaid is statutorily able to pay for a broader range of services than those circumscribed by Medicare and private health insurance. This includes services that are helpful to the general population enrolled in Medicaid as well as those that are of particular interest to persons with special needs, including those with behavioral health concerns. Transportation to and from health care related services; case management; rehabilitation services and clinical services all fall within the range of reimbursable Medicaid services.

<u>Individualized services hold strong potential for overall cost effectiveness.</u>

A relatively new focus for Medicaid as well as other health insurance has been examining whether services that are provided to their enrollees are evidence-based and cost effective. The recent health care literature has been replete with discussions on evidence-based practices (EBP) with regard to mental health services. The Centers for Medicare and Medicaid Services (CMS) recently published an article entitled *Medicaid Support of Evidenced-Based Practices in Mental Health.* (CMS) The paper discusses the role of Medicaid and how the system can potentially reimburse for certain EBP services. It also discusses the statutory and regulatory limitations of the Medicaid program. It would then be incumbent upon providers to be able to "braid" funding sources to allow them to deliver a comprehensive array of services that can be provided in a manner that is client specific. The publication cited a number of innovative practices that could be reimbursed by Medicaid. For example, Assertive Community Treatment (ACT), client specific team treatment planning, individual supports for activities of daily living, coordination of a wide range of services and individual clinical interventions are all part of ACT. Such services can be covered under the Rehabilitation Services benefit (Rehab Option) of Medicaid. (Section 1905 (a) (5) (A) of the Social Security Act and 42 CFR 440.50) In addition, it is possible to claim the case management activities under the Targeted Case Management benefit under Medicaid. (Section 1915 (a) (9) and 1915 (g) Supported employment is a comprehensive approach to vocational rehabilitation and the treatment team work to integrate supported employment with mental health treatment to assist in promoting recovery. Vocational training is among the few services statutorily excluded from Medicaid reimbursement. However, Medicaid can pay for the medical services that enable an individual to function in the workplace. These EBP services can include psychiatry and psychological services, rehabilitation planning, therapy and counseling. These services can be provided under the rehab option, targeted case management and/or the clinic services option under Medicaid. (Section 1905 (a) (9) of the Social Security Act and 42 CFR 440.90) Further, these person and family centered therapies can be cost effective as they are generally provided in the community versus the more expensive per unit cost institutional settings. However, cost effectiveness studies concerning mental services in general and person and family centered therapies have not had as extensive review as that of EBP. This issue will be discussed in the "Barriers" section

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Barriers to Implementing Model Person/Family-Centered Planning

Person/family-centered planning is trendy and providers are willing to jump on the band wagon.

A real danger to integrating person/family-centered planning into service delivery systems is putting the latest language on old methods for supporting people (Smull and Harrison 1993). This is particularly true when there is external pressure to change systems of support. Traditional responses to change efforts typically consist of sending a few designated staff members to get "trained up" on the newest process or procedure and then bring back the learning in a condensed quasi cookbook approach. Consequently, the training becomes the end unto itself.

Person/family-centered planning is hard work for everyone.

Person/family-centered work requires a shift from traditional approaches to a realignment of existing relationships and structures. Human services exist in an era that has many contradictory messages for rehabilitation professionals; demands for "efficiency" and "cost effectiveness" are regularly presented alongside calls for "partnerships" and "community involvement.," (Lord and Church, 1998). Authentic person-centered services and supports demand a shift in the familiar balance of power that exists between a provider of service and the person or family that receives the service (Osher, Osher, & Blau, 2005a). Person/family-centered service delivery relies on a willingness to evoke significant change in the ecology of the service delivery system (Osher & Osher 2001).

Defenses are easily raised among participants of person-centered training forums. Across project communities can be heard protestations of "we are already doing it;" "there is not enough time;" "there is not enough staff;" "we have too much paperwork" (relative to matters of compliance).

There must be a willingness to learn new skills, including strong interpersonal and/or emotionally intelligent approaches to working with people. There must be a willingness to relinquish the role of expert on behalf of service providers (Osher et al., 2005a).

There must be a platform for change across the organization and into communities. Top-down directives will not effectively promote the type of change effort that is needed. This requires a commitment to a certain vulnerability from leaders to be comfortable with asking questions rather than with having the answers. Person-centered is both a philosophy and a set of related activities that leads to multi-level, co-occurring change (Mount, 2002).

Facilitation of person-centered planning is best undertaken by individuals who are independent of the support system from which a person receives their services. This poses logistical challenges for getting planning processes started and kept going.

Current systems of accountability reinforce traditional systems of service delivery.

Complex, comprehensive service designs have been years in the making based upon deliverable outcomes required of program sponsors. Most systems are pre-designed for service recipients well before the person or the family arrives to be served, (Kendrick, 2004). Managers of these systems are confounded by and even fearful of the consequences to altering these reliable systems of compliance and accountability, consequently restricting creativity, innovation and individualized responses.

Person/family-centered approaches are often seen as contrary to the responsible management of risk (Osher, Osher, & Blau, 2005b). There is a strong "either-or" belief system that erroneously presumes that to operate from a paradigm of person-centeredness means to abdicate the use of reasonable judgment and responsibility. Approaches that reflect the principles of person-centeredness require a willingness to work toward realigning the traditional relationship between provider (authority) and receiver (recipient) of service toward the development of relationships of mutual benefit. Contemporary rhetoric uses the word "partnership" in an attempt to convey this. What can be seen, however, is a monumental gap between the proclivity to profess to engage in partnerships with people and the ability to actively develop them. The difficulty appears to be, at least in part, anchored in the reality that partnership means different things to different people, and each stakeholder will have a uniquely different perception of what the benefits are to them (Lord, 1994).

Fiscal control remains firmly in the hands of service providers rather than in the hands of service users. Existing structures make the portability of one's service dollars impossible. Consequently, individuals are not free to shop around to weave together the type and frequencies of services that may best respond to their individual interests, preferences and supports (desired or needed).

Providers and practitioners believe that the existing fiscal structures have no room for creativity, innovation and flexibility. Programs that are successfully utilizing creative alternatives to traditional designs are seen as rare examples with variables so extremely different (that only works in the mr/dd system; they live in the city; they live in the country; they are "high functioning") that the feasibility of replicating any of the model is believed to be impossible.

While there is a plethora of anecdotal examples of the positive and often profound impact person-centered practices has on the quality of life of people who engage in the planning, very limited quantitative data exists that objectively proves the effectiveness of using person/family-centered approaches.

Cost effectiveness studies on person and family centered care, particularly as it pertains to those services that are reimbursed by Medicaid and other insurance are not as extensive as they could be. This is becoming of particular concern to third party payers such as Medicaid, given the cost constraints of these programs. Regulatory agencies could encourage providers to utilize more research-oriented approaches to providing

innovation to using existing resources flexibly and in response to person/family-driven interests and needs.

A brief review of the cost effectiveness studies of various interventions demonstrate mixed results. For example, a large study of the effectiveness of mental health case management and assertive community treatment was published in *Psychiatric Services* in 2000 (Ziguras, S. and Stuart, G.) Meta-analytical methods were used to investigate the effectiveness of case management and to compare outcomes for assertive community treatment (ACT) and clinical case management. Controlled studies of case management published between 1980 and 1998 were identified from reviews. The results were quantitatively combined and compared with results of studies of mental health services without case management or ACT. Forty-four studies were analyzed; 35 compared assertive community treatment or clinical case management with usual treatment, and nine directly compared assertive community treatment with clinical case management. Both types of case management were more effective than treatment provided without case management or ACT in three outcome domains: family burden, family satisfaction with services, and cost of care. The total number of admissions and the proportion of clients hospitalized were reduced in ACT programs and increased in clinical case management programs. In both programs the number of hospital days used was reduced, but ACT was significantly more effective. ACT had some demonstrable advantages over clinical case management in reducing hospitalization. However, more extensive studies on cost effectiveness should be done in order to evaluate and improve these programs. It can serve to assist person and family centered care in working with Medicaid, private health insurance among others to develop and reimburse for these services.

Recommendations:

- Build on the momentum that has been gaining in support of person/family-centered practices across the country.

- Reinforce the building of platforms for organizational change by funding incubator or pilot projects that are specifically designed to support non-traditional approaches to service delivery. Within the context of these pilots, provide for research regarding innovative and flexible use of existing accountability structures.

- Create Benchmarks for Person-Centered Approaches and practices and use them for continuous quality improvement and accountability.

- Organize a national institute for facilitator training with facilitator training "hubs" across the country. Embed training curriculum in person-centered practices into the facilitator development for on-going dissemination. Establish commitments of intent from organizations wishing to enroll potential facilitators into the institute.

- Foster the building of on-going learning communities through the intentional design and implementation of research-based projects that will track and inform the field of proven and promising person-centered practices.

- Further utilize the on-going learning communities, and build upon existing curricula, to advance a curriculum that specifically addresses health care financing issues, with an emphasis on Medicaid. The curriculum would stress those specific person/family-centered actions and changes that could be taken under the present statutory and regulatory requirements. It would also be accompanied by on-going mentoring support that is provided by experts in these issues.

- Utilize existing curricula, such as *Foundations for Person-Centeredness*, as a foundation curriculum to provide consistent, continuant accessibility across the nation to effective person-centered practice and planning methods. Utilize distance learning technology, residency competency training for facilitators and on-site technical support for learning communities and person-centered implementation plans.

- Expand the research around person and family-centered Evidence Based-Practices and cost-benefit/cost effective studies and implement the programs that are proven to be both. Any analysis should contain an opportunity to improve the quality of services based upon factual information from these future studies.

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