

Emerging Practices for Service Coordination / Case Management: Transition To What? (Individualized Funding, Service Brokerages, Personal Agents, Person Centered Planning, Microboards)

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Concepts around consumer/ family fiscal control, empowerment, and separating choice and direction of services from the system's own staff continue to gain credence within academic, advocacy, and governmental forums nationally and internationally. Increasingly, students with disabilities transitioning from special education into adult society and attendant services must learn to navigate through and actively choose from a wider range of options than heretofore thought feasible. This trend is a healthy move into a more accomplished vision of empowerment (and more importantly, power and control). Yet, questions and issues still emerge that demand exposition, exploration, and critical analysis. Many of these questions revolve around the specific issues inherent in creating a publicly supported service coordination/ "case management" system that truly is directed by and controlled by the consumers it seeks to serve. These questions and conundrums will be attended to briefly later in this paper and more extensively in the Institute itself.

But before examining these systemic issues, it is useful to reflect briefly on the broader topic related to control and power out of which lineage, these more recent designs flow. The concept of consumer-directed and consumer-run service delivery can trace its roots back to a panoply of social and political movements over the years. The American legislative focus on non-discrimination had its roots in the Civil Rights legislation of the 1960s. It culminated in the 1990 passage of the Americans with Disabilities Act (ADA), with the major intermediate step of Title V of the Rehabilitation Act of 1973. The self-help movement for people with various kinds disabilities is only about 60 years old (Gartner & Riesmann, 1984). The growth of political power for people with severe disabilities really began with the Independent Living movement in Berkeley, CA in the 1960s and has continued apace through legislative, social and legal advances (DeJong, 1979). The concept of consumers with disabilities *controlling* their own service delivery mechanisms has been enshrined in rehabilitation legislation beginning with the Rehabilitation Amendments of 1978 and continuing on, almost unabated, with the great emphasis placed on consumer control and satisfaction in the Rehabilitation Amendments of 1992. Empowerment of individuals with disabilities was first raised as an issue within the independent living movement (DeJong, 1979) and the self-help movement in the mental health field (Chamberlin, 1978). More recently, calls for greater empowerment can be found associated with a variety of groups, such as people with cognitive impairments (Jenkinson, 1993; Wehmeyer & Metzler, 1995). The issues around power and control get

embodied for transition age students into the related, but not identical, concept of “self determination” (Field et al, 1997; Wehmeyer et al, 1998; West et al, 1997).

Truly empowering systems seek to develop "a process **of assumption or transfer of legal power and official authority**" as Webster's New World Dictionary, 10th Ed., 1994 defines "empowerment." The ability to direct one's own funding is one clear manifestation of this definition in practice. This process incorporates both concepts of *Choice* and *Control*. *Choice* is the *ability to freely select from a range of options*. Choice requires alternatives. *Control* is the *ability to implement personal decisions regarding what resources are created as well as how supports and resources are used* (Hagner and Marrone, 1995). The US consumer society tends to form many system perspectives about how these concepts of choice and control should influence the design of helping systems. As consumers, people tend to be wary of obtaining help with plan development from people who stand to benefit from the plans that are developed (Butterworth, et al, 1993). For example, we suspect that if we ask a real estate agent whether it is wiser to buy a new home or enlarge our present home, we can predict that they will favor a new home purchase, whereas if we take our problem to a building contractor we will get a different viewpoint. So many consumers and families may prefer an independent process for identifying needs and making plans, while relying on professionals to provide important pieces of technical information.

When individuals with disabilities need life planning assistance, concerns arise if the process is dominated by the same service providers who have a direct interest in the outcome. Transition planning with students still in the education system is inherently more enmeshed with the educational structure that controls the service delivery because its linchpin is IDEA, which has no real analog in adult services except the resultant state system changes subsequent to the Olmstead Supreme Court decision. This target group is young people needing “education”, not adults seeking citizenship opportunities; and families are presumed by definition (in the IDEA law and social custom) to hold more sway in decision-making for youth while this influence is more subject to debate and interpretation in adult systems. Ideally, the planning participants, timing, location, and planning topics should be chosen by the person, and involve friends, family, and community members as the individual wishes no matter what the focus, educational transition or adult services (Marrone, Hoff, & Helm, 1997). When someone assists with formulating plans who also could benefit financially from what is planned, this conflict of interest should be identified and discussed.

In order to be effective, planning strategies must have as their focal point the personally meaningful goals of the individual, *not* the individual's weaknesses and problems, *not* the services available, *not* what is realistic to pursue, nor even the individual's objectively-determined characteristics and needs (Marrone, Hoff, & Helm, 1997). Marrone, et al (1997) use the term *facilitative advocate* to indicate a person who would help coordinate person-centered planning as well as assist the person in achieving the expected results. That advocate must be passionate about helping the person with a disability achieve goals. The facilitative advocate must work to see that these aspirations, hopes, and dreams are not thwarted, but supported in their achievement, despite demands or doubts imposed by systems or helpers. Individuals with disabilities, like anyone, formulate personal goals based on needs and aspirations as each person perceives and defines them. Envisioning an expansive future for oneself despite current constraints or seeming implausibility is inextricably woven into the fabric of American culture, enshrined in terms such as the "American Dream" and the "Land of Opportunity." As plans are implemented, reality often intrudes and barriers must be confronted or plans modified along the way. But this process only makes sense insofar as it reflects each person's evolving vision.

At least in theory (and thus fueling much of the growth in individualized funding and service brokerages as exemplars of service coordination across the US and in other countries) is that when funding is tied to the implementation of individual plans, consumers do not fill "slots" in a system of prearranged services. When something is not available, a request for proposals or a help wanted ad is developed or staff recruited with the help of an independent "broker", social networks are canvassed, and the good or service is *made* available. More in theory than in practice to date, there then is minimal process oversight of funds and flexibility in how closely consumers and families are accountable for the broad uses of these funds.

Although sometimes viewed as the ultimate expression of empowerment, individualized funding systems are not without their problems. Some degree of accountability and quality control is always required both to monitor expenditure of public funds and to insure that individuals are not harmed. Fragmentation of service providers may eliminate some economies of scale. Some judgments about service competence may require technical expertise that is difficult or expensive to obtain. And recruiting a committed, high quality human service work force might be more difficult for organizations unable to count on predictable annual funding. However, almost all other professions and organizations in our society thrive despite having to project consumer demand, including, lawyers, contractors, hospitals, restaurants, colleges, etc.

Consumers can deal with selection, contracting, and monitoring issues successfully if provided with planning and decision-making assistance recommended above, such as through mechanisms as "service brokerages" (Roehrer Institute, 1991, 1994), which can assist individuals to select and contract with service providers and maintain accountability of funds. The concept of support brokerage began in the 1970's from the work of a group of families in British Columbia, the Woodlands Parent's Group, who all believed that institutional models of care were inappropriate, and sought not only to return their sons and daughters to the community, but to find a way to release financial and other resources bound up within institutions as well (Smith, 2001). Brian Salisbury, an advocate for individualized funding and service brokerage from British Columbia defines service brokerage as a "...system function & process in which advice, information and technical assistance is made available to individuals who request support to: identify & access needed community services & supports [and] negotiate for & use individualized funding" (Salisbury, 2000a), and as "the provision of information and technical planning assistance, form a community based context that reduces conflict of interest, that individuals sometimes require in order to identify and access needed services and supports, using the financial resources provided by the government" (Salisbury, 2000b). To put it somewhat more succinctly, brokers should be advocates for and instruments of the person with a disability to identify what they want and help them get it.

Because of this variety of broad social and more specifically disability oriented forces at work over the last several decades, there has been expanded interest and, more importantly, system design initiatives, especially throughout the US and Canada in the companion concepts of service brokerage and individualized funding especially within the developmental disabilities field. The remainder of this paper will be devoted to exploring and discussing some of the more specific questions that must be answered for this systemic improvements to propagate and endure. As students and staff get involved in transition planning involving post secondary and employment options in society, in practice, they often concurrently move into a different system of services and supports funded through funding streams developed for adults and predicated on some alternative but connected premises to the educational system. Conceptually, most significantly, that while the emphasis in education/ transition services has been on self-determination skill development, in adult systems there has been a growing focus on structures (often financial in nature but also involving service planning and community supports) that shift the balance of power and control. Therefore, it is crucial for students, parents, and staff engaged in transition from school to adult citizenship options to understand the trends and systems with which they will interact so often.

How have concepts of individualized funding and service coordination been applied in different places and what sort of adult system has been created? First of all, support brokerages in conjunction with individualized funding policies in various guises have been incorporated in a wide variety of states and provinces in Canada over the last 10 years or so. This due to a variety of contributory factors with each instance influenced in varying degrees by one of more of the following: court decrees (especially based on the Olmstead decision reasoning but also predating that case), family advocacy, formal group advocacy, foundation system funded change projects (e.g., the RWJ demonstration), and philosophical shifts within federal and state governmental structures (to some extent fueled by a politically conservative view of government as a problem not a solution as well as some assumptions about cost savings to be made by this more informal community structures these efforts have often spawned). The approaches most philosophically consistent with the social policy roots described above

combine independent support brokers or service brokerages with some sort of individualized funding stream, controlled by the individual and/ or their families. Some of the specific state and local interventions have separated the control of funding (leaving this decision within the public contracting process) from the concept of independent brokers or service coordinators hired by the person with a disability or his/ her families but it seems that it is technically possible but intellectually difficult for brokering to exist without funding control. A variation on this theme is the development of "microboards" (a Canadian term coined by the developer, the Vela Corporation in B.C., Canada or SDSC- "self directed support corporations" (the technical term used in many jurisdictions in the US) are both small (in number) boards with individuals forming a board around the person needing supports. The person needing the supports is the director of the board. In the US, the board is then incorporated and often becomes a provider for one person in states using the Medicaid HCBS waiver and becomes responsible for assisting the person with the disability in identifying the supports needed in their life. Using the principles of self-determination they establish individual budgets, individual support brokerage and fiscal intermediaries. The goal of SDSC's is the establishment of a person-centered corporation to meet the person's unique support needs (Golden, 2002). In the US, Maryland, through the Maryland Self Determination Initiative has been one of the places most heavily focused on the use of microboards but other states have developed them also.

Are public (state, county, provider) case managers/ service coordinators superfluous if states adopt a service brokerage model? One of the dilemmas created by this increasingly popular service design is the public human service tendency to layer, without discarding. So, for example, while states such as Washington and Oregon have moved aggressively towards individualized funding and independent service brokering, they have not dismantled the existing traditional case management systems. Oregon is most illustrative in this regard as it recently settled a federal lawsuit issued by a federal court in 2000 and phased in over six years, 2000-2006. The settlement ended class action litigation filed by Medicaid-eligible adults with developmental disabilities who were on long wait lists for services. This decision entitled these Medicaid eligible adults, most of whom live at home with their families, to support services designed to help them be stable at home and engaged in their communities. In theory, Oregon will provide all these services mandated under the consent decree through a set of 11 service brokerages (employing individual service brokers- some as employees, some as independent contractors). At the same time, the existing county run DD case management system remains in place and in one major anomaly, Multnomah County (where Portland is) has its existing case management system as well as a brokerage, with a "firewall" erected between the two entities. So one open question under these parallel designs that occur in most areas that brokerages exist is whether this arrangement constitutes a comprehensive system reform, a "boutique" service for a favored few, or a redundancy?

Who are the service brokers in states that use this model? Should there be qualifications for them? Who should pay for them? Another concern that reliance on a system of independent brokers raises is that this form of service coordination is essentially based on the assumption that case managers/ service coordinators who work for the public system, either directly or for a private vendor under contract, are inherently compromised by virtue of this employment relationship and cannot easily operate with the client's best interests uppermost. Of course, helpers of any sort usually have personal interests that intervene (e.g., the independent real estate agent who is acting on your behalf as a buyer still needs to make his/ her commissions with sales). It seems there is a subtle premise that somehow "good" people can be selected versus public bureaucrats who don't care as much. In practice, it is unclear exactly how differently service brokers operate from their traditional peers (assuming both have access to some sort of individualized funding to use on the client's behalf). Also, as the system mushrooms, organizations get created that employ multiple brokers and offer benefits and health insurance that most employees want. So, what safeguards remain in place to ensure that these don't just become another type of contracted service coordination vendor that are in place in many locales through the traditional system developed over the last 30 years?

The issue of qualifications for brokers is a thorny one. The whole concept is premised on creativity and individual problem solving. Many advocates worry that the more these systems and staff

get institutionalized, the less they are able to operate in the ways that they see as intended. Yet, as states and other public systems make these innovations a concrete part of their service systems, there is increasing pressure to set standards and qualifications, similar to those to which others in the public funding stream must adhere. This strain comes out of several directions: a genuine desire for quality services, demands from organized public workers who see this as a way systems are trying to cut personnel costs, a concern for liability, a "guild" mentality that often infects new cadres of workers (e.g., the movement to certify job coaches or psychiatric rehabilitation specialists), and concerns about fairness and equity to other groups who must meet requirements, and the increasing efforts many state agencies have put into insuring that their contractors meet some sort of minimal institutional standards (e.g., CARF, The Results Council, etc.)

What are the benefits and disadvantages of divorcing service delivery and system roles from client advocacy and "service brokerage or coordination"? Part of the genesis of service brokerage or coordination, whether provided by agency paid staff (case managers) or independent brokers is the presumed benefit of separating the delivery of service from the planning of service. Case management/ service coordination was viewed as providing the required independence and neutrality, i.e., someone with no vested personal or financial interest in any one particular service that was delivered. However, case management in itself did not always adequately address the issue. Case managers, often with minimal training and large caseloads and low expectations of the clients in the system by the system, often did not have the depth and quality of relationship required to assist with the subtleties of providing assistance to a person in working through a decision, and may have a host of inter-agency allegiances or conflicts that interfere with objectivity. Finally, the term as well as the traditional practice of "case management" suggests a highly unequal power relationship and a fundamentally bureaucratic approach that takes as its starting point the system of services rather than the individual. Smull and Smith (1994) note that, these "independent case management" systems have been unsuccessful for the most part, because they have "had responsibility without authority; lacked the tools (e.g. person centered planning) needed; been independent only in name; been co-opted as just another compliance check; drowned in excessive paper requirements; and, had too many people for each case manager to support". The movement towards the service brokerages and independent service coordinators developed in great measure from the desire to create even more separation between the delivery and planning functions.

Yet, despite this accepted wisdom, at the same time, a firm belief exists within the disability field about the importance of relationships to work and school success for people with significant disabilities (Hughes, et al, 1999, Marrone et al, 1995; Story & Garff, 1999). In some ways it is hard to reconcile these dual strains vis a vis the need for a "pure" planning role distinct from service delivery with the emphasis on support and relationship building as way for people with disabilities to overcome the difficulties in making any major life change. This is also one area where the mental health and developmental disabilities fields diverge somewhat in that in current community mental health rehabilitation "best practice" stresses comprehensive, multi-faceted roles for staff in assisting clients to achieve life goals related to education and employment, with the trend moving away from case management/ service coordination generic planning activities as a role in itself.

What about when family and individual needs don't coincide? To some extent, this issue of dichotomy between family and individual needs is somewhat overblown. Benjamin, et al (1998) found that individuals who received their services from family members reported feeling more safe, having greater choice about when and how services were provided and having a stronger desire to direct their providers work than did consumers who received services from nonfamily members. Certainly family members have a right (and duty) to be concerned about and have opinions about the person with the disability, especially so in the case of transition age adolescents living at home. Factors such as their legal status vis a vis guardianship, the client's age, whether the family is the primary caregiver or is providing housing, and the nature and quality of the relationship the professional helper has with the consumer all have to be taken into account in weighing competing needs. In sum, client and family (and provider) needs are usually complementary, but not identical. Therefore, it is important to identify and make everyone's needs explicit, not implicit and the individual with a disability can choose to make his/her

needs secondary to family considerations, as we all do at one time or another. Marrone, et al (1995) note that family participation and agreement will more easily come about if families are involved from the beginning in developing plans for services. New ideas and strategies can be discussed prior to implementation with enough time to address a family's questions thoroughly. This can increase a family's willingness to go along with the risks inherent in new ideas. The role the family plays cannot simply be viewed in terms of the stated preference of the consumer. The values of consumer choice and empowerment need to be considered within the family context. The family's need to be informed and exercise some control in decision -making should hold greater weight if the individual is younger or they are financially (or legally) responsible for the individual. The challenge for staff is in both involving families while treating adult children respectfully and sensitively.

Some members of family constellations, just as members of other groups, may not have the resources or desire to help in any person - centered planning endeavors. However, there is enough practical experience in person centered and consumer controlled models that indicates that the opposite thesis is more likely, i.e., that family members provide vital resources, energy, caring and love that professionals may not be able to muster (Turnbull & Turnbull, 1993). Problems that inclusion of family members make by their understandable concerns for the safety, security, and happiness of the person with a disability are counterbalanced, except in the most extreme situations of abuse or dysfunction, by the support offered for the planning and goal achievement process (Marrone, et al, 1997).

LIMITS ON CHOICE/ CONTROL?

What is informed choice and how important is being informed relative to having choice? As noted earlier, Hagner & Marrone (1995) distinguished between the concepts of *Choice* and *Control*. There is concern that people with disabilities, who heretofore have had no experience with or support for making their own major life choices, will not be able to fully reap the benefits of person-driven planning, individualized funding, and service brokerages/ microboards unless they are armed with enough information. To some extent, informed choice is somewhat of an oxymoron as real choice/ control is most evident when a person can make stupid and ill-informed choices. Choice and control subject to making what is perceived as "informed" choice is necessarily dependent on an outside person's judging what is adequate in terms of information. This constraint is not intrinsically bad but a limit on choice nonetheless. Making a decision regarding how much information is enough, especially when most information, of necessity gets filtered through the prism of outside helpers, does not lead to obvious answers. Some ways of informing people more adequately would include asking service providers to make a presentation regarding how they would meet the individual's needs, getting references from the organization or person seeking the business from others they have helped, and making outcome data easily accessible to all, not just buried in official reports or in quality assurance or accreditation surveys. These strategies would apply equally well to choosing a service broker or independent support person as they would to selecting a service provider. Youth should be assumed to need more information in order to exercise effective choice because of their smaller range and length of life experiences. There is also greater responsibility on both parents and school systems to provide a more secure safety net for youth than would be necessary for adults.

When should individual choice be subsumed to broader social policy mandates? There is a role for broad social policy transcending any individual's personal freedom or even total well-being. To what extent does one individual's choice outweigh any others when needs conflict, as they inevitably do in a pluralistic society. Or, viewing from a broader context, in a democratic society, some individual choices get subsumed by social policy (e.g., a worker cannot waive his/her right to minimum wage or workers' comp). Also, having power and control implies responsibility as well as authority. In our society, work is an expectation so that people should work, not just have the opportunity to work. Employment is neither a service stream nor merely an "option" analogous to what movie a person chooses to see; it is a citizenship responsibility.

Consumer empowerment requires that the services allow and expand access to the settings and resources that are available in the community at large, not restrict such access or prescribe different

options. Obviously, there will always be some limits on the choices that can be supported -- from the unethical, such as buying drugs, to the impractical such as a job in the tropics for six months a year. The world all of us inhabit has limits based on resources, looks, personality, class, race, gender, etc. The role of an empowering service system or service provider is to minimize those limits based on disability (Hagner & Marrone, 1995).

What responsibility, if any, do staff have to influence choices people make in an individualized funding/ service broker system? Person-driven service delivery with an emphasis on individualized funding and service brokerages should not mean:

- That the staff member "just says *Yes*" to any request.
- That the staff member's only role is placating people so they do not complain.
- Never having an opinion or offering advice.
- Abdicating responsibility to influence behavior. Any responsible service provider must advocate values such as the importance of working and personal responsibility.
- Shifting the blame or punishing the client for failure caused by not listening to you as the service provider ("I told you so").
- Just listening to people without actively helping. Action is required by providers, even in consumer-driven service delivery.

Staff roles should be more, not less, activist in that they offer opinions, advice, suggestions, clarifications in an assertive manner designed to seek agreement- not limited to a "take it or leave it" approach. There is often discussion, debate, argument, and heightened tension as staff legitimately try to influence consumers to do things. In relationships where formal power disparity does not exist there is usually an expectation that one person will often seek to influence the other, without unduly analyzing whether they have the "right" to do so. In interchanges in life of any sort, there is some attempt to affect behavior, attitudes, and thoughts. Whether in simple matters like what movie to see or what to have for dinner or more complex human issues like whether to have sex or buy a house or in arenas like religious choice or political beliefs, it is common and expected that individuals will use persuasion of one sort or another even when (especially when) power roles are equalized.

Furthermore, context clearly makes a difference. Different "professionals" have differing levels of power (psychiatrists, clinical social workers, for example) have more power than job coaches or case managers yet they all tend to have more power than clients or families themselves, unless people push hard. The context should determine roles. A treating physician should have more control in an emergency room medical crisis than a community advocate or the patient but shouldn't when it comes to medical follow-up, in which the patient should have more control. A person with a disability should always be able to choose their personal case assistant and the type of job they wish to pursue but, it is paternalistic that they would choose whom they work with (e.g., liking co-workers as a measure of good job placement). Youth with disabilities, as other adolescents, require a balance in their lives between parents and educators caring enough to provide strong opinions about acceptable behavior, while at the same time recognizing the developmental need of all in this age group to experiment, take risks, and separate themselves from parents and others in favor of peers.

How do these approaches need to be modified to reflect the differing needs of youth and adults? Or disability label? Or gender? Or sexual orientation? Or racial/ gender/ ethnic/ linguistic/cultural background? Personal support planning and service coordination cannot be viewed as a mechanistic strategy that can be reduced to a standardized template. It is obvious that adaptations to the methodology must be made to account for factors such as:

- * Adolescents/young adults living at home might be more open to involving family.
- * Adolescents might be more secretive about social or employment problems vis a vis involving peers than older people who may be comfortable with "networking" or "self help."
- * People with non-apparent disabilities like mental illness or seizure disorder might be reluctant to expose themselves to disclosure by open support in the community or workplace.

Disability is only one of the factors shaping the individual and may not play a dominant role in self-image. Moreover, the view of disability as all encompassing and the primary shaper of a person are

stereotypes that disability advocates seek to shatter. Webster's 10th Collegiate Dictionary (1993) defines "culture" as: "... 5A: the integrated pattern of human knowledge, belief, and behavior that depends upon man's capacity for learning and transmitting knowledge to succeeding generations; 5B: the customary beliefs, social forms, and material traits of a racial, religious or social group...". The role[s] various elements such as class, religion, race, gender, ethnicity, and sexual identity play in person - centered planning are largely unexplored, since the core concept itself has not been well researched for efficacy or utility. Nevertheless, since culture, by definition, influences "beliefs and behavior," any advocate must seek to understand how these cultural components converge with and diverge from the helping process, in order to maintain his/her credibility and viability.

There are general guidelines relating to assisting people from different cultures -- using advocates from the same language and cultural background as the client, having materials in the person's most comfortable language, asking the person about cultural issues that may be important, rather than assuming based on general knowledge, being non-judgmental about the cultural norms from which the person is working, etc. (Shafer, et al, 1995) Some questions to be raised in the context of individualized funding/ support and service coordination:

- If some members of an ethnic group are not comfortable with the Western ideal of personal control, choice, and empowerment how can the advocate manage the process in a way that legitimizes a more interdependent and collective decision-making approach?
- If a person's major role identity is that of a homosexual or bisexual orientation, yet is reticent about "coming out" especially to family, how can many key supports be included without breaching this confidentiality?
- If the person getting helped is from a racial minority group and feels victimized by the white majority, how can a white advocate be helpful? The same question can be applied to issues of gender with the Western history of male domination.
- If the person's getting helped is from a poor socio-economic class with no history of family monetary and career success, how does a seemingly logical planning process of marshaling resources, identifying goals, and taking action fit into that person's life experience?
- If the person's getting helped is female with a history of being physically or sexually abused, how well can a process founded on a concept of power, choice, and control fit the needs of a person who may shy away from exercising this sort of hegemony at this point in her life?

The helper should try to adapt his/her style early in the helping process to fit into the family's cultural context (e.g., being more liberal about time issues with people whose cultures don't view appointment times as precisely as Western society; spending more time in personal "small talk" with people where that is the norm, rather than professional distance). However, as the relationship progresses, American cultural mores should rightfully be presumed to hold sway in arenas where negative consequences might flow from continued non-normative behavior (e.g., continual lateness in interactions where promptness is required). In other areas of social nuances or politeness (e.g., using Mr., Ms., or Mrs. for people older than yourself; or avoiding direct eye contact) then the consumer's own cultural preferences should continue to dominate the interaction.

How should the effectiveness of these new models be measured? Or are they inherently better than older models of "case management" and "contract services"? Fundamentally, this question can be summarized within a simple dichotomy: Are individualized funding and service brokering strategies outcomes or process indicators? While there does appear to be an important concept of controlling one's own life and resources that defies simple measurements in this regard, it is also true that systems and individuals have devoted much time, effort, and money into creating these sorts of structures over the last decade. So, it is reasonable for policy makers and system change advocates to say that something concrete should happen differently as a result of these revisions. Most importantly, people with significant disabilities should be able to achieve better outcomes as indicated by measures such as employment, earnings, income, leaving public assistance, living independent housing, personal satisfaction with quality of life, and personal satisfaction with quality of services. As a matter of public policy and fiduciary responsibility, there should be objective measures of good and high quality outcomes

that are equally important as personal satisfaction with them. Moreover, if, when people are given control and power over funding, and very few shifts in resources are created, then 2 further questions have to be asked: 1] Was there enough information given? and 2] If the answer to #1 is yes, then is the concept worth the effort in time and energy if people's needs were met well enough anyway?

It is possible that the penetration of individualized funding and service brokerage systems have not been widespread enough to date so that it is time to measure success. Trying to calibrate success or failure too early stifles system change and innovation; not trying to ascertain objective success at all belies the reason for engaging in these efforts in the first place.

What is the role of quality assurance systems if person/ family controlled funding and service brokerages are established? This final question seems most amenable to a simplistic answer. If individualized funding and consumer controlled services were achieved, then the roles of quality assurance and certification of programs, beyond health and safety standards, seem redundant and should be eliminated from systems. Service providers and service streams then become consumable items (similar to gas stations, supermarkets, foodstuffs, clothing, etc.) in that quality is best left to individual choice (i.e., people vote with their feet) except in areas where private citizens could not be presumed to have expertise (health or safety requirements). Quality assurance is a distinct concept from a public system's responsibility to purchase services that fit its stated mission and values, even if an individual client in the system might wish other options. An example would be a state or county DD system's not funding sheltered workshops or a local mental health authority's only funding community case management, not day treatment. Such black/white judgements need to be made judiciously but they nonetheless need to be made.

Is there a "middle class" bias in these service designs? To date, individualized funding and consumer/ family directed funding has benefited and been steered towards middle class families and people with "acceptable" disabilities rather than poor people and those with more fearfully stigmatizing disabilities, such as mental illness. Is this something amenable to change as without broadening its base of impact, it runs the risk of remaining a middle class, "boutique" service?

Why have these concepts been applied so unequally in disability fields outside developmental disabilities? While the principles enunciated vis a vis individualized funding and service brokerage are universal in nature and not disability specific, the fact remains that they have not been equally applied to people with various disability labels. Most of the systemic reforms in the US and elsewhere have really been devoted to services for people with developmental disabilities. The reasons for this are not certain, but probably manifold including:

- greater advocacy from the developmental disability (DD) community and advocates
- people with DD seen as more "worthy" than people with mental illness
- with people with DD this is often a concession to families while with people with mental illness there is concern about giving them greater control directly versus through a family or advocate intermediary
- people with DD often have greater support from families and advocates.

In order that these concepts get practiced more universally, this disparity in application by disability label must be discussed and analyzed.

How "individualized" should funding be while still preserving equity in public systems? One of the core premises of individualized funding is that every person has unique needs so a "slot" system or generic case rated funding inevitably leads to inadequate service interventions for people with the most significant or low incidence disabilities. Yet many of the state and county systems of independent service coordinators, brokerages, and individualized funding developed specific standardized rates (often with some exceptional circumstances clauses that allow deviation) that must be used when developing individualized funding plans. This is partially due to fiscal constraints and partially to due process issues in regard to funding equity among all clients of any public system. There is no simple answer to these equally worthy competing interests (special needs of persons with significant disabilities versus fairness in both legal and philosophical senses). This issue is roughly comparable to political

issues in many states related to how school funding should be generated (i.e., should rich districts be able to spend more on their pupils or should funding be equalized through some sort of statewide funding formula?)

How active should families have to be in determining services and supports? Many of these designs are predicated on the needs and desires of families to be in control of their relative's services because they are closest to the situation and are most involved. Greater involvement with professional helpers should not become a situation where staff turn to families to assume responsibility for all gaps or shortages in the service system. Families are a crucial support system in many cases, but other community supports should also be tapped. There is a whole range of natural supports to explore on the client's behalf especially when families don't have the resources or feel comfortable in providing direct supports. Families will often spend their whole lives involved with and supporting the family member with a disability, sometimes concerned with not providing enough support to other children, their spouses, or themselves. Care must be taken that service system demands are reasonable and don't place undue stress or burden on the family's time and energy. There is also another dimension to this discussion as there are many areas of social policy where we willingly cede control and specific fiduciary responsibilities (e.g., police and fire protection). This delegation does not free us from reporting crime or fires or even taking direct action. Yet, we assume that as citizens we can trust these surrogates to perform their duties on our behalf. We should be wary of assuming that it is always seen as a benefit to families to expect them to "take charge" in all instances. There is also a value to exercising a proper governmental role in assisting people with disabilities so that their families can feel confident in trusting their representatives to act competently in their family members' and their best interests.

There is no doubt that the strategies in supports and coordination encapsulated in interventions such as individualized funding, service brokerages, microboards, independent service coordination represent great promise and potential for dramatic improvements within the public service system for people with significant disabilities. Yet as in any new technique or social policy innovation, many issues remain to be tackled and many questions still remain unanswered. For the full potential of these approaches to be reached and able to be measured in terms of both better life outcomes and increased consumer satisfaction, some difficult and complex matters must be attended to by theorists, public policy analysts, advocates, service providers, and consumers and families themselves. The additional level of analysis and critique that this paper and accompanying Institute are meant to stimulate will help what are currently innovative "techniques" reach their full potential as revolutionary system reforms. Otherwise, we run the risk that these strategies remain mere palliatives that enable proponents to assume an air of moral superiority over those who have not yet adopted them, without helping people with disabilities achieve full citizenship and concrete improvements in their lives in multiple areas.

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