

Empowerment and Self Direction Relative to the Design and Governance of Personalized Service Arrangements

Michael Kendrick

Volume 19, Number 2, October 2011

De l'appropriation du pouvoir et de l'autodétermination : le parcours du mouvement social des personnes ayant des incapacités
Empowerment and Self-Determination of People with Disabilities: History of a New Social Movement

URI: <https://id.erudit.org/iderudit/1086900ar>

DOI: <https://doi.org/10.7202/1086900ar>

[See table of contents](#)

Publisher(s)

Réseau International sur le Processus de Production du Handicap

ISSN

1499-5549 (print)

2562-6574 (digital)

[Explore this journal](#)

Cite this article

Kendrick, M. (2011). Empowerment and Self Direction Relative to the Design and Governance of Personalized Service Arrangements. *Développement Humain, Handicap et Changement Social / Human Development, Disability, and Social Change*, 19(2), 57–68. <https://doi.org/10.7202/1086900ar>

Article abstract

The attempt to create services that are designed and directed by service users has been growing in prominence in many human service sectors and has spawned a wide variety of policies, systems and examples in many jurisdictions. This article has a focus on how decision-making and of this kind can be operationalized by demonstrating how organizational authority can be transferred to and employed by service users and their allies both singly and in conjunction with other parties. It describes various levels of empowerment relative to service decision making as well as the common organizational forms that user directed services have taken to-date.

Empowerment and Self Direction Relative to the Design and Governance of Personalized Service Arrangements

MICHAEL KENDRICK

Kendrick Consulting Services, Massachusetts, USA

Article original • Original Article

Abstract

The attempt to create services that are designed and directed by service users has been growing in prominence in many human service sectors and has spawned a wide variety of policies, systems and examples in many jurisdictions. This article has a focus on how decision-making and of this kind can be operationalized by demonstrating how organizational authority can be transferred to and employed by service users and their allies both singly and in conjunction with other parties. It describes various levels of empowerment relative to service decision making as well as the common organizational forms that user directed services have taken to-date.

Keywords : self-direction, empowerment, service decision-making

Résumé

La tendance à créer des services qui soient développés et dirigés par leurs utilisateurs a gagné en popularité dans plusieurs secteurs des services sociaux. Elle a eu également pour effet d'engendrer dans plusieurs pays le développement d'une variété de politiques, systèmes et modèles s'en inspirant. Cet article s'intéresse à la manière dont l'autorité organisationnelle peut être transférée et utilisée par les utilisateurs et leurs alliés, ainsi que les prises de décision réalisées individuellement et en partenariat avec d'autres parties. Il décrit également les différents niveaux d'appropriation du pouvoir pouvant être exercés dans le cadre de la prise de décision de la gestion des services dirigés par les utilisateurs et formes organisationnelles qu'elles ont prises jusqu'à ce jour.

Mots-clés : autonomie, appropriation du pouvoir, prise de décision dans les services dirigés par les utilisateurs

Introduction

The last half century and in particular the last thirty years, has seen the unprecedented appearance and growth of what we now call "human services". These apparently historically novel creations do not appear to have had a presence in any of the many civilizations for which we have some written or other evidential sources. They are largely, as best we can tell, a creation of the late 20th and early 21st centuries. Their character and features are also quite distinctive as a general matter, though there is ample enough variation amongst them to make contemporary human services quite difficult to typify without risking over generalization. They are largely "technocratic" in nature i.e. they represent a fusion between an emphasis on methods, processes and systems and bureaucracy. Much of their character has come into human services from the broader corporate world and it's culture, so it would be reasonable to say that modern human services are part of a larger process in global society of the growing dominance of corporations and a dependence upon them that simply was not present to the same degree in the earlier half of the 20th century.

For the most part, they are "top down", prescriptive, hierarchically organized, professionally and managerially dominated, organized into layered and interconnected systems, politicized, replete with competing vested interests of all kinds, ideological, spanning both state and civil society interests, consumptive of vast amounts of public monies, highly complex and non transparent and difficult to reform and hold accountable. In almost all jurisdictions that can afford them, such agencies and systems have been growing in size and budgets almost without any permanent cessation in their aggrandizement. At one point prior to the creation of the US Homeland Security Department, the National Health Service in the UK was said to be the largest government agency on the planet.

Human services systems now have influence in almost all areas of life, including health, educa-

tion, social services, leisure, housing, mental health, disability, addictions, child protection and so on. Countless millions of people worldwide have become dependent upon these systems and services and many other millions of people who work in such systems are also now financially dependent upon their continuation to maintain their economic livelihood. So, it would not be stretching things a great deal to assert that human services are a defining feature of modern affluent societies and that they have become rapidly so in what amounts to a generation or two. Whether they will disappear as quickly as they emerged is unknown, but they are now a fact of life that we are just learning how to contend with.

One aspect of the emerging dominance of human services in the lives of increasing numbers of people, is the co-existent phenomena of how disempowering they can be for the persons who have to rely on them for important supports in their lives. It will be this aspect of their functioning that this paper will begin with by illustrating the ways that human service organizations operate in regards to delegated authority such that they deprive service users of their inherent capacity to be decision-makers and designers of many of the crucial features of how the services they receive could be provided. In particular, attention will be given to the role and uses of delegated authority in such organizations and the considerable variability in terms of who gets to exercise personal authority and decision-making and to what degree. Lastly, it will describe common examples of how people who have sought a higher degree of empowerment for service users have been able to succeed at doing so.

"Authority", in an organizational context, is normally the sanctioned use of power that is legitimately held by organizations and it is usually delegated from the highest levels in organizations to whatever lower levels might exist. Normally, delegated authority comes with conditions attached to its use and so the holder of delegated conditional authority, will be entrusted to use their authority within whatever framework of constraints ensures that such authority is used for its intended purposes.



Even so, it is important to recognize that authority can be used in quite different ways, such that there are distinctive patterns of its use that could be classified into descriptive "models of use" of organizational authority. In this instance, these "authority models" can be helpful as a heuristic for seeing the contrasting ways that authority can be used and the empowering or disempowering consequences of these models.

These models will be presented here using simple schemata that focus solely on how authority is used organizationally. In these models a small number of symbols are used. It is important to recognize that these models are designed solely to depict authority relationships in the service delivery process and are not intended to be complete representations of the entirety of the process of service delivery. Below is a brief description what each symbol refers to. They are coded for convenience.

- "A" represents people in roles of organizational authority such as professionals, staff, managers, etc.
- "B" represents people in service user roles including the primary service user and possibly their friends, family and networks.
- "(S)" represents the specific individual service arrangement provided to "B".

FIGURE 1
EXAMPLE ONE : "A FOR B"

A creates S for B (i.e. "A for B")

In this model, the service arrangement that is created for B i.e. S, is created, implemented and overseen entirely by people in the A role. Notably, A is creating the service arrangement for B and thus has all of the authority and organizational sanction to do so as well as the resources. Why this is the case is often justified by the idea that A is some sort of expert and has special knowledge or competencies that B lacks. B for their part may actually like the idea

that there exists an A that can devise a solution to their needs given that they would like their needs addressed effectively and this is what many services claim that they can do. In such an arrangement, B's role is one of being "needy", dependent upon A, unable to solve their own problems and willing to submit to whatever A offers. Needless to say, B will make no decisions at all in regards to the design, implementation and oversight of the proposed remedy for their needs i.e. S. In case it is not obvious, B essentially lacks any power or authority and is thus distinctly disempowered relative to service decision making in regards to the service they will specifically receive.

This model might nonetheless satisfy B to a great degree if they did get their needs met effectively. However, this model does not actually assure that outcome, as it would mean that everyone in the A role is competent to address potentially any and all of B's needs. Obviously, professionals and services may vary in their competencies, the state of the art may be such that no remedy exists at the time to meet a given need, there may be service capacity issues or limitations, or some in the A role may be in error, inept or otherwise harmful to B. This does not mean that the "A for B" model might not have *some* validity in terms of *at least some* potential outcomes, but even these would be predicated on a disempowering approach to service decision-making.

This model is the dominant underlying authority model in regards to service design and implementation in virtually all jurisdictions that can afford technocratic service systems, though there are instances in such systems where a different model of authority is in use. These notable exceptions will become more apparent as we proceed, but it is important to recognize that systems and even agencies embedded in them can have radically different ways of using authority and these can coexist within a system. However, though they are simultaneously present in a temporal sense, they most definitely do operate in distinctly different manners.

FIGURE 2
EXAMPLE TWO : "B FOR B"

B creates (S) for B (i.e. "B for B")

In this model, there is no one in the A role. B creates and implements their own solutions to their needs. B has control of all of the available potency, authority and resources that they can muster. "B for B" can operate either within an organization specifically set up to accomplish what they need, or B can operate entirely outside of service systems. This is because, in modern parlance, "B for B" is essentially what many people call "self help", i.e. B takes care of meeting their own needs through their own efforts and capacities. In the long sweep of history, this was essentially how most of humanity has gotten their needs met. In the current era, both informal and more formalized self help, grassroots and "bottom up" ways of addressing unmet needs flourish, but usually outside of or alongside formal service systems. Most people will get the vast majority of their needs met through actions they take to do so.

Obviously, if B is entirely in charge of crafting their own remedies to their needs, the only party that has that authority is themselves. Consequently, B does not have a disempowerment problem originating from how authority is being used, except possibly in instances where people in the B role might disempower themselves. In many instances, despite a presumption by many that professional solutions to meeting needs would work better than those crafted by ordinary citizens, the solutions created by B might be superior to what A might create. A good example of this would be a comparison of the outcomes of professionals trying to raise children in services and the results obtained by ordinary families raising children. Another example might be the contrasting benefits obtained when professionals entirely manage heart disease and the affected person remains passive and compliant, versus what happens when those with heart disease decide to rely on themselves to manage the disease through proactive stress reduction, diet and exercise.

Obviously, even with all of the potential potency, empowerment and other advantages of self help, this way of meeting needs will falter at the point where B is unable to find, create or pursue a means of self help that works to meet their need. If, for instance, B is unsure what is wrong or what would help, or lacks the means to pursue the remedy or is limited by other problems of capacity, then self help would be ineffectual. It is at that point that B often gains ground by seeking out others in the B role that can extend their ability to help themselves.

FIGURE 3
EXAMPLE THREE : "B FOR B"
VARIANT : "B WITH B"

B creates (S) with B (i.e. "B with B")

This variant on "B for B" is essentially an instance where B extends their capacity to meet their personal needs by joining with other people in the B role who may be able to help them with needs that they themselves cannot meet. In this sense, if you cannot fix your lawnmower, but your friend is quite adept at this, then acting together to get the lawnmower fixed can be accomplished without relying on experts or professionals, even if B rewards the friend that assisted with dinner. Barter and informal reciprocity, amongst people in communities, accounts for a great deal of how people get many of their needs met. Obviously, in the instance of, self help groups, B comes together with other people who share the same need and they extend their capacities to meet their needs through supporting each other.

This mutual support is easily seen in everyday life and in support groups of various kinds, but there are other forms of this that involve the mutual creation of shared specialized resources that are targeted specifically to both their personal and shared needs. In many significant ways, a credit union acts as a tool of its members to come together to meet common financial needs. Similarly, a small member governed grassroots service that creates in home supports for families supporting a family



member with dementia would also be a resource for meeting needs that could only exist through the creation of a collective resource in the form of a specialized community agency for this purpose. Another example might be where people with disabilities form a member controlled housing society that provides support so that each member can be assisted to live independently in their own home. Of course, these can only meet the unmet needs if those involved are aware of a solution to their needs and have the capacity to create it. These individual and collective self help strategies could be visualized as falling into these four broad categories of both "B for B" and also "B with B". Later in this paper we will make these options a little clearer in terms of how they are organized.

| | |
|---------------------------------------|---------------------------------------|
| Informal Individual Self Help Options | Informal Collective Self Help Options |
| Formal Individual Self Help Options | Formal Collective Self Help Options |

FIGURE 4
EXAMPLE FOUR : "A WITH B FOR B"

A with B create (S) for B (i.e. "A With B For B")

One of the obvious additional limitations with self help is that it can at times focus principally, or even exclusively, on what the person or collective can do to meet their needs solely through their own efforts. It does not always address the fact that professional and agency resources can be combined with self help strategies, though many people in the B role would very much like this to be the case. The difficulty of course, as can be seen in the "A for B" paradigm, is that unless the relationship between A and B is set up such that they can fashion a partnership agreeable to both, then the relationship between A and B may not be sound enough to properly capitalize on what each could bring to the table.

If conditions are such that neither A nor B sufficiently trusts the other, then there would not be a basis for A and B to come together to devise a service arrangement (S) that is optimal due to the adaptive blending of what A can bring to a problem with what B can bring. Obviously, if an eventual service solution can draw on the strengths of both A and B, then the resources of both will be reflected in the outcome, thereby expanding the benefits that B could garner from those obtained through their own efforts, to a merging of these with the resources that can be obtained through the world that A inhabits. Though such a fusion of solutions may present any number of technical issues that could limit this theoretical potential for an enhanced outcome for B, there nevertheless remain many advantages for B if the partnership can be made to work.

The crucial initial issue is normally going to be that of establishing "right relationship" between A and B, such that an ethical and honorable partnership ensues and this, in turn, enables A and B to establish sufficient trust to make their way through the many technical challenges involved in crafting optimal solutions to B's needs that eventually do work to B's advantage. Even if A and B are thwarted from achieving quite as much as might be hoped for, there may still be considerable merit both in terms of the "right relationship" benefits that are obtained, as well as the quality of the response to B's needs that such a partnership can conceivably yield.

It is not assured that A and B, even with a quite optimal partnering relationship, will always be able to come up with a response to meeting the needs of B, simply because there may be many instances where neither A nor B knows, or has the capacity to create, effective solutions to the needs of B. In other words, the "state of the art" may simply be so inadequate that even their combined efforts may end up being inadequate due to the absence of a substantive answer when it comes to addressing the needs of B. For instance, in many areas of service provision, neither A nor B has a good sense of what ideal answers, if any, might exist to meet people's needs because the field (or

science) itself simply has not as yet solved the inherent problems. This can be seen, for instance, in the persistent difficulties in defining and treating autism, the huge guesswork involved in managing epilepsies, the inability of service systems and families alike to deal adequately with the social inclusion needs of people with disabilities and so on.

Nonetheless, the "A With B For B" formulation can help resolve the disempowerment problem, if A and B essentially have equal power, such that all key decisions are joint decisions of A with B. This, of course, presupposes that an agreement exists between them that this will be the case and that such an agreement is negotiated to both parties liking. It would also require that a structure and process accompanies such an agreement that largely works in practice to each party's satisfaction. Neither A nor B can act unilaterally in such a joint decision making framework, though it is quite likely that A and B will variably each contribute more or less depending upon what challenge has to be faced and what each may have or not have to contribute at that moment. This is quite predictable, given that A and B should be normally have their own unique strengths and limitations depending upon the problem to be addressed. In organizational terms, an arrangement would be needed wherein the organization that is created or modified to be congruent with the "A With B For B" premise, assigns equivalent authority to both A and B to each be decision makers and that A and B proceed with decision making in the joint manner prescribed. In some instances, it is possible for such an organization to go further than to stipulate a joint decision making model and instead take a stance whereby the organization states it preference to normally defer to B's decisions, if at all possible.

This stance of positive presumption that B will most likely make the best decision most of the time, would not mean that A and B were not in a partnership, nor that B somehow had gained license to do as they please on the strength that the organization preferred a situation that eliminated as much as possible the kinds of unilateral empowerment of A that was seen in

the "A For B" model. Rather, what the preference for B to decide key matters first would represent, is simply an intentional deference to B symbolized by the courtesy of extending first decision making prerogative, the first and prominent presumptive role of B being the likely decision maker wherever possible. Nonetheless, A does not relinquish its authority or its option to disagree with B. Instead, it would represent a decision to give priority to B, since B is the party most likely to be affected by any such decision. Nonetheless, both sides would recognize that the relationship and partnership will only work through good faith negotiations between A and B. Otherwise, both are stymied and each party will have to weigh whether they might do better with staying in the agreement or abandoning it. As such, what is essential to such agreements is that they are voluntary in nature rather than that either party is compelled to cooperate by a higher authority that cannot be defied.

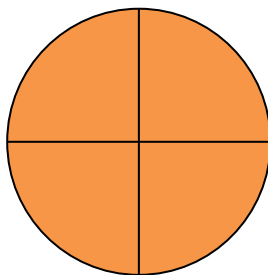
The Question of the Scope of Service Delivery Decision Making Authority Available to Service Users : Levels of Empowerment

The circular figure on the next page is essentially a representation of decision making as it relates to the entirety of a service arrangement for a given individual i.e. an (S) as per the previous models of usage of authority. If one asked most people whether they would like to personally make *only a portion* of the decisions made about how their personal support might be managed, they would be quite dissatisfied. In other words, the authority to make 25%, 50% or even 75% of service delivery decisions would be unacceptable in comparison to making 100% of such decisions. Consequently, it becomes clear that there might well be a continuum created in some personal service governance arrangements wherein the service user is authorized by service organizations to make only a percentage of the overall decisions about their specific service arrangement. In contrast, there might also be a situation where this same service user might have the delegated authority to largely make most of the key decisions in regards to service delivery. It all depends upon what portion of the decision



making is delegated to them to make. Since most people seem to prefer to be "captain of their own ship" and authors of their own destiny, having near to 100% of most decisions be theirs to make, then we could imagine a continuum from virtually no decision-making authority regarding services to almost complete authority to make most decisions.

FIGURE 5



If this continuum were plotted from low to high levels of empowerment, then something like the following sketch of "levels of empowerment" might capture this variation from low to high levels actual decision making relative to the designing and implementation of a personalized service arrangement.

- **Level One (Passive)** : The person is largely in a passive and compliant role. The service authorities make all of the decisions.
- **Level Two (Informed)** : The person is informed on occasion about what the service authorities have decided to do i.e. upcoming service practices are explained to the service user.
- **Level Three (Consulted)** : The person is consulted on occasion concerning service matters and gives advice when permitted to do so. The person possibly serves on an advisory committee.
- **Level Four (Significant Minority)** : The person is authorized to make up to a significant minority of the decisions concerning their service arrangement.
- **Level Five (Significant Majority)** : The person is authorized to make up to a significant

majority of the decisions concerning their service arrangement.

- **Level Six (Almost All)** : The person is authorized to make almost all of the decisions concerning their service arrangement, such that they are essentially now unconcerned about disempowerment.

It is likely that the vast majority of people receiving services in conventional "A for B" service models would be at Level One and Level Two most of the time, with the exception being those considerably rarer instances when they are asked their views in regards to at least some aspects of their personal service arrangement. Even so, the decisions that those with service authority will be making with the benefit of this consultation, will still be theirs to make unilaterally in their "A" role, since advice does not have to be heeded. Though conventional services will, on occasion, speak the language of partnership, empowerment and what-not, their actual habits of service decision making are largely unilateral, top down and non-negotiable. Since, the service is "theirs" to manage then the role of those who get the service is described with terms such as "service user", "service recipient", "consumer", "client", etc. These terms quite correctly portray the person as taking advantage of a service, but clearly not designing and overseeing that service, hence their passive role as "receiver" of a service designed and overseen by others. Curiously, a person in an A role who may have been hired the previous week, will normally have more authority in regards to what they service user may receive than will the service user, even though it is their life that will be impacted by such decisions.

Negotiable Service Design And Oversight Rather Than Prescriptive Models

It has become increasingly common for governmental systems to create policy in favor of ways of operating that are variably referred to as "self-directed", "self determined", "consumer/family governed" and the like. In most instances, some version of individualized funding is simultaneously put in place to enable the



person to have an allocation of a set amount of resources over which they have authority for spending purposes. These remain public funds usually, but with the provision that the person now has say in how they should be spent.

Typically, these notably more empowering options can be subdivided into service arrangements that the person directly oversees *and* administers or service arrangements which the person opts not to administer directly, but still retains complete key decision making authority even if they choose not to always use it and instead let the service provider make the decisions as long as they are to their liking. The former option is quite attractive to many people who do not feel burdened by the workload, demands and bureaucracy involved in the self management of an individual service arrangement. Those who opt for personal governance, but without an accompanying set of administrative duties, will usually be people who want to maintain unambiguous decision making authority, but are averse to what they see as the personally burdensome tasks that come with direct service management responsibilities. As such, the "personal governance" of an individual service arrangement can be achieved with either option, routinely at empowerment level five or six.

Obviously, when all aspects of an individual service arrangement can be negotiated and decided by a partnership between A and B, then B is no longer passively involved. Instead, B would have decision making rights. These "rights" to negotiate would not be the same as "entitlement rights", since an entitlement bestowed by a government or system is essentially a guarantee of a particular outcome, such as a right to an education, a minimum wage, access to housing or health care and so on. In contrast, "participation rights" are rights to be part of *the service design and operation process*, but these do not extend to the assurance of a particular outcome or entitlement. In many systems, the authorities have no choice in the matter, as they are not authorized by law to make such entitlement commitments. Typically, such systems serve people not on an entitlement basis, but rather on a "resource permit-

ting" or priority driven basis based upon what resources are available at a given moment.

Nonetheless, when people are offered the chance to negotiate the design, funding and operation of their service arrangement, it transforms services from being "set" or "fixed" models and makes them much more flexible and responsive to the specific requirements of the end user of the eventual service arrangement. Even so, these flexibility gains would inevitably be constrained by the capacities of the service itself. In essence, the service user would normally seek the best available service arrangement that could be shaped at the time, but would eventually have to settle since that is always the ultimate result of a negotiated solution. Consequently, while the service user is notably empowered as a decision maker in negotiated flexible arrangements in comparison to conventional "A for B" power arrangements, this does not mean that the service arrangement itself will be entirely satisfactory, whatever its comparative advantages with what might have preceded it.

Common Well Established Organizational Options That Are Empowering For Service Users

There exists, in many locations, a variety of organizational options that routinely ensure that the service user exercises Level Five or Six decision making authority. These examples have often been in operation for decades, though it is quite common that many people do not know that they exist and how they operate. This is likely to change as the principle that the service user is best served in empowering service models gains greater policy prominence. This gain in empowerment for the service user does not necessarily mean that the service arrangement itself will be of high quality, as these challenges are separate matters and are driven by quite different factors. Even so, there would still be some people who would assume that if a service is empowering it will also be of good quality given how much the empowerment dimension has been touted by advocates as being the "*sine qua non*" of desirable service practices. In reality, achieving comprehen-



sive service quality at a high level is a complicated and multi dimensional undertaking.

The Member Directed Mini Agency

It has often been the case that service users who have wanted a more empowering service arrangement have joined common cause with others who shared this same ambition. Together they have formed small member governed agencies that have ensured that they had the ultimate authority to design and oversee their own service arrangement as a matter of organizational policy. Since they are not hostage to the policies of an existing agency controlled by others, all of the residual decision making authority regarding the design and ongoing oversight of their service arrangements is theirs to exercise. Since they control the mini agency's governance board is dominated by the service users who are the organization's members, the members essentially have collective governance authority over the agency itself. At the level of each member's personal service arrangement, it is normally the case that each member would direct their own service, though its actual administration might be assigned to the mini agency.

The mini agency typically would have its own distinct philosophy with service user empowerment being prominent as one of its core aims. Its legal status is that of an incorporated body with a governance constitution that ensures that the members remain in control of their agency. This type of organization would have essentially the same administrative relationship with funders as would any agency including the usual requirements for transparency, audits, periodic reporting adherence to contractual obligations and so on. Since much of this kind of burdensome bureaucratic work would be carried by the organization itself, it is quite common that the service user would be spared having to carry it personally. In some instances, if the mini agency is allowed to grow in size to the point where the governance board represents only a small portion of the actual members, then a given member may retain considerable authority over their own personal service arrangement i.e. "personal gover-

nance", but have only weak influence on collective governance. This is why many of these organizations limit their size so that the individual members have significant influence and authority in regards to both forms of governance.

In many localities, these mini agencies may be referred to as "collectives" or "cooperatives" with the focus of their work being to support the members to have the capacity to be in charge of their own service arrangement. These service cooperatives might quite easily grow out of informal self help groups and networks and are formed at the time where it becomes necessary to have an incorporated body in order to receive funding for the services they seek to create. Depending upon the type of funder and the type of service being sought, the members may be allocated quite different amounts of funding that might vary according to their needs. This allocation may be made by the funder on an individualized funding basis or, in some instances, a large block of funding is given to the mini agency and this is then allocated internally to the members.

Incorporated "One Off" Individual Service Arrangements i.e. "Microboards"

In various jurisdictions, most notably in western Canada, there has existed for many decades what are called "microboards". These are specially created incorporated agencies designed to support the administration of a single person's service arrangement. They often arise because there may be individuals or families that are dissatisfied with what is offered by mainstream agencies and want instead to design and oversee their own service arrangement. In most instances, this will mean that they also have to administer it as well, though some aspects of this task can be sub contracted. Since all incorporated bodies need to have a constitution and a governing board, the individual service user would then legally need to share governance of their service arrangement with a sufficient number of other people. This creates an opportunity for the person's control and authority to drift into the hands of others, thereby potentially leaving the person some-

what vulnerable to losing control if they do not have the means to control who gets to be appointed as well as whether his or her personal empowerment is enshrined as a core purpose in the organization's constitution.

Like all other incorporated agencies, these "microboards" will have to partner with funders in order to receive funding and this brings with it all of the usual compliance requirements of governments as well as compliance with not for profit or charitable organization obligations such as the holding of annual general meetings, the maintenance of a governing board and so on. All of these obligations, taken as a whole, can involve a considerable amount of work, particularly when combined with ongoing service administration responsibilities such as staff recruitment and supervision, scheduling, acquiring insurance, reporting, data collection, payroll and the creation of enough monies to assure whatever minimal fund balance is stipulated by funders for purposes of maintaining cash flow. It is a testimony to the level of dissatisfaction with the disempowerment encountered in conventional agencies that people would taken on such burdensome responsibilities and see them as still being better than being subordinate to conventional services.

Unincorporated "One Off" Individual Service Arrangements

The requirement that individuals be legally incorporated in order to receive government monies may not always be a requirement. Consequently, in such localities, it then becomes possible for individuals to obtain funding for individual service arrangements directly from governments, but to instead administer these monies through a special agreement with the funder that would function as a contractual agreement. Typically, this would require budgetary transparency and all of the usual compliance obligations of agencies, but often in with an intentional reduction in the bureaucratic burdens these may pose to individuals whose service arrangement it is. In some instances, the funder will allow or even encourage the involvement of various support organizations to ease the workload and demands on the person

such as payroll services, "fiscal intermediaries" or even subcontracts with existing agencies for various routine administrative or bureaucratic functions.

Obviously, while the individual may be more empowered relative to what might be the case in conventional service arrangements, it should not be assumed that the level of funding is adequate, nor that the person will be proficient in creating a high quality service arrangement, quite apart from whether there will be worrisome vulnerabilities present for the person that are not properly offset by sufficient safeguards. These qualitative dimensions of the service arrangement and its overall effectiveness, apart from its empowerment dimensions, will vary from one situation to another and whether the individual is supported with these challenges will often depend upon whether these types of issues are recognized and taken seriously by both the service users and the authorities. Again, a lot will depend upon how what is assumed by people to be involved in assuring quality.

Agency Hosted Unincorporated Individual Support Arrangements

In these kinds of arrangements, the service user will seek out an existing agency that they can partner with while still maintaining the necessary Level Five or Six decision making authority. Typically, the agency will take care of most of the administrative and bureaucratic work as per the individual's preferences and the decision making regarding the design and oversight of the service arrangement then technically becomes shared between the person and the agency. This is because the "hosting" or "auspice" role means that the service arrangement is now legally the agency's responsibility, even if that agency chooses to assure, by written agreement with the person, that the person will remain empowered. Practically speaking, these arrangements mean that the person does not need to be incorporated, as the agency takes up this function as well as most other bureaucratic, financial and administrative functions subject to whatever supervision arrangement the two parties negotiate in



regards to these functions. The "employer of record" would be the host agency though typically the individual provides the oversight and supervision of the staff that they select and utilize for their supports.

It is normally the case that these individual hosting agreements are of the "A and B for B" variety, though this will depend upon the precise understandings and interpretations each party has in regards to empowered decision making as well as service quality. In many jurisdictions, it is common practice that the hosting partnership arrangement can be dissolved by either party, usually in a prescribed orderly way, should they no longer want it to continue. This often requires the tacit or explicit consent of the funder that the individual's funding can be moved to other agencies, should a new hosting arrangement be formed. In effect, the hosting arrangement is a "stand alone", internal, semi-autonomous, arms length, self governing individualized service arrangement that is able to function quite autonomously from how the given agency might operate its other services. The limits of this operational autonomy are specified in the hosting agreement and concluded by negotiation.

Agency Hosted Unincorporated Collectively Governed Individual Support Arrangements Project

This option is based on the creation of a member governed (collectively governed) project to provide individual service arrangements. At an operational level, it allows for the formation of specialized projects targeted to the requirements of the involved members for individual supports optimally suited to their specific personal needs. It largely resembles an incorporated member governed mini agency or cooperative, except for the fact that it is hosted by an existing agency rather than being incorporated itself. Like an individual hosting agreement, the project would seek a negotiated hosting agreement with the host agency and thereby come under its legal authority but retain a semi-autonomous, internal, arms length manner of operating. It is common that the governing board of these projects negotiates and settles

their host agreement details with the board of the host agency rather than the senior staff of the agency, thereby cementing a board-to-board relationship. This negotiation can often take several years to finalize. However, once they are finalized as acceptable to both parties, they can often be in place for years without any adjustment.

These projects can provide their members with the kind values solidarity that they seek concerning their shared needs for empowerment and personally tailored individualized services. It also allows for the easy sharing and accumulation of experience and expertise over time, thereby greatly reducing the need for people to repeatedly "start at square one", as a roadmap already will exist for how to solve various problems. These projects are quite complicated to set up, though their day to day operations once established is usually relatively easy to oversee once the start up phase is done. The people that start them normally will have to be very proactive and provide considerable leadership to bring them into existence. However, people who join them once they are established will bypass these challenges and simply have to contend with the comparatively easier ongoing operational issues. Like all of the previous examples, these projects may also have quality of service issues and similar challenges notwithstanding whatever empowerment gains they may ensure.

Conclusion

What this paper has briefly described is the thinking behind empowered decision making in the design and operation of services and the typical kinds of well established organizational arrangements that support these. It makes it clear that such arrangements are feasible and that the thinking underlying them can be quickly grasped. It also makes clear that while empowerment around service governance can be obtained, this does not always ensure that the resultant service necessarily is going to be of high quality, nor does it assure that the person's needs will always be met by the resulting service arrangement. However, neither does it mean that high quality of service cannot be

coupled with high levels of empowerment. Rather, it simply suggests that each challenge be taken up in their own right.

References

- BRAGDON, T. (2009). *The case for inclusion 2009 : An analysis of Medicaid for Americans with intellectual and developmental disabilities*. Washington, DC : United Cerebral Palsy. Retrieved from <http://www.ucp.org/uploads/inclusion%20ReportLR.pdf>
- BAMBARA, L. M., & AL. (1998). Translating Self-Determination Concepts Into Support for Adults with Severe Disabilities. *Journal of the Association for Persons with Severe Handicaps*, 23, 27-38.
- BROWN, M. (undated). *Self Determination And Independence Versus Force And Dependency*, National Empowerment Center Articles, National Empowerment Center, Lawrence, MA.
- BROWN, F., & AL. (1998). Self-Determination for Individuals with the Most Severe Disabilities : Moving Beyond Chimera. *Journal of the Association for Persons with Severe Handicaps*, 23, 17-26.
- CHAMBERLAIN, J. (undated). *A Working Definition of Empowerment*, National Empowerment Center Articles, National Empowerment Center, Lawrence, MA.
- CONSUMER DIRECTED HEALTH CARE (2004). *How Well Does it Work?* National Council On Washington, DC.
- COPEMAN, I. & KING, N. (2009). *An evaluation of a community cooperative for people with learning disabilities in the East End of Newcastle Upon Tyne*. Housing & Support Partnership, Northern Rock Foundation.
- DEHEM, J., & CHAPMAN, L. (1997). Self-determination : Transferring agency control by Re-thinking its role. *TASH Newsletter*, 23(10), 9-11.
- IMPLEMENTATION OF CONSUMER-DIRECTED SERVICES FOR PERSONS WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES (2009). A National Study, Policy Research Brief, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota, 20(1).
- FENTON, M., ENTRIKIN, T., MORRILL, S., MARBURG, G., NERNEY, T., & SHUMWAY, D. (1997). *Beyond managed care : Volume II, an owner's manual for selfdetermination*. Durham, N.H.: University of New Hampshire, Self-Determination for Persons with Developmental Disabilities, Institute on Disability.
- KENDRICK, M. (2000). Examples of Some Successful Strategies in Empowering Those Who Utilize Services. *Interaction*, 13(2).
- KENDRICK, M. (2001). The Limits and Vulnerabilities Of Individual Support Arrangements. *Interaction*, 15(2), NCID, Australia.
- KENDRICK, M. J. (2002). "Self-Direction" In Services And The Emerging Safeguarding and Advocacy Challenges That May Arise, Discussion Paper of The Connecticut Office of Protection And Advocacy For Persons With Disabilities.
- KENDRICK, M. J. (2004). Levels of Empowerment. *Planet Advocacy*, 7(March), 6-7, London.
- KENDRICK, M. J., PETTY, R. E., BEZANSON, L., & JONES, D. L. (2006). *Promoting Self-Direction And Consumer Control In Home And Community Based Service Systems*. ILRU Community Living Partnership, National State To State Technical Assistance Center Publications, Unlocking The Code Of Systems Change Papers, ILRU, The Institute For Rehabilitation And Research, 2323 South Shepherd, Suite 1000, Houston, Texas, 77019.
- KENDRICK, M. J. (2008). The Key Ingredients Of Optimal Partnerships Between Service Users And Families And Their Possible Human Service Partners. *Interaction*, 22(2), Canberra, Australia.
- LAKIN, K. C., FIELDS, T., SELTZER, B., & AL. (2000). *A Guidebook on Consumer-Controlled Housing for Minnesotans with Developmental Disabilities*, 2nd Edition, Arc Minnesota and the Institute On Community Integration.
- MOSELEY, C. (2000). *Making self-determination work*, Durham, N.H. : University of New Hampshire, Self-Determination for Persons with Developmental Disabilities, Institute on Disability.
- MOSELEY, C., LAKIN, C., & HEWITT, A. (Eds.) (2004). *Impact : Feature issue on consumer-controlled budgets and persons with disabilities*, 17(1). Minneapolis, MN : University of Minnesota, Institute on Community Integration.
- NERNEY, T. (2007). *The Meaning of Self Determined Lives In Publicly Funded Systems Of Long Term Care*, Center On Self Determination Publications.
- OLMSTEAD, J. (1999). *Implementing self-determination : Perspectives from eleven states. Research and data analysis for Department of Social and Health Services*. Olympia, WA : Washington State Department of Social and Health Services.
- POWERS, L. E., & AL. (Eds.) (1996). *On the Road to Autonomy*. Baltimore : Paul H. Brookes.
- REINHARD, S. C., WALSH, M. A., BEMIS, A., & HUHTALA, N. (2005). *Participant Centered Planning and Individual Budgeting*, State Policy In Practice, Rutgers Center For State Health Policy.
- RYAN, R. M., & DECI, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55, 68-78.
- TRITZ, K. (2005). *Long-term care : Consumer-directed services under Medicaid. CRS Report for Congress*. Washington, DC : Congressional Research Service.
- WAGLE, R., AGOSTA, J., & MELDA, K. (2004). *Arkansas consumer directed personal assistance services and supports : Project evaluation. Prepared for the Division of Developmental Disabilities Services*. Portland, OR : Human Services Research Institute.
- WALKER, P. (2009). *Getting A Life In Wayne And Oakland Counties, Michigan : Using Self Determination As A Foundation For Organizational Change*, Center on Human Policy, Syracuse, NY.
- WEHMEYER, M., & STANCLIFFE, R. J. (2003). *Self-determination across the lifespan*, In M. L. Wehmeyer, B. H. Abery, D. E. Mithaug, & R. J. Stancliffe (Eds.), *Theory in self-determination : Foundations for educational practice* (p. 299-311). Springfield, IL : Charles C. Thomas.

