

**Title: Family Governed Flexible  
Family Support: The  
Massachusetts Small Project  
Example**

**This paper was sponsored by  
Massachusetts Families Organizing for  
Change and Uniting Families for Change Of  
Western Massachusetts**

This is an unpublished paper was written by;  
Michael J. Kendrick PhD  
January 05, 2001  
Please do not duplicate without permission  
Please send comments to:  
Email: [kendrickconsult@attglobal.net](mailto:kendrickconsult@attglobal.net)

## The Massachusetts Family Governed Flexible Family Support Projects

Considerable interest exists in the strategy of supporting grass roots family governed family support projects that has occurred within the state of Massachusetts. This strategy was developed extensively during the 1990's and continues in the present. This paper will attempt to describe and analyze these projects from the viewpoint of the key lessons they offer for how services of any kind might be developed. It should be recognized that the situation in Massachusetts is a dynamic one, and it is quite possible that events may overtake this quite limited portrayal of conditions there.

This strategy developed initially in the region of western Massachusetts in the form of several pilot projects. It eventually spread quite widely throughout that region and quickly, though not nearly as extensively, took hold in various instances in the other four regions of the state's Department of Mental Retardation. All of what had first begun as pilot projects became permanent ongoing community services. The earliest projects were, by the year 2000, over a decade old, and the total number of such projects of this kind in the state is estimated to be from 30-50 projects of all different sizes and focal groups. It is estimated that these projects now serve many thousands of families. There is, at present, no statewide compilation of the core data concerning these initiatives.

These projects developed with considerable momentum in western Massachusetts, as the success and example of one project stimulated the development of another. Very early in this process, family groups organized around the ethnic and cultural needs of minorities, quickly saw the merit of the approach, and thus spawned initiatives in the Hispanic, Haitian and Cambodian communities, to be followed later by other minorities in the State. The period of rapid growth of these projects largely came to an end by the mid 1990's, though a very small number of new projects continued to form in the Boston metropolitan region and in western Massachusetts.

There are many strategies that can be summoned to assist with the empowerment of families. Consequently, this particular strategy should be seen as being able to co-exist with and benefit from other deliberate empowerment strategies. For instance, the considerable efforts by proponents of families to ensure that people from linguistic minorities could access family education, leadership development and family support services in their own language has been dramatically successful where attempted in Massachusetts. This strategy has been very much helped by the ability of cultural and linguistic minorities to design and oversee their own family support, as well as participate with great prominence and ease in mainstream family organizations.

The programs described here, as well as the systemic strategies that made these outcomes possible, are very positive in the benefits that have flowed from them. Nevertheless, in describing a situation such as this where progress has been both real and enduring, it is also important to note that what may exist “in principle” or “on paper” may not be present quite as fully in practice. The instance of Massachusetts is no different. Families in Massachusetts by no means feel secure that they are entirely in an empowered role, even if there are presently many advantages in their situations that they can point to. Families continue to encounter all sorts of people, situations and attitudes that are often hostile to the kinds of ethos and ethic described here. They also widely perceive that their relative position is eroding in the State and is in need of defense. Nevertheless, the gains and advantages presented here have endured and are still in effect for the moment. What the future may bring is, of course, to be determined.

The essential principles that underlie this flexible family governed support strategy have also been present in various guises within some services in Massachusetts that families rely on beyond family support. This would include transportation, residential services, day services, employment and so forth. This paper will not take up these, though their ethical and philosophical foundations and practices would constitute a kind of allied or “sister” effort to strengthen the influence of service users and families. These presently lack some elements of the overarching bureaucratic legitimacy and protection that the Massachusetts Department of Mental Retardation Family Support Guidelines provide, but they nonetheless constitute a long established and significant minority of the mainstream services in Massachusetts. Nonetheless, they share the insecurity of being tolerated by the mainstream, but at times without much robust official or professional enthusiasm for their aims.

## **The Essential Features Of The Family Governed Family Support Projects**

### **Trust That Families Can Substantially Define and Prioritize Their Own Needs Themselves**

A defining ethic of these projects, which was eventually incorporated officially into the State’s Family Support Guidelines, was that families were capable of, and ought to be the key definers of what “family support” should mean in their particular instance. It started from the premise that families were qualified to define their needs, as well as craft adaptive responses to them. Further, it posited that professionals were not necessary for this purpose, nor ought they be put in a position of having more authority on these matters than the families themselves.

It did not mean that professionals were unwelcome, just that they would play a role only as individual families thought best. It did not presume that families were infallible, or that they wouldn’t benefit from the assistance of

others in defining and meeting their needs. It simply gave families the recognition and responsibility to be the authors of their own family support strategy. It is also important to note that this premise incorporated a view of families as still learning, rather than that they were invariably expert on many matters.

It would be useful to note that this ethic also captures the sense that families are not merely family support “problems” waiting to be solved. Rather, families are seen as having their own strengths, creativity and resilience, that can be tapped into as part of meeting the family’s needs. This might be put as an emphasis on families not being seen as solely “deficits” but as also having “capacities”. It also means an openness to families as being people who will behave responsibly and whose stewardship of their family members best interests should not be reflexively doubted.

### **An “Open Menu” Of Family Support**

The overriding principle is that these projects do not provide a “fixed” or pre-determined menu of services, but rather that the support that is offered is defined by the people served. Some people refer to this as the “whatever it takes” principle. Priorities and needs arise from each family on a family-by-family basis. These needs, and the priorities that families may give them, are the basis of creating “family support”. Consequently, virtually nothing is excluded from the category “family support” if that is how families define it. It is often noted that what may make sense to a family, from its viewpoint “inside” that family may often puzzle outsiders. However, there are often quite good, but not always obvious reasons why families have had to act as they have.

### **The Flexibility Of Family Support**

The family support that results from the family governed projects is not “fixed” into invariant categories, nor is it something that has to be received in a set pattern such as “x” numbers of hours per month or week. Families have the option to vary what they receive daily, weekly, monthly or in any pattern that best suits their family. Most families do not require such ultimate flexibility, but the option is there for them should it be needed. It is not assumed by this that an infinity of family support resources are available. On the contrary, such resources are seemingly always scarce, so the meaning of flexibility in this context is in its reference to flexibility in regard to what is available or in hand. Part of the advantage of flexibility in the “how to” of receiving support is that it permits the needs of families to change unexpectedly from one point in time to another. Consequently, the plan of family support can be changed almost as easily.

## Families Ought To Govern Family Support Services: The Mechanics Of This

It followed from the granting to families of trust and confidence, at least as a starting premise such as the principle of positive presumption in an honor system, that families should have the guiding authority in the shaping of family support. This took two basic forms. The first was that family support projects, initiated by groups of families were formed and largely controlled or "governed" by these same families. These families arose or came together as groups, in a myriad of ways, some expedient, some thoughtfully and others quite casually. Almost always there was some manner of facilitation involved.

These family groups were characterized in various ways by their needs and circumstances. Often, the communities they came from were lacking in some of the supports they needed. Often these communities were ethnic, cultural or linguistic minority communities and thus the projects were defined by these factors. These included projects for inner city African Americans, Cambodian, Chinese, Vietnamese, Russian, Hispanic, Haitian and other groups. In other instances, families from these same backgrounds were successfully supported to be part of existing family support projects.

Sometimes the defining need was not variables such as these, but rather other needs of family such as geography, (there were quite different challenges that families faced in rural and small communities), the age of the families, (there was one project just for widows over 70 years of age with disabled offspring still living at home), particular priorities, (there was one project for intensive in-home medical care for families with family members with significant health issues, a regional project having various concerns relating to autism) and so on.

The projects were typically governed by some sort of overseeing committee, that was elected from the families who were the projects "membership". Almost universally, the projects were not incorporated. They usually entered into what were quite distinctive "hosting" or auspice arrangements. These commonly took the form of semi-autonomous internal "mini-projects", within the legal framework of existing not for profit organizations.

These organizations would act as a "host" for the project, and the specific terms of this hosting were negotiated between the families and the organization concerned. For the most part, these projects operated outside of the normal chain of command and structures of the given agency. They usually functioned quite autonomously in this regard. Importantly, they could elect to leave the host organization and find another if they were dissatisfied with the way the hosting relationship transpired. This happened only rarely, as the host

agencies, by and large, respected the need for the projects to function under family rather than agency governance.

The Department of Mental Retardation, as the key funder of family support, supported these arrangements in several important administrative ways. One was to essentially transfer family support funds to the overall control of families via these projects. The second was to permit family projects to change hosting organizations. These arrangements were accomplished through the Department's normal contracting for service mechanisms and were not specifically addressed in the State's guidelines. Nevertheless, as a matter of practice, the funder has accommodated such requests. In these contractual arrangements, the host agency acted legally as the designated agency funded to provide family support, but did so via the mechanism of a family governed project. The projects had to abide with all state imposed obligations on service providers.

In practice, almost all of the projects had their "own" staff to help them accomplish the work of the project that they hired, guided and let go as the case may be. In a legal sense, these employees were employed by the agency, but the agency delegated their supervision to the family governed projects. The family governed projects live under the same contracting, audit and funding restrictions as any other funded service though the average participating family may never notice most of these since either the host agency or the projects own staff typically handles most of these bureaucratic demands. All of the projects establish their own form of governance, establish who is a participating family, set their own priorities based on the needs of the families and gear their spending accordingly.

These arrangements occur under the authority of the funder's guidelines, the "Family Support Guidelines" of the Massachusetts Department of Mental Retardation. This document, (still in effect), contains guiding principles that authorize flexible family support and the use of any public funds designated by the Departments area and regional service contracting officials for this purpose. Public funds are transferred via the usual purchase of service arrangements to eligible agencies. Once in the agencies, the host arrangements take over, and the control of the funds is delegated to the participating family governance mechanism that then distributes resources to each family according to individual need.

The amount of funding received by each project is negotiated with the funder annually, depending on need. Individual families can request both direct cash assistance from these projects, as well as general assistance in defining their needs, accessing other resources and so on. There is no upper "ceiling" for a given family as to what amount of funds they are eligible for, though the average family would receive only modest support of less than \$1000.00 per annum. Nonetheless, there are families served whose needs are so extensive

that they receive many tens of thousands of dollars of support each year. Each family negotiates their funding with the project governance group, usually with the assistance of project staff. In some of the earlier and quite small projects, the families simply divided the available funds equally, as they had difficulty coming up with rationales for an uneven distribution that reflected differing family need.

The project as a whole, usually involving the host agency, deals with the funder on budgetary matters. Once the project receives an annual allocation it must, like everyone else in the world, live within this budget. Each participating family must submit an annual one page report on what it has done with the resources it received that year. Other than that, the individual family has no other "official" obligations. In some projects, participating families are urged by the project itself, to attend occasional meetings, but this is not a requirement in the official Guidelines of the Commonwealth of Massachusetts.

One obligation of only some participating families, specifically those receiving more than \$3000.00 per year, is to keep receipts. Families below this threshold do not usually have to do this as a stipulation of the State Guidelines. Nevertheless, in some instances, the host agency may request that this be done due to the host agency's unique surmises about what other regulatory State agencies might consider prudent, such as the State Auditor. The "close scrutiny" monitoring mechanisms, such as tracking receipts, make the most economic sense only in regards to the relatively small percentage of families whose allotment is in the "big ticket" range.

In effect, the projects oversee and hold families accountable, and could conceivably act to restrict their use of funds if problems developed. This is almost unheard of in practice, given that most problems are ironed out informally, if they occur at all. It was originally a great worry amongst many persons that families ought not to be trusted with cash assistance, as they would invariably do something irresponsible or even criminal with such funds. To the credit of families overall, such conduct has been virtually unheard of, and easily resolved when detected. It is a real possibility, but at such a very low percentage of families, that managing this sort of problem does not figure very prominently in either the Guidelines or daily practice. Curiously, people unfamiliar with the actual operation of these programs, are the ones most likely to raise this issue.

### **An Appraisal Of The Benefits Of These Projects**

These projects have produced many benefits that may not be immediately apparent. They are briefly noted and discussed here, with a view to establishing their importance. Some of the benefits are for the individuals served and others relate more to their programmatic or systems related benefits.

## **Direct Family Related Benefits:**

### **The Projects Affirm The Value Of Families**

The process of supporting a person with a disability, in the context of the usual strains of family life these days, ought not to be underestimated in terms of what it takes. Inevitably, many families can become worn out to some degree by the responsibilities involved, and the many hassles involved with the plethora of agencies, professionals and bureaucracies this entails, can be quite demoralizing. Consequently, hidden amongst the pressing needs of these families, is a need that their labors, commitment, worry and resourcefulness be given worth and value.

Not surprisingly, one of the comments made regularly by participating families, is the pleasure and comfort it brings to them to be able to deal with a project that values and affirms them. This is not unique to these projects as such affirmation may come through other means. Nonetheless, a certain weight must be given to their relief to be able to deal with people, they describe as being, "people who one doesn't have to explain things to", i.e. other families "like us". In this sense the projects are clearly "family friendly", irrespective of any other practical benefit that may come with them. It is also significant that the family is "trusted" as a starting point, rather than automatically being presumed to be a pathology waiting to happen. This is affirming of the premise that they both have the capacity to do the right thing and likely will do so when given the chance.

### **Families Are Not As Isolated**

It has long been recognized that people function immeasurably better when they are receiving regular social support, whether this is formal or informal or both. The families associated with these projects receive, as a kind of automatic benefit of participation, immediate entry into a very extensive, and usually quite supportive, network of highly connected and resourceful families and, by extension, their personal, professional, and even political allies. This happens with little fanfare, but it does offer to these persons the many practical advantages that come with being able to tap into these many resources they might never access otherwise.

It is very interesting, as can be seen in the case of the regional autism project, that many eligible families, (upwards of 25%), have actually declined the use of cash assistance in favor of other non-cash social supports, such as newsletters and support groups, that better address what they feel their family actually needs most. This would be counterintuitive for many cynics, who feel that most people would never turn down cash. In fact, the Massachusetts experience shows a routine willingness by families to return resources that they

have already been allocated but that they discover they now do not need. When asked why they do this, they reply that perhaps another family might need these more than they had thought they would.

### **They Get Highly Relevant And Very Needed Family Support**

Since the resources they receive are so acutely directed to precisely where, and in what specific form and amount, and at the best possible timing for the individual family, the family support is likely to be highly effective. It is not just that it arrives, it also arrives in a way that is deeply empowering for the family and where they believe it will do the most good. This is said notwithstanding the relative pittance that many families get. The important point to note is that, no matter what they receive, the chances of it being used relevantly is very high. The model itself predicts this to some degree, but the very fact that families have a decided interest in not squandering what they receive, given that they would simply be injuring themselves. The satisfaction of their needs, even to a degree, is a very strong incentive.

### **The Families Have Virtually No Direct Bureaucratic Involvement With The Funder**

Though it may seem strange to some people to cite this as a benefit, it is a considerable advantage for the families to not have to interact with another bureaucracy and yet nonetheless benefit from the service it authorizes. The DMR Guideline related requirements of the participating family are, *for the majority*, simply a matter of being certified once as eligible for service, completing annually a simple one-page report on their use of the service, and petitioning the local project for service at least once a year. All of these contacts are largely done through the local project, and therefore the family does not *have to* interact with state bureaucracy. Given the frustrations most families have with having to penetrate and comply with multiple bureaucracies, this advantage rises to a new level of “consumer friendly” significance.

The state bureaucracy is still there, operating in the background, but the participating family is not required to “interface” or interact with it. In fact, the operating principle is typically that such interactions are handled by the host agency. This is no accident, since the Family Support Guidelines of the state were written to deliberately minimize family interaction with bureaucracy, including that of the host agency. The net result is that families are “shielded” from bureaucracy in the sense that they almost never see it or have to deal with it. Consequently, for the family, they get the benefit of a highly desirable, flexible and responsive service without much “exposure to bureaucracy” personal cost. For the funder, the arrangement works well, given that the host agencies are typically quite schooled in meeting their routine bureaucratic demands.

### **The Family Can Personally Define, Invent and Improvise “Family Support”**

The universal experience of service users, of all sorts of systems, is that of having to fit into a system that was not designed by you. Even if the designers of the system are well intentioned, there is always a risk that they will design systems to meet their own sense of what is needed. It is also very probable that they will design a system for the general use of many people and thus create a uniform or standardized service that compels users to “fit in”. The principle of the lowest common denominator then has dominance. This will come at the cost of addressing all of the complexity and variability that nevertheless exists in the population being served.

The advantage of these projects is that each person’s supports are unique to them in the sense that they grow directly out of the family’s situation and needs. The participating family does not have to take into account what other families are or are not doing when it comes to devising their own family support. Part of this is achieved through the flexibility of having the programs resources in the highly flexible form of “cash assistance”. Another reason is that the family is unencumbered by having to take others into account, and can thus focus on their own issues unreservedly. In the end they improvise with what resources they are able to obtain.

In setting things up so that the family is the fundamental definer and designer of family support, it greatly, if not almost completely, reduces the risk that a person unrelated to the family, (i.e. a “stranger”), somehow has more authority than the family to define and shape what is needed. Such people can be taken advantage of as a professional resource at will by families if they are thought to be able to be helpful, but this is quite different from giving to such people controlling say over defining what the family needs. It is true that families still have to petition the project itself for resources, but they can largely set the terms of what they need and how this will be addressed.

### **The Family’s Cultural and Linguistic Context Is Respected And Influential**

The majority group in a population always have the advantage that comes with greater numbers. It should be no surprise that majority status brings with it a tendency to domination relative to minorities. Yet in the context of these projects in Massachusetts, there has arisen through the “mini-project” mechanism, the ability to create family support projects that return the authority in family support back to the minority cultural or linguistic group. In doing so, a great deal of the disadvantage of being in a small minority disappears. In reality, the projects are largely unrestricted in shaping family

support so that it fits the cultural sensitivities and parameters of the minority culture *as defined by the people themselves*.

It should be noted that, for the broader minority community from which these families are drawn, these projects both serve as an edifying and empowering example of dignified self-help and as a very practical way in which highly practical needs are addressed. This advantage may even extend to classes of society in the sense that the needs of poor people do differ from the more affluent. Consequently, a common reporting anecdotally of how resources got used did show that poorer families devoted a greater percentage of their family support to "necessities". This is not unexpected, and reflects the family's ability, (and that of families similarly positioned), to make the final determination of what is a priority in their lives *as they see it*. Even better, they were far less obligated to justify their choices and values to someone who was an "outsider" to their culture, traditions and language. This was a clear result of the fruits of the "positive presumption" principle at work.

#### **Indirect Benefits:**

##### **The Stability Of The Family Governed Projects**

Many people might be tempted to think that such citizen run, grass roots projects would ultimately prove to be undependable and thus impractical. The opposite has proven to be the case. None of the projects established thus far has either collapsed or been forced into dissolution through its own ineptness or misguided conduct. In fact, they all remain vital and viable over a decade later. The importance of this is that it is now quite possible to examine the use of this strategy, not as an experimental or pilot strategy, but as a possible ongoing way in which services might be organized.

In saying this, it is not meant to suggest that any such project could not conceivably become fatally unstable. On the contrary, anything human can fail. However, these projects have established credibility via their actual performance over time, where it is only reasonable to note that they do not suffer from any evident inherent instability, and are in fact remarkably stable. This is said with the qualifying note that, not only have the participating families accounted for this, it has also likely been very helpful that the Department of Mental Retardation has remained as steadfast in its support for this approach. Further, the host agencies have also clearly been very important in taking much of the taxing work out of these projects through considerable, though frequently unnoticed, practical assistance and support. Thus, the projects need to be seen in this supportive systemic context, rather than as a "stand alone" strategy.

##### **The Projects Are Extremely Cost Effective**

Since the resources go where they do the most good, and since they result in such high approval by their users, these projects represent an exceptional value in terms of the use of public dollars. They also are generally very inexpensive to administer, in the sense that they are typically not carrying a lot of overhead. Some might wonder whether the “proliferation” of small projects is wasteful and duplicative. It must be remembered in the response to this possible worry, that not a single new agency was created by this strategy since they all use existing agencies. Thus, there is absolutely no duplication at the organizational level. It is also important to note that all that is different is that these projects are administered by the agencies *in a slightly different way* from their usual practice. This change actually produces *more* benefit for the family *at roughly the same or less cost*. Thus the projects are more cost-beneficial as opposed to being more costly.

It is also worth noting that once a person, (whether adult or child), leaves the care and support of their family, and enters into a residential service, (i.e. they are formally “residentialized”), then the cost to the funder for their support typically rises dramatically. This true both in that fiscal year, and particularly if one calculates the multi-year costs of such care. This can amount to many tens of thousands of dollars in a given year, and may not, in a thoroughly clinical sense, actually mean that they are better off in terms of what they actually need. In fact, there are countless individuals who have a place to live who do not have much of a life upon close scrutiny.

### **The Projects Develop And Educate A “Reservoir” Constituency Of Connected And Informed Families And Family Leaders**

It is far less likely that families will “get lost” in the system if they are connected to a project of this kind, since these projects provide such a crucial preventative resource for them. They are much more likely to get to what they need, and thus do not present to the system as a potentially expensive “crisis”. As their needs are met, they also become educated as to how to get these needs met in the future, including all sorts of ways that fall outside of the formal systems i.e. “natural supports”. In this way the families are extracting the value they need from whatever is available both formally and informally.

This strategy helps create an educated constituency relative to services, and frequently helps produce the kind of informed family leaders that are needed for sensible advocacy and the eventual mobilizing of the authorities behind unmet needs. It is true that this may mean that many families might lose their passivity and naivete relative to the systems they use, but with the advantage of allowing for there to independently develop, *within the community*, a constituency for change and improvement. This educated constituency ultimately means the eventual emergence of a better system, though at the price of some informed dissent concerning the present one.

## **This System Permits “Bottom Up” And Person Centered Service Design**

A great difficulty that systems experience is that they often work in a “top down” way. In fact, this is widely the case despite many aspirations to the contrary. This strategy has largely avoided this danger by delegating sufficient authority to the projects and the individual families so that they only rarely have to go “up into” the system to get permission for what they need. In this way authority rests “close to the ground” and the system then can operate in a way that allows the person and their family to shape what happens. The system can, in theory, step in at any point and overturn this if it is concerned, but it need not manage the universe “from above” since most of the decisions are made very, very close to the people themselves.

## **The System Adds Value And Options With Each Satisfied Family**

By permitting families to play a decisive role in creating needed support options the system is constantly re-inventing itself in the direction of greater relevance. This done not with some overall innovation plan but rather by letting the innovators be the people closest to the need. Each option that they develop that succeeds in essence sets a new benchmark of what is on offer by the system. I.e. the pool of options grows. In this step-by-step way a better system of family support, driven by needs and individual variation, comes into being.

## **The Limits Of The Massachusetts Family Governed Flexible Family Support Strategy**

### **Technical Assistance To Families For Spawning Innovation**

All systems have their limits, and this one is no exception. Limits are not always weaknesses, but may simply be the thresholds under which something maintains its validity. In this case, the creativity of what happens at the grass roots level is hugely influenced by the kind of support and assistance that the families receive. A given family might have some potential for innovation and wise action but this is lessened considerably where they are not provided with the stimuli of inspiration, critical counsel and exposure to the exemplary. Even with these, innovation is hard to expect as a routine matter. Obviously, many families will not realize what is possible, or may require quite a bit of reassurance to try things that are out of the ordinary.

### **The Possibly Hidden Problems Of Relying On Formal Family Supports**

It is also a matter of some ambivalence as to whether the introduction of formal family supports to families may act to undercut a family’s reliance on the “natural” supports of their community and culture. For instance, one very

experienced advocate of Puerto Rican heritage noted the strong and persistent determination of families from this background to keep their family member at home and ensconced in their Puerto Rican sub-community. She wondered whether the acceptance of formal family supports, even of a "family friendly" version of this kind, was the beginning of an "Americanization" or assimilation of these families to the mainstream reliance of families on agencies and systems i.e. "clienthood", rather than their "natural" supports and community. She foresaw the danger of unwittingly forfeiting the possibly hidden or unappreciated advantages of culture and community. In this she had many allies amongst mainstream activists who were also worried about the possibility of undercutting and losing natural supports and becoming clients of impersonal bureaucracies.

### **Erosion Of The "Family Friendly" Ethos and Values**

This assimilation issue is not restricted to cultural matters as many supporters of these projects also saw a kind of "reverse innovation" process at work. They saw this in that the more conventional bureaucratic systems that these projects interfaced with were gradually having the effect of reconverting these projects back into traditional agency/manager/ professionally controlled projects by very small increments. This "slipping backwards" was viewed as largely an unintentional process, but worrisome nonetheless. Given that the core underlying ethics of consumer and family influence and governance were seen as being so weakly understood and supported in these "external" systems, the proponents of these projects foresaw the gradual erosion of the projects ability to sustain their "counterculture" of "family friendly" ways without the help of a new round of official and professional endorsement of these values. This concern included both the host agencies and the Massachusetts Department of Mental Retardation but was also seen as coming from other mainstream sources as well.

### **Limited Financial Resources Devoted To Family Support**

It is also true that flexibility, empowerment and technical assistance can only go as far as the resources available to work with. If one needs more than that which is available then needs cannot be met, no matter how ingenious one is. It is important to remember that the family support system described here does not offer the average participating family all that much in net dollar terms. The western Massachusetts average per capita expenditure per family is approximately \$1200.00. In reality, the family support system is funded proportionately, of all the services that the State agency funds, at the lowest level. Family support expenditures have also grown at a slower rate than have other services. It very much reflects the low status of both families and family support not only in Massachusetts, but rather more broadly in North America as a function of the unconscious biases of professional and managerial strategies. In other cases, some of the projects are comparatively very expensive on a

“per person” basis, as the persons needing assistance require so much more than what might be revealed by the general averages. Nevertheless, this has to be balanced against what they might cost if served in a, (usually more expensive), conventional service.

### **The Difficulty Of Meeting Fundamental Needs Potently**

As has been pointed out previously, it is certainly unwise to assign cash as somehow a panacea for what many families actually may need, particularly when the amounts are so trifling. It is also unrealistic to expect that families somehow mystically know about strategies, solutions or even mindsets that could be helpful for them. Thus, “need” is better seen as being a subject that requires considerable interpretation and re-interpretation, as the life of a family unfolds. Families are not static in either what they may need, or in their perspectives on their own needs. This argues for the merits of a system such as described here that permits families and their allies to change their minds and priorities irrespective of the common bureaucratic preference for unchangeability and uniformity.

### **Limits On Family Leadership And Project Capacity**

Another limit is the amount of family leadership available at any given time and the potential demands placed on this finite pool by the demands of the projects themselves for people to innovate, lead and govern. This has not surfaced as a fatal limitation, but the efforts by families to create and sustain these projects are costly to them personally even if the system does not see this. However, if the system has the wisdom to add on supplemental “people building” investments in family leadership, education and technical assistance then these limits are rarely troublesome. The families, and the projects they joined in such large numbers, should be seen as having had to provide for this leadership and ingenuity from within their scant resources. These “people” resources have at times been increasingly taxed by the system assigning its most difficult family emergency situations to these projects to solve. This constitutes in its own way a kind of inadvertent systemic “responsibility dumping” that is quite out of proportion to what their comparatively tiny infrastructure resources can sustain on an ongoing basis. It is a credit to their competence and ingenuity that they have actually succeeded quite remarkably in adaptively managing what to the system would have been a worrisome “emergency” .

### **Emerging Advocacy Related Conflicts Of Interests**

It is not all that surprising that many of these projects have chosen family members to be their staff. Often these individuals are some of the most articulate and compelling of the available pool of family leaders. Nevertheless, this places such persons in a considerable conflict of interest when it comes to

them being able to quite as *independently* advocate for their own family or the families of others. The lack of new emergent and rigorously independent family advocacy groups willing to tackle the authorities straight on in Massachusetts may be partially related to this unintended "structural" inhibition. At the same time, the mobilization of families does require *independent* family organizations specifically set up for such an intentionally conflictive role. These have not been widely attempted, as yet, in Massachusetts.

### **The Building Of Future Family Leadership and Influence**

To the credit of the Massachusetts system, there has been a steady investment in each region in supporting families to create their own family leadership education series for over a decade now and involving thousands of families. There have been increasingly less targeted resources made available for families to create other educational and training initiatives though this has not disappeared completely. In only one region had there been any extensive independent technical assistance been made available to families and this is no longer in place. Not surprisingly, these factors in combination with a barely discernible increase in family support expenditures, has resulted in a virtual halt in the rise of new projects. These limits do not undermine the validity of the strategy itself but they do underline the fact that these approaches are very dependent on the funder and the advocates recognizing their place and virtues.

### **Conclusion**

This paper is an attempt to begin the process of evaluating what has been achieved in this arena over the past decade and longer, so that it may be possible to formulate an updated agenda for future action. It has been initiated by the family movement itself, though it is clearly of interest to many other parties that work in association with the families. The challenges identified here would be easily recognizable in many other jurisdictions as they mirror the struggle everywhere to come up with positive and useful ways that service users and their families might get what they need in an empowering way. The experience of Massachusetts can help to a degree in this regard and the cataloguing of this initiative contributes to this learning both within and outside Massachusetts.