

CENTER for SELF-DETERMINATION
POLICY ANALYSIS OF NEW JERSEY'S SELF-DETERMINATION EFFORT

Thomas Nerney with Kathy Harris, Esq.

The meaning of self-determination since its inception a decade ago has always rested on a set of principles: Freedom, Authority, Support, Responsibility and now Confirmation of the important role that individuals with disabilities must play in the development of this movement. In this ten-year time frame our understanding of self-determination has deepened and broadened. New and highly relevant issues surface as more and more individuals in states across the country begin to implement self-determination for themselves, and issues surface as well for the systems that are the stewards of public funds. Just as individuals with disabilities and families have taught us so much as they gain control of the funding, so, too, have we learned about the systems change elements that make the goal of self-determination more attainable.

While self-determination in New Jersey has much strength, it still functions on the periphery of human services and its promise remains unfulfilled. Self-Determination operates at essentially two levels: the individual and highly personal level, and the systems or service and organizational level.

The goal of self-determination, the creation of meaningful, culturally appropriate lives deeply embedded in our communities and suffused with real relationships, requires that the system of long term care change in significant ways. This goal will be attainable by only a few individuals or not attainable at all unless both policy and practice issues are jointly addressed. Difficult public policy issues need to be resolved. Among these issues are the following:

- Can any person with a developmental disability benefit from self-determination?
- Will self-determination become a viable option for all those served?
- Will the system of human services agree to re-design supports for individuals, especially those with intellectual and cognitive disabilities, in conjunction with these individuals and close family and friends?
- Can a system of supports for the future be designed that is truly cost effective and open to those who presently go without supports and services?

Best practices across the country answer these questions with a resounding affirmation. In fact the growing context for carefully and strategically re-designing the entire system of long term care for individuals with disabilities rests on two

emerging crises that threaten the long term viability of community supports for individuals with developmental disabilities:

Increased competition for scarce Medicaid resources, and
The dwindling supply of direct support workers to serve those with disabilities

The future interests of individuals with developmental disabilities as well as all other disabilities are inextricably linked with one of the greatest cultural, social and economic changes in American History: the aging of America. The issue of how resources are allocated in the future is directly related to the very adequacy of those resources.

As the demographics of this country inexorably change from 12.5% of the population over age 65 to 20% over the age of 65, we can accurately predict the following crises:

- The competition for scarce Medicaid resources will increase dramatically. The fastest growing population of those who are aging will be those most in need of assistance-those over the age of 85.
- While the vast majority of assistance to this aging population is given freely from family members today (over 80% and mostly by adult female children), within twenty years this cohort of adult children will diminish significantly. As the population of older Americans doubles the population of adult female children increases by only 7%. This will exacerbate the problem of increasing significantly the pool of potential direct support workers. This "double bind" is described by Mary Ann Wilner:
Since women in this age group provide the vast majority of both paid direct-care services and family care, this care gap in the United States will increasingly become a double bind: families who cannot care for their older members by themselves will find relatively fewer paid staff available when they turn to the formal system for assistance. (Wilner, M. A., 2001)
- The current pool of direct support workers is shrinking in dramatic fashion as a result of inadequate wages and lack of status across all human services. It already constitutes a national crisis.
- Even if the public-support dollars were to increase significantly to keep pace with the growing population of those requiring some assistance, there is little hope under the present system that an adequate and trained or interested workforce could be developed.
- Within the field of developmental disabilities alone, demographic projections indicate that within twenty years the more than 500,000 individuals with a developmental disability currently living at home with an aging caregiver will

more than double. Aging caregivers are caught between their own aged parents and their adult children with disabilities-an excruciating double bind.

As America ages the competition for scarce resources, especially under the Medicaid program, is going to increase dramatically. This dilemma has the potential for dwarfing the twin crises in Medicare and Social Security.

In the face of this crisis two problems remain intractable: the near total impoverishment of individuals with disabilities within this system of long term care and the low wages and attendant difficulty in attracting and keeping a workforce to support individuals with disabilities. (See Filthy Lucre at: self-determination.com)

These crises have led to deeper and deeper reflection on how the system of long-term care must change in fundamental ways. The most important issue then for all concerned is how to begin to address these problems without hurting individuals with disabilities. Indeed, the central policy question becomes how to design a system that improves upon quality, is founded on freedom and responsibility, and results in better value and cost-effectiveness.

What follows is a brief policy analysis of self-determination in New Jersey within the context outline above, and some recommendations for possible changes that will augment the effort so successfully begun here. This paper is divided into three sections:

- Self-Determination Policy and Practice in New Jersey
- Training and Technical Assistance
- Recommendations for Improving the New Jersey Self-Determination Initiative

Section 1

Self-Determination Policy and Practice

Division Circular #33 outlines the policies developed by the State of New Jersey to implement self-determination. Together with "Guidelines for Participants on Allowable Costs for Division Funds" these documents outline the basic policy and practice standards for the implementation of self-determination in the State of New Jersey. What follows is a basic policy analysis of these standards based on the original intent of the self-determination movement (Nerney, T and Crowley, R, 1995; Nerney, T. & Shumway, D., 1996) and a review of best practices across the

United States through the work of the Center on Self-Determination. This analysis is also based on many interviews with Division personnel, regional personnel and family members including family meetings.

Division Circular # 33 clearly spells out the basic policy and meaning of self-determination:

Under Self-Determination, individuals with developmental disabilities, together with their guardians, families and friends, can choose their own supports and design new, innovative, cost-effective living arrangements.

This circular clearly points out that self-determination is not a "placement". Rather it is an alternative to a residential placement. This policy analysis has identified the following issues to cover:

- The availability of funds
- The amount available for an individual
- Allowable costs
- Contributions by individuals with disabilities and guardians
- Case manager assignment
- Support broker service
- Fiscal intermediary service
- Day program exclusion
- Role of guardians

The Availability of Funds and the Amount Available to an Individual

Self-Determination in New Jersey is limited to those who become eligible for services as dollars are appropriated annually for individuals on the waiting list. As individuals come off the waiting list for services they are free to choose traditional agency directed services or "self-determination". It is unclear from this document and others reviewed how determinations are made with regard to the second issue mentioned above, viz., the amount available to an individual.

Apparently, the amount of dollars available is both limited by the appropriations process and limited by what can be purchased under "allowable" costs. This raises the question of what is the actual average expenditure for traditional or agency-directed services and what is the actual average expenditure for self-determination.

Interviews with family members and individuals with disabilities led to the conclusion that this information is not offered and, in fact, may not be available. In other

words participants did not have this information and often going into the planning process did not know how many dollars might be available. There is negotiation possible based on the plan developed by the person with a disability/family with the assistance of a support broker. (The issue of how much money to make available remains a difficult issue across the country)

Allowable Costs

The Division annually issues directives on allowable costs for specific expenses. These guidelines include up-front costs of up to \$4,000 a year for support brokers and facilitation of "circles of support" for the individual with a disability. This enables the person to begin planning prior to receiving an individual budget.

For individuals residing at home it is expected that SSI/SSDI will be contributed toward the person's room and board. For those within and outside a family member's home the allowable costs are divided into nine categories ranging from typical household expenses (including home modifications), transportation, clothing, staffing, medical, recreation/leisure, other and adaptive equipment. The list is fairly inclusive. Several items stand out. There is no category for "management" or administration. Several of the categories include dollar ceilings such as food, clothing, recreation and leisure including vacation, as well as transportation. In some cases there is a range and in others there appears to be a dollar ceiling. Costs for "day program" needs including job development and job training and placement, are not included. In fact, self-determination in New Jersey with some exceptions does not include this aspect of a person's life unless they are employed. Some ceilings, recreation/leisure and vacations e.g., have a total dollar ceiling even if the person's own money is used.

Contributions by Individuals with Disabilities

It is naturally assumed that individuals will contribute to the cost of their supports whenever possible. This means that the individual's SSI/SSDI will be used for typical room and board expenses and that dollars earned from work will also become a contribution. However, it appears that all of the SSI/SSDI must be part of an individual budget and that, if a person works, all of that person's wages must be included in the individual budget of support. This does not appear to be true for those who live in typical human service environments such as group homes.

Case Manager Assignment

In addition to the selection of a freely chosen support broker the Division also assigns a case manager to the person enrolled in self-determination. This case manager together with the self-determination coordinator fulfills the role of first line of approval and contact with regard to both individual budgets as well as other concerns of the individual as well as the Division. There is no mention of individual choice with regard to the case manager.

Support Broker Service

One of the unique features of the New Jersey self-determination initiative is the ability for the individual to hire a support broker, i.e., some individual who will provide essential planning and coordination supports as well as monitoring and even help with arranging the supports. This function is independent of both service provision and case management. The person is essentially hired by the individual, guardian or support circle and clearly works for the person with a disability. Conflict of interest is avoided in this way. There is a provision that each support coordinator undergo training provided by the Boggs Center.

Fiscal Intermediary Service

New Jersey contracts with Easter Seals to provide fiscal intermediary services to those in the self-determination initiative. There is a prohibition under Medicaid for giving dollars directly to individuals. Fiscal intermediaries can be the place where the dollars for an approved budget get deposited. The fiscal intermediary then pays the bills outlined in the approved budget. Easter Seals also insures that appropriate taxes and benefits are paid on a timely basis. For those individuals who do not contract with an established agency for personal support, this fiscal intermediary will become the "employer of record" for purposes of handling issues related to the employment of personnel including benefits, taxes and unemployment compensation. Easter Seals uses its own benefit package in these instances.

Day Program Exclusion

If an individual with a disability participating in self-determination is already working some of the individual budget may be directed toward supporting employment-related expenses. However, there appears to be a general exclusion of the dollars available for day and vocational programs from the individual budget. Individuals in self-determination are typically directed to an agency where there

might be a slot or opening available. Officials interviewed indicated that this is not always the case if an individual asks for something different.

Role of Guardians

State policy requires the appointment of a guardian for those who are deemed not capable of managing their own supports. For those with public guardians there is a requirement that a private guardian be appointed. The "allowable" costs document permits an expenditure of up to \$1500 for this purpose

Section 2

Training and Technical Assistance

Training for virtually all participants in self-determination is the responsibility of the Elizabeth M. Boggs Center on Developmental Disabilities (UMDNJ) and to some extent the dissemination of information with the New Jersey Developmental Disabilities Council. Among a myriad of training opportunities The Boggs Center offers specific training in self-determination:

Orientation to Self-Determination

This includes an introduction, history, philosophy and an overview of the New Jersey self-determination initiative. This specific training is also a requirement for potential support brokers.

Families and Self-Determination

This training focuses on the details of planning and implementation of supports.

It is offered as well to family members who will serve as support brokers.

Support Broker

This training is specific to support brokers and the two-day session is a requirement for anyone choosing to become a support broker. Individuals from Easter Seals (the fiscal intermediary) and the Division of Developmental Disabilities Regional Coordinators augment Boggs Center staff. Successful completion results in a certificate.

Section 111

Recommendations

There are issues in this section that necessarily overlap. Some redundancy then is produced in keeping them in sequence. For example, the exclusion of day program funds obviously overlaps with the availability and the amount of funds. Allowable costs and the contribution of individuals with disabilities also are good examples.

The Availability of Funds and the Amount Available to an Individual

This issue is a thorny one in virtually all of the states implementing self-determination. One of the early-on experiences of administrators in self-determination projects was the request for information on typical human service costs from families and individuals with disabilities. These average expenditures for a typical residential, day, and vocational program was largely unknown outside of key management and administrative staff. Since typical provider contracts average the various and sometimes-unique costs associated with individuals it is not always possible or easy to discern true individual costs.

In addition, many states' reimbursement policies differed in what a particular agency might receive based on historical entry into the provider system, the significance of the disabilities of those served and the type of programs operated. All residential programs, e.g., are not equal. Sometimes ICF-MR group homes would receive higher payments than Waiver funded group homes. In some states, supported employment programs would receive higher or lower reimbursement than day activity or workshop programs. That said, however, administrators were often reluctant to make this information public to families and individuals with disabilities.

Finally, self-determination has held out the implied promise of "cost-effectiveness" and often resulted in states adopting a priori strategies to fund self-determination at lower amounts than typical human services. This has served to compound the second issue of how to fairly determine how much money an individual will get to budget under the rubric of self-determination

A more thorough analysis of this issue is available in "Filthy Lucre" (www.self-determination.com). No state has yet developed the "perfect" system to allocate funds to an individual. That said there are strategies and recommendations that appear to be necessary in order to address these issues.

The Division should consider:

1. All information on current costs for all typical human services should be public and easily accessible to both individuals with disabilities and family members.
2. When new appropriations are available average costs associated with both typical human services and self-determination initiatives ought also to be readily available. This means that if there are fiscal incentives or disincentives to choose one or the other, then these should be known and understood ahead of time. If fiscal incentives are built into the self-determination initiative these should be explained carefully to all potential participants.

States across the country are experimenting with ways to become more cost effective. They have an obligation to do so and individuals with disabilities and families have a similar obligation to be part of this design and experimentation. In this coming generation it is conceivable that the demand for supports and services across all disabilities and aging will dwarf the resources available to states.

3. New Jersey should consider bringing individuals with disabilities and family members more directly into the design of future self-determination demonstrations including the current one. Only by creating this mutual trust will more cost-effective ways be found and sustained. Both individuals with disabilities and family members have the potential to teach administrators and managers how to obtain better value for current expenditures. Otherwise, self-determination may fail if it rests solely on states' desires to "save" money or if the motivation to be cost effective is not widely shared. This means at the implementation level that greater flexibility must be sought.

Allowable Costs

There is an ongoing temptation for fiscal agents for funding sources to control overall expenditures through the micro-management of individual line items. Experiences from self-determination demonstrations across the country reveal a better methodology. Consideration should be given to the following strategies:

4. In return for agreeing to some flexible but targeted amount of total dollars, allow participants in self-determination much more flexibility in the amounts budgeted for particular line items and allow for increased flexibility in moving dollar amounts within an approved budget.
5. Allow participants a wide variety of choices in purchasing supports and services of all kinds. The exact opposite of traditional managed care-shaped

purchasing appears to be more cost effective. Instead of reducing or circumscribing the amount or number of vendors and individuals from whom purchases may be made, opening up this universe has a salutary effect on total costs. This may appear to be counter intuitive to those used to traditional cost containment measures but preliminary results from other self-determination projects strongly suggests that better value (read "cost-effective") may be possible when proscribed limits are lifted. New Jersey already senses this in its definition of self-determination with the reference to "...new, innovative, cost-effective living arrangements".

6. In particular it is a mistake to set ceilings on certain line items that include, e.g., contributions that individuals may make to that cost through income from work. Room and board costs, e.g., may not exceed \$600. Not only may this not be realistic in certain geographic areas, but it precludes private income from being encouraged to support these costs. (This problem is really a creation more of the federal restriction on Medicaid payments for room and board) The recreation/leisure/spending money/ vacation line item is an even better example. Here the instructions are explicit. The total spending limit is set at \$2500. Yet, personal funds are required for "spending money" and "vacation". It seems somewhat arbitrary to limit what an individual may spend with dollars generated through work. This does not mean that individuals with disabilities should not contribute to their own support. Rather, a fairer system that also encourages private income could be instituted.

Simplifying the approval process should also be incorporated into changes that more carefully honor the choices that individual may make within a total amount of dollars available. Just as micro-management of line items adds frustration for individuals and families, so, too, does an elaborate and bureaucratic process of approval.

The chart of allowable costs does not include a line item for management or administration. Apparently, either the person with a disability is responsible for all aspects of management (unless they use an agency) or the family member or guardian is. This has serious repercussions for families, especially elderly families, and for individuals without the interest or experience to manage schedules and keep records. Once the self-determination approach moves away from family support to support for an adult living on his/her own there is an absolute necessity for some dollars for administration of supports. Virtually every demonstration on self-determination has recognized this issue. The temptation in this instance might very well be to compromise the integrity of the independent support broker by moving management responsibilities under their purview.

This omission has the unintended effect of limiting self-determination to families who want to provide this function or to individuals without cognitive disabilities who prefer to perform the management themselves. Families who are elderly, families who are otherwise too busy with other responsibilities and individuals with cognitive disabilities are almost forced to use traditional agencies or to forgo the benefits of self-determination.

Consideration should be given to the following:

7. Allowable costs should include a line item for administration and management so that supports can properly be organized and structured without this burden being imposed on families who may not have the ability or individuals who would otherwise need assistance. Precluding administrative costs has one other terrible consequence. Families who now provide this support will want to know that when they no longer can do it, the person with a disability will not have to move backwards to traditional or typical human service environments, surrender the freedom they have gained and lose the effects of years of care, personal planning and implementation. The message sent by this policy is that self-determination may very well be temporary instead of a more permanent and meaningful way for individuals with disabilities to be supported.

Contributions by Individuals with Disabilities and Guardians

There appears to be another potential disparity in that all of a person's SSI/SSDI needs to be budgeted within these line items. This is not true for typical service arrangements and may constitute a disincentive for self-determination and more creative arrangements.

Consideration might be given to the following:

8. Create a fair playing field on the use of SSI/SSDI for both those in self-determination and those in typical human services.
9. Create incentives for individuals to earn money through the world of business and commerce. This means that some of those earnings will be allowed to purchase supports or items that would otherwise not be eligible for public reimbursement. An equitable way of sharing earnings both for non-reimbursable items and for the cost of support needs to be developed.

Case Manager Assignment

The state's case manager system with regard to self-determination is the front line for the state in monitoring and evaluating the status of individuals. Case managers, however, may vary in both their understanding and support of self-determination.

10. In conformance with the Federal Medicaid requirement individuals with disabilities and families need to be given the opportunity to change case managers if they are unhappy with their support or understanding. This may in practice be the case but individuals and families need to know that they explicitly have this opportunity.

Support broker Service

New Jersey's approach to independent support brokers is among the most innovative and creative in the country. It remains one of the cornerstones of successful implementation of self-determination and needs to be both conflict of interest-free and reimbursed adequately. The Division's approach meets these criteria. Support coordinators also need to carry the requisite authority in order to truly and adequately represent individuals with disabilities.

11. The Division might want to reinforce the authority of these individuals once they are approved and hired by the person with a disability/family. In special circumstances it might also be prudent to allow a presently excluded family member to receive reimbursement for this function.

Fiscal Intermediary Service

Easter Seals provides the fiscal intermediary service for all participants in the New Jersey self-determination initiative. By most accounts individuals are pleased with the basic services they receive. However, there is no choice of a fiscal intermediary and choice among salaries and benefits may be limited by this arrangement. Individuals with disabilities and families either choose a human service agency or Easter Seals. As self-determination grows this may become more problematic.

12. There is great advantage to providing a choice for individuals and families when it comes to this important function. There is a growing realization across all self-determination efforts that competition can result in better service. In addition there is much merit to the idea that this function remains close to the individual and family in order to increase communication and ease of problem solving.

Day and Vocational Program Exclusion

Under self-determination the bifurcation of individual lives between "day" and "residential" has ended. It is not possible to fully implement the principles of self-determination without all of the dollars for support available for planning and budgeting.

There are important personal and policy as well as fiscal reasons for this.

On the personal level it is extremely important that the person with a disability be able to conduct real life planning, holistic planning, that melds important activities that may happen during the day with important aspects of living and being part of one's community. It makes no sense to say the person with a disability is free to organize a creative, individual life around where and how that person lives (residentially) but must surrender that right during the day. In addition, self-determination is moving strongly toward a vision of individuals "producing income" through the world of business and commerce. From typical jobs to creating microenterprises, having control of typical day program revenues is becoming increasingly important.

On the policy and fiscal level, controlling all the dollars in one individual budget holds out the promise for greater value and increased cost-effectiveness. Typical day programs have heavy costs associated with transportation, may include much "downtime" where no discernable outcomes are produced, and force the individual with disabilities to accept both what is offered and who offers it. There are of course some agencies who are willing to structure highly individual supports for a person with a disability, but, forcing someone in self-determination into an existing opening or slot shuts down both the promise of self-determination and the possibility of additional cost-effectiveness.

Strong consideration should be given to the following:

13. All dollars needed to support an individual including those dollars associated with typical day or vocational programs need to be available and controlled by the person with a disability and freely chosen family and allies.

Role of Guardians

Guardianship as it is traditionally understood represents one of the most formidable barriers to self-determination. It is also one of the most difficult issues to deal with in a society that still may not understand both the potential of individuals with disabilities when they have the right support

and the legal and cultural harm that befalls those labeled "incompetent". While most guardians, especially committed family members, desire the best for individuals with cognitive disabilities, the effect of the imposition of guardianship is the exact opposite of the major tenet of self-determination.

It seems implausible that stripping an individual of their rights guaranteed under the Constitution and The Bill of Rights would be an acceptable practice especially under the rubric of self-determination. New Jersey policy seems to accept this contradiction in spite of yeoman's work on the part of the Division to ameliorate the effects of plenary or full guardianship and the work of the New Jersey Developmental Disabilities Council in their 1996 monograph on improving the state's guardianship statute.

Several strategies could be adopted.

14. Under self-determination, when a person has a guardian, there needs to be objective evidence that the plan and budget developed are reflective of what the individual with a disability desires. While this does not solve the contradiction, at least this addition of clear public policy will ameliorate the potential danger of guardians superimposing their values and plans on the person with a disability. Usually this takes the form of refusing to listen to the person carefully and those close to the person who are in committed relationships. Additionally, the Division of Developmental Disabilities should seriously consider getting out of the business of providing public guardianship as an essential conflict of interest. There appears to be an implicit acknowledgement of this issue in their policies on self-determination.

Guardianship statutes vary widely in their breath, their degree of due process protections and their predilection for intrusive or more limited forms of guardianship. A preliminary review of the New Jersey guardianship statutes reveals some weaknesses.

New Jersey Guardianship Statutes

There is not a lot of due process specified, (such as a right to an independent evaluation, to cross examine, etc.) Also, although an "attorney is appointed" it is clear that the statute does not really mean that an attorney is appointed to represent the person with a disability:

The attorney, after conducting an investigation into the matter, which shall include an interview with the alleged incapacitated person, an interview with the proposed guardian, and, if there is cause to question the alleged incapacitated person's level of functioning and need for a guardian, the report of an independent expert professionally qualified to render an opinion on issues pertaining to incapacity, shall advise the court by way of a report in affidavit form whether there is cause to dispute either the contention of the commissioner that the appointment of a guardian is necessary or the commissioner's recommendation as to whom that guardian should be. If the alleged incapacitated person expresses an opinion on the subject, the attorney shall advise the court of that opinion . . . If, after reviewing the report of the attorney, there appears to be no difference between the position of the commissioner and the findings of the attorney, the court may proceed in a summary fashion to appoint a guardian. A plenary hearing shall be held if requested by the alleged incapacitated person, his attorney, or anyone acting on his behalf.

These are the duties of a guardian ad litem not an attorney for the person with a disability.

There is a right to trial by jury, and they establish a guardian of the person or estate, or both. The powers may be limited if requested, but there is no preference for limited guardianships. The Division of Developmental Disabilities does however insist that this be addressed.

There is also a section stating that a guardian "has the same powers, rights and duties respecting his ward that a parent has respecting his unemancipated minor child, except to provide for the ward from the guardian's own funds." This is demeaning to the status of an adult person with a guardian. The statute remains unclear on other issues such as whether someone with a guardian can vote.

Some recommendations follow:

1. The need for the judge or "Commissioner" to determine whether there is a need for guardianship, not just whether a person is incapacitated. Both Iowa and Pennsylvania Supreme Courts have ruled that help from 3rd parties, including family and friends, etc. must be considered in considering the need for guardianship.
2. Much stronger language about limiting the powers of a guardian. It should be the preferred way to appoint a guardian, and there should be

clear and convincing evidence that a person needs a guardian in every area given to a guardian.

3. Some language about alternatives needs to be inserted - that they should be considered, including power of attorney, trusts, support from others, etc. If they won't work, (presumably) something on the record about why they "won't work" should be mandatory so that these findings can be challenged if they are wrong.
4. The language about the duties of the "attorney" is clearly describing the duties of a guardian ad litem. Either give a person an attorney who will represent what they want, or don't claim there's a right to an attorney when there clearly is not.
5. In the ideal statute that truly promotes self-determination, the principles would be reflected as articulated by the following two state Supreme Courts.

"Persons cannot be deemed incapacitated if their impairments are counterbalanced by friends, family or other support" In Re: Perry, 727A.2d 539 (Pa. Sup. Ct. 1999)

"In the determination of competence, 'credible evidence of third-party assistance produced from a source must be considered'." Iowa Supreme Court

In Michigan, the statute was changed last year to state a judge must make separate finding of incapacity and necessity. This is to reflect that a person may be completely "incapacitated" and still not need a guardian if they have the proper supports to meet their needs.

The following are suggestions for amending the New Jersey statute:

6. In Sec. 30:4-165.8 add the language in bold: "The affidavits shall set forth with particularity the facts supporting the affiant's belief that the alleged incapacitated person suffers from a significant chronic functional impairment to such a degree that the person either lacks the cognitive capacity to make decisions for himself or to communicate in any way...AND IS IN NEED OF A GUARDIAN. For the purposes of this section, "significant chronic functional impairment" includes, but is not limited to, a lack of comprehension of concepts related to personal care, health care or medical treatment. **"IN NEED OF A GUARDIAN" MEANS THE PROPER SUPPORTS FROM FAMILY, FRIENDS AND PROFESSIONALS DO NOT MEET THE NEEDS OF THE INDIVIDUAL.**"

7. In Sec. 3B:2-2, add the language in bold: "'Mental incompetent' means a person who is impaired by reason of mental illness or mental deficiency to the extent that he lacks sufficient capacity to govern himself and manage his affairs, **OR DOES NOT HAVE THE SUPPORTS FROM FAMILY, FRIENDS OR PROFESSIONALS TO MEET HIS NEEDS.**"

Clearly, the statutes are weak and need to be brought into the most recent legal and ethical theory that honors individuals with cognitive disabilities while ensuring their protection without taking away their legal rights.

Training and Technical Assistance

The types of training and technical assistance and the depth of that support are critical elements in promoting self-determination. Because self-determination has been an evolving concept with myriad issues unfolding over time it is important that this component keep abreast of these developments and share current knowledge and practice with both participants and policy makers. The Boggs Center has performed these tasks well within the strictures of present policy in New Jersey. However, it might be desirable to consider adding some training and technical assistance components that reflect where self-determination has grown beyond its initial concern with transferring power and authority to individuals with disabilities. Today self-determination has evolved to a deeper concern with understanding that this transfer of power and authority is simply a tool, albeit a necessary tool, for individuals to craft a meaningful life in their communities. A more comprehensive history of this evolution is also helpful to participants as well as policy makers. There are many ways to organize training and technical assistance. The following are just suggestions based on the most recent evolution(s) of self-determination.

15. The Tools of self-determination. These components would revolve around the three structural changes necessary for implementing self-determination: independent support coordination, fiscal intermediaries and individual budgets. New Jersey already covers the first two but experience elsewhere indicates that creative, highly personal, and cost effective individual budgets are of paramount concern and where self-determination frequently falters. While there is some disadvantage with day or vocational dollars not accessible for individual budgets, this component remains the most essential.
16. Barriers to Self-Determination. Many of the barriers are included in the policy and practice section above. Guardianship remains one of the most difficult to change but seems essential if self-determination is going to be available to all

individuals with cognitive and intellectual disabilities. This is a long range and complex undertaking. Added to the issues surrounding guardianship discussed above is the issue of representative payees-- another example of loss of control. This too is complicated by the regulations of The Social Security Administration. Both issues are solvable if difficult. Individuals with disabilities and family members as well as policy makers need to know that there are alternatives that are much more respectful and still provide the assistance that persons with disabilities require.

17. The role of self advocates and the self advocacy movement. This in particular is an issue that is now entering center stage across the country as systems change evolves and it becomes more and more apparent that the very individuals most affected by these changes have a right to be intimately involved in policy making regarding just how these changes will evolve. Support for the independent self advocacy movement needs to be an integral part of the self-determination movement.
18. Creating Economic Futures. One of the important directions that self-determination has taken in recent years is aimed at the "forced impoverishment" of individuals served by the human service system. The goal of real, integrated employment and the development of microenterprises are demonstrating once again the possibility for any individual no matter the significance of their disability to generate private income.

The eventual development of special savings accounts and assets that previously seemed unattainable under the present system are now in discussion at all levels of government. The release very recently of model Waiver Templates by CMS is only the latest example of the recognition of this and other issues and the intent of relevant government agencies to address it.

General Recommendation

19. The benefits of self-determination properly implemented are now recognized and supported by a majority of the states. New Jersey is poised to consider whether this reform will be available not only to those newly entering the system but also to those already served by human services. This requires a great deal of thoughtful planning. As competition for scarce resources intensifies and as the federal government begins to enforce the "portability" of Medicaid funding among qualified Medicaid providers (a requirement of Medicaid) the time may now be right for the Division to begin planning to carefully implement self-determination for all individuals with intellectual and cognitive disabilities.

Our community systems are in crisis with the growing scarcity of resources, waiting lists for those who are unserved or underserved and the diminishing cadre of direct support workers. This may be the time, not to retrench, but to imagine a new system based on principles that honor individuals with disabilities and families much more than the present system.

Reference

Wilner, M. A. (2000). Toward a Stable and Experienced Workforce. *Generations; The Journal of the American Society on Aging*. 60-65.