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A Federal Mandate for a Conversion to
Community-Based Residential Services':
A Proposal for Legislative Action

by

Hank A. Bersani, Jr., Ph.D.

Assistant Professor

Division of Special Education and Rehabilitation

Syracuse University

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Head: Federal Mandate

Abstract

This paper proposes a legislative plan to convert federal expenditures from a predominantly institution/large facility-based system to a small, family-oriented community based-system. Analogies are drawn to the impact of legislation on the public education of children with handicaps, and a proposal is offered to develop a residential equivalent to P.L. 94:142. Issues addressed include: due process, parental involvements, safeguards, and supports for families and individuals.

A Federal Mandate for a Conversion to Community-Based
Residential Services: A Proposal for Legislative Action

What shall we call it? Deinstitutionalization, a conversion model, institutional depopulation, normalization, communitization, community development—call it what you will. There is a strong movement to facilitate family and neighborhood living for people who have previously lived in institutions, large private facilities, and other residential services that do not meet peoples' real needs. This movement to stay in the community, or to return to the community, is a true social movement and as such, we can conceptualize three spheres of activity or change: ideological, practical, and legal. The dramatic changes in the education of children with disabilities over the last 15 years provides a useful example of the interrelationship of these three spheres.

Practice. In the sphere of practice, we witnessed a dramatic shift within the field of special education. At one time we did not know how to teach some children with certain needs in regular schools and regular classes. In fact, there were some children who we did not know how to teach at all. Now we clearly have the practical ability to teach all children in integrated settings. It is not just a good theory these days, it is good practice.

Ideology. In parallel developments, in the sphere of ideology, we saw a shift from positions that said some children needed special schools and other children did not belong in school at all to a position that children should, to the maximum extent possible, all go to school together. The philosophy of education has slowly but surely shifted.

Legal. In the third sphere—legal, we have witnessed a change that in many ways has been more visible. That change has been the direct result of The Education for All Handicapped Children Act of 1975, more commonly know as P.L. 94:142. That federal mandate (in conjunction with the developments in ideology and practice we discussed earlier) has made it possible for children to be educated in the least restrictive environment; for parents to participate in the development of an individualized educational program; to use due process procedures if there is a disagreement between the parent and the school. Due to this law, students and parents have rights, school systems have obligations, and we all have a body of legislation, regulations, and case law to build on.

Is everything in the schools perfect now? No. Are things better than before the passage of this cornerstone legislation? I am convinced that they are.

What does all of this have to do with where people live? What can we learn from our experiences in the field of education that can help us in offering people quality places to live? What we need is the analog—the residential

equivalent of P.L. :94-142. What would it take to accomplish that? How would we know it if we saw it? If legislation is to be passed and to succeed and in reshaping family supports and residential services on a national level will need three parts: (1) basic principles and provisions. In P.L.:94-142 we have provisions of free, appropriate public education; safeguards – provision to minimize the risk inherent in the change. In P.L.:94-142 we have safeguards of due process and IEPs; (3) political palatability – provisions or considerations that will make possible a level of legislative support to pass both houses of Congress. Provisions without safeguards are too risky, and good provisions and safeguards that cannot succeed politically are only an academic exercise.

Keep in mind that, as in the field of education, passing a law will not guarantee integrated living. Legislation is a starting point, not an end point. We can mandate a process, but only facilitate an outcome.

It would be nice if everyone got what they need because well-trained, well-supported professionals do what needs to be done, because it is the right thing to do. That is the ideal, but in some cases, it has taken the power of law to get people what they need and deserve.

Basic Principles

A clear statement of value.

A federal policy on community services must begin with a series of statements that encapsulate the fundamental principles of community. Such statements might include the following:

- * Children should live with families.
- * People with developmental disabilities should be served in their home communities.
- * Community living arrangements should be family-scale and located in residential neighborhoods.
- * Services should support people in typical homes, jobs, and community environments.
- * Services should foster the development of practical life skills.
- * Parents and people with disabilities themselves should be involved in the design, operation, and monitoring of services.

These statements reflect a philosophy that families are important, community participation is essential, that integration is better than segregation or isolation, and that small is better.

Where do we begin? Right now, the single largest "system" that affects people with severe disabilities is the Medicaid system. This year, state and federal expenditures under Medicaid will total over 6 billion dollars. The

majority of that money has traditionally been spent in institutional settings. (Braddock, Hemp and Howes, 1985).

Today, the Medicaid system is the largest "cause" of institutionalization in the country—paying for most of the over 100,000 people living in U.S. institutions today. If all of that money (or a sizeable percentage) were to be directed to family and community oriented living, we would see a transformation at the national level at least as dramatic as what has happened since P.L.:94-142.

What would such legislation be called? For the purposes of discussion in this chapter, let's call the proposed legislation the Family and Community Life Act, since the value statements just reviewed stress the need to first keep families in tact, and second, to support people with even the most severe disabilities in their natural communities. The basics of Medicaid.

The Medicaid program was established under the Social Security Act in a section of that act which is known as Title XIX, "Grants to States for Medical Assistance Programs". As can be seen from the name given to this section of the Act, the original intent of this legislation was primarily medical in nature. This has led us to the largely medical, institutionalized system that we have today.

Medicaid is said to be an "Entitlement" program; that is, people who meet the disability and income guidelines as specified in regulation are automatically entitled to have their costs paid for services which they need, which are

suggestions for system-wide change in the Medicaid system.

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Medicaid Eligible. A variety of critics have offered These include dramatic shifts in the philosophy and implementation of the Medicaid system to make it less medical, less institutional, and more family and community based.

Basic Provisions A
system of incentives and/or disincentives.

In the sport of wrestling there is a saying, "Where the head goes, the body must follow." In service funding the rule seems to be, "Where the dollars go, the service will follow." In order to promote the development of community options we need to reverse the system that currently presents a financial incentive for institutional placements and a financial disincentive for family and community. As a matter of political reality (to be discussed later) it is much more palatable to promote disincentives (financial cutbacks) rather than incentives (financial supplements). Thus, Family and Community Life legislation must state that federal financial participation (FFP) in federally funded programs (Medicaid, Title XIX) would favor community development and placement over institutional or "large" settings. Several methods have been suggested. Later we will address what is politically possible, for now, let us stipulate a principle that: No Title, XIX monies may be spent in non-family, non-community settings.

Money must follow people, not programs.

Easier said than done! Today, in most systems, if someone moves from a large, institutional Medicaid "bed" into a small, personalized home that costs 60% less, that money typically vanishes back into the general treasury. In fact, the reduced funding needed may not be available at all. Money needs to follow people, and surplus money from one person must continue to be available to other people in the system.

Defined measures of progress.

How will we know if progress is being made? A federal mandate must include clear, obvious measures that reflect progress toward stated goals. For the purposes of deinstitutionalization, or the conversion to a community-based system, some relevant measures include:

The number or percentage of people returned to the community (from segregated settings); The number of people placed in community programs (from family homes as well as from segregated settings); The number or percentage of dollars diverted to the community (from segregated settings); The number or percentage of dollars in the system spent in the community.

One or more of these measures could be stated as a reflection of the progress being made at the national or state level. Given the premise stated above, that where the

money goes the service will follow, a measure of the percentage of dollars returned to the community seems most appropriate. Size guidelines.

Size is an issue! Today, it is popular to say that the data are ambiguous, that size may or may not be an issue; that size in isolation is not as important as other factors, etc. The fact of the matter is that size is important, and small is better. One very easy way to know this is to look at the personal lives of those who say size does not matter. They typically go home at night to relatively comfortable, fairly "individualized" "community-based" "family-style" residences that they call "home." None of them (that I am aware of) go home to 15 bed "facilities." This paper is not the place to review the literature on the effects of size. However, to restate the point; Family and Community Life legislation to promote the conversion to a community based system must address the issue of size in such a way that "small" is an integral part of the definition of "community". For legislative purposes, size is probably best described in terms of census data for households in the area where a home is to be located. This has several advantages: it points out that one issue of size is that large programs overwhelm neighborhoods, it "pegs" the limit to objective data, and it allows for normative, regional differences. As a starting point, let us state a principle that: No "programs" that serve more people than the average household size in the neighborhood may be funded under Title XIX.

Time frame.

In any program plan for a student or adult today, we would expect the stated goals to be assigned a time frame. We should ask no less for the goals of movement of thousands of people and billions of dollars into the community. Legislation must set long-term goals such as "a 100% conversion to the community in 10 years"; or "an 85% conversion in 15 years". However, this alone is not sufficient. How will advocates, consumers, legislators, and agency personnel know if the conversion process is on schedule? Legislation must not be written in a way that allows insincere or ineffective effort to persist until the long-term deadline, only then to take action. If, for example, legislation allows a 10 year conversion period, then 10 goals, one year each, might be appropriate, or 5 goals of two years each. Legislation must promote a process not just conversion by legislative fiat. For now, lets stipulate that under a Family and Community Life Act: All Title XIX funds must be diverted from non-family, non-community -settings within 10 years..

Focus on Process.

It is easy to focus on the product alone, to describe desired size homes, in appropriate settings, and to think that the end product is all that counts. If we look again at P.L.:94-142, we see that such was not the case. P.L.:94-142 does not specify self-contained classes, or any other single form of education. That law specifies a process: a free,

appropriate, public education in the least restrictive setting. Similarly, family and community living legislation must set up a process. The process is to use the diversion of medicaid funds from institutions into family and community settings. Fund An Array of Services.

Just as P.L.:94-142 allows funding for a variety of educational settings - provided that they fit the process of free, appropriate, public education in the least restrictive setting, - so too we must be prepared to fund a variety of residential options. We do not need any "group home" legislation, because group homes are only one (fairly limited) alternative. However, we also do not need a full continuum of theoretical services as was once suggested. -The relative merits of a necessary "array" versus an excessive "continuum" is a discussion beyond the scope of this paper. See Taylor, Racino & Knoll (1985) for a full exploration of this issue.

Current funding patterns are clearly biased towards larger, out-of-home placements; (group homes) and medically-based facilities (ICF's/MR). Family and Community Life legislation must promote support for families - "natural", adoptive, and foster. It must also promote the use of small (1 & 2 person) houses and apartments. Group homes, as currently conceptualized, may need be funded, but should be third priority, after families, and other 1 & 2 person options.

Transition Period.

As mentioned above, state and federal participation in Medicaid funded residential programs (mostly institutions) is in excess of 6 billion dollars (Braddock, Howes & Hemp, 1985). A system that size can not convert instantaneously. Rather, a long-term time frame is necessary. During that transition period, a "dual system" will be in place: a dying institution-based system, and a developing community-based system. These two systems combined will be more expensive and more cumbersome than either system alone. Family and Community Life legislation must acknowledge this fact, and provide for enriched levels of funding for systems during this transition. Legislative guidelines for the transition period must also address the issues of staff realignment, and the income produced by the divestment of institutional buildings during the transition period. Additional Services.

Under current legislation, Medicaid offers two classes of services: those which the state is required to offer under the state medicaid plan, and those which are optional and may be offered if the state chooses. Family and Community Life legislation will need to expand both areas of offerings. The "mandatory" list must be expanded to offer services that are indispensable in supporting true family and community life, and the "optional" list will need to be expanded in order to allow for greater responsiveness of states to specific needs of their citizens. Suggestions for additional mandatory

services include the provision of respite supports for families, attendant care for individuals living in the community, and Habilitation services.

Safeguards

Personal Protections.

As people move from centralized institutions to scattered sites-homes, throughout neighborhoods, additional safeguards will be needed to insure that each individual is well cared for, safe, and is receiving all appropriate services. These personal protections must include at least the following forms.

Independent case management. We must make sure that as people move into communities, that they receive well coordinated case management. In order to minimize conflict of interest, the case manager for an individual must not be employed by any of the other agencies serving that person.

External, Paid Advocacy. There are many forms of advocacy: some agencies use staff advocates (internal), some communities have independent (external) advocates, some are paid, some are volunteers, all are necessary. Legislation cannot (and should not) deal with volunteer advocates, such as citizen advocacy protects. However, even in systems where strong citizen advocacy exists, there is a need for external, paid, advocates, like the existing protection and advocacy (P & A) system. The existing P & A system is in the appropriate format, and has a good track record. However, to

cope with a massive transition, a great deal more funding must be made available to that system.

Adult Protective Services. In many states today, there is no structure equivalent to Childrens' Protective Services. As growing numbers of adults move into the community, there will be a need for an agency to address concerns of abuse and neglect. Such an agency may need the power to conduct investigations, to subpoena records, and to act to protect adults at risk in the system.

Due Process. One of the innovations of P.L.:94-142 has been the concept of due process. Just 15 years ago in some school systems students could be tested, labeled, placed in special education classes, or even expelled without due process, and without parental involvement. Now, educators know that in order to test, or label a student, or change the educational services, that a rigorous set of procedures must be followed. Thousands of families across the country can testify to the fact that due process has improved their ability to get the services they want and need for their sons and daughters. The need is no less in residential services. Due process must include notification and consent of parents or guardians for assessment and testing, participation in decision making, written notification of rights, etc.

Interdisciplinary Team. Where a person lives should be the center of their life, and other services (education, vocational training, etc.) should be coordinated from the - home. Family and community living legislation must require

that decisions be made by an interdisciplinary team, following due process, and involving the family and the individual receiving the service to the greatest extent possible. Additional participation on the team should include representatives from major disciplines and agencies serving the individual (medical, rehabilitation, education) .

Individualized Written Plans. In education, the requirement for written, individualized educational plans, in conjunction with due process and parental participation, has allowed parents for the first time to hold schools accountable for the provision of agreed upon services. Similar plans, which might be called individualized written habilitation plans or individualized program plans, are a necessary safeguard in the move to the community.

Service Identification/Implementation. Although these have been flaws in implementation, P.L.:94-142 specifies that needed services be identified and available at the time the plan is to be implemented. Today, in many systems, people move to the community first, and only then do efforts begin to identify needed services. Legislation should require that no one move into a new setting until needed services have been identified or initiated and are ready for prompt initiation at the time of the move.

Private Right of Action. This term refers to the right of" an individual to bring legal action against the State if they feel that they are not receiving appropriate services. Such a right must me stipulated in order to be in effect, and

is essential to safeguard the rights of persons who are receiving services under Family and Community Life legislation.

Attorney fees. Once one has the right to take legal action, as mentioned above, it is important that such a right is not obviated by the problem of the cost associated with bringing such legal actions. If only wealthy people can afford to bring a legal action, then the right of private action becomes only a privilege of wealth. For this reason, there must be a provision for plaintiffs to recover legal fees incurred as a result of the legal action. Some advocates would like to see recovery of legal fees for unsuccessful actions as well. Recent experience Congress with the Handicapped Childrens' Protection Act seems to indicate that recovery of fees for successful claims is practical, but reimbursement for unsuccessful suits (which implies that the plaintive was wrong) are not politically palatable in the current climate.

Time limited waivers of state-wideness and comparability. In the past, the Medicaid program has required that services be provided equally to the citizens in a given state. The state has had to demonstrate that the Medicaid plan respects the principles of statewideness—that all regions of the state are treated equally; and comparability—that all persons with comparable needs are receiving comparable services. Originally, these provisions were designed to prevent favoritism within state Medicaid

services. However, their presence is also a deterrent to innovation. If a state wishes to add a new, optional service under its medicaid plan—respite care for example, they must immediately offer that new service on a state-wide, comparable basis. In many cases, the state is uncertain what the service will cost, how many people will use it, etc., and so the pressure is to not add a new, unknown cost.

An effective bill to promote family and community life, would include a time limited waiver of these two provisions. For a given period (say 2 years), a state could offer the new service on a limited basis, to test the concept, get cost information, to judge popularity, or as a "pilot" to test a specific delivery mechanisms. However, at the end of the waiver, the state would have to act; either cease to offer the new service all together, or expand to offer the service on a basis that demonstrates statewideness and comparability. Of course, such a provision would apply only to optional services. States would not be allowed to waive statewideness or comparability stipulations in the provision of mandatory services.

Maintenance/Effort? There is a possibility that as states and the Federal Government redirect Medicaid dollars to the community that the so-called "new" resources will supplant existing community dollars instead of supplementing them. Family and community life legislation must specify that states and the Federal Government must maintain current levels of fiscal effort and "new" resources must support, not supplant, existing community resources.

Multiple monitoring methods. In order to safeguard the quality of service being provided people under such legislation, the law must require some types of monitoring or quality assurance, and must enable additional optional monitoring mechanisms. Family and Community Life legislation will need to mandate review and approval of state plans by the Secretary of Health and Human Services. Plans that were not approved would not be funded. Plans that were approved by the Secretary would be implemented. In order to be approved, the state plan must stipulate (among other things) that money spent in community residences (as opposed to family supports) will be spent only in residences which are licensed, or certified by the state, and which conform to minimal standards promulgated by the Secretary of Health and Human Services. Additional monitoring mechanisms that might be encouraged by the legislation would include provisions for parent/consumer monitoring. Fiscal responsibility.

Any new program, or massive reallocation of Federal funds is bound to be greeted with skepticism at the Congressional level. There will be a need to demonstrate or insure some degree of fiscal responsibility under the proposed legislation. There is a problem with arguing that new Family and Community Life services will necessarily be cheaper, since it implies that cost is the only factor to be considered. In addition, if legislation leads to better quality services, it is likely that high quality services in

the community will be more expensive than institutional neglect. Thus, instead of stressing lower cost in the absolute sense, we should stress the greater fiscal responsibility from a new system better services, for more people, in more appropriate settings, keeping families intact as much as possible, at a cost that is reasonable.

Regulations.

As with any piece of Federal Legislation, Family and Community life legislation will actually be implemented under a set of regulations, in the case of Medicaid reform legislation such as this, such regulations will be developed by the Health Care Financing Administration (HCFA). Such regulations have a great deal of power to enhance the original intent of the legislation, or to stifle it if they are written improperly. After legislation is passed, HCFA will draft proposed regulations which will be published in the Congressional Record for comment. Groups that have supported the legislation must not assume that once the bill was passed the task is over, proponents of the new legislation must take the time to comment on the draft regulations, especially in instances where the proposed regulations conflict with the original intent of the legislation.

POLITICAL PALATABILITY

As mentioned earlier, having principles is essential; however, ultimately such principles need to be refined into legislative proposals with political palatability.

Broad base of support.

Medicaid reform legislation will need to be passed by both houses of Congress and signed by the President. To get that approval, there will need to be support far beyond a few interested groups, and the fact that it is a "good idea". Successful legislation will require the support of a variety of groups:

Professional organizations (such as AAMD and CEC)

Parent/Consumer organizations (ARC, UCPA)

Administrative Agencies (state DD councils) the

general public Key Congressional support.

In both the U. S. Senate and the House of Representatives, there are "key" leaders in specific areas. In the area of services to persons with disabilities, there are a handful of Senators and Congressman who have the reputation of being most concerned and informed on the topic. Other "key" members are those who chair important committees (such as the finance committee), or sit on important committees (such as the subcommittee on health). Key Senators include Senators: Packwood, Dole, Chafee, Kennedy and Weicker. In the House of Representatives, key members include Representative Waxman.

As mentioned in the introduction, effective provisions, and well designed safeguards are only two-thirds of the task to 'create such a sweeping reform. Ultimately such proposed

legislation must be politically palatable. We must remember that in the legislative realm, the ultimate question is not "Is it a good idea?", but rather "Can we get it passed?".

To review, the basic principles of a Family and Community Life Act would stipulate the total removal of all Medicaid funds from non-family and non-community settings over a 10 year period. Under the provisions of the act, Title XIX monies could only be used for services that support families, and for community-based living in settings no larger than the average household size in the area. All though a variety of other provisions were presented in this chapter, these are the most likely to be controversial. In fact, they were the basis of legislation entitled the Community and Family Living Amendments of 1983 which were introduced by Senator Chafee. At the end of the 98th Congress, in December of 1984, the bill had only a handful of supporters, and so, with thousands of other bills, died with the Closing of Congress. Early in the 99th Congress, Chafee reintroduced the bill as the Community and Family Living Amendments of 1985, with several compromises included. These changes were in response to criticism that while the general purpose of the bill was laudable, that several specific provisions were too severe. While the 1985 version of the bill is substantially different than the 1983 version, for purposes of this discussion, we will focus on the three most significant, and most controversial provisions: the total

elimination of medicaid payments into institutional settings, the 10 year time frame for conversion, and the size limitations on programs that would be approved for funding.

Diversion of Title XIX funds. In our fictitious Family and Community Life Act, we stipulated that 100% of all Medicaid monies would be diverted into family and community settings. In his 1983 proposal, Chafee attempted this as well. Critics maintained that some people would always need institutional settings, and thus, this provision was unrealistic. Chafee continues to maintain that no individuals need institutionalization, however, he points out that some systems may not be able to totally shift to a community based system. Thus, in the 1985 bill, Chafee allowed for federal reimbursement for up to 15% of a states budget spent in other than community settings.

Phasedown period. In Chafee's original legislation, the phasedown period was stipulated at 10 years. Critics claimed that while the intent was good, that only a decade was insufficient for sincere efforts to convert from a largely institutional based system to a community based system. In 1985, Chafee's revised version of the bill allowed for federal matching dollars for up to 15% of the states medicaid expenditures to be in larger settings.

Size. In our Family and Community Life Act, we proposed that no programs be approved if more people lived there than would live in the average household in the neighborhood. As appealing as this provision is, even Chafee's 1983 proposal

was not so bold. In that bill, Chafee proposed that homes could have a number of residents not to exceed a number three times as great as the average household size in the area. While this would allow for homes of much larger than family scale, the decision was made that this still represented a significant departure for current practice, and would be a major leap in the right direction. This provision remained unchanged in the 1985 version of the bill, however, in response to critics who said that this was too demanding, an exception to the provision was included, this provision allowed for the "Grandfathering-in" of programs that serve up to 15 people regardless of the average household size in the area. Only programs in service at the time the act was passed would be included.

Support for this clause seems to come from two camps. First parents who have fought hard to get their sons and daughters into programs that are "small" by today's standards (10-15 people) which might be disqualified from Medicaid funds under the Chafee provisions. Second, state and private agencies that have recently invested substantial efforts and resources to develop these "small" settings. They feel that they would be "punished" as severely as an institution for 1,000 people, while they are clearly more a part of the community movement than opposed to it. Where does it all stand now?

Chafee in his 1985 bill made several serious concessions to moderate the bill. As a result, there has been increased

acceptance, however he is still significantly short of the level of support needed to pass such landmark legislation. When the 99th Congress drew to a close in December of 1986, Chafee had still garnered openly 10 co-sponsors—only one-fifth of the support needed to pass the bill through the Senate.

In a parallel movement, Congressman James Florio introduced a nearly identical bill in the House of Representatives. In the House, the proposals met with some what greater support. At the close of the 99th Congress, Florio had the support of over 75 members of the House. Still, this is substantially short of the number of votes needed for passage.

What will happen next?

As this book goes to press, the 100th Congress will convene, in January of 1987. Both Congressman Florio and Senator Chafee have pledged to reintroduce their bills for an additional two years. Various advocacy, professional, parent, and agency organizations are in constant communication with Chafee, Florio and the supporters of their bills. Further compromises are being considered in order to make the bill more palatable. However, advocates fear that excessive compromises may result in a bill that is palatable enough to pass, but too weak to create the desired reform in a very weak sense. Professionals, advocates, and voters are

being asked a very real question "How much can the provisions of the bill change, and still make it worth the support of those of us who are working for the goal of Family and Community Living?