

COMMUNITY AND FAMILY LIVING AMENDMENTS:  
SEPARATING THE MYTHS FROM THE FACTS

**DRAFT**  
Not For Quotation

Hank A. Bersani, Jr., Ph.D.  
Center on Human Policy  
123 College Place Syracuse  
University Syracuse, NY  
13224-4130 (315) 423-3851

Running Head: CFIA: Myths/Facts

Community and Family Living Amendments:  
Separating the Myths from the Facts

During 1985, Senator John H. Chafee received over 2,000 letters opposing the Community and Family Living Amendments. During the 12-month period of a fellowship with the Senator, I reviewed each of those letters, and personally responded to hundreds of calls regarding this most controversial piece of legislation. This paper compiles the many "myths" that became evident during that period.

Three types of myths.

Myths about the Community and Family Living Amendments (CFLA) fall into three categories: myths about the details; myths about the implications; and myths about the philosophy. The first category, myths about the details, refers to myths about what has and has not actually occurred, and what language is and is not actually contained in the bill. The fact that such myths exist is not as surprising as the reader might first assume. After all the bill has a 4-year history, is 40 pages long, written in legal jargon, and makes complex references to various sections of the Social Security Act, to which most people do not have access. The second category, myths about the implications, includes myths about what life will be like if the bill is passed. In this area, there can be no exact science, there is only well-informed insight and understanding congressional intent. In the third category, myths of philosophy refers to differences in ideology regarding the relative roles of

institutions, community services, Medicaid, and Federal involvement in the lives of individuals.

MYTH: "This bill originated as a whim of Senator Chafee for political purposes, without consultation of parents, professionals, or the public."

THE FACTS: Over the last several years, Senator Chafee and his staff have met with virtually everyone who has requested a meeting. He has coordinated both formal and informal public hearings on the bill, and representatives of every major parent and professional organization in the country including Voice of the Retarded, Association for Retarded Citizens, United Cerebral Palsy, the American Civil Liberties Union, the World Institute on Disability, the Head Trauma Association, and the Association for Persons with Severe Handicaps.

MYTH: "Only one formal hearing has been held, in Washington, far from the strongest opposition, the panels were stacked with supporters, and Chafee has refused requests to hold formal hearings in other states."

THE FACTS: Senators cannot schedule formal hearings at will. Chafee requested a hearing in 1984, and Senator Packwood, as the chair of the ruling committee (Finance Committee) scheduled the hearing, and selected panelists. A reading of the transcripts of that hearing make it clear that opponents were in

the majority. Chafee has scheduled two additional informal forums on the bill, one in Rhode Island and one in Illinois (Chicago), the state with the strongest opposition to the bill. Chafee has requested additional hearings on the bill, but has thus far succeeded in only in getting hearings on the Medicaid system as a whole, not specifically his bill. Again, senators cannot schedule formal field hearings at will. Hearings can only be called by a senator on the ruling committee, and only for their state. Thus a given state can only have a formal hearing on a CFLA if one of the state's senators sits on the Finance Committee and if that senator requests a formal hearing. To date, there has been no such request from any state.

MYTH: "Although there was a hearing held, Chafee ignored the criticisms raised in that hearing and continues to push the bill with no changes."

THE FACTS: As a result of the 1984 hearings, a revised version of the bill was introduced with over a dozen substantial changes recommended at the hearings. Both the ARC-US and TASH now circulate copies of a comparison of the original and revised versions of the bill. The changes include lengthening the phase down period by 50%, allowing a substantial percentage of the Federal match money to remain in large (institutional) settings, the grandfathering in on many existing programs that would not otherwise qualify for funding under the previous version, the addition of several mandatory services to families and

individuals in the community including respite care and attendant care, a change in the eligibility, etc. Each of these changes can be tied directly to the feedback generated by the hearings and the flood of mail Chafee received when the bill was first introduced. Even as this report is being written, Chafee and the co-sponsors of the bill are meeting with a broad spectrum of disability groups, including opponents regarding possible additional changes to the bill.

MYTH: "CFLA is supported only by a few organizations that would directly benefit from the provisions."

THE FACTS: CFLA has been supported by over 20 national disability groups including parent groups, professional organizations, and consumer groups. In addition, dozens of state and local organizations have expressed their support for the bill.

MYTH: "CFLA declares all programs with more than 15 residents as "institutions," and "incapable of providing quality care."

THE FACTS: No definition of institution is offered, and none is needed. CFLA is only amendments to existing legislation, and the existing language defines services eligible for Federal support. The bill does define "community services" for the first time. The limit of 15 residents does not exist in the bill as

such. The bill does specify that in order to receive Federal support the program may not have more residents than three times the number of residents in the average home in the area. The bill does not comment on the quality of care in institutions at all. In addition, a special "grandfather clause" does exempt existing facilities with 15 or fewer residents from certain provisions.

MYTH: "CFLA would outlaw all institutions; public, private and charitable, and would require all large programs to close."

THE FACTS: First, the bill only applies to programs that receive Medicaid funds. The bill does not affect programs that operate without Federal dollars. Second, the bill does not make any type of service, including institutions, "illegal". the bill does specify new guidelines to qualify for federal funds, and greatly restricts the availability of Federal funds from programs that do not meet the proposed size guidelines. State may continue to spend their own dollars as they see fit, charitable and other private organizations may spend their money as they see fit, and parents may pay with their own funds for any services they see fit. The bill only restricts the flow of the Federal share of financial support.

MYTH: "The bill would mean that for each person in an institution, the state would receive only 15% of the current budget."

THE FACTS: Opponents who believe this myth point out that no one can exist on 15% of their current budget, which is clearly true. The bill proposes two complicated changes to the reimbursement system that will result in a substantial decrease in Federal payments to large programs. In any case, the mythical 15% applies to the current level of Federal match, not the total budget. Under the bill, states receive Federal match for up to 15% of the money they spend in institutions, but this does mean that total expenditures will be cut to 15% the current level, since states currently contribute up to 50% of Medicaid costs, and this state share is not restricted by the bill.

MYTH: "The bill discriminates against various groups (the mentally ill, the elderly, the physically handicapped, families that have kept members in the community)."

THE FACTS: The Amendments in Community and Family Living Amendments refers to amendments to the Social Security Act. It is not a new statute, but rather a set of additions and deletions to the existing law. That law has many flaws, and only some of these flaws are corrected in the bill. Under the Social Security Act, only a few types of mental health services are funded. CFLA actually increases the eligibility by adding childhood mental illness as an eligible group. Likewise because the bill stipulates that an individual must manifest their disability by age 35 in order to qualify for services, people assume that it

discriminates against older citizens. In fact, the current law requires the onset of the disability by age 21, so it actually includes new people as eligible. While it is true that the benefits to persons with physical disabilities were unclear in the original bill, the current bill requires states to offer services specifically to persons with physical disabilities, including attendant care. Lastly, critics say that the bill only helps those from institutions. In fact, the bill mandates respite and family support services which are specifically aimed at families in the community.

MYTH: "The bill takes power away from parents."

THE FACTS: The CFLA specifies new rights for family involvement. It provides for the participation of parents or guardians on the interdisciplinary team, and for the first time requires due process procedures in residential placements. CFLA also stipulates a private right of action that allows families to sue if they feel that the state compliance plan has been violated.

MYTH: "CFLA puts the cart before the horse by putting people out into communities where there are no services for them."



THE FACTS: The bill specifies that the services a person needs are to be detailed in writing by the interdisciplinary team, and that no new placement may take place unless those needed services are in place.

MYTH: "CFLA is a dumping bill, designed to push people out into the community as fast as possible."

THE FACTS: CFLA could actually be called an "anti-dumping" bill. Each of the problems that occurred in the massive psychiatric deinstitutionalization in the last decade has been addressed in the CFLA. Under "dumping" conditions, people move without written plans, without services being available, without a commensurate flow of dollars to the community, without a formalized state plan, and without Federal supervision. Under this bill, no one moves without a written plan or without services in place. The flow of money to the community is tied to the movement of people, and must occur in the context of a state plan filed with and supervised by the Federal Government.

MYTH: "The bill would set people in the community with money for services but not for room and board, so that we would have thousands of new street people."

THE FACTS: This myth is apparently rooted in a phrase in the legislation that states that resources under this bill may be spent for services only, and may not spent on room and board.

This is a technical requirement. In order to qualify for Medicaid, people must have a disability that qualifies them for existing programs for room and board (just as are used now in community residences and institutions). This is nothing new, it does not mean that people will not have access to room and board supports. Because the bill makes such dramatic changes in the services eligible for funding there was a need to specify room and board charges continue to be ineligible for reimbursement.

MYTH: "CFLA would force parents to take home their sons and daughters against their will."

THE FACTS: The bill does contain provisions that would encourage families to stay together, and would support families that want to stay together, but there is no such requirement. There are no provisions in the bill that could be used to force families to take home family members that they felt unable to care for.

MYTH: "CFLA will force people in the community into competition for resources with people being returned to the community from institutions."

THE FACTS: In fact, the current dual system of institutional and community services sets up a competition between institutions and the community, and thus far the institutions have received the majority of the resources while

the community serves the majority of the people. If anything, the diversion of massive amounts of dollars previously spent in institutions into the community would reduce competition between groups.

MYTH: "CFLA would prohibit the development of services for more than 15 persons, and would mandate the closure of existing state and private programs for more than 15 residents."

THE FACTS: CFLA does provide financial incentives for smaller programs and disincentives for larger programs but does not prohibit any type of service. Because CFLA is a set of amendments to Title XIX, it would have no effect on state and private programs that receive no Title XIX dollars. In addition, the bill would allow up to 15% of a state's FFP to be spent in programs of any size. The state retains the right to determine which programs will receive those monies. Services which are funded totally by state dollars, or by private funds, are exempt from the bill.

MYTH: "Most of today's institutions for the mentally retarded are well-run places that provide quality care and training for the residents."

THE FACTS: As a result of federal look behinds, large numbers of institutional programs have been decertified for failure to meet minimum standards. In a hearing held by Senator

Weicker in 1985, the Senate heard three days of horror stories of unmet needs and abuse in our nation's institutions. Lastly, the continuing trend of successful litigation against institutions makes clear the need for a systematic replacement to the institutional model.

MYTH: "CFLA focuses too much on size and size is not really the issue."

THE FACTS: Size is a very real issue for people who live in larger settings. Anyone who has ever visited larger and smaller homes immediately knows the difference. Other things being equal, smaller is better. Clearly, size alone does not determine quality, but then size is not the only quality issue raised in CFLA. Size is one factor in quality, and size is one of many factors in the bill.

MYTH: "Groups homes and community based living facilities for people with severe and profound mental retardation are still in the experimental stage."

THE FACTS: Clearly, we have a longer history with institutional services than with community services. However, community-based services for people with a variety of disabilities are hardly "experimental". The literature is replete with success stories of children and adults living in a variety of community settings. Case studies from across the

country document people living in the community with challenging behaviors, complex medical needs, severe physical disabilities and profound mental retardation. While such success stories are not yet commonplace, they are far from experimental.

MYTH: "More research is needed."

THE FACTS: No amount of research will ever resolve the philosophical differences that separate the two opposing camps on the issue of deinstitutionalization. From the perspective of supporters of community services, we have more than a preponderance of data demonstrating that everyone can live in the community, in small, family-like settings. From the point of view of supporters of institutions, no amount of research will be sufficient to change their positions. The issue is one of values, and Senator Chafee has proposed a bill that supports families, promotes community, encourages integration, and values the lives of citizens regardless of their disability.