

COMMUNITY MANAGEMENT INITIATIVE SMUES
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CRISIS IN THE COMMUNITY

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by

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PREFACE

The publication of Michael Smull's paper, "The Crisis In the Community," represents a new direction for the Association's Community Management Initiative (CMI). The Association's staff found Smull's paper to be both provocative and insightful. Publishing papers such as this was not one of the original objectives of the Community Management Initiative. We believe, however, it embodies the spirit of the CMI project- namely, to provide state MR/DD agency personnel with information about leading edge concepts and practices. Michael was gracious enough to allow us to share his paper with NASMRPD member agencies.

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The views expressed in 'Crisis In the Community' do not necessarily reflect the opinions of the National Association of State Mental Retardation Program Directors, Inc. or its member state agencies.

Robert M. Gettings
Executive Director

FORWARD

Burgeoning waiting lists, rising service costs, growing concerns about the quality of services, tight state budgets, high community worker turnover. These problems are surfacing in a growing number of state developmental disabilities service delivery systems. State officials, policymakers, advocates, parents, and service providers are deeply concerned that these problems are becoming intractable. At stake is the very capacity of community service delivery systems to respond quickly and effectively to the needs of persons with developmental disabilities.

In "Crisis In the Community," Michael Smull argues cogently that the best hope of addressing these problems is to fundamentally reconceptualize the system's service delivery aims; in other words, what types of services should become the mainstays of community programs? Smull contends that contemporary community developmental disabilities services are dominated by specialized, "facility-based" programs that attempt to replicate -- in one fashion or another -- the nature of institutionally-based programs (i.e., the intensive use of paid staff, "comprehensive care," a clinical orientation, and programs that are organized around activities furnished at special sites). Pointing out the clash between this orientation and key philosophical values that the MR/DD movement is attempting to achieve, Smull concludes that continued reliance on the current, dominant service delivery models will lead to systemwide "gridlock." The public funds necessary to sustain or expand the use of these models will be enormous, and, Smull suggests, there is a diminishing likelihood that the needed funds will be available. He also contends that other critical factors -- particularly labor market trends -- may frustrate the state's efforts to reduce waiting lists by expanding existing services that rely on labor-intensive delivery models . . . even assuming that funding becomes available.

The solution that Smull advances is that states and communities begin to emphasize the delivery of a flexible set of supportive services to families and individuals with developmental disabilities. Under his vision of the future, supervised, group living arrangements would be replaced as the core of community residential programming by an organized system of supportive services to persons who reside, not in an agency-operated "residential units" but in housing of their own choosing. Preserving the integrity of the family unit would replace the all-too-common phenomenon that services are available only at the point of family breakdown.

Smull's contention that "supportive services" are the best possible solution to the present "crisis in the community" no doubt, will be disputed by many who fear that "supportive services" represent a means of limiting society's obligations to persons with severe disabilities. To prevent such an outcome, the "supportive services" framework clearly demands fresh approaches to managing community services.

In many states, the reconceptualization that Michael Smull is calling for is already underway. There is growing interest in -- **and more and more actual** -- examples of -- supportive living arrangements programs that emphasize the delivery of flexible supports in non-specialized housing. Supported employment services are challenging the longstanding dominance of sheltered vocational training facilities. In addition, the states are initiating, expanding, and enhancing family support programs.

Smull's contribution is that this relates the growing backlog of problems in community programs to more fundamental issues in the structure of services and the management of community programs. While his prescriptions might be disputed, few would argue that there is a growing need to reexamine how community services are delivered in light of the accumulating evidence that the public funding is finite and attracting (and retaining) community workers is becoming an increasingly difficult undertaking.

Gary A. Smith
Director of Special Projects

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Crisis in the community
Michael W. Smull

Today's crisis

Community programs for people with mental retardation are entering a period of crisis. Increasingly, the quality of care and the capacity to expand community services are being adversely effected by understaffing and underfinancing. Difficulties in expansion are compounded by the use of agency owned or rented housing, with its escalating acquisition costs and the community acceptance issues inherent in labeled, congregate housing. Today's crisis is the unintended result of the transfer of institutional patterns of service development and delivery to community programs. Resolution of the crisis requires a reconceptualization of these patterns. Alternative patterns of service development and delivery, which account for the individual characteristics of people with disabilities and make use of the resources of the community, must be developed and adopted. It is time for us to give up the paradigm of programs and adopt a paradigm of support.

In the transfer of institutional practices to the community we have continued a practice of unnecessary control over the lives of people with disabilities. We have ignored the diverse riches of opportunity and support that the community offers while depriving people of the satisfaction that comes from exercising

choice. Instead of the integration we promised we have created new, albeit smaller, islands of disability in the community. The practice of developing programs first and then putting people in them must be replaced by a process that starts with the individual (Racino & Walker, 1988). Staffing patterns that rely on paid staff who do everything for the individual must be replaced by a mix of community members and paid staff.

The symptoms of the crisis are problems of scarcity. There is:

- not enough money;
- insufficient qualified staff;
- too few services;
- inadequate training; and
- too few program alternatives.

Demands and expectations have risen faster than funding. The "slack" in the system that was used to cope with unanticipated problems is gone. Institutions are operating at capacity with plans to reduce their census. Many community programs have few vacancies and no plans to expand. For those waiting, the practice of offering no support and only serving the truly desperate is maintaining a backlog of people-in-crisis. As the community service system, the institutions, and the "waiting list" all move into more acute crisis they create a set of mutually reinforcing pressures.

As the expansion of community programs was a response to a

crisis in institutional services, the answer to a crisis in the community is not to return to the institution. To do so would ignore what we have learned. We must recognize that it is not the community that has failed, it is we who have failed the community. We need to move away from practices that help people to live in the community without becoming part of the community (Bogdan & Taylor, 1987). We need to support people in the community rather than putting them in programs. If we are to

adopt a paradigm of support, we must:

- Change the way we think about people and services;
- Change the way our programs are staffed and organized; and
- Change the way in which we fund and regulate services.

Yesterday's Crisis, Yesterday's Solutions

Twenty years ago the President's Committee on Mental Retardation (PCMR) reviewed the services of the time. They found a system where:

¹¹ there is little good news in writing about residential facilities in the United States... Typically, public residential facilities have been plagued by a triple problem: overcrowding, understaffing, and underfinancing" (Kugel, 1969).

The PCMR report recommended the development of small community residences coupled with institutional reform.

These solutions were implemented nationally. From that time to the present, the number of people residing in institutions has declined

while the number of people living in out-of-home

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residential, settings in the community has increased. The concepts of normalization and deinstitutionalization left the realm of theory and became the central goals of the community service movement. However, these new national efforts also continued the de facto policy of deferring residential services for people living at home.¹

By most measures, the community service movement has been successful. Over the last decade the number of people living in institutions nationally has declined by one-third (Braddock, Hemp, & Fuijiura, 1986), while the percentage of people living in relatively small (15 or fewer beds) community residences has increased from 16.3% to 41.3% of the total served (Lakin, Hill, White, & Wright, 1987). We have not only demonstrated that community living is feasible, but that people with disabilities acquire more skills when living in the community (Conroy & Bradley, 1985; Eastwood & Fisher, 1988; Haney, 1988). We have moved from housing people in groups of thousands, to groups of hundreds, to groups of tens, and now to three or six people living in typical houses in typical neighborhoods. In a number of locales we have begun to support people in living arrangements of their own choosing.

¹ When the PCMR report was written, in 1968, it was estimated that 50,000 additional "beds" would be required to eliminate waiting lists. National data indicate that, for the next ten years, the total number of "available beds" remained relatively constant as an absolute number and declined when expressed as a rate per 100,000 of the general population.
(Lakin, Hill, White & Wright, 1987)

Moving from Success to Crisis

We have heard, read, and lived the success stories of people who have moved from the institution to the community. The accomplishments of these individuals are related with pride-and pleasure. This is the success we sought, and we have basked in its glow. However, these stories have been changing over the past several years. our focus has shifted from the success of consumers to the failures of our system.

The most common topic

sentences of the stories that we now hear relate to system problems:

"We cannot hire qualified staff";

"We cannot keep the staff we do hire";

"All of the 'easy' people have been served";

"We spend more time on paperwork than we do with the consumers";

"We cannot find competent program managers";

"There is no training for staff";

"We are so underfunded we may not be able to continue to provide services"; and

"We are having so much trouble providing adequate services to the people we are serving that we cannot serve any additional people".

Such indications of pervasive problems among community program providers are reinforced by findings of researchers, and

reports of licensing and funding agencies. For one group of people who have left an institution, an investigator found that the abuse of psychotropic medications was more common in their community programs than in the institution (Conroy, 1988). Anecdotes and newspaper reports tell of a few community programs where the quality of services has become so abysmal that state funding agencies have forced changes in management or closed the program. While success is still the rule, we are seeing research findings (Bercovici, 1983) and anecdotal stories regarding people who have traded the social segregation of the institution for social isolation in the community.

The Movement of Institutional Practices to the Community

Community residences are typically organized to serve people with a particular label in the same fashion as are cottages or wards in institutions. This pseudo homogeneity is attractive for the professionals responsible for placement, planning, and operation of the programs. There is a seductive simplicity in programs for people who have labels based on test scores, ambulation limitations, or diagnoses. There is a **perception that** labels are the answer to the problem of placement. The difficulty is that people are more complex than-their labels.

When community programs were being developed only by enthusiasts, who saw their efforts as a movement rather than a job, efforts were made to look beyond labels to the people.

Attempts were made to individualize services within the context of the program. The number of programs now in existence far exceeds the numbers of enthusiasts. We now have a "program provider industry" with leaders and staff who simply have jobs. Where service provision is just a job, staff do not look beyond the boundaries of the program model they operate to meet the needs of individuals. As the evolutionary descendants of institutional cottages and wards, these community residential programs define themselves on three axes:

- the labels of the people who are to live there;
- the number of people who are to live together; and
- the number of hours of paid staff time per day or week.

Within the program service model, these three dimensions are seen as related. People labeled as more severely disabled have more hours of paid

staff time and are more likely to live with a greater number of other people. The actual need for paid staff should be determined by an analysis which takes into account:

- the need for supervision to assure physical safety;
- the demands of the setting contrasted with the skills of the person; and
- the resources of the community which could be developed to meet the needs identified (Taylor, Racino, & Rothenberg, 1988).

How many people a person lives with should be determined by preference rather than program model.

The comment that there are no more "easy people" left to move from the institution to the community further illustrates the problems with the program model. With few exceptions, community programs are not configured to meet the needs of people who have needs that go beyond those encompassed by a single label. Many people who remain in institutions have complex medical or behavioral needs that require services that are individually designed. They are seen as challenging because the services offered in the community focus on the hours of "supervision" needed rather than the characteristics of the person.

The system of community programs typically has only three or four residential and day program options-to offer. Efforts to meet the needs of people who do not fit in these program boxes usually involves adding more services to compensate for the poor match. If the cost of the additional services is beyond what is supported by cost formulas, we say that the person is not ready for the community rather than explore alternatives to the programs offered. Past successes reflect the adaptability of people with disabilities more than they reflect efforts to provide services designed to meet individual need.

Our system has been designed to serve "average" consumers. We have developed programs for labels rather than individuals, and we reflect our lack of commitment to individuals by speaking of numbers of beds, placements, and slots funded. Existing

available resources are referred to as vacancies, and we "place" people in vacancies based on where their names appear on a list rather than on an understanding of their unique configuration of desires, skills, and needs.

Yesterday's Solution is Today's Crisis

The institutional crisis we were to solve two decades ago and today's community crisis have remarkable parallels. The President's Committee on Mental Retardation cited institutional problems of underfinancing, understaffing, and overcrowding. Underfinancing and understaffing are the two most frequently mentioned problems facing community programs. Yesterday's solutions to overcrowding have become part of today's problems. The movement of people, in groups, to homes that agencies rent or own in small areas of the community has created an issue labeled "community saturation" where communities complain of an "excessive" number of houses for people with a variety of disability labels. (The phenomenon of not wanting agency houses in the neighborhood is also known as the "not in my backyard" or "NIMBY" syndrome.) Simultaneously, deferring the provision of residential services has created a large number of people waiting for services.

Thousands of people with severe disabilities are living at home with their parents or other relatives (Davis, 1987; Smull, Sachs, Cahn, & Feder, 1988). Despite families role as the

largest single provider of support to people with disabilities few families receive any support at home from the disability service system (Lakin & Bruininks, 1985) even though the families' capacity to provide care is subject to other family stressors and the aging of the caregivers (Black, Cohn, Smull & Crites, 1985). The consequence of the absence of support to families is that we are continuously confronted with individuals needing immediate out-of-home residential arrangements because caregivers have "burned out". When the ability to wait is defined by the level of desperation, families experience increasing distress as they wait without support. When people with disabilities leave school and wait without meaningful activities they lose the skills they have learned and gain problem behaviors.

Although institutions are much smaller, they are still with us and many exist in a chronic state of crisis. While the reduction in size and the increase in the quality of care have been substantial, many institutions continue to fall short of meeting the standards of care required for receipt of federal funds. As state officials weigh the costs and uncertainty involved in meeting the evolving interpretations of the standard of "active treatment" (42 CFR 405.1202) of the Health Care Financing Administration against the potential loss of federal funds if those standards are not met, they see continued reductions in population as the best option. As people leave the

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institution, they enter the community service system, sustaining the pressure for expansion.

The institution's capacity to serve as a community "safety valve" is diminishing. When the community failed to meet someone's needs, that person was sent to the institution. Plans to reduce the number of people living in the institution means that there are fewer beds available. As the pressure mounts to provide all people living in the institution with "continuous active treatment" the reluctance to admit people with challenging needs increases. The capacity of the institution to be able to meet the challenge by offering services such as a consistent behavioral response across three shifts of direct care staff is open to question. Failure to meet these needs may cause the loss of federal funding.

Doing more of the same will not work

Projections of the funding, staffing, and housing required to "fix" and extend the current system of community services indicate that simply doing more of what we are already doing will not work.

- If federal participation in financing community services does not increase it is unlikely that there will be enough money to fix both the current system and to provide the same services (at the appropriate cost) to everyone waiting.
- If there were funding to increase salaries, the pool of potential qualified residential staff may not be large enough given the demographics of a shrinking labor force and the competition with business for entry level employees (Smith, 1988).

- If the quantity of staff improved, turnover would continue at an unacceptably high rate., Stability, in a residential model where staff share their lives with consumers, requires social commitment as well as adequate pay (Cherniss, 1987). The proportion of current or potential staff who have the requisite commitment appears likely to remain small.
- If adequate staff were available, a housing model that moves people in groups, to live in housing owned or rented by agencies, assures that the "not in my back yard" (NIMBY) syndrome will be an increasing problem. Areas with affordable housing, with access to public transportation and other needed services, already have a disproportionate number of agency owned/rented housing units occupied by groups of people with a variety of disability labels. moving into new areas will entail higher costs as well as coping with the "NIMBY" syndrome.

The present can be made better. Better management, more training, and increased funding could make marked improvements. But these are interim solutions. They postpone the looming disasters, but they do not prevent them. If we are to "fix" the existing system and provide a reasonable array of services to those people who are waiting, then "fixing" the system requires a more fundamental change. We must change the way we think about service delivery (Minnesota DD Council, 1987) and the way we provide services. We need a paradigm shift.

As proposals for change are developed and implemented, however, we need to keep in mind that the components of the service system are interconnected. We cannot fix just the "waiting list" problem, just the institutional problem, or just the community programs problem. Devoting attention to one without looking at the effects on the others invites disaster.

- If we ignore the institutions they will lose certification and the federal money that goes with it. Where decertification has occurred the costs of "recertification" have often absorbed all available state funds, including funds that would have been used for the community service system and for those waiting for services. (Recent examples include Oregon and Ohio.)
- If we ignore the waiting list problem we will increase the number of people going into crisis from a lack of support. When people are about to become homeless, community programs will be pressured to expand regardless of capacity and institutions will grow larger regardless of the effects on certification.
- If we ignore the problems of community programs, expansion will cease and some community programs will get smaller. We will have no place for the people from the waiting lists or the institutions to live.

Within the context of a balanced approach to all of the problems, solutions for the problems of community services need to:

- decrease the need for full-time entry level staff;
- increase the rate of pay for entry level and mid-level staff;
- more efficiently meet the needs of people receiving services and people waiting for services; and
- use housing models that do not elicit the "NIMBY" syndrome.

A better future has choices and opportunities

A better future is one where people with disabilities are living in the community with real choices and real opportunities. The future should have choices for each individual, choices about where to live, where to work, and with whom to spend time

(Turnbull, Turnbull, Bronicki, Summers, & Roeder-Gordon, 1989). There must be opportunities to be a part of the community to make friends, to contribute, to go places, to do things, to be paid for work and to continue to acquire skills (O'Brien, 1987b). People with disabilities should not be making the forced choices of the current service system where a typical "choice", is to live in this house with these people, or to be homeless. Opportunities and choices are viable for each person only when "no" is as valid an answer as "yes". The opportunities available should allow people to become connected to the community within their own pattern of interdependence (Hitzing, 1987).

The goals for people with disabilities might be summarized as:

- having choices and opportunities regarding major and minor life decisions (Kennedy, Killius, & Olson, 1987); and
- having the support available to make use of the choices and opportunities.

The future we want is one where the needs of people with disabilities are in balance with the resources available. We need a future with:

- a reasonable array of choices at an affordable cost; and
- opportunities for people with disabilities that are implemented with a reduced demand for full-time staff.

To achieve this future, we must give up the paradigm of programs and develop a paradigm of support. We will have to change the way we think about meeting the needs of people with disabilities.

opportunity and efficiency require partnership

To offer opportunities to people with disabilities (while increasing the efficiency of the service system) requires that we use the resources that surround our programs. We need to stop operating programs that are in the community but not part of the community. We need to reach out and forge a partnership with the entire community. We need partnership with families; schools; businesses; friends; and neighbors.

Families provide more support to people with disabilities than all of the formal components of the service system. Too often families must provide all of the support without our assistance. Meeting the support needs of people living at home requires that we recognize and meet the support needs of their families. While the person is living at home, we need to ask families what they need for themselves and for the member with a disability (Taylor, Racino, Knoll, & Lutfiya, 1987). Where families have been asked these questions we find that most of their requests are reasonable and modest.

We need to explicitly acknowledge the family's role as advocate, support coordinator, and support provider. Families must be actively involved in developing plans for the future (Turnbull, et. al., 1989). When the person with the disability moves out of the family home, some of the family's roles can and should continue. We need to make effective use of the resources

that families offer, regardless of where the person lives.

Schools are the second largest source of support for young people with disabilities. During the past ten years, schools have placed increasing emphasis on helping people with severe disabilities acquire the skills they need to live in the community. But the educational system needs to move beyond teaching daily living skills to the teaching of social and vocational skills. People with disabilities need to know how to make friends and relate to the community if they are to be part of the community- Further, people with good social skills are more likely to keep their jobs than those with poor social skills (Lignugaris, Kraft, Salzberg, Rule, & Stowitschek, 1988).

For students nearing the end of their education, vocational and social skills training should be an integral part of their education. People with disabilities need to have opportunities to learn to interact with people without disabilities in social and work-settings.. We need a system where the person starts paid employment while in school and continues after graduation, with a seamless handoff of support from the school system to the adult service system (Hasazi & Clark, 1988, Nisbet & Callahan, 1987). Pilot efforts have demonstrated that starting paid employment while in school can work (Hasazi, Gordon, Roe, Hull, Finck, & Salembier, 1985). A new partnership between the educational system and the adult service system can assure that years spent learning skills will not be followed by a purgatory of isolation

and inactivity, where skills are lost far faster than they were acquired.

Businesses are a valuable resource that we are just beginning to learn to use. Businesses are not only the suppliers of employment, but they are an untapped resource for job coaches and financial support for-supported employment. Part of the solution to the future shortage of job coaches (which we will face well before everyone receives supported employment) is to look to co-workers (Nisbet & Callahan, 1987, Rusch & Hughes, 1988) and to management to replace the need for the staff which we may not be able to recruit (Nisbet & Hagner, 1988). We also need to look to business to assist with the cost of supported employment. Experience has shown that supported employment makes sufficient economic sense to business for business to be willing to share in the cost.

Friends and neighbors are the least used resource. Either for pay or as volunteers, they can meet a number of support needs for people with disabilities (Mount, 1987), reducing the need for full time staff. Friends and neighbors also offer the potential for stable relationships which can span years rather than months (Strully & Strully, 1985). Members of the community can become the paid roommates or the paid neighbors who meet the support needs of people with disabilities. It is through our participation in civic and religious organizations that many of us contribute to the community. People with disabilities need

same opportunities to contribute and these organizations can provide the structure for their contributions.

Being connected to the community by using the community it sounds simple and sometimes it is. on other occasions it takes people with skills and connections of their own to help someone become a part of the community. But it can be done and it is being done. If we are to reduce our dependency on full-time staff and help people with disabilities be part of the community we must make the effort and achieve a new partnership.

Moving from service to support

Partnership is essential but it is not enough. In moving from a paradigm of service to one of support we need a new way of thinking about what people with disabilities require and how we should support them.

We need to:

- begin with understanding the person; - help the person make choices;
- coordinate and develop supports to enable the person to exercise a reasonable array of choices- and
- recognize that choices and supports need to change as the person changes and as our understanding changes.

Understanding the person - beyond the standardized test

Understanding the person means stepping beyond our traditional assessments of adaptive and maladaptive behavior, test scores and labeling. Traditional assessments provide a

fragmented picture of the person. They often emphasize what people cannot do-or what they have done that is "wrong." Assessments rarely tell us what a person does well or why others like this person. They do not help us know where someone wants to live or where that individual would like to work. They do help in telling us some (but not all) of the supports a person may need once a place is chosen.

Understanding a person requires

that we be able to answer questions about each person such as:

- Who would that person like to live with?
- What does that person enjoy?
- What are that person's dreams and nightmares? and
- What does that person dislike?

Understanding takes place in the context of the person's life. Beyond the traditional psychosocial history, it is important to know:

- When things have gone well for the person and why;
- What friends and/or relatives are (or could be) involved
- With the person and how they can help understand and/or support the person;
- What is important to the person; and
- What should not be a part of the person's life.

Regardless of the-nature.or the severity of the disability there are people to whom the person has expressed preferences - there are people who know the person. These people are more than willing to help us understand someone who has difficulty speaking for him/herself.

Several organized efforts to achieve understanding and guide service development have been described in the literature. One technique is "life-style planning" or "personal futures planning" developed by John O'Brien, Connie Lyle, and Beth Mount (O'Brien, 1987a). Other techniques include "functional life planning" or "twenty four hour planning" (Green-McGowan and Kovacs, 1984) and "the kaleidoscope" (Forest & Lusthaus, 1988). Each of these techniques has the intent of focusing the user's attention on the individual and the individual's relationship with the community. Each will assist in understanding the person but none of them is a substitute for the effort required to see each person as a unique individual.

Making Choices

The purpose of seeking to understand people with disabilities is to help them make effective choices. In making choices that work for the person and the system we need to abandon our narrow concepts of services and programs. We need to look to the wide range of choices that are available to everyone in the community. The range of choice available to anyone depends on:

- the skills of the person;
- the person's social network;
- the funds available to the person; and
- the resources of the community.

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The choices for people with disabilities have been artificially constricted by excessive reliance on the resources of the formal service system. We have ignored the resources of the person and the community. As a result, we have placed people into a narrow range of settings based on a partial assessment of their skills with little or no consideration for their preferences.

Choices will continue to have boundaries. All of us find that our choices are restricted by law, convention, and culture as well as the restrictions imposed by our own resources. For people with severe disabilities the issue is to not change the boundaries of choice available in the community but to make full use of what the community offers. The challenge is to not abuse the shared responsibility of choice making. We should articulate choices for another person based on our understanding of and respect for that person.

Supporting choices

Part of the process of understanding people with disabilities is to explore with them how their choices might be supported. One mechanism to determine the support required and how it might be provided is to:

- List the demands/activities that exercising the choice requires;
- List the activities that could enhance the choice for the person;
and
- Develop a support plan with the person using a process which considers the following-questions -

- Can the activity be accomplished by the person without support?
If the answer is no -
- Can the support needed be provided-informally, that is by family, friends or the community?
If the answer is yes -
- Are there objections to the use of informal support?
If the answer is yes or if informal supports are not available-
- Can the support needed be provided through the generic services available from the formal support system?
If the answer is no -
- How can the formal disability system best provide the supports needed?

This process has two purposes. First, it organizes how we are to ". . . bridge the gap between the demands of the environment and the ability of the person" (Knoll & Ford, 1987). Second, it assures that informal support resources are reviewed before formal support services are put in place. Where there is an absence of significant informal resources consideration needs to be given to how the current system has impoverished the lives of its participants. For these people, having friends and neighbors may be the most important goal.

Balancing the needs of the person with those of the service system

People with disabilities seek to have lives of their own choosing with the highest possible quality of life. Their objectives are to maximize choices and opportunities without regard to cost. The formal service system seeks to serve the largest number of people, for the smallest number of tax dollars,

with each person achieving a reasonable quality of life. In meeting this goal the disability service system should be biased toward minimizing reliance on the formal service system and maximizing reliance on informal supports. This bias must be balanced by the preferences and needs of the person. Using informal supports creates an array of choices that would otherwise be absent. However, there are individuals who need to rely on the supports of the formal service system and this process must not be used to create another trap of inadequate or inappropriate services for people with disabilities.

Within this paradigm we are not just "placing" people in programs. We are supporting people in community settings that they have helped to choose. If we assume that most people will make "good" choices, in settings that will work for them, then we have increased the probability of success. When there is failure, the supports or the settings need to change, not the person.. Supports are inherently more flexible than programs (Taylor, Racino, & Rothenberg, 1988). There can be-as little or as much support as the person needs. The support can be from agency staff, family, friends, or members of the community. Within a support model, the limits are our creativity, not our programs.

As we move from the paradigm of programs to the paradigm of support, we can define people's needs in more detail and obtain support from family, friends, and neighbors. Whether the needed

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support is help with a household chore, assistance in managing money, or having someone to spend time with, much of it can come from people who are not full-time staff. Just as we are connected to family, friends, and neighbors in mutual interdependence, so people with disabilities can be connected to others in their community (Mount, 1987). Interdependence involves giving as well as receiving. A system that induces dependency denies people with disabilities the opportunity to make their own contributions to relationships and to society.

There are concerns that individualized efforts such as these would be too expensive. These concerns assume that we have changed the old model only by having fewer consumers live in each home. Anecdotal reports from those places where support models are being implemented indicate that they are less expensive for people with mild disabilities and about the same cost for people who need extensive supports. 'A support model broadens the-range of costs for individuals. It will reduce the need for increased public funding for many of our current programs but will not provide a cheaper service model for all people with disabilities.

Our current paradigm of programs hinders the provision of discrete support in selected areas. The support paradigm allows us to offer individuals the support they need in the areas where they need it and stay out of their way in areas where support is not desired or required. The program model typically has one paid staff member who

does everything for the person.

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This staffing model is one of the problems that we have carried over from the institutional model. The duties of institutional direct care staff were described in the 1969 PCMR report as including "... an incredibly wide array of responsibilities, ranging from being a substitute parent, janitor, and record keeper to being part nurse, part physical therapist, part psychologist, and part educator" (Butterfield, 1969). This description still applies to our current community residential staff and suggests that even with increased salaries staff with these qualifications are difficult to find and impossible to retain.

The paradigm of support should not be interpreted as forcing the person from a system with excessive reliance on paid staff to a system with excessive reliance on family or volunteers. Within the paradigm of support, the formal service system has two functions. First, it provides the assistance required for the person to make informed choices, including help in determining what supports are required to implement the choices. Second, the formal service system provides those supports that are not available or not wanted from the community.

A messier service system

Moving from a paradigm of service to one of support results in a system that is not tidy. Some people would live by themselves, some with people without disability labels, some with

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family members, and others with people who have disability labels. Some people would live their lives in one place while others would want and/or need to move from time to time. Some people would hold one job for a long period while others would move through a number of jobs. We would no longer have programs for people with a particular label, whether the label is for the severity or the type of disability. People would live and work together for reasons that reflect their preferences rather than their labels.

The use of paid staff would vary with the needs and resources of the people being supported. There would be a reduced need for full-time direct care staff and an increased need for a small cadre of highly skilled people who could design positive behavior programs, conduct an ecological or task analysis, and other technical tasks. There would be a need for new types of staff, for "community guides" (Mount, 1987), paid neighbors, or paid "mentors" (Nisbet & Hagner, 1988).

Although a few service providers have begun to change to a support paradigm, there must be systemic change if we are to begin to resolve the crisis. During the transition, we will face a number of challenges. Some of the most difficult will be to:

- Stop developing programs first and then putting groups of people in them (Taylor, 1988). We need to see beyond the four or five standard models of residential and day services that we typically operate. We need to look at one person at a time and then design supports around that person.

- Stop being service providers and become support coordinators.
- Stop thinking about people with disabilities as the objects of our process and help them become full partners in the development of their own systems of support.
- Stop talking of "terminal placements" and recognize that as people change their settings and supports should change with them.

Getting from here to there - service coordination

The foundation for a system based on support are people whose roles are: to understand the person with a disability; to help the person make choices; to arrange for the person to receive needed support to exercise those choices; and to assist the person in *finding settings* that fit with the person's choices and the available support. Those few community service providers who have become community support providers have employed staff to perform these functions and they appear to do it well. However, if we are to have a system where support starts while the person is still living in the family home, and where responsibility spans home, work, and leisure *environments, then we* need people whose responsibilities begin and end with the person.

The label for this role is service coordination (or case management). We have people with this label now but they are often not involved until decisions have already been made, or they only assist the person in picking from already existing services, or they have so many people to help that they lack the

time needed. We need service coordinators who are trained to understand the person, not just interpret assessments of the person. We need service coordinators who are involved with people with disabilities while they are still living at home. We need a relationship of mutual trust between the service coordinator, the person, and the family before there is an emergency. We need to defer those out-of-home placements which result from a lack of support while enhancing the quality of the lives of the person and the family. Service coordinators must be able to develop an "out-of-home" support plan based on the person and the broad resources of the community rather than a plan which seeks the "best fit" with existing services.

From Residential Service to Residential Support

Residential service providers face the greatest challenge in changing from service to support: they need to become residential support coordinators.² Meeting this challenge requires change: in the way they think about people and services; in their management structure; and in the way they work with people with disabilities. Instead of trying to determine how the agency can provide all required services they need to enlist the person as a partner and develop supports that use a mix of community and

². For illustrative descriptions of agencies providing residential support see Taylor, S.J., Biklen, D., & Knoll, J. (Eds.) Community Integration for People with Severe Disabilities (1987). For a description of one model program see Johnson's .-Belonging to the Community (1985).

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agency resources. For example: they may be the guarantors of leases rather than the signers; they may make sure that the neighbor is helping with the budgeting rather than doing it themselves; they may help someone find a roommate rather than providing one. Neat organizational charts with housing units, staff, and coordinators will be replaced with a fluid structure driven by individually determined living arrangements.

Supported Employment From Segregation to Integration

Across the United States people with disabilities are working in the community alongside employees without disability labels for real wages (Kiernan, McGaughey, & Schalock, 1988; Wehman, 1988). The challenge for habilitation programs is to truly implement what has begun: to convert from the pattern of segregated employment for low wages to integrated employment for average wages. Supported employment holds out the promise of people working in settings and on jobs that fit their needs. A wide range of behavioral norms and expectations are found in the work sites in all communities. The behavioral patterns and status needs-of the person are much more likely to be matched in the community than they are in the two or three "day programs"- available. The potential for abuse, however, is also present. We can place people in supported employment based on vacancies or on the jobs we have developed without regard to the individual's needs and characteristics. We can mismatch people and community

jobs as readily as we have provided people with years of meaningless "work" in our habilitation programs. We can make people lonely while we give them a job (Wieck, 1988). We can also make use of the large variety of employment environments to find the "right" job for each person. we can recognize that what is "right" today may not be what is "right" tomorrow and that we all have our own ways of discovering the need for a new job.

We will need to look at the way we provide support and ask if we are giving the people more support than they need or if there are not co-workers or others who could Provide all or part of the support. We will need to learn how we can provide-support only when it is needed, which may mean that we provide very little support this week and a great deal of support next week.

Flexible Funding, Reasonable Regulations - Oxymorons?

The challenge faced by funding agencies is to determine how to fund and regulate supports that are flexible and individually designed. Implementation of the support paradigm requires that funding be available to purchase what the person needs and not to force the person into supports or services that are not needed. Funding must change with the changing needs of the person. Reimbursement must be linked to the supports provided by the formal service system rather than the setting in which the person lives.

Regulations must encourage the provision of needed supports

Crisis in the community but not require unneeded supports, assessments, plans, or documentation. Reasonable oversight is still-required, however. Not all providers of support will perform as they should. Regulations should provide a framework of expectations and requirements sufficient to enforce minimum standards and maintain accountability. The transition will be challenging for regulators who have required that there be mirrors in the bedrooms of people who are blind and six weeks of menus posted in an apartment where two people live. Funding agencies can provide the leadership and vision that will accelerate change or they can stop meaningful change in its tracks.

From Today's Crisis to Tomorrow's Solutions

We have come a long way from the time when we warehoused people by the thousands. We no longer measure our-progress by the yardstick of adequate custodial care. Issues like decent clothing and shelter are taken for granted and we are appalled when they are absent. Thousands of people with disabilities have moved from institutions to the community. We need to acknowledge our accomplishments while we face today's crisis, for we have a service system on the verge of *unravelling*. *What we-*, have been doing will no longer work. We need to look critically at our efforts and move on.

We need to give up our paradigm of programs and adopt a paradigm of support. Change will take years, however. The

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current community service system is underfunded and will need to be sustained while it is in transition. We need more funding and we will still need to make the hard choices of how to spend the additional dollars. We will have to balance the current need for adequately paid staff against the needs of those waiting for services and the demands of our institutions. The implementation of a paradigm of support will allow us to use the community funding we receive more efficiently. The new paradigm encourages the use of the resources of the person, the family, and the community.

We will still need staff, but we can use them in radically different patterns. We will need fewer full time, entry level staff who do everything. We will need more people performing specific support tasks, but they may or may not be labeled "staff". Within this paradigm, we-can configure pay-and work to address our staffing problems and reduce turnover rates.

With a housing model where people live where they choose, with the people that they choose to live with, we can escape from the "NIMBY" syndrome. If the houses people live in are no longer "agency houses" with few people living in them, then we will have stopped the labeling of people by labeling their home. If people choose where to live they will be more dispersed and the problem of concentrating people with disabilities into small areas will diminish.

If we wait for the crisis to force change, expediency-will rule.

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We will then spend years undoing the effects of the "quick fixes" forced on us. We still have time to develop a system that supports people rather than placing them in programs. We need to recognize, however, that there is much we do not know. The support paradigm is still being implemented by enthusiasts who compensate for deficits in structure with determination and effort. We need to learn how a system of support can be implemented by people who are caring but lack the fervor of pioneers. we need a system that will improve the lives of people with disabilities as well as "fix" our problems. We need to avoid abuse of -the support paradigm by using it just to solve funding or staffing shortages. We need to listen to what people with disabilities are asking for and help them get it.

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