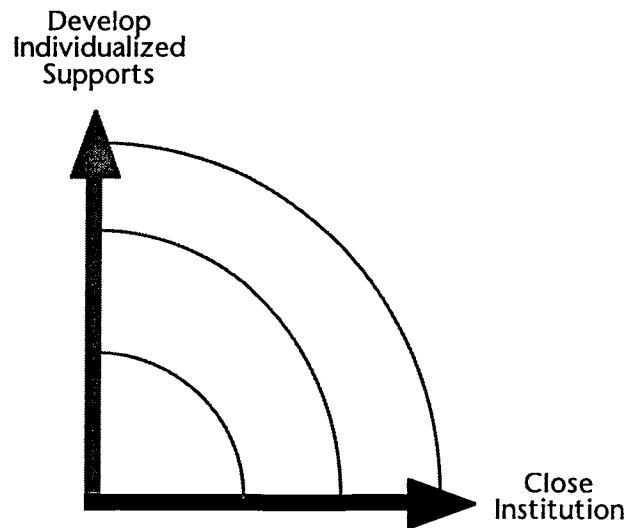


## Developing Individualized Supports While Closing Institutions\*

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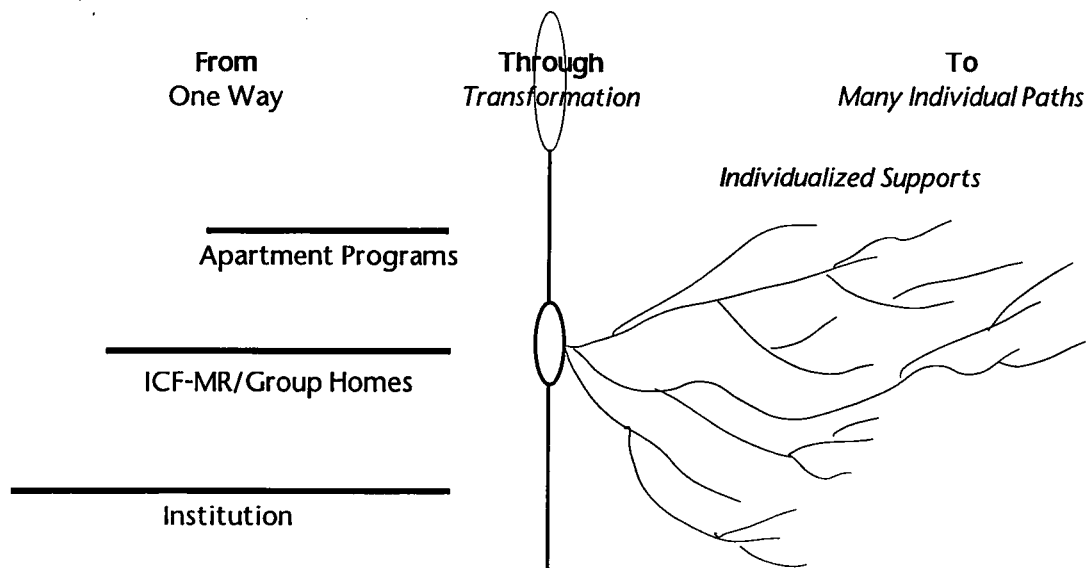
Policy makers and administrators face a significant leadership challenge in developing, negotiating, and implementing strategies to effectively balance two important goals:



- To close institutions within a reasonable period of time by moving hundreds of people from institutions into local services and, in many cases, expanding the system to provide services to people now living with their families.
- To create individualized community supports for as many people as possible by changing the pattern of service provision to encourage the development of services based on individual choice and needs, rather than placing people into programs designed to serve groups on the basis of common, professionally assessed characteristics. The image of moving from a few, pre-defined roads moving in a single direction to many, branching paths captures one aspect of this transformation.

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Both of these goals are highly desirable; people now living in institutions deserve the chance to live outside the restrictions and stigma of institutional life, and all people with developmental disabilities benefit from supports developed to fit their individual capacities, interests, and needs. Achieving either goal is demanding: implementing a substantial increase in local service capacity and moving a large number of people into new arrangements while honoring commitments to family members, local agencies, and state workers calls for effective administration; learning to transform the ways in which people receive necessary support requires strong and skillful leadership. Pursuing both goals within a short span of time creates a powerful strategic problem:

*How can available human, organizational, and fiscal resources be aligned to both close institutions and create new forms of assistance?*

Engaging this problem thoughtfully and carefully could greatly expand the opportunities available to people with developmental disabilities.

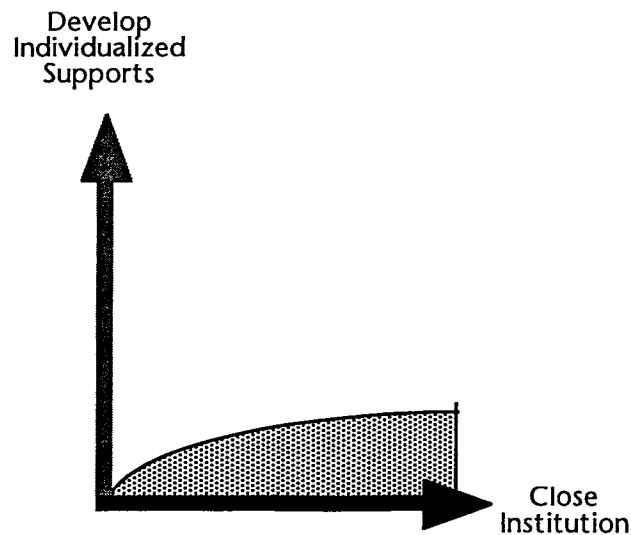
*Closing Institutions Can Interfere with Developing Individual Supports*

It seems reasonable to assume that progress toward closing institutions on time could take precedence over developing more individualized supports for at least four reasons:

- On time closure fits statewide priorities and plans and is thus likely to get greater weight when the two objectives conflict.
- Developing more places in existing types of services calls for doing more of what providers and administrators already know how to do. Developing more individualized supports calls for learning new ways to design, fund, deliver, manage, and assure quality. It is easy to talk about individualized supports, but difficult to learn how to provide them.
- Many service systems lack the necessary to allow the provision of individualized supports.
- The ability to provide individualized supports on a large scale takes years, rather than months to develop. This is especially true when a strong and influential group of service providing agencies must undergo significant change in order to provide individualized supports.

### *A Possible Future*

The shaded area on the figure below suggests one possible, positive outcome of the work of closing institutions. Institutions close on time; over time, a slowly growing number of people benefit from individualized supports, though most people move into the kind of small congregate programs that have become typical. Some people move directly from institutions into individualized supports. But more people move from existing, congregate programs into more individualized supports and their places are taken by people moving out of institutions.



### *Four Key Issues*

How many people benefit from individualized supports depends on how effectively public agencies, the service providers, and local advocates can deal with four key issues:

- Building commitment to organizing individualized supports.
- Re-designing systems and re-organizing patterns of service to provide individualized supports.
- Systematically, and very substantially, decreasing the time elapsed between identification of an individually responsive service activity and the final decision about allocation of resources to provide that service.
- Managing the closure of institutions in a way that frees resources (including leadership time) to focus on developing individualized supports.

### *Measures of Improved Service System Performance*

These issues suggest three summary measures to track improvement in the quality of service system performance:

- The ratio of the total number of people placed from institutions to the number of planned placements per month.
- The cumulative number of people supported individually.
- The elapsed time between proposed individual supports and a final decision on allocation.

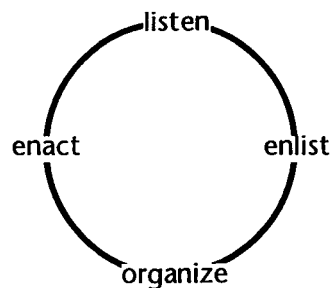
### *Building Understanding of Individualized Supports*

Some involved people are deeply concerned that the opportunity to provide individualized supports will be lost due to failure to build a clear understanding of what they are and how they are different from existing services. They point out that the path of least resistance lies in changing rhetoric, rather than patterns of service.

Taking this path would contribute to cynicism as, for example, group living arrangements are re-labeled "people's own homes." Avoiding it means living publicly with a substantial gap between what leaders espouse and what providers deliver to most people.

It has become increasingly common to identify individualized supports with service labels (such as "supported living" or "supported employment" or "family support") or with service principles (such as "separate housing and support" or "use non-licensed facilities"). These are helpful as far as they go. But a deeper understanding of individualized supports calls for continuing debate and discussion.

Experience among providers suggests the pattern of action necessary to provide individualized supports. At the direct service level, at the provider management level, and at the system management level, people accustomed to administering programs for groups of people must learn ways to: *listen* better to people with developmental disabilities and their families and friends; *enlist* active involvement from families, associations, organizations, and political decision makers; *organize* supports based on understanding of individual capacities, interest and needs; and *enact* supports over time, as people change. This pattern is cyclic: better individual support results in better understanding of individual capacities, interests, and needs which restarts the cycle of learning.



At the **direct service** level, providing individualized supports means learning to:

- Remain available to people as their interests and needs change.
- Continuously increase the effective control people have over the supports they receive and the choices they make in lives.
- Revise and repair supports as people change and as better information about how to assist people becomes available.
- Actively negotiate for necessary changes in agency and system practice and policy.
- Make the best possible use of available system funds.

At the **agency management** level, providing individualized supports means learning to:

- Match people with developmental disabilities and support workers and then sustain and contribute to the improved effectiveness of these relationships.
- Focus problem solving on an active search for community opportunities.
- Develop community opportunities such as accessible housing and transportation, recreational opportunities, and jobs.

- Make available system resources as flexible as possible as opportunities and support needs change and actively negotiating for necessary changes in system policy and practice.

At the **system** level (county, region, state), providing individualized support means learning to:

- Negotiate common mission, strategies, and mutual accountability among the people and agencies that provide and govern services.
- Continuously increase the flexibility and responsiveness of available public funds by creating new ways to insure accountability and new ways to budget and disburse funds.
- Discovering and communicating what is possible for people with developmental disabilities
- Promoting learning from action by discovering and disseminating what works and what doesn't work in providing individualized supports.
- Systematically shift the system's "center of gravity" from group provision to individualized supports.
- Clarify the difference between truly individualized supports and improved versions of traditional approaches.

Engaging the problem of developing individualized services while closing institutions thoughtfully and carefully can increase the opportunities available to people with developmental disabilities. A failure to acknowledge the complexities presented by this problem is likely to create even more difficult problems in the future.