

Adapting to Scarcity

Searching for a Sustainable Service System¹

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Scarcity troubles the future of services for people with developmental disabilities. Growing U.S. waiting lists for services signal insufficient funds to meet the identified service needs of more than 100,000 people for more than 200,000 different services, though data collection and reporting problems make estimates uncertain (Davis, 1997). Increasing difficulty in recruiting and retaining qualified direct support workers testifies not only to insufficient funding to create an adequate career structure in existing services, but also to a crisis of meaning in the work of serving people with disabilities which leaves many workers trapped in jobs that are poorly paid because they are assumed to be no more than babysitting for inconvenient people of little value (Braddock & Mitchell, 1992; Larson & Lakin, 1999; Smull & Bellamy, 1991). When the service system fails to cope with scarcity, people with developmental disabilities and their families have no choice but to cope with the effects of scarcity. Making up for lack of necessary assistance, making do with poorly fitting living arrangements, and dealing with discontinuity and unpreparedness among service workers imposes hardship and loss of opportunity on people with disabilities and their families, especially their mothers and sisters (Hayden & DePaepe, 1994; Traustadottir, 1995).

Clearly, attracting more public money goes a long way toward supplying this scarcity. Growing interest in legislative campaigns to unlock waiting lists, redirect funds from nursing homes into community services, and pay workers fairly should increase public investment, as should state efforts to make the most of the opportunities for federal financial participation, as might litigation aimed at establishing state responsibility to deal equitably with all eligible people. However, the situation calls for more than more

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money. Scarcity of services and scarcity of workers challenges people with developmental disabilities and their families, service providers and system managers to design and develop a sustainable system.

A sustainable system can persist over time because it is “far-seeing enough, flexible enough, and wise enough not to undermine either its physical or its social systems of support... [It] meets the needs of the present without compromising the ability of future generations to meet their own needs” (Meadows, Meadows, & Randers, 1992, p. 209).

Sustainability matters because money sufficient to clear current waiting lists can't alone neutralize the forces that generate shortfall. Several trends continue to rise ahead of budget improvements: the number of family caregivers unable to continue their work because of their own disability or death, the life-expectancy of most people with developmental disabilities, the intensity of advocacy for upgrading services that fall below a rising standard of expectations, the number of efforts to expand service eligibility to include new conditions, and the strength of competition for long-term support funds with elders and other groups of disabled people as well as with funding for acute medical care and other public purposes.

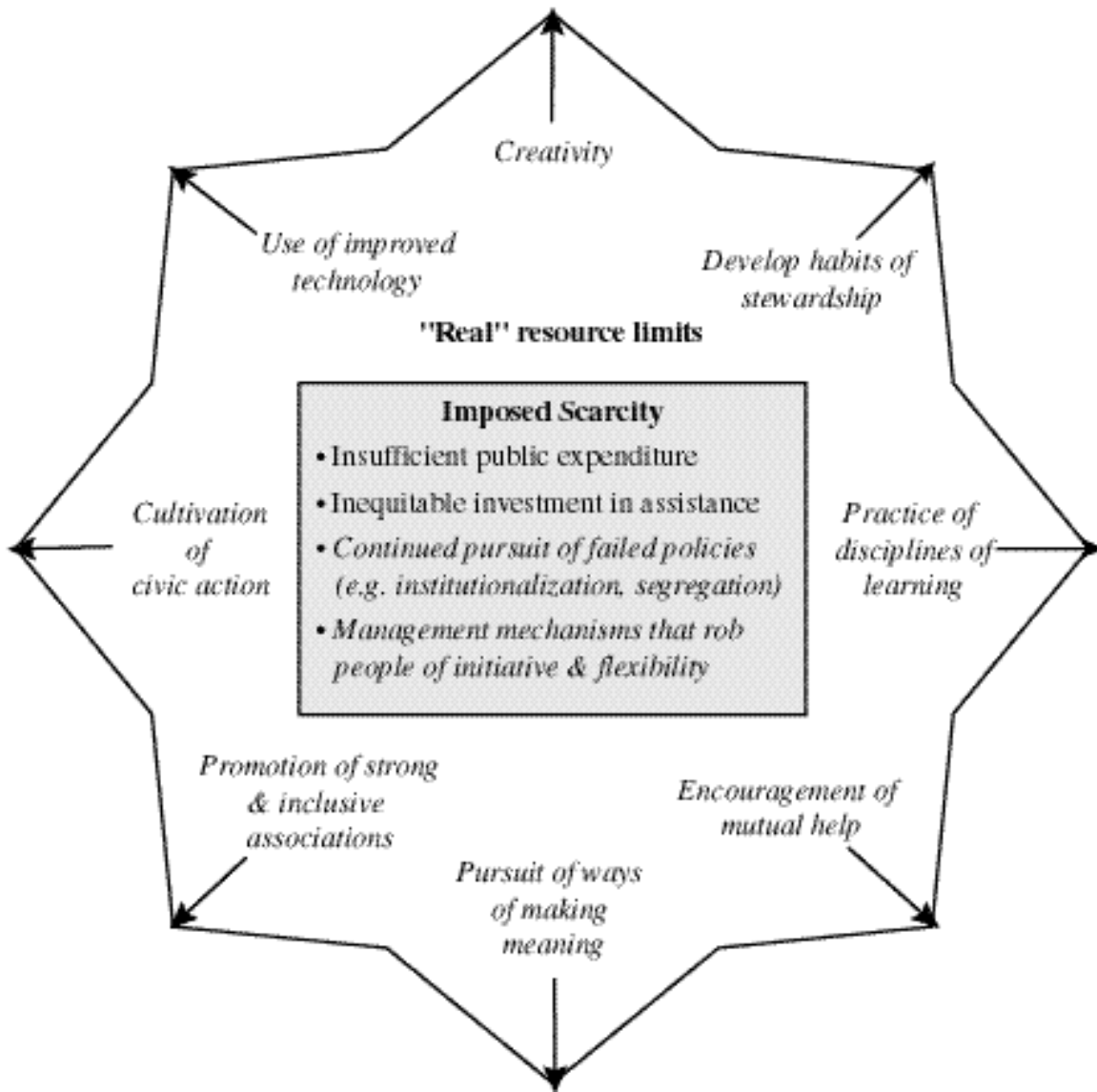
Improving sustainability poses an adaptive challenge in a way that political action to increase funding does not. Increasing budgets makes hard work for uncertain rewards; too often people must settle for small increments and wait for the next session of the legislature or court. But clear numerical targets do capture what victory means and many people know and can teach the tools of organizing to influence political and legal processes. Though sometimes difficult and discouraging, political organizing holds the excitement of a contest. Coalition around the conclusion that others deny us the money we deserve submerges even deep disagreements about what's to be done with the proceeds of victory. Improving sustainability calls for reconsideration of our service system's principles and reinvention of the means to realize those principles. Such a search takes time that many people do not feel that they have, surfaces differences in perspective and principle that threaten concerted action, and demands new kinds of relationships, new ways of working, and new agreements. It asks for new ways of understanding scarcity and more creativity and greater responsibility in engaging scarcity.

Understanding Scarcity

If we explain scarcity only as lack of money, then money will denominate every solution. Cost cutting will trump investment. Innovation will depend on new allocations. Advocacy will primarily react to the politics of budgeting. Promises of cheapness will overshadow arguments from justice. Quantity will overshadow quality. Families who have substantial funding may feel guilt if they consider the circumstances of families struggling with very little. Emotion stirred by a group sense of powerlessness to supply what is needed will cloud thought: groups constellated by the illusion of entitlement will polarize the energies of groups constellated by the illusion that care is manageable; bureaucratic realists will distance themselves from lived realities and activists will escape into slogans of self-determination; those who have will be reluctant to risk, those waiting will be too tired to act, and everyone will hold too tightly to current problems and favorite solutions.

The way out of reactivity runs through a deeper understanding of scarcity in terms of the actions necessary to develop a sustainable system. Two distinctions aid a long-term understanding and wiser, more flexible action. Those committed to sustainability distinguish between growth and development. Growth means increase in size by getting more, and a sustainable service system will serve more people and thus cost more money. Development means improved desire and ability to satisfy one's own legitimate interests and those of others by learning to deal creatively with opportunities and difficulties (Ackoff, 1999). A sustainable service system will create structures and practices out of the difficulties imposed by scarcity which will assist people with disabilities and their families to do more with all of the resources available to them. Those committed to sustainability also distinguish between scarcities imposed by policy and reversible over time by political and administrative decision and resource limits defined by earth's carrying capacity, the functioning of local economies given multiple legitimate demands on public funds and human energy, and human finitude.

Figure 1
Real Limits and Scarcity Imposed by Policy



This diagram suggests some applications of these distinctions. The edge of the box represents the scarcity that is created as a matter of public policy. The area between the edge of the box and the star represents the resources people can claim by working “outside the box” through such activities as community building (Kretzmann & McKnight, 1993; O’Brien & Lyle O’Brien, 1996) and assisting people with developmental disabilities to benefit as actors in local housing and labor markets (Klein, Boyd Wilson & Nelson, 1999; Mank, Cioffi & Yovanoff, 1977). The actions identified in *italics* both inside and outside the box require learning for development rather than just advocacy for growth. For example,

institutionalization persists until a system adopts a new understanding of the nature and costs of institutionalization and develops the capacities to provide people with disabilities sufficient assistance to participate in community life; otherwise, institutionalization persists but in smaller settings located in ordinary neighborhoods.

Policies that impose scarcity serve important social and political interests such as minimizing taxation, or returning profit to nursing home operators, or protecting staff working conditions, or reducing contact with socially devalued people. In this arena, change comes when people mobilize to engage in productive conflict with the powers that such restrictions serve. Victories in these political conflicts reduce the social costs of keeping people waiting for adequate assistance.

Bracketing the real in “‘real’ resource limits” acknowledges both that these limits constrain action and that people can sometimes develop capacities to push back these limits. Figure 1 identifies eight of these capacities. These capacities for organizing and expanding resources fall outside the power of policy makers to command. They lie within the power of groups of people with disabilities and their families and their friends and their co-workers and schoolmates and neighbors. Policies can encourage or discourage these kinds of action, but people must engage one another in making the most of what is available to them. Imaginative, responsible people who have the benefit of strong mutual support and access to knowledge, skills, materials, and funds have the best chance of producing satisfying results in ways that promote sustainability by increasing available resources.

Adopting A Sustainable Goal

A service system cannot sustain the goal of meeting every need by providing housing and occupation for every eligible person, though the practice of investing the majority of system funds in offering some people services in congregate settings for which thousands of others wait implies that the current system pursues this goal. (According to Braddock and his colleagues (1998), only about 7% of total 1996 U.S. expenditures on developmental disabilities services went for services that assist people in ordinary settings: supported living and personal assistance (2.9%), supported employment (1.8%), family support (2.3%))

A system under pressure to meet every need for housing and occupation will tend to control significant details of people's daily life such as where and with whom citizens with developmental disabilities live and how they spend their days and justify this in the name of cost control. Its managers will decide how trade-offs will be made, determining the scale of congregate settings based on their notions of economy and the intensity of personal and family disruption necessary to move up waiting lists. Its agents will quibble over eligibility and press expectations down in the name of economic realism. The satisfactions of controlling the life conditions of so many with shrinking resources are sparse and cold and emotional defense against this coldness feeds the urge to elaborate bureaucratic structures deeper and deeper into personal and social life.

The goal of housing and occupying all people with developmental disabilities fails the criteria of sustainability. It's pursuit undermines its own systems of support by demoralizing and exhausting those people with disabilities and their families who must wait for appropriate assistance, by shrinking the opportunities of those who receive services to fit the boundaries of congregate settings, and by turning workers whose main contribution is the creation of productive relationships into petty functionaries. In less than one generation, the pursuit of services comprehensive of need has already shaped a system incapable of meeting the needs of succeeding generations. It is unsustainably costly to construct a service world that duplicates the functions of the ordinary world. The era of institutionalization tried such simulacra and their collapse into dehumanization should instruct us.

A sustainable system goal would be to assist people with disabilities and their families and friends to participate as contributing members of their communities. Meeting this goal entails funding necessary personal assistance in ways that encourage and strengthen people with disabilities and their families and friends to mobilize all of the resources available to them. This goal limits the control the service system assumes over people's lives to the allocation of a fair share of available public funds and leaves responsibility for trade-offs created by insufficient funding in the hands of people with developmental disabilities or their families. It also limits the service system's mandate to the provision of a fair share of available funds rather than the provision of an all-embracing service that guarantees health and safety and happiness. This is not because health and safety and

happiness are unimportant but because of the counter-productivity of efforts to manufacture them as a bureaucratic outcome of state government (McKnight, 1995).

Objections to this goal arise, including for example these. This goal embodies the nightmare of those families who trust that the service system will provide a comprehensive answer to the question, “What will happen to my child when I am gone?” Embracing it may confirm legislators in the fallacy that the system can get by without substantial new money. Many people with significant disabilities lack relationships with family members or guardians or friends willing or able to invest in their day-to-day lives. Facing the practicalities of redistributing funds between people with similar needs for assistance whose services cost \$250 per day if they live in a state institution and \$25 a day if they live with their parents challenges imagination and courage. Dealing with differences among states’ investment in services to people with developmental disabilities poses a national problem when the three states that invest the highest proportion of their people’s wealth in developmental disabilities services exceed the fiscal effort of the three states that invest the lowest proportion by almost 6 times (Braddock, Hemp, Parish, & Westrich, 1998).

These objections counsel prudence in the pursuit of a sustainable goal. A new settlement with people with developmental disabilities and their families can only be achieved through a process of shared learning that is likely to have to contain important conflicts long enough to generate suitable resolutions. Both the process and its outcome call for a stance toward people with developmental disabilities and their families and communities that expects, supports, and strengthens resourcefulness rather than assuming and attempting to manage incompetence and irresponsibility (Dunst, Trivette, & Deal, 1994). However, these objections point to current difficulties that we will not become wiser or more flexible by hiding from. More money alone, even when it can be had, cannot resolve them.

The Foundation of A Sustainable System

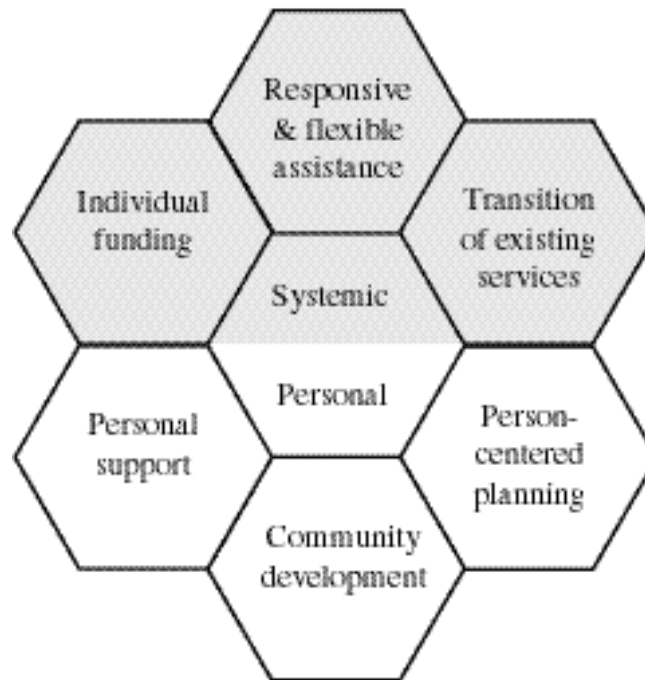
Knowledge accumulated through more than 20 years experience roots the search for a sustainable system. A growing number of people with disabilities and families live lives remarkably different from those anticipated by people with low expectations of them and

their communities. With adequate support and assistance, people with disabilities create lives deeply meaningful to themselves and significant to others who encounter them as classmates, co-workers or members of a common effort. With adequate support and assistance, people with disabilities know themselves, and come to be known by others, as possessed of gifts and responsible to make real contributions to other's well being. With adequate support and assistance, people with disabilities become increasingly able to communicate the direction their life should take, make better choices, and build the resiliency to recover from poor choices and difficult circumstances. Given the opportunity, people with disabilities find ways to challenge prejudice and discrimination that change the beliefs and behavior of those who meet them with open-able hearts and minds.

Of course, some people with developmental disabilities and some families sometimes behave irresponsibly, get overwhelmed, become psychotic, do things dangerous to themselves or others, and commit crimes. But a service system shaped with these occurrences at its center of gravity can be nothing but a system of incarceration whose sustainability depends on cheapening the conditions of confinement. This would be wasteful because sufficient experience in encouraging and strengthening capacities exists to justify centering the search for sustainability on what people with developmental disabilities can achieve with adequate support and assistance.

Then following diagram identifies six building blocks that interlock to form the foundation of a sustainable system. Three of these building blocks concern the architecture of the service system and three define the responsibility and contribution of people with developmental disabilities and their allies.

Figure 2
The Foundation of a Sustainable System



Individual funding. This provides each eligible person with adequate public funding to pay a fair price for necessary assistance through an open process of negotiation and re-negotiation with a funding authority. The terms for receiving individual funding expect that people with developmental disabilities and their allies exercise discretion in allocating resources to meet their requirements for assistance, responsibility to prioritize requirements for assistance and to take action within their individual budget without prior approval from professionals, and authority to hire and fire providers (Lyons & Mason, 1994). The process for establishing eligibility and receiving funds minimizes the costs of time, effort, intrusiveness, and stigma.

Responsive and flexible assistance. Such assistance offers a combination of personal assistance services, assistive technology, professional services, and personal management (including, for example, help in designing a personal assistance system, recruiting, training, employing, scheduling, supervising, and accounting for assistants). This personalized combination of assistance enables participation in community life, respects individual dignity and responsibility to contribute, and adapts to changing requirements.

Transition of existing services. This involves a disciplined process of organizational learning that continually improves the deployment of staff talents and skills and service system money. The most urgent transition involves recycling the resources now sunk in services that congregate and control people with disabilities by design.

Personal support. A person experiences personal support when she or he has allies who consciously and thoughtfully share life experiences through time; encourage the discovery, development, and expression of individual gifts; join in creatively figuring out what forms of assistance work best as life circumstances change; help to mobilize available resources to improve the person's experience of life; offer practical help; and confront threats to well-being whether those threats come from others or from the person him or herself. Those involved in personal support announce, through their lived experience, the benefits of living in mutual support. They can be parents, brothers and sisters and friends; they can also be people who become interested in the person as classmates, co-workers, neighbors, or personal and professional assistants.

Person-centered planning. This happens when a person with a developmental disability knows that other people are concerned to know, understand, and take direction from the person in how they use whatever resources they will agree to make available to the person. These resources may be shared time, or skills, or contacts, or practical help, or technology, or money. It suggests a systematic process for making, implementing, checking, and revising plans and ways of understanding the person's identity, capacities, impairments, challenges, and preferences (O'Brien & Lyle O'Brien, 1998).

Community development. Community development involves systematic effort to increase the number of community members directly engaged in good relationships with people with developmental disabilities in such roles as classmates, neighbors, co-workers, association members, and friends. Opportunities for such relationships increase substantially when people have assistance to organize and maintain support circles, family groups, assistance cooperatives, mutual help groups, and other associations of people with developmental disabilities and their families and allies which aim to offer personal support.

Building the Foundation

Service systems easily absorb new words and new techniques without much increasing the power available to people with developmental disabilities and their families. Without deep change in the beliefs, responsibilities, relationships, processes and structures that make up culture, the search for a sustainable system will fail. Despite the claims of popular management books, quick and easy ways to change culture can't be found. Culture changes as adaptations and innovations accumulate. Solving the problems of assisting growing numbers of people with developmental disabilities to make real contributions to common life as economic, political, and cultural actors works the necessary changes. Images of working cultural soil to allow deeper roots that can support more complex and interesting and powerful relationships and images of bees carrying pollen from growing tree to growing tree capture this essential work more accurately than images of industrial strength training events or media campaigns do (Schwartz, 1997).

Successful political work determines the scope of possibilities for developing a sustainable system. Negotiating a new settlement among people with disabilities and their families, service provider agencies, system management and cost management agencies, and elected officials requires the gifts of talented negotiators. Convincing legislators and executives of the benefit of investing in more flexible services to significantly more people tests the persuasive powers of those with a capacity for organizing at local, state, and federal levels.

Important bureaucratic work will free up the soil in which more resourceful and sustainable relationships can grow. Those with managerial gifts must accept primary responsibility for creating the administrative means to disinvest the system from the services and regulatory mechanisms that absorb so much energy and money in unsustainable pursuits. Their creativity in designing and refining fair and efficient methods for allocating and administering individual funding moves the system.

Professional work will create the means of delivering the assistance people with developmental disabilities require in effective and efficient ways.

Relationship work underpins both the change process and a sustainable system. This necessary work has at least three aspects: assisting people to form mutually supportive

relationships; creating and maintaining groups that can contain the anxieties of changing a world that often seems unresponsive if not downright prejudiced and focus energy on change; and helping people find ways to implement and sustain action that creates and realizes opportunities for participation and contribution.

While many people with developmental disabilities and family members will make their essential contribution to building a sustainable system by the way they go about organizing the support they need and living their everyday relationships, some people with developmental disabilities and some family members have a call to exercise more public leadership. Strengthening advocacy groups and challenging those who do the necessary political, bureaucratic, professional, and relationship work to notice and support leadership from among people with developmental disabilities (especially people who use non-typical means of communication) and their families deepens the change effort.

Working to build a sustainable system is in itself an important contribution that people with developmental disabilities and their families and friends can make to the common good. They must seriously consider accepting responsibility for overcoming the fears and barriers imposed by currently unresponsive cultures and assuming a central role in transforming those cultures (Vainer, 1998). Vulnerability neither excludes nor excuses people with developmental disabilities and their families from the possibility of creating new relationships, influencing new structures, and strengthening community. It would be a great mistake, founded in paternalism, to imagine that others have to get the world ready before people with developmental disabilities can participate in it.

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