Today’s Crisis – Tomorrow’s Opportunities

Working Toward A Sustainable Future in Support of People with Developmental Disabilities
Sustainable Futures
April 28, 2003

*Sustainable Futures* is a collaboration of The Arc of the United States and the Human Services Research Institute to assist and work with stakeholders in states around the country as they confront some of the most difficult challenges that our field has faced – both in the near term and looking forward. In virtually every state, the hard won gains in supporting people with developmental disabilities and families that have been won over the past decade are in jeopardy due to enormous state budget shortfalls. This budget crisis has compounded other serious and long-standing problems resulting in the deterioration of the capacity of the public system to meet the needs of our nation’s citizens with developmental disabilities. We believe that it is absolutely imperative that stakeholders in each state honestly confront the new budgetary realities and coalesce in developing and actively pursuing an action agenda in pursuit of the best possible outcomes for people with developmental disabilities.

The Arc of the United States
www.thearc.org
1010 Wayne Avenue, Suite 650
Silver Spring, MD 20910
(301) 565-3842
Steven M. Eidelman, Executive Director

Human Services Research Institute
www.hsri.org
2336 Massachusetts Avenue
Cambridge MA 02136
(617) 876-0426
8100 SW Nyberg Road (Suite 205)
Tualatin OR 97062
(503) 885-1436
Gary Smith, Senior Project Director
John Agosta, Vice President
Valerie J. Bradley, President
Today’s Crisis

The Budget Train Wreck

Across the country, states are experiencing enormous budget shortfalls. The sluggish national economy coupled with the plunge in the stock market has left state budgets in their worst shape in decades. State revenues have nose-dived. At the same time, states have seen Medicaid spending surge and are coping with other financial pressures. As a result, nearly every state is scrambling to balance its tattered budget. Hopeful that the crisis would be short-lived, states used stop-gap measures such as drawing down reserves and freezing hiring. As budget deficits continue to widen, states are making deep cuts in core human services. In some cases, states have raised taxes and imposed new fees. The extent of state budget retrenchment is unprecedented. In many states, policy makers are still not certain whether the worst is over.

There is no area of the state budget that is going to be shielded or off limits.

Angela Monson, President National Conference of State Legislators

Medicaid, an essential funder of many human services, is also being cut back. Recent years have seen Medicaid spending grow at a double-digit pace and states expand their programs to provide expanded health care to children and more home and community services to people with disabilities and older persons. To balance their budgets, states have had to scale back their Medicaid programs. As a consequence, many families and individuals – including people with disabilities – have seen their Medicaid eligibility disappear and vital benefits reduced or eliminated altogether.

Services for people with developmental disabilities are also being caught up in the unfolding budget crisis. In some states, family support programs have been cut sharply. Efforts to reduce waiting lists have ground to a halt and waiting lists are spiraling upward again. Some states have frozen their Medicaid home and community-based services (HCBS) waiver programs. Provider payments also have been frozen or cut. Around the country, many provider organizations have laid off staff, and some have gone out of business altogether due to state budget cuts.
The turnabout in state budget fortunes was very abrupt. It followed a period of extraordinarily healthy state budgets. Things were going so well that states could both grow their budgets and cut taxes. Because the turnabout happened so quickly, many state leaders did not realize how serious the problem was. As a consequence, they have been scrambling to balance their budgets ever since. The full dimensions of the present budget crisis still are not clear. Even after making major cuts, many states still face additional deficits.

Unfortunately, the prospects for state budgets recovering anytime soon are not good. Their recovery hinges on the revival of the national economy and it is uncertain when such a recovery will gain traction. Long term, the consensus is that it is unlikely that state budgets will grow at anywhere near the pace they did in the 1990s.

**Prospects for Developmental Disabilities Services**

Prior to the budget crisis, developmental disabilities systems benefited enormously from the combination of healthy state budgets and the leveraging of massive amounts of additional federal Medicaid dollars through the HCBS waiver program. Arc-sponsored Unlock the Waiting List Campaigns paid off in increased numbers of individuals receiving supports in the community. Elsewhere, states settled waiting list lawsuits that also resulted in many people obtaining long overdue services. Some states also boosted payments so that higher wages could be paid to community workers. While the infusion of new dollars into systems did not fix every problem, the past decade saw vigorous growth in spending for developmental disabilities services in nearly every state.

At the end of the day, however, the financial health of developmental disabilities systems can be no stronger than the state budget itself. Not surprisingly, developmental disability systems, like other state systems, are being squeezed. Making matters worse, to finance HCBS waiver expansion many states have already used up their available “state dollars” as match to leverage federal Medicaid dollars. Likewise, other states already shifted all or most of their dollars from institutions to the community. As a result, in many states, the Medicaid refinancing “piggy bank” is now empty or nearly so. Going forward, developmental disabilities systems will face constricted budgets and will grow at a far slower rate than they have over the past ten years or so.

**Thorny Issues**

Slow budget growth means that it will be even more difficult to address the complex, thorny issues that confront developmental disabilities services. These problems pre-date the current budget crisis and will persist after it passes. Some of these issues include: steady increases in service demand, growing cultural
diversity among service users, workforce shortages, and the protection of the well-being of people with developmental disabilities over time.

**Service demand** is surging. Due in part to advances in medical care coupled with the demographics of an aging population, the demand for developmental disabilities services will continue to increase. People with disabilities are living longer. The parents of many adults with disabilities are growing too old to continue to provide care at home. Middle aged baby boomers are finding that their children with disabilities are now aging into the adult system. Consequently, the pressures on the long-term supports system for adults with disabilities can only grow over the next several years. As budget growth slows, the outcome will be that more and more people and families will spill over onto waiting lists and there is great peril that the community of people and families increasingly will be divided between the “haves” and the “have nots.” Absent action, achieving the goal that systems are inclusive of all people who need help will become less and less attainable.

Almost one-third of the U.S. population is from racially, ethnically and culturally diverse groups, a proportion that is expected to grow steadily. Within this group, more than 10.5 million U.S. residents report they speak little or no English, up from 6.5 million in 1990. It is increasingly evident that human services systems – including developmental disabilities – have not responded well to our nation’s changing demographics by fostering culturally competent services. Many of our nation’s citizens are excluded from service systems or find that systems are not flexible enough to accommodate diverse cultures.

For many years, it has been a struggle to recruit and retain a stable, skilled workforce to support people with developmental disabilities. This struggle continues and could be even more challenging in the future as many industries chase a shrinking pool of workers. It is well known that one of the root causes of this problem is that wages and benefits are too low. Until this problem is overcome, it will be hard to expand services and service quality will suffer.

**Quality** has emerged as an enormous concern. Rapid system growth has outpaced many states’ capacity to effectively manage quality, safeguard the
well-being of individuals and achieve positive outcomes for people and families. Increasingly, “getting by” supports are substituted for the types of services that help people grow and contribute to their communities.

In the past, our solution to troubles like these was to advocate for more dollars. In many cases, such advocacy was successful. Going forward, advocates must confront the reality that state budgets will not be growing fast enough to permit us to “buy our way out” of our problems. Solutions to these problems will need to be found elsewhere.

Understanding the New Reality

All of a sudden our expectations about the future have changed. The new reality is that dollars will be in short supply and that the major problems we face in supporting people and families in the community will still be with us.

This new reality can be very difficult to accept. Many of us hope that it will not come to pass and the present budget crisis is just a “bump in the road” or “it will be better next year.” But all signs point to slow recovery and, therefore, lean budget times. This is an unpleasant prospect but it is the new reality within which we all will be working.

Absent action, the new reality will mean that systems will be squeezed in one fashion or another. Waiting lists will grow larger and individuals will suffer as a result. Some people will lose benefits or will be denied supports altogether. Funding levels will erode, putting service organizations at risk. Quality will suffer.

State budgets always have to be balanced. Decisions will be made that will have enormous consequences for people and families. If we do nothing, others will make those decisions. We will be placed in a position of reacting to these decisions, continually fighting rear-guard actions to preserve the current system as best as possible. This is unacceptable.

Tomorrow’s Opportunities

We cannot successfully confront the challenges we face by continuing to do business as usual. Times have changed and the systems that we put into place decades ago are not up to the challenge. Accepting the new reality, however, does not mean that we should become its victims. Change, after all, imposes choice—to either adapt and accommodate or to seize the opportunity to move the system forward. The latter course challenges us to take a hard look at every dimension of the current systems in order to ensure that scarce resources are put
to best use while canvassing new opportunities and looking outside the “system” to support people and families. Inevitably, we will need to redesign systems to work more efficiently to achieve purposeful outcomes. And we must do so with limited, slow growing budgets. We must take action, all of us together, to form a sustainable future for the services and supports that make it possible for people with disabilities and families to lead meaningful lives in their communities.

Establishing a sustainable future must begin with a commitment to a series of overarching values and to the maintenance of the quality of the supports offered. All policy actions, both large and small, must be based on these fundamentals.

**A sustainable future must be value driven.** As stakeholders pursue an action agenda, we must maintain our dedication to the vision of community inclusion and membership of all people with developmental disabilities in our communities. We must always keep in mind that:

- People and families are at the center of our work;
- Our purpose is to support people to pursue their own dreams and aspirations;
- Inclusion is not only a moral imperative but a vehicle for mobilizing natural, unpaid supports; and
- Supporting people to make contributions amplifies resources.

**A sustainable future requires a commitment to quality.** We must not retreat to custodial care or “make do” services. As systems and ways of offering support change, we must assure that the health and well-being of individuals are not traded off. Throughout, the principles of person-centered supports must guide and energize all our endeavors. This is essential because we know that a steadfast commitment to such quality leads to positive outcomes in people’s lives and will ensure that dollars are used in the most effective ways possible.

**Where Are the Opportunities?**

Building a sustainable future is also predicated on another important proposition – there are opportunities to improve efficiency and enlist new resources in support of people with developmental disabilities that must be vigorously pursued. Realizing some of these opportunities might require making changes that disturb the status quo or that require rethinking the critical dimensions of...
public service systems. However, unless these opportunities are pursued, we will not be able to achieve the best outcomes possible for people with developmental disabilities and families.

Coming to grips with the new reality is absolutely vital. It also is essential that we all understand that business as usual will not take us toward a sustainable future. Consequently, we must find and create opportunities to promote efficiency, collaborate with new allies, and forge new partnerships with old friends and adversaries.

*A sustainable future requires efficiency.* We must pursue every opportunity to seek real value for the dollar. Promoting efficiency might mean adopting new business models, shifting to a person-centered system architecture, divesting from low value/high cost services, valuing and rewarding high performance, and cutting service system overhead.

*A sustainable future requires collaboration.* Our service systems are terribly fragmented. Rather than offering cohesive responses to need, systems typically sort needs into neat categories and assign responsibility for meeting needs to this or that public agency. As a result, people and families must negotiate across several service “silos,” cobbling together what they can to meet their needs. Embracing collaboration — seeking new opportunities to weave together the resources of public agencies — is essential. Overall, we must work to enlist the talents and commitment of professionals, individuals and families to tear down funding “silos” through cross-population/cross-system integration, and creating new organizations that enable people and families to share and exchange resources.

*A sustainable future requires partnership within communities.* We discover and utilize every community’s capacities. One of the strongest assets any community has is its people. People volunteer daily to do any number of tasks for others, formally through structured groups or spontaneously through individual initiative. Beyond individual efforts, any community also has an array of other potential community serving entities, such as churches, schools, colleges, businesses, libraries, neighborhood associations, clubs, recreational entities and other community serving organizations. We must forge reciprocal alliances with individuals and the vast array of community assets available to find additional means for supporting people and families. In addition, we must do so in ways that give people with developmental disabilities opportunity to participate fully in their communities, acting alongside others to improve local circumstances.

*The significant problems we face can not be solved at the same level of thinking we were at when we created them.*

Albert Einstein
Opportunities to work toward a sustainable future can be found in many places. It is time to take a hard look at how systems are structured and whether structures that were designed two-three decades ago should continue. It is time to examine the costs of operating fragmented systems that have multiple service sectors with different rules, goals and objectives. Many do not represent the best way that we can support people and families.

Clumsy payment and rate systems that breed and often reward inefficiency must be re-examined. There must be an aggressive search for ways where we can cut costs by applying information and other technologies to make most effective use of scarce human resources.

Cultivating new partnerships with civic and other organizations can unearth heretofore untapped resources. There should be serious discussions about adopting a “what people need but nothing more” principal to guide the allocation of resources. We must make sure that all people and families receive vital supports but new boundaries may need to be established.
It will also be important to re-examine how we build coalitions. This is a time when the survival of responsive systems is at stake and when it is time to reach out to individuals and groups who share the majority of our values.

When times were good, systems could “afford” to ignore efficiency, collaboration and community. It was possible to avoid making difficult choices or taking measures that might disturb the status quo. That time is past. Now everything must be on the table. It is vital to adhere to our values while searching for “value.” In doing so, an “action bias” must take hold in states whereby policy decisions more often than not promote change favoring a sustainable future.

How Do We Work Toward A Sustainable Future?

Every community, locality and state finds itself in the same crisis, but the specific context and therefore the specific solutions are different. Opportunities to promote efficiency, collaboration and community will also differ. The fundamental question is the same: “What changes do we need to make to achieve the best possible future for people and families?”

For example, many states have exhausted opportunities to maximize federal Medicaid dollars but others still have untapped opportunities. Some states are farther down the road in building a person-centered architecture. In other states there are better opportunities for building alliances with other disability groups. The shape of the strategy toward a sustainable future must be state-based.

Most importantly, working toward a sustainable future should start with enlisting the key stakeholders who are willing to confront the new reality, identifying the opportunities for change, and building an action agenda that all participants are committed to pursuing.

“Sweet are the uses of adversity. . .”
William Shakespeare

The answer to “How do we work toward a sustainable future?” starts with “we.” Self-advocates, families, advocates, service providers, state officials, and legislators must come together as collaborators to grapple with the thorny problems that we as a field face. Together, we can identify where the opportunities lie, and make a commitment to pursue change that will lead to the best possible outcomes for individuals and families. In the end, stakeholders must embrace, encourage and support an action bias for change and mobilize alliances in each state.
What The Arc and HSRI Will Do

The Arc of the United States and HSRI will collaborate in hosting and facilitating two-day meetings of state stakeholder teams who want to start the process of working toward a sustainable future. We can provide a safe place for stakeholders to honestly discuss the implications of the new reality in their state, identify opportunities and sketch their action agenda. We can provide facilitators who will be resources to teams and make sure that stakeholder teams keep on task. Both organizations will contribute resources to this endeavor. However, state teams must be prepared to help meet the costs of these meetings. The Arc will take the lead in working through its state chapters in determining interest and willingness of stakeholders to participate in these meetings and form the nucleus of a work group after the meeting.

“When an elephant stands still, it is more bothersome for the person underfoot than for the rider on the top.”

Indian Proverb