

## **Community Services – The Way Forward**

### **Summary/Overview**

The Lanterman Act was passed into law in 1969 to create a community alternative to State Developmental Centers in California. Over subsequent decades, the Act has been gradually updated and strengthened. Through this process, the state has affirmed two fundamental principles which form the foundation of California's developmental disabilities system:

- ❖ Every Californian with a developmental disability has the right to be included in his or her community as a full and active participant.
- ❖ The individual program plan (IPP) - through which individuals choose the services and supports they need to realize their life goals – is the system's driving legal document.

But what happens when these two principles are in conflict? What happens if a consumer's choice is, or appears to be, in conflict with the system goal of community inclusion? This paper considers the importance of the two principles, discusses the ways they interrelate and concludes that everyone working in the system has a moral and a professional responsibility to support them both.

The paper also addresses the key role of consensus-building in moving the system forward and emphasizes the importance of including the views of affected consumers and families when major policy changes are being considered.

The paper acknowledges the intense and passionate nature of debate on these topics and suggests that those engaged in the debate actually share a great deal of common ground. Based on this common ground the paper suggests the necessary elements of sound public policy to guide the system in moving forward.

## **Introduction**

In the summer of 2006, the California State Legislature passed a law that encourages a fundamental change to community based day programs and work activity programs for individuals with developmental disabilities. The language was introduced late in the budget session, passed as part of the budget process and has become law as Section 4691.8 of the Lanterman Act without discussion or debate. As the language became known in the community, many people were surprised that such a significant policy direction had been implemented without benefit of discussion or debate.

Subsequently it has become clear that there is a lack of agreement within the community about how the system should best move forward. This paper was written in response to the law change and the community's reaction to it. This paper is an effort to avoid the kind of philosophical polarization that can distract, divide and weaken an advocacy community. It attempts to identify the core issues involved and analyze them based upon the most fundamental values of the Lanterman Act – values that every stakeholder can and must share.

## **Community Services – The Way Forward**

### I. The Commitment to Community Integration

The Lanterman Act was passed into California law in 1969 to create an alternative to the State Developmental Centers. The Act established a community-based service system to provide individuals with developmental disabilities the opportunity enjoyed by those without developmental disabilities to live, work and play in their communities. As decades passed, the Lanterman Act was gradually updated to strengthen the state's commitment to assuring that every Californian with a developmental disability has the right to be included in his or her community as a full and active participant.

The Lanterman Act's longstanding commitment to full community participation for individuals with developmental disabilities is a clear direction for the future of California's developmental disabilities system. Everyone working in the system has a professional and moral responsibility to encourage each consumer to reach his or her maximum level of independence, self-sufficiency and inclusion in his or her community.

### II. The Importance of Individualized Services and Consumer Choice

In the 1980s, an attempt by the state to proscribe specific services and supports due to budget constraints resulted in a lawsuit and eventually a decision by the Supreme Court of California. That decision answered an important question: How is the Lanterman Act to be implemented? In other words, how is the goal of the Lanterman Act supposed to be achieved? Who decides what services and supports will be purchased for individuals served in the system? Is this something the state can dictate, or, is this determined on an individual basis through the IPP process? In 1985, the California Supreme Court clarified, in *ARC v. DDS*, that the Lanterman Act entitled individuals with developmental disabilities to the services in their Individual Program Plan (IPP). The decision put clear limits on the state's authority and affirmed the supremacy of the IPP in determining the types and levels of service each individual receives. The court's ruling made it clear that the IPP is the system's driving legal document.

Then, in the early 1990s, through an extensive community stakeholder process known as SR 9, a state-wide consensus emerged about the importance of consumer choice. Consumers and their families wanted to strengthen the IPP process to emphasize their role in choosing the services and supports needed to implement their IPPs. As a result, in 1993 the Legislature added language to the Lanterman Act that affirmed the central importance of consumer choice.

California's commitment to individualized service planning and consumer choice is remarkable, and unique. Our system of services and supports for people with developmental disabilities is one of the few existing governmental endeavors expressly designed, by law, to be driven from the bottom up rather than from the top down.

With the California Supreme Court's affirmation that the Lanterman Act intended the IPP to be the driving force in the system, and with the Legislature's emphasis on the importance of consumer choice, another clear direction for the future was defined. Everyone working in the system has a professional and moral responsibility to recognize the IPP as the driver of the system, to encourage each consumer to make informed choices for him or her self, and to actively support the choices consumers make for themselves.

Thus two important principles are clear:

1. The purpose of the system is to maximize independence and inclusion in the community.
2. The choices made by consumers through the IPP process should drive the evolution of the system.

### III. Values in Conflict

But what happens if these two principles are in conflict? What if a consumer's choice is (or appears to be) in conflict with the system goal of community inclusion? What if there is question about whether the consumer is making a well informed choice? And who determines when an individual consumer's choice is or is not consistent with the system's goal? This is where the philosophical debate begins.

It is a theoretical debate more than a practical one. Most of the time, these questions can be resolved on an individual basis through the IPP process and through common sense applied in everyday life. The beauty of the Lanterman Act is that it was designed to assure that such issues are resolved at the local level, on an individual basis, in a planning team process involving the consumer and those who know and care most about him or her. Once a real person's needs, preferences and life goals take center stage, the theoretical debates stop and the best way forward comes into focus.

But as a general topic of discussion, as a philosophical and intellectual matter, the debate can become quite divisive. It takes many forms, and becomes most intense when the subject turns to money - funding for various types of services. When efforts are made to redirect funding or to eliminate a type of service from the system, the values of community inclusion and consumer choice can be in conflict. But even while this is happening, no one can deny that the goal of the system is community inclusion, and no one can deny that consumer choice is intended to drive the system towards that goal.

So how can these two values be reconciled when it comes to redirecting funds or removing certain service options from the system? Such decisions are only appropriate when widespread agreement exists. The key here is consensus. Consensus in this case meaning that the overwhelming majority of stakeholders are in agreement. In such an atmosphere of agreement, the redirection of funds or the removal of options can take a natural course. When choices made by consumers are driving policy decisions, the appropriateness of eliminating specific service models will become self-evident, or it

won't. This process would be simple and straightforward if policy makers had access to statewide aggregated data from the IPPs of all consumers. But without good statewide data on consumers' needs and preferences, our consensus will arrive only when the overwhelming majority of consumers, their families and other stakeholders agree that a particular option is no longer of value. Absent that consensus, the debate must continue.

The value of achieving consensus among all stakeholders on these and other related issues needs to be honored at all the key decision-making points in the system. This is not easy to accomplish in a culture that has come to expect all decisions to result in winners and losers. But California's developmental disabilities system was designed to be different. Most importantly, there must be consensus in the individual program planning (IPP) process. And to honor the fundamental values on which this system was built, stakeholder consensus must also drive the long range planning activities of service provider agencies, the resource development activities of Regional Centers and the related policy setting activities at DDS and in the Legislature. In all of these arenas, the voices of the consumers and families who will be impacted by the decisions must be heard and respected.

Of course, policy makers can decide to act without consensus, but that is ill advised. Consider two examples our society has witnessed: Prohibition and Smoking. With Prohibition the law was changed to stop the sale of alcoholic beverages. But there was no consensus in the community and eventually the effort failed. With smoking a more gradual approach has been taken and as consensus builds, the goal is gradually being achieved. History has amply demonstrated that those who govern, those who set public policy, must have the support of those affected by their decisions in order to be successful.

#### IV. A Critical Time in California

When major policy decisions are made without the necessary consensus, the stability of the entire system is jeopardized. Right now California is at a critical point. Major policy changes are occurring at the state level without the awareness or agreement of the consumers and families who are affected by the decisions. At the same time, a gap has developed between the promise of the Lanterman Act and the everyday reality that consumers and families experience. There is great concern throughout the community that existing service options serving tens of thousands of individuals are being gradually starved out of existence before sustainable alternatives have been developed to replace them. There is also great concern that new service options have been and will continue to be developed without the funding or regulatory support to sustain them over time. These are extremely critical issues that require candid and thorough discussion on a statewide basis to build the necessary consensus needed to move the system forward in a progressive and responsible way.

## V. The Way Forward

California law and the Supreme Court have made it clear that change in the developmental disabilities system should be driven by choices made by consumers through the IPP process. Legislative intent is clear that every effort should be made to encourage every consumer to reach his or her highest level of independence, self-sufficiency and community participation. Everyone working in the system has a responsibility to support both of these principles.

In order to build consensus about the future of community services, the discussion must continue and must extend beyond groups of like-minded people talking only with each other. Advocates for the elimination of site-based or group community services, as well as those who value traditional services, must be free to promote their views without fear of ridicule or retribution. Consumers and their families – the people whose opinions matter most - must be invited to participate in the discussion. A healthy democratic process must be allowed to unfold.

Meanwhile, the question is not *whether* the system will move towards more inclusive services and supports. The question is: *How will this be accomplished?*

Given the guidance provided by the Lanterman Act, and given recent experience in California's community service system, it seems clear that a sound policy for the future of community services and supports for people with developmental disabilities would include the following elements:

- ◆ New options that bring greater opportunities for community integration should be encouraged.
- ◆ Existing options should be sustained unless and until a clear consensus – including affected consumers and their families - emerges to the contrary.
- ◆ The importance of service quality and sustainability must remain at the forefront of all efforts to move the system forward and there must be recognition that service quality depends upon much more than just where the service takes place.
- ◆ All service providers must take the Lanterman Act's values to heart, resist the status quo and do their best to advance community participation and greater independence for each and every person served.
- ◆ Efforts at any level to change or convert existing community service models must be carefully planned to avoid unintended consequences and undertaken with the awareness and support of those affected in order to assure long term success.
- ◆ At all levels, professionals in a position to influence public policy must solicit the views of affected consumers and families when major policy changes are being considered.

The last point is worthy of further comment. By honoring the rightful role of consumers and their families to guide the evolution of the system, policy makers will be

demonstrating a commitment to self-determination for people with developmental disabilities. For California to stay true to its core system values, planning for the future of community services must incorporate the views of the vast majority of affected consumers and their families.

We know professionals have a significant influence at all levels of the system. In order to find the right way forward, every professional has a responsibility to assure that his or her actions are consistent with the system's two core values.

- ◆ Service Providers must base their long-range planning activities on the needs and preferences of those they serve.
- ◆ Case managers must honor their mandated responsibility to make consumers and their families aware of all their available options so that informed choices are made.
- ◆ Regional Centers must assure that their resource development and purchase-of-service activities are responsive to the needs and preferences identified in consumers' IPPs.
- ◆ Policy makers must resist the temptation to use the state budget process to implement major public policy changes with limited public debate.

Professionals must have the courage to stand up and object when they see the fundamental values of the system being ignored. This is not always easy to do, but given the importance of our shared mission it is appropriate that we be subject to high expectations.

As we move forward in support of both of the system's core values, everyone involved should recognize that those who take sides in the philosophical debates are actually standing next to each other on common ground. We should recognize and respect the connection we all share – a heartfelt commitment to people with developmental disabilities. Regardless of how passionate the debate sometimes becomes, we have far more in common than not. We would do well to remember this because there are forces around us, particularly those with only fiscally driven priorities, that can make very effective use of our lack of unity.

People will continue to debate about which services are good and which services are not until a clear consensus is reached. This is a natural process. It is part of what it means to live by democratic principles. We should encourage it. If an open dialogue takes place, one that genuinely includes all the people for whom the system exists, the right path to the future will surely emerge.