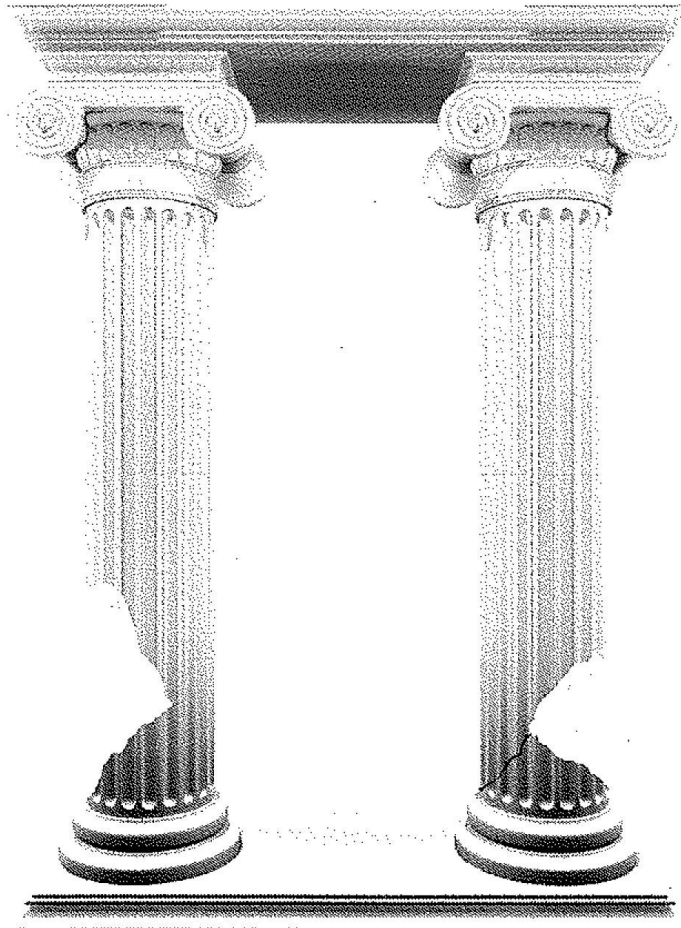


In Danger of Collapse

**A Survey of the Community Services System for People with
Developmental Disabilities**



by

Keeping the Lanterman Promise (KTLP)

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We are KTLP

Family members and friends of individuals with intellectual and other developmental disabilities working together to restore, preserve, and defend the promise of the *Lanterman Act* established in state law and upheld by the Supreme Court of the State of California

In Danger of Collapse

A Survey of the Community Services System for People with Developmental Disabilities

A KTLP online survey launched in November and completed by over 250 organizations representing over 1000 vendored providers shows that services for individuals with developmental disabilities have reached a “tipping point” in their efforts to provide quality services and supports in the wake of continuing cuts and freezes. Even if no further cuts are forthcoming, many programs may not make it through the next year.

History of Underfunding Our Community Service System

Recent funding cuts come on top of a system that was already in serious jeopardy. For over a decade, community service providers have warned of an erosion of service quality. Their concerns have been verified in reports by the State Bureau of Audits and the Department of Developmental Services.

Last year a study by the UCLA Center for Health Policy Research found that 41% of non-profit community service providers in this field operated with a deficit in 2007, 2008, or both years. And in February, 2010, the Board Presidents of 98 separate non-profits serving over 51,000 children and adults with developmental disabilities in California notified the Department of Developmental Services that the cut being proposed would result in the collapse of programs and, in some cases, entire non-profit agencies that the state relies upon to deliver services. Fortunately, after determined advocacy by people with developmental disabilities and their family members, that proposed cut was greatly reduced, although not eliminated. Each new state budget proposal brings with it new cause for alarm.

Our Worst Fears

The most shocking findings of the survey are that 10% of the responding organizations say they are within a year of going out of business if present trends continue, and over 33% report they are on the verge of having to close or consolidate programs/services in order to survive. KTLP commissioned the survey after hearing alarming stories about the ability of many services to continue to meet the needs of our loved ones with developmental disabilities. **We were concerned that the “defunding” of the community service system would be the final “chipping point” that ends the Promise of the Lanterman Act, after 43 years in law. It appears our worst fears are being realized.**

Action of the State Causing the Greatest Concern

Providers report that the decision by the state to cut payments to all community services by 4.25% over the last two years has done the greatest harm to their financial stability. Rate freezes and cuts over the last decade and longer also have had a huge negative impact on services.

Other alarming findings are that three-fourths (75%) of the responding organizations say they have frozen or cut salaries and wages over the last three years, about the same percentage (72%) have cut benefits to employees, and as a consequence are increasingly unable to hire direct support workers with adequate education and experience to provide quality support to the individuals they serve.

Impact on Individuals with Developmental Disabilities

As a result, the outcomes for people with developmental disabilities are suffering. Many providers report that they are placing fewer individuals in jobs, they are working less hours, and achieving fewer IPP goals and objectives. Through this anonymous survey, a majority of providers have admitted that the quality of their services cannot be maintained and is beginning to erode.

Why Providers Participated in This Survey

It wasn't easy to gather this information from such a large sample of community service providers. No one wants to admit to the people they serve and their families, and to their funding sources, that their quality is deteriorating, or that they are on the verge of insolvency.

We believe many providers took part because they won't be identified and were anxious to help clarify the current reality about community services for individuals with developmental disabilities. They believe it's important because regional centers and government agencies have made no attempt to collect this information.

Some state officials have indicated that there may be too many providers and that allowing some to fail is a good thing; that survival of the fittest is not bad. In reality, some of the best services are among those that will fail first. In a service system that doesn't operate on free market principles, the quality of a service holds little relationship to the rate that is paid or to the financial stability of the provider.

"According to our results, it isn't simply a few providers around the state – everyone is hurting and it's affecting the quality of services to our family members and their successful achievement of Individual Program Plan objectives," said KTLP President, Chad Carlock.

What We Must Do to Help

Family members were the driving force behind the passage of the Lanterman Act legislation over 40 years ago. Gradually our collective advocacy voice has become subdued, for many reasons, including our own complacency. The good news is – it's not too late for us to be heard.

This year, individuals with developmental disabilities and their families face urgent challenges to keep our precious entitlement from being chipped away to the point of collapse. When resources for people with developmental disabilities disappear in a community, they will likely never return. Even if the services and supports your family member is currently receiving are stable, or at least appear stable, many are vulnerable and cannot survive another round of cuts. In fact, they need immediate financial relief.

Last week, Governor Brown announced a new budget that includes \$200 Million more in cuts to the Department of Developmental Disabilities budget. **It is time for our voices to be heard to ensure that any additional cuts that are made to our service system are made as far away from the individuals receiving the services as possible.**

But we can, and must, do more. The 4.25% rate cut to providers is due to end (or "sunset") according to the law, on June 30 of this year. **We need to work with other advocates to ensure that this happens and that it isn't extended into the next fiscal year as it has been in the past.** This rate

decrease has already been extended three times by lawmakers in Sacramento, when it was supposed to have sunsetted. Enough is enough.

According to one provider, “Four and one-quarter percent (4.25%) may not seem like much but with all our costs going up it is the difference between providing quality supports to people we serve and marginal support. Ultimately, it’s about our survival if it continues any longer “

KTLP now has nearly 2000 family member followers and hundreds of people who have attended our sessions on “The IPP Process and the Value of One Life.” You know how important our entitlement is and how fragile it has become as budget cuts have eroded the fundamental rights established in the Lanterman Act for people with developmental disabilities in California. We hope you will work with us as we identify strategies for a unified family member effort wherever you are located and no matter how limited your resources.

We want this to be the start of many efforts to preserve and restore the Promise of the Lanterman Act for our family members and for those to come after us.

We have summarized the responses to our survey below. We know you will find them informative.

For those that want to read the survey questions and study the graphs of each of the main questions, we have included them as appendices below and placed them on our website where they can be downloaded.

Summary of Provider Survey Results

Note – The percentage shows the portion of respondents who said this statement applies to their organization.

Actions of the state that have caused the most problems for providers:

- **The single most devastating decision of the state affecting providers is the cut in the rate of reimbursement to all community services of 4.25% (90%).**
- Freezes in the rates over many years for almost all community services have also had a huge negative effect on services (72%).
- Extra “unpaid holidays” forced on providers as a way to cut rates even more has been extremely harmful to the financial viability of community services (60%).
- Longer delays in authorizations to begin service have impacted services and people with developmental disabilities significantly (40%).

The economy has compounded the problem for many community services. In normal economic times, a typical non-profit organization raises 25% or more of their total revenue from sources other than state reimbursement.

- Non-profits completing the survey say they are receiving fewer donations to augment funding shortfalls (over 60%), less revenue from business enterprises (56%), producing less revenue from event fundraising (54%), and that fewer grant opportunities and dollars are available (54%). *(Note: These percentages were adjusted to factor out the 12% of for-profits service providers who said the above issues do not apply to them.)*
- The economy has also hindered job development and work available to individuals with developmental disabilities due to high unemployment and business downsizing in our communities (58%).

Cuts and freezes by the state have impacted organizations in the following ways:

- Services are increasingly unable to hire direct support workers with adequate education and experience to provide optimum support (71%).
- Direct support workers receive less training and are less qualified (31%).
- Employee turnover has increased (55%).
- Staffing ratios have increased so individuals with developmental disabilities receive less personal attention (18%).
- Fewer individuals with developmental disabilities have been placed in jobs and they are working less (39%).
- Individuals with developmental disabilities are achieving fewer of their IPP goals and objectives (30%).

As a result of all of the above, providers report the following:

- They have cut or frozen wages and salaries within the last three years (75%) and a large majority have had to discontinue some employee benefits and increase employee cost participation (72%).
- The changes providers have been forced to make have already impacted the quality of their services or soon will (53%).
- The lack of adequate resources due to the cuts and freezes has impacted their ability to include consumers in the community and/or find them jobs (40%).
- **Many services are on the verge of having to close or consolidate their services in order to survive, as reported above (33.6%).**
- **A surprising and shocking number of services are within a year of going out of business if present trends continue (10.1%).**

Additional Survey Details

- The provider survey was anonymous and conducted online, beginning November 15, using a link in emails that allows responders to go directly to it.
- Seventy-Five percent (75%) of responding organizations were non-profits
- Providers from over 200 zip codes in all 21 regional center areas participated.
- Provider service codes included virtually all the DDS funded Day and Work Service categories.
- In a follow-up survey, each responding organization represented an average of 5.1 vendored services, making the total number over 1000. While many responders had one or two services, some had 10 or more.
- Fifty-seven (57) representatives of the participating providers gave personal comments on their financial circumstances and their ability to provide quality services.
- Over 100 (49%) responders provided their email address

Provider Survey Appendix

1. A Printable Copy of Provider Survey
2. Graphs of Responses to Key Survey Questions

Introduction

It is important to know how Day and Work programs and services in California have been affected by budget and other legislation in Sacramento and by decisions made by the Department of Developmental Services.

While all of us have stories about the services we provide and the people we support, and many have told these anecdotes to decision makers in very compelling ways, no one has collected quantitative information that we can collectively use to show legislators and others that these stories are not all that different from many others throughout the state. This **anonymous survey** is our opportunity to do this.

We will publish the results of this survey if we receive enough responses to ensure that we have obtained a representative sample of these programs and services throughout the state. For that reason, we hope you will pass along this direct link to other providers in case it may not reach them in some other way. We are particularly interested in reaching smaller providers who have no affiliation to a state organization.

KTLP (Keeping the Lanterman Promise) is a family member and friends initiative devoted to preserving our precious entitlement legislation that has existed for 42 years. We are circulating this survey because we are extremely concerned about the future of community services in California. If present trends continue, the service system won't meet the needs of our loved ones and friends, and the promise of the Lanterman Act will be an empty one. KTLP is not associated with any other advocacy or provider group and we believe our independence provides a measure of objectivity as the originator of this survey.

Each vendored service is likely different, even within organizations, therefore, we recommend that you complete this survey for each of your vendored programs if you have more than one.

You will notice that we have not included certain service categories and that most of these omissions are related to residential living. We are aware of the circulation of surveys in these areas and we did not want to duplicate their effort. If you provide residential services, look for an announcement about them on KTLP.org.

The way this data is collected assures anonymity so please consider providing your zip code and the regional center where your program operates as it may help us with future advocacy efforts.

1. What is your position with your organization?

- CEO/Executive Director
- CFO/Finance Director
- Day Program Director/Manager
- Other (please specify)

2. Is this a nonprofit service or support?

- Yes
- No

3. Identify the Regional Center which provides your program or service with the largest number of referrals.

Regional Center

4. What is the zip code from which this program or service originates?

Zip Code (Optional)

5. What is the service code and descriptive category of your program? If you have more than one service code in one location, please select "Other" and list these codes in the provided comment area.

- Activity Center (505)
- Adult Development Center (510)
- Behavior Management (515)
- Community Activity Support Services (063)
- Community Integration Training (055)
- Independent Living Services (520)
- Infant Development (805)
- Respite Services (862, 868, 869)
- Social Recreation (525)
- Supported Employment Program Group and/or Individual (950, 952)
- Work Activity Program (954)
- Other (please specify)

6. Which system changes and cost-cutting measures over the last three years have affected your ability to provide a quality program or service? (Select all that apply)

- New oversight and transparency requirements
- Cuts (4.25%) in the rates over the last three years
- Freezes in the rates over the last eight plus years
- Implementation of half-day billing
- Forced closure days
- Fewer hours of authorized support
- Fewer referrals
- More transportation difficulties
- Longer delays in authorizations to begin service
- None of the above have affected the quality of our program or service
- Other (Please describe other measures your Regional Center may be using to cut costs that affect your program or service)

7. In what ways have the current economic conditions affected your service or support and/or your organization in general? (Select all that apply)

- Fewer donations to augment funding shortfalls
- Fewer grant opportunities and grant dollars received
- Event fundraising is increasingly difficult and less productive
- Less net revenue available from business enterprises
- Human resources and technology needed to support the above activities are inadequate due to downsizing
- We are a for-profit business and none of the above apply.
- Fewer jobs and/or work available to the individuals we serve due to the high unemployment rate and business downsizing in our community.
- Other (please specify)

8. In what ways have cuts and freezes over many years impacted your program or service and the individuals you serve or support? (Select all that apply)

- We are able to help consumers achieve fewer of their IPP goals and objectives.
- We currently place fewer individuals in jobs and provide less work and vocational opportunities.
- Our staffing ratios have increased (i.e., from 1:4 to 1:8 for senior services) so less individualized attention is provided.
- Our direct support workers receive less training and therefore are less qualified.
- Because of our wage and salary scale, we are increasingly unable to hire direct support workers with adequate education and experience to provide optimum support.
- Because of our wage and salary scale, we have experienced an increase in employee turnover.
- The individuals we serve or support have experienced no negative impact from the cuts and freezes to date.
- Other (please specify)

9. As the result of cuts and freezes over many years, which statement(s) below best describe(s) the state of your program or service and/or your organization in general? (Select all that apply)

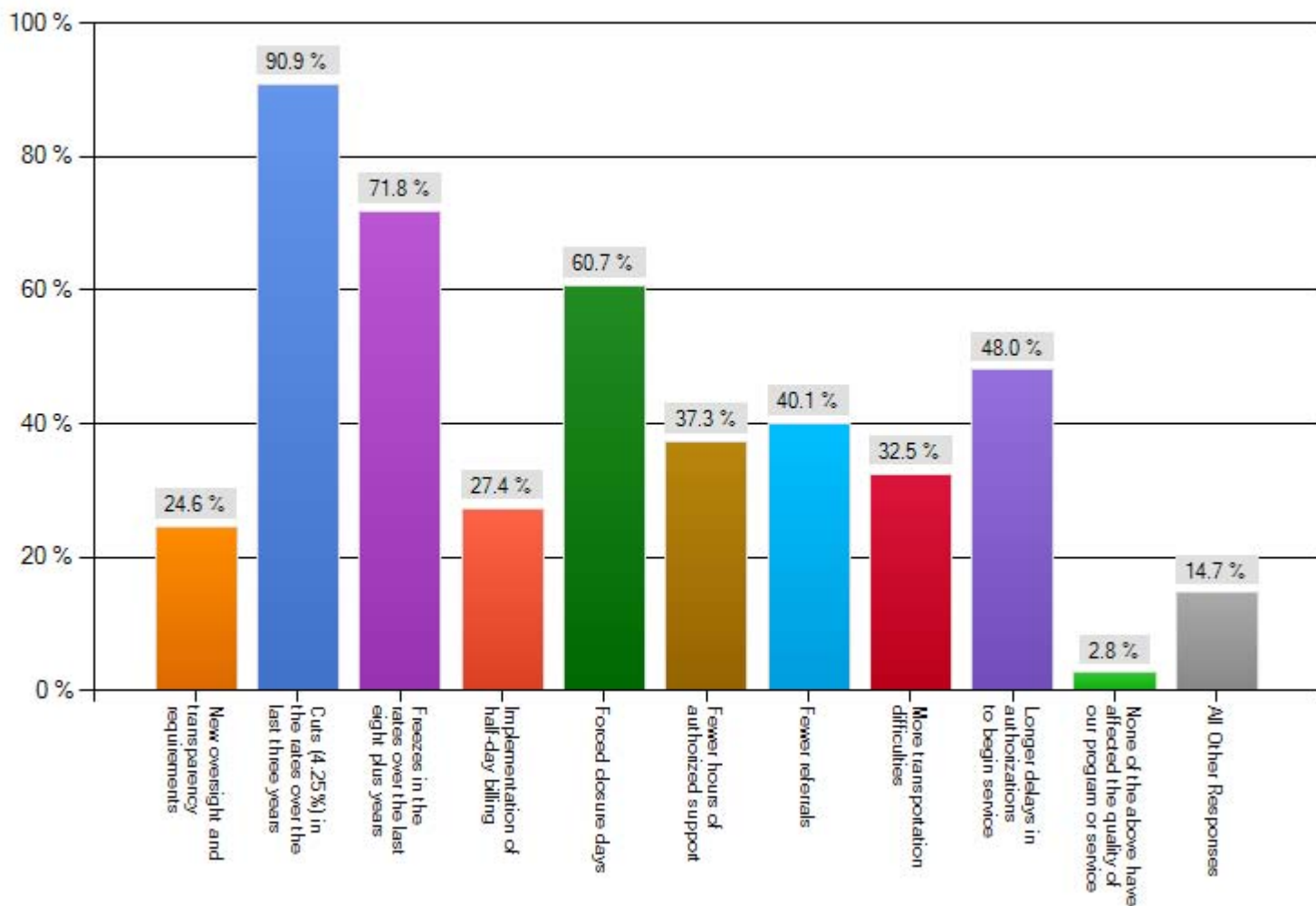
- The changes we made have impacted or threaten to impact the quality of our services and supports.
- We are on the verge of having to close or consolidate one or more of our programs in order to make things work for our organization financially.
- We have cut or frozen wages and salaries within the last three years for our employees.
- We have discontinued some employee benefits and/or increased employee cost participation.
- The lack of adequate resources has seriously impacted our ability to include consumers in the community and/or find them jobs.
- As a direct result of state budget allocations to our service and supports, individuals we serve are generally in more restrictive environments than two years ago.
- We will not be able to sustain an acceptable quality of services and supports in the near future if present trends continue.
- We have experienced no negative changes in the way we conduct business in the last three years.
- We are within a year of going out of business if present state budget trends continue.
- Other (please specify)

10. Please feel free to comment further on your ability to provide quality programs and services.

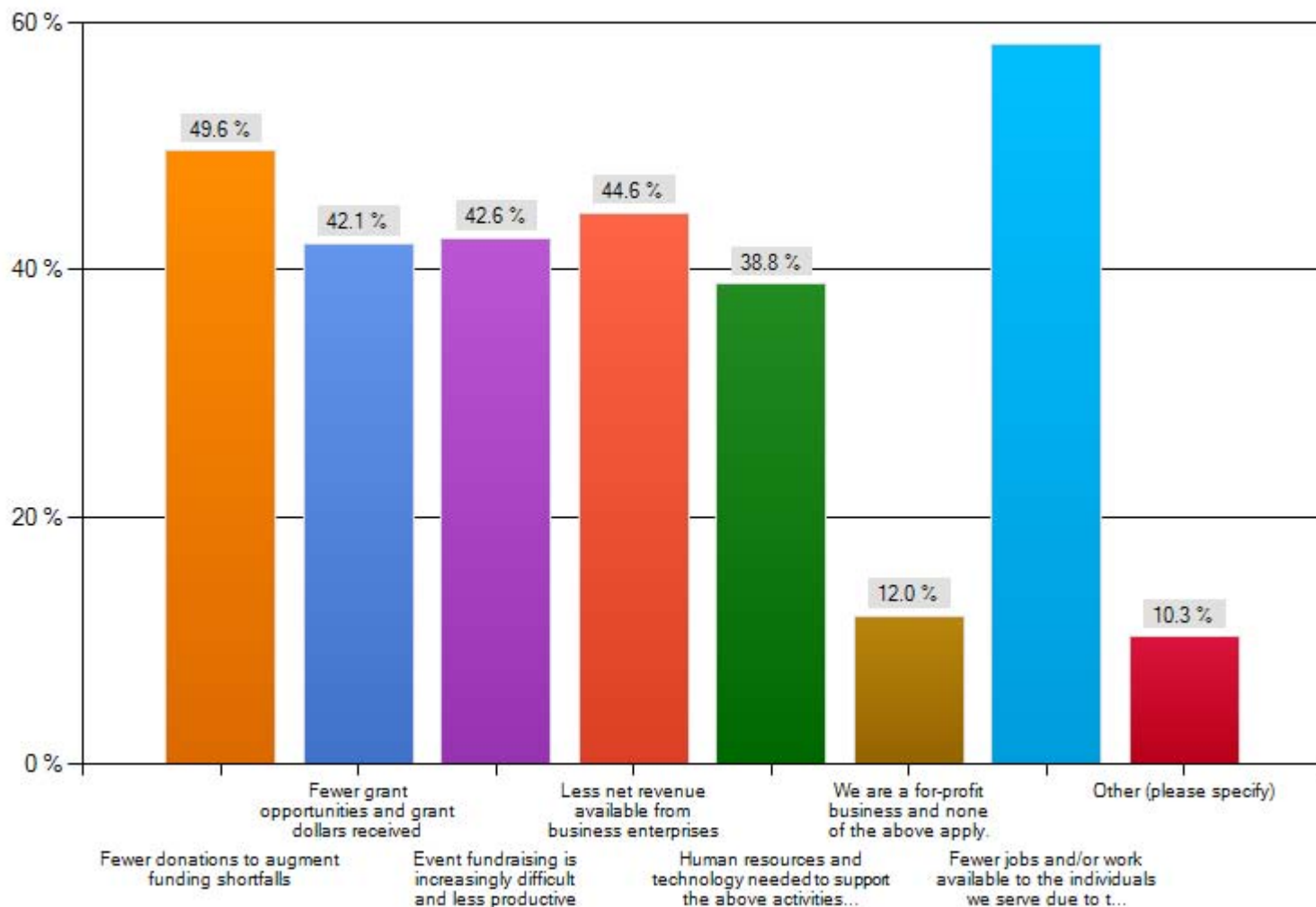
11. Optional: Please add your email address to our growing list and we will email you the results of this survey and notify you when others are available. Your email will not be associated with your responses to this survey.

Email Address:

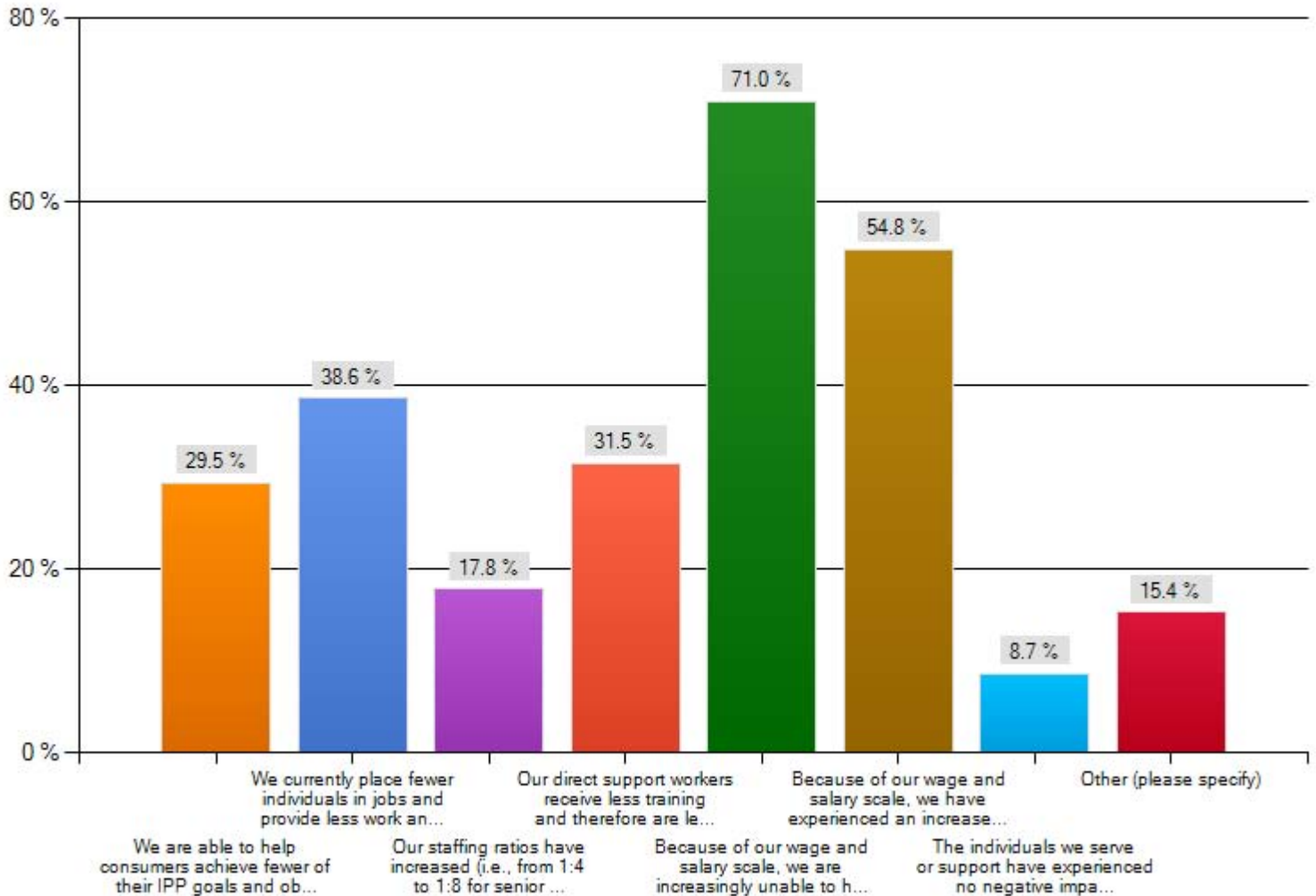
Which system changes and cost-cutting measures over the last three years have affected your ability to provide a quality program or service? (Select all that apply)



In what ways have the current economic conditions affected your service or support and/or your organization in general? (Select all that apply)



In what ways have cuts and freezes over many years impacted your program or service and the individuals you serve or support? (Select all that apply)



As the result of cuts and freezes over many years, which statement(s) below best describe(s) the state of your program or service and/or your organization in general? (Select all that apply)

