

The State of State Report  
The Arc California Executive

Director  
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***The Arc***™

***California***

# System Sustainability: Legislative/Policy Approach

- The Executive Directors within The Arc California made an appeal to the board of directors to include in their public policy work a serious effort to address the antiquated funding model that no longer has any association with service cost.
- In partnership with the Lanterman Coalition, we have been engaged in dozens of meetings with policymakers to fund the initial cost increases expected to impact the community providers in the upcoming year.
- Since 2009 we have had about 60 changes to the Lanterman Act and many of these changes have caused great harm to our constituents with I/DD and other have contributed greatly to the destabilization of the service system. We are currently analyzing these changes with members of the Lanterman Coalition and we are mapping out a course for a restoration plan for developmental services.
- Recognizing that funding the immediate impending new costs does nothing to address the current instability of the system of services for people with I/DD, we are working with groups focused on pursuing legislative attention to the question of sustainability and supporting others pursuing discovery of the underlying issues.

# System Sustainability: Legal Action Approach

- We recently won a major victory in our lawsuit, *The Arc v Douglas, Delgadillo*. Charges the state violated the Medicaid Act, reverses the half-day billing and the holiday schedule.
- We continue to manage and pursue our lawsuit filed against the state with the following claims:
- That the State has and continues to violate the Lanterman Act by ignoring the Act's mandate that the State establish and maintain an equitable, cost-based rate setting process to assure the delivery of suitable, high quality services promised by the Act.
- That the State's unjust rate system and illegal cuts have a discriminatory impact, particularly on those with more severe disabilities that require higher, more costly levels of care. Those programs are most in jeopardy of closure, leaving the most in need without services.

# *Ideas for Innovations:* **System Sustainability**

- *The work in this areas is well underway and the partnerships are critical in this endeavor. We cannot achieve this needed change initiative only with United Cerebral Palsy, we need the system as a whole to continue to work on all the pieces together.*

# Crime and Abuse

- We were informed almost a year after the Taser Torture of residents at the Sonoma Developmental Center (SDC) by a reporter from the California Watch.
- What was most egregious was the fact that no one in law enforcement was doing anything to bring justice to the 11 people with disabilities at the SDC who suffered from being tortured by the use of a taser gun in September, 2011.
- Prior to this incident we tracked the police response to a case involving over 100 hours of rape of women with severe developmental disabilities and eventually pressured the law enforcement community into prosecutions.
- Last year another case came to light of a young woman who was non-verbal and severely physically disabled who was raped in a community care home that thanks to the diligent work of the case managers and our constant checking-in and our connections with the local reporter helped get a satisfactory prosecution though it took a long time.
- Working with The Arc Riverside we are closely watching the development of prosecution on a case involving the death of a consumer who was left in the car after being restrained and we are working with The Arc Los Angeles and Orange County on SB 663 to address many of the problems we see in the criminal justice system's response to crime against our constituents.

# *Ideas for Innovations:* **Crime and Abuse**

- *We recently began to organize a new Criminal Justice workgroup meets March 2015.*
- *We need to develop a strategic plan that provides us with the capacity to act quickly to incidents of crime and abuse and improve our working relationships with policymakers on a local and statewide level in the law enforcement community.*

# Employment

- We maintained the Alliance for Full Participation to keep the flow of information on best practices for increasing competitive employment for people with disabilities, however, the regularly scheduled monthly meetings have recently discontinued.
- We continue to participate in the SCDD Employment First Committee and the California Committee on Employment of People with Disabilities (formerly the governor's committee) to help improve employment outcomes for our constituents including sponsoring and lobbying for the passage of AB 1041 Chesbro.

# *Ideas for Innovations: Employment*

- *We could put together an annual conference that brings together all the recommendations from the guidepost for employment studies highlighting ways to help parents, providers, to improve employment outcomes for people with disabilities and profits for businesses as a direct result of qualified workers with disabilities.*
- *This year will dedicate an hour of our policy conference to employment development and access policy.*

# Children and Families

- We continue to serve as a community partner in the Early Start ICC, reporting on legislative updates impacting children and families and prevention activities.
- The Arc California president has appointed a position on the board of directors from the Family Resource Center Network of California, and The Arc CA board is currently 85% family members.
- We are involved through amicus supporting a court case that gives families the right to demand results from CCS and if not to receive outside professional clinical help and to use the information in the therapy for class purposes.

# *Ideas for Innovations:* **Children and Families**

- *We could organize a collaborative similar to the one we have with UCP to create a political force focused solely on children and family services and supports.*

# Health Advocacy

- We have been working extensively with Clarissa Kripke, MD from UCSF to help raise awareness of the poor health outcomes for people with developmental disabilities and the problems in care coordination and physician preparations.
- Working closely with leadership in the legislature we are organizing legislative activities that will bring attention to these issues from a policy perspective and link the healthcare issue to the closure process for developmental centers.
- Our national office has a CDC grant called HealthMeet focused on health advocacy and our San Francisco chapter is implementing it in the Bay Area.
- Together with the coalition for People with Complex Needs, presented a consensus paper on need for increased and improved care coordination etc. for people moving from developmental centers to the community and others already in the community.

# *Ideas for Innovations:* **Health Advocacy**

- *We could establish a statewide conference or training events that looks at the problems of poor health outcomes and teaches advocates how to become strong health advocates.*

# Workforce Development:

- Our workforce development is focused in two areas including professional development for executive directors in The Arc movement and the professional development of the direct support professionals who support people with I/DD in the community settings.
- We organized a conference in October 2012 National Ethics Training by the National Alliance for Direct Support Professionals (NADSP) and this year we organized the Shift Happens in California events in Los Angeles, Oakland, and Sacramento. The events sold out and we have heard from 10 community non-profits who are currently implementing strategies from the Shift Happens to improve the hiring and maintaining of quality DSPs.
- We have about 30 DSPs in our California chapter of NADSP.
- As far as the activities for professional development for Executive directors goes we continue to play a leadership role in the NCE by serving as the president, vice president, and engage with other California leaders such as Jim Baldwin and Kevin MacDonald. Through our work in NCE we provided outstanding professional development and collegial support for the professionals in the movement in service to The Arc.

# *Ideas for Innovations:* **Workforce Development**

- *Now that every California executive director is a member of NCE we need to know what your needs are in your local chapters, especially for developing the staff in all professions (finance, fund development, communications, etc.).*

# Education

- In addition to monitoring adult education policy (Tim Hornbecker does community college and adult education policy and advocacy). Carlos Palacios, membership coordinator, attends a variety of transition fairs to help raise awareness of self-advocacy and The Arc advocacy efforts.
- We speak with many families every year and inform them of the services of the local chapters and public policy advocacy of the entire network.
- We are active participants in the yahoo email list for special education advocates and the CAC special education list.

# *Ideas for Innovations: Education*

- *Add IEP training into the community organizing weekend training along with the IPP training to diversify the outreach to advocates.*

# Mental Health

- For the past 10 years we have been an active participant on the Mental Health Collaboration between the Regional Center Directors and the Mental Health Directors chaired by Carlos Flores, San Diego.
- While the participation from the mental health directors has significantly decreased over the years the committee continues to work on building capacity for the regional center consumers with dual diagnosis.
- We continue to be advised by our counterpart association in mental health, NAMI, on legislation and public relations and sigma issues.
- Recently the CDC reported that 20% of American children have a mental health disorder.

# *Ideas for Innovations:* **Mental Health**

- *We should strengthen our working relationship with NAMI and find ways to collaborate on issues of shared interests.*

# Coalitions

- We continue to accomplish the majority of our large scale systems change initiatives in collaboration with other statewide associations and organization.
- The Lanterman Coalition is the most significant collaboration in the state and its membership now includes about 19 statewide organizations. This past year we worked together on more items than we have been able to in the past 12 years.
- We coordinate the CASACC (vendor advisory member chairs), we are a founding member of the CC for LTSS (California Coalition for Long Term Services and Supports), we participate in the community organizing of the Gamaliel California and the Sacramento project, we maintain the Statewide FASD Task Force, and our latest is the Coalition for People with Complex Needs, a collaboration of state hospital parent associations and community organizations.
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# *Ideas for Innovations: Coalitions*

- *Last year we started to collaborate with the CDSA on our public policy conference we could consider bringing in other groups similar to our national collaboration for public policy.*

# Prevention

- Our prevention activities include maintaining the California Fetal alcohol Spectrum Disorders Task Force which centers on policy and public information work to reduce the incidence of FASD and to improve treatment options and criminal justice interactions.
- Prevention also includes information on preventing intellectual and other disabilities by reducing brain trauma induced disabilities through our water safety activities.
- The policy work this year in prevention was focused on all the above and we added screening activities in genetics testing and the reduction of the traumatic impact associated with early onset dementia and Alzheimer in people with Down syndrome.

# *Ideas for Innovations: Prevention*

- We would like to consider hosting a conference with the theme of Prevention to show case all these activities and expand our reach to the general community about the importance of prevention.*
- School districts and universities could partners for us.*

# Questions



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