



Californians for Olmstead



Advocacy Toolkit

"There's No Place Like Home"

CaliforniansForOlmstead.org



Individuals Featured on the Front Cover:

Lois Curtis was a plaintiff in the Olmstead court case that defined the right to home and Community based services for people with disabilities.

Anthony was assisted out of a nursing facility by the Silicon Valley Independent Living Center San Jose.

Mary Ann was assisted out of a nursing facility by the Independent Living Center San Francisco.



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The Olmstead Advocacy Toolkit

The Olmstead Advocacy Toolkit is a resource designed to assist advocates to advance implementation of the Supreme Court's Olmstead decision and to promote home and community-based services within local communities. The toolkit is intended to provide resources to communicate with opinion leaders, policy makers, community-based organizations, ombudsmen, skilled nursing facilities, hospitals, individuals with disabilities and the public. All materials in the toolkit are available on our website, www.californiansforolmstead.org.

These are the resources and materials included in the toolkit:

- *Implementing Olmstead at the Community Level* is a step-by-step advocacy guide that includes ideas for taking action in local communities and key tactics to support Olmstead policies at the local level.
- *The Supreme Court Olmstead Decision* is a Fact Sheet that can be downloaded from our website and distributed as an informational resource.
- *There's No Place Like Home* is a Poster that can be downloaded from our website and distributed as an informational resource.
- *Home is Where I Live Now, Home is Where I Belong* is a brochure that describes the Transition to Home program, which assists people to get support to transition from a nursing home or institution to the community. It can also be downloaded from our website and distributed.
- *Contradiction and Conflict: The History of People with Disabilities in California* provides an overview of segregationist policies that targeted people with disabilities as well as the major achievements of the disability rights movement.
- *The Supreme Court Olmstead Decision: What it Means for Communities, Individuals and Families* is a PowerPoint presentation that can be downloaded from our website and used by advocates to make presentations at local meetings, forums, hearings and other venues. Slides 2 and 35 can be personalized with your contact information.

- *Key Messaging Tips: A Quick Reference Guide for Communicating About Olmstead* is a handy overview of communications strategies.
- *The Media Outreach Manual for Promoting Olmstead Implementation* is a manual with resources and examples for designing and implementing a communication plan.

This toolkit was designed as a companion to our report on statewide Olmstead implementation, *A Blueprint for Advocates: Recommended Next Steps to Advance implementation*, <http://tinyurl.com/3ofxwot>. California's Implementation of the Supreme Court's Olmstead Decision. It is also supported with educational training provided in our Olmstead Webinar series. This series of five webinar trainings on key Olmstead topics may be accessed for free at any time on our website, under Training Materials.

Californians for Olmstead

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Implementing Olmstead at the Community Level: A Local Disability Advocacy Campaign

Advocacy is putting forward one's views to the public and decision-makers about a major issue that affects the community. It begins with identifying a problem or challenge, but it is more than just offering criticism. Advocacy is positive action to effect change, and it involves educating, engaging and making an impact. Public policy advocacy specifically aims to change laws and regulations in order to make a change for the better.

For many years, it was acceptable public policy to institutionalize people with disabilities, segregating them from the rest of the world in what were often poor conditions in hospitals, nursing homes and other institutional settings. However, with the passage of the Americans with Disabilities Act (ADA) in 1990, segregating people on the basis of disability was prohibited. In 1999 the Supreme Court decided in the case of *Olmstead v. L.C.* that institutionalizing people with disabilities violates the “desegregation clause” of the ADA, and states could no longer maintain public policies that forced people with disabilities into institutions by providing funding only for institutions rather than for community services. The court wrote that *“Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”*

Many of the requirements of the Olmstead decision are placed on states, and advocacy activity to implement Olmstead often occurs at the state level (see our report [*A Blueprint for Advocates: Recommended Next Steps to Advance California's Implementation of the Supreme Court's Olmstead Decision*](#) for a description of state-level Olmstead advocacy). However, when people with disabilities do not live in institutions, they live in communities, and many needs that would have been provided for in an institution, such as housing or transportation, need to be accessed at the local level through mainstream community infrastructure and services. By and large, local communities have limited knowledge of Olmstead and the critical role that local infrastructure and policies play in the implementation of Olmstead and in meeting the needs of their community-members with disabilities to live and thrive in community settings.

This lack of knowledge is a major roadblock to local public policies and administration that should appropriately provide strong support people with disabilities. In addition, “realignment” proposals under discussion, to shift more responsibility for service delivery to the local level, make this an even greater concern. Advocates must position themselves now to become an important voice in local government and community processes, to continue to educate communities about Olmstead and to be a strong voice for local policies that support community-living.

There are many ways to craft a local advocacy campaign; many Independent Living Centers are already actively involved at the local level, and creative groups of disability advocates will probably come up any number of campaign ideas. This Toolkit is intended to validate the importance of those efforts, to introduce local Olmstead policy advocacy to those who may be new to the endeavor, and to provide resources and support for local disability advocacy campaigns.

I. Seven Steps of Policy Advocacy

Step One: Bring Like-Minded People Together

People with common concerns are the most effective when brought together to work toward an objective. There are already people in your community who work in or advocate for home and community-based services (HCBS). They are natural allies. In addition, reach out to include new people; an inclusive group of people with diverse experiences and perspectives will make your coalition innovative and dynamic. Make sure that the objective that you choose is a change that your group cares about and really believes is important. This will make the work more meaningful and keep everyone motivated.

Step Two: Identify and Analyze the Problem

Strive to understand and describe the central problem. Ask questions, such as “What are the origins of this problem? What are its main causes, and its impacts? What are the future consequences of the problem, and what additional information is needed to make our case?”

Defining the problem can often be done by describing deficits or excesses: for example, there are too many people who are homeless, or there are too few people with disabilities who are employed. Try to quantify these descriptions, for example: “The Housing and Urban Development Department estimates that there

are 250,000 homeless families in our state.” Missing an important opportunity can also be defined as a problem.

Avoid defining the solution into the statement of the problem, for example, “There are too few shelters for homeless families.” This implies solutions before analysis and can weaken your case.

After you have zeroed in on what the problem is, research the reasons it exists, its impacts, and previous efforts to address it. You may rely in community needs assessments, policy reports, stakeholder input or news stories to develop your understanding of the issue. After you develop your analysis, go back and see if your understanding of the problem may have changed. Then identify the facts that will make the biggest impact on decision-makers, allies and opponents.

Step Three: Identify Decision-Makers & Influencers

There are two key audiences for policy advocacy – decision-makers who have the power to make the decision that impacts your chosen policy (the primary audience), and those individuals and groups that can influence decision-makers (the secondary audience).

Begin by understanding the primary audience, decision-makers. Who is it that has the power to make the change you seek? Ask questions, such as what is their decision-making role and their area of influence? What are their current positions on the issue? What is their level of knowledge about the issue, and what beliefs do they hold that impact it? Finally, what is the degree of their interest, based on their willingness to actively support or oppose the advocacy goal? Much well-intended advocacy falls short because advocates focus energy on people who do not have decision-making power over the area of concern; make sure you thoroughly understand the decision-making process and the people with power to change it before launching your campaign.

After you have identified and assessed the primary decision-makers, consider who makes up your secondary audience -- those who can influence the decision-makers. Who are potential allies and opponents? What strategies can be used to engage allies in assisting with your advocacy, or lessen the impact of opponents? The information you assemble about your audiences that can serve as a road map for future action.

Step Four: Determine the Decision(s) that Can Be Influenced and Set Goals

Based on your information-gathering and analysis of the issue and the process, you will now be in a position to understand and focus on which policies can be influenced and changed at the local level. Take into account the context and constraints that decision-makers face, as well as the timing of the decision. While your campaign may encompass several changes, for best results, focus on a particular decision at a particular time. This will require your coalition to work together to establish consensus around goals and priorities for the campaign. Take into account potential risks and benefits, responsiveness to the needs of coalition members, long-term perspectives, and strength of support of allies.

Policy campaigns can be organized with any number of goals, including agenda setting, policy development, policy adoption, policy implementation, policy blocking, policy monitoring and evaluation, or policy maintenance. But clearly defined goals are the basis of any successful strategy. General descriptions of intent fail to form convincing arguments and typically do not garner the support needed for change. Your policy goal needs to have a well-articulated, clear and logical relationship to the defined problem.

A method for understanding whether you have effectively set goals is the SMART criteria (Specific, Measurable, Achievable, Realistic and Time Bound). If you goals don't meet the SMART criteria, consider what changes need to be made, and revise.

Step Five: Form and Implement an Action Plan

The next step in the process is to form a detailed action plan that addresses both goals and strategies; organizing them into short-term objectives, outlining specific tactics and activities that are required to achieve the objectives, and determining time lines and individual responsibilities.

This plan describes the full spectrum of activities and your method of advocacy. It selects the tactics that will have the greatest effect on the target audiences, such as meetings or forums, letters, outreach to the media, debates, monitoring and reporting, sign-on letters, or other activities that your group has determined will have the greatest impact and be most likely to achieve the goals of your campaign.

In setting out time lines and individual responsibilities, the action plan moves beyond generalities and becomes a group work plan, with individuals agreeing to their part, understanding what their contribution will be, and when they need to

accomplish it. The action plan incorporates all of the information and findings of the previous four steps and moves the group into strategic and specific actions to accomplish its goals, serving as a rationale, a road map and a tool for accountability for the campaign.

Step Six: Review, Revise, Repeat

After you have implemented your action plan, do a self-evaluation to understand the outcomes and process what you learned. What worked, and what didn't? Review challenges, objectives, your identification of decision-makers, and the effectiveness of your research and information-gathering. These are some questions it is useful to ask about the campaign:

- Was the policy goal relevant?
- Were short-term objectives achieved?
- Were new or desired outcomes achieved?
- Was information-gathering and research effectively utilized?
- Do we need more information?
- Has the nature of the problem changed?
- Were communications effective?
- What were the most important relationships?
- How do we build stronger alliances?
- What is our organizational capacity?
- How timely were our responses?
- Can we better utilize our resources?
- Are coalition members encouraged and commitment sustained?

After your evaluation, update your strategies based on changed conditions as well as what you learned in the campaign. Meet and discuss your findings with your

coalition so that your group stays together to address future concerns, and decide on follow-up or next steps that incorporate what you've learned.

Step Seven: Celebrate Success

Policy advocacy is a process, not just an activity or outcome. Effective advocacy campaigns are positive and bring people together for a common cause; they are also inspirational and engaging.

Advocating for good policies is one way to make lasting change in your community. If you are successful in improving and expanding home and community-based services, the impact of that change should last well beyond the end of your project, creating better opportunities for people with disabilities to live successfully and thrive in your community. At the end of your campaign, be sure to celebrate your coalition's efforts and their contribution to ending the segregation of people with disabilities and ensuring that all are welcomed and treated as valuable members of society.

II. Some Key Advocacy Tactics

There are a variety of tactics that advocates can use to promote home and community-based services in local communities, including research on critical issues, developing policy briefs, and budget analysis. In addition, one-on-one meetings, presentations to groups, letters and petitions, public information campaigns, and marches, rallies and sit-ins have been successfully used by disability advocates to promote their agenda. These are specific suggestions on using some of these key advocacy tactics.

One-on-One Meeting

If there is one primary decision maker to influence, try to get an appointment to meet with that person individually. One individual or a small group can go to speak to the person. If you go as a group, be clear about the roles of each person in the meeting. Keep in mind that you may only get five minutes of the person's time, so it's essential to be well-prepared and organized. Practice making a two-minute pitch that includes:

- Issue you want to discuss;
- Why it is important to you;

- The change you are seeking;
- How your change will improve the situation;
- What you are asking the decision maker to do;
- Why he or she should do it.

In making your case, remember to appeal to both the decision maker's sense of moral fairness and his or her self-interest. Bring written information with you to the meeting, such as fact sheets and other resources that support your presentation. Be prepared to answer questions with information you have discovered through research, including discussion of local impacts and how other communities are handling the issue. Remember to thank people you have met with for their time before you leave. You should also follow up with a written thank-you note within a week of the meeting.

Presentation to a Group

If you are trying to influence a group of decision makers, such as a Board of Supervisors, City Council or a board or commission, try to get on the agenda of one of their meetings to make a brief presentation. For your presentation, you will want to include the same elements of your argument that you would for an individual meeting (see above), but the delivery will be different. Clear and well- designed visual aids can help convey information to a group. A PowerPoint presentation and photographs, charts, or maps illustrating your themes can help the listeners focus on the main points of your presentation.

The presentation may be made by one individual or a small group, but everyone's role should be well defined, and the presenters should practice several times in advance of the meeting. It's also a good idea to have concise handouts containing the main points of your presentation for both the decision makers and the audience to take home. If the meeting is open to the public, invite additional members of the group to attend to show support for the presenters and for the proposed policy change. Be sure to stay until the end of the meeting. There may be potential allies in the room to talk to you after the meeting to discuss collaboration and mutual interests. Making these contacts is called networking and is an important skill in all types of advocacy.

Letters and Petitions

If you cannot schedule a face-to-face meeting, or the meeting is unsuccessful, consider a letter-writing campaign or petition drive to reach the decision makers. The more people who write letters or sign your petition, the more impact this tactic will have. When communicating in writing with legislators or other decision makers, keep in mind:

- Hard-copy letters in hand-addressed envelopes often receive the most attention.
- If time is short, e-mail and faxes will do the job more quickly, but you'll need to collect more of them to make an impact.
- People in public office are kept there or removed by voters. Therefore, collect as many signatures as possible from registered voters ages 18 and older.
- Use the proper term of respect when addressing your letter (e.g., "The Honorable [name]" or "Dear Representative X").
- Verify the address, fax number, or e-mail address where you will be sending your correspondence so that your efforts will not be wasted because your correspondence didn't reach its destination.
- If you do not receive a response within a week, follow up with a phone call, making reference to your correspondence.

Public Information Campaigns

You can use the media to build understanding of and support for Olmstead implementation at the local level. A public information campaign can be used to influence your primary audience of decision-makers, as well as a secondary audience, those individuals and groups who can influence decision-makers. Before beginning a public information campaign, develop an audience profile to assess the existing knowledge and beliefs of your audience. Keep in mind your goal of policy change when developing your campaign. Public information campaigns can be especially useful with elected officials, as they need public good will to be re-elected. Use their dependence on votes to your advantage by getting the public on board with your policy proposal and putting political pressure on your official(s) to

support local home and community-based services. The Olmstead media manual can provide you with detailed information on developing a communications plan.

Marches, Rallies, and Sit-ins

These are protest tactics that can be used when decision makers are unmoved, unresponsive, or opposed to your policy proposal. In order to be effective, these tactics require gathering a large number of participants and setting a tone that is non-violent; violent protestors tend to discredit themselves in the eyes of both the general public and the decision makers, which is counter-productive to winning support for your issue. The rights to peaceably assemble and to petition the government are protected in the Constitution, but you may need a permit to hold your event in a public space. Check with your local police department.

Remember that one tactic is not a campaign. You need to put careful thought into your goals and overall strategy, and be prepared to try several different tactics to achieve your goals. Be sure to celebrate small wins along the way to keep up your spirits and your momentum.

III. Ideas for Local Olmstead Campaigns

Deciding which local policies are most important for your group to work on will be an important decision for local advocates to make. These are a few suggestions to get the dialogue started with your group:

Olmstead Presentation to the Board of Supervisors

Boards of Supervisors have a very important role in home and community-based programs; they have major decision-making authority in housing, transportation, In-Home Supportive Services, mental health, aging and other HCBS. An educational campaign that includes a presentation that introduces the Olmstead decision and the importance of local implementation would be very valuable; launching an effort to ensure that Boards of Supervisors receive this presentation in all of California's 58 counties would be a meaningful campaign. In large urban areas, City Councils and other major boards or commissions would also be a good target for an educational campaign about Olmstead.

Housing Advocacy

The critical need for affordable and accessible housing for people with disabilities is a concern noted in nearly every policy report on Olmstead. The local level is one of the most important arenas to make an impact on housing. There are three main avenues of local housing advocacy; a campaign might focus on specific goals that involve any of them.

First and most significant are Housing and Urban Development (HUD) Local Entitlement Jurisdictions. These are often the local housing redevelopment agency or another city or county department, which report to the county Board of Supervisors or the City Council. Among other programs, these entities administer the HUD HOME Investment Partnership Program, which provides an opportunity for creating new housing stock. HOME funds can also be used to develop Tenant Based Rental Assistance programs, which could be specifically targeted to vouchers to assist people to transition from institutions. One strategy for beginning advocacy with Local Entitlement Jurisdictions is to participate in the development or annual update to their local Consolidated Plans, in order to ensure that they fully address the needs of people with disabilities; especially those transitioning from institutions. More information about the Consolidated Plan process can be found here: (<http://www.hud.gov/offices/cpd/about/conplan/local/index.cfm>)

A second housing opportunity is to work with Public Housing Authorities; they administer Section 8 housing vouchers. Public Housing Authorities (PHA) do not have much opportunity to expand housing because they are subject to the limitations of federal funding for Section 8; however, they have recently had the opportunity to respond to special voucher releases that were reserved for people transitioning from institutions, and advocates with strong relationships with their PHA were successful in persuading them to apply for these special vouchers. Finally, public private relationships with developers can result in direct competitive awards for local housing development through the HUD 811 or 202 programs; the statewide housing non-profit organizations have the strongest relationships with private developers and the most expertise in this arena.

Transitioning People from Institutions

Transitioning people from state and federally-funded institutions into local home and community services is a hybrid arena that is often connected to statewide policy through California's Money Follows the Person program, the California Community

Transitions program. But transition providers, including many Independent Living Centers and other community-based organizations, are often working with local services to put together a package of HCBS that will support the person to live at home.

A local campaign that collaborated with local transition providers to promote HCBS solutions that would support people transitioning to communities, identified local barriers to transition, and worked to improve policies to support transitioning residents, would be a very innovative marriage of policy and program coordination.

Understanding the population of individuals who are institutionalized in your community would be important in this type of campaign. You can get more information about skilled nursing facilities and intermediate care facilities in your region here (<http://www.skillednursingfacilities.org/directory/ca/>) or here (<http://www.carepathways.com/nhg-state-CA.cfm>).

Mental Health System Advocacy

Mental health services in California are delivered through a county-administered system that serves people with psychiatric disabilities only “to the extent that resources are available.” As a result, people with mental health disabilities are frequently subject to institutionalization simply because they don’t receive appropriate community-based services. Many have exposure to short-term institutionalization as they revolve through emergency rooms and acute psychiatric facilities; others are subject to loss of their rights through conservatorship and are admitted to skilled nursing facilities designated as “Institutions for Mental Disease,” or IMDs. These are locked facilities in which residents are held indefinitely and do not have the right to leave.

Emphasizing prevention and early intervention rather than wasting resources on ineffective and expensive institutionalization is a policy choice; every county has a Mental Health Advisory Board or Commission that oversees mental health funding decisions. A local advocacy campaign that promoted transition of people living in IMDs to community settings, or funding appropriate community-based mental health services to prevent revolving door acute psychiatric institutionalization, would be an important local Olmstead campaign. More information about where IMDs are located in your community may be found here: (www.dmh.ca.gov/Services_and_Programs/Adults/IMD.asp).

Developmental Disability System Advocacy

Although California has built an effective system to serve people with developmental disabilities through the Lanterman Act, people with developmental disabilities are still institutionalized in California in both large-scale developmental centers as well as skilled nursing facilities designated as Intermediate Care Facilities for the Developmentally Disabled (ICF-DD).

Twenty-one non-profit regional centers provide home and community-based services that maintain people to live in the community and over time have assisted many to move from institutions to the community. Many of these regional centers have consumer advisory councils and all are required to have service provider advisory councils that address the range of Olmstead and HCBS issues; a local campaign that concentrated on assisting people with developmental disabilities to transition to community settings could potentially be developed in collaboration with these advisory bodies. A list of California's regional centers can be found here: (<http://www.dds.ca.gov/RC/RCList.cfm>).

Aging System Advocacy

California's aging services are organized into a network of 33 Area Agencies on Aging (AAA). Each AAA covers a geographic region that encompasses one or more counties. AAA's plan, develop, coordinate and administer services to assist older adults, adults with disabilities, and their caregivers. They deliver services directly or by contract.

Each AAA has an advisory body; sometimes the local Adult and Aging Commission functions as the advisory body, and sometimes it is a separate Advisory Council. These local entities have a very important role in aging policy in every community; especially in helping to prepare communities to meet the challenges of a rapidly aging population. Without planning and assertive advocacy, the current system of HCBS is inadequate to meet this demographic challenge. The rapid growth of the aging population may be the most important Olmstead issue in the future, and collaboration with Adult and Aging Commissions to prepare communities to meet the demand for services would be an excellent local Olmstead campaign. A list of California's Area Agencies on Aging can be found here: (http://www.aging.ca.gov/local_aaa/AAA_listing.asp).



There's No Place Like Home

Home is where
we have:

- Choice
- Independence
- Family
- Work
- Community

Nobody wants to leave home and move to a nursing home, hospital or other institution. So let's stop funding expensive stays in nursing homes and institutions, and instead support home-based services.



Californians for Olmstead

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“Home is
where I live now,
home is where I belong.”

Call to Find a Transition Coordinator Near You:
(877) 427-0387 • (800) 900-0706 TDD



Transition to Home
www.TransitionToHome.org

Photo: Mary Ann lived in a nursing home and was assisted by a Transition Coordinator to return to the community.

Do you want to move back to your home or community but need help to do so?

A Transition Coordinator can help you identify programs that can assist you in finding housing, and paying for moving expenses. They can help you get grab bars, ramps installed and find assistive devices, like wheelchairs and other medical equipment that make it easy for you to live independently. Most of all they can help you figure out what works best for you.

Many people qualify for In-Home Support Services that can assist with you with getting in and out of bed, getting dressed, cooking, laundry and light housekeeping.

Para-transit services are available in many communities for people who need accessible transportation to get around town.

Owen's Story, "10 Months is Enough!"

After spending almost 10 months in a nursing home following surgery for a pressure sore, Owen wanted to be out on his own again. But he needed help. The Transition Coordinator and Owen developed a budget and figured out what he would need to live on his own. Together



Photo
Mary Ann lived in a
Transition Coordinator

they completed an application for a Transition Grant from the Department of Rehabilitation. Owen used the grant to secure an apartment and purchase necessary household items. He also found an In Home Support Services caregiver and was able to move out of the nursing home in a few short weeks.

Home Quiz

istance available to
a place to live?

e available to help
new place with
household items?

ay for me to get
to the grocery
ch and the doctor?

ce available to help
activities?

way for me to keep
wheelchair, shower
other things that
to get around?

“There’s no place
like home.”

- DOROTHY

Transition Coordinators meet people everyday who say, “I went to the hospital and next thing I know, here I am. I don’t know what happened to my apartment.”

A lot of family and friends think, “Well the doctor said he needs to be in a nursing home, so that’s that.” People don’t realize they can get services in their own home.

So who do you talk to?

If you would like to talk to a Transition Coordinator then tell a nurse, social worker or nursing home administrator. They will refer you to a Local Contact Agency for assistance and get you started.

on Front Cover:

nursing and was assisted by a
or to return to the community.

FACT SHEET:

The Supreme Court *Olmstead* Decision

- Before the passage of the Americans with Disabilities Act (ADA), people with disabilities experienced a long history of social exclusion, forced commitment to institutions, abuse, neglect and discrimination in education and employment.
- The ADA was the world's first comprehensive prohibition of discrimination on the basis of disability, passed after Congressional hearings documented the "staggering isolation" of people with disabilities. The ADA was passed by overwhelmingly bipartisan majorities and was signed into law by President George H.W. Bush on July 26, 1990.
- In 1999, the ADA was the basis of the Supreme Court's decision in *Olmstead v. L.C.*, which ruled that unnecessary segregation in institutions is a type of discrimination that violates Title II of the ADA.
- Like *Brown v. the Board of Education*, the primary focus of the *Olmstead* decision is on the right to integration, in this case the integration of people with disabilities into the community. **The Court wrote that unnecessary institutionalization "perpetuates unwarranted assumptions" that people with disabilities "are incapable or unworthy of participating in community life."**
- Federal courts have consistently ruled that the protections of the *Olmstead* decision apply to people living in the community, not just to those who are already institutionalized.
- Courts have also held that bad economic times for a state do not alone relieve it from its obligations to citizens with disabilities under the ADA or the *Olmstead* decision.

Contradiction and Conflict: The History of People with Disabilities in California

Professor Paul K. Longmore

San Francisco State University

**Testimony before the California State Assembly Select Committee on Disabilities
February 2, 2010**

The history of people with disabilities in California has involved two conflicting societal perspectives and two contradictory sets of public policies. The one was exclusionary and segregationist, the other democratic and integrationist. The former has viewed people with disabilities as not just inferior but in many ways dangerous to society. The latter has affirmed their claims to civil rights and self-determination. In both, California has reflected and often set national patterns.

In the late nineteenth century, many US cities passed unsightly beggar ordinances that excluded people with visible disabilities from appearing in public places. The first such law that we know of was adopted by the City of San Francisco on July 9, 1867. It declared: "Any person who is diseased, maimed, mutilated, or in any way deformed so as to be an unsightly or disgusting object, or an improper person to be allowed in or on the streets, highways, thoroughfares or public places in the City or County of San Francisco, shall not therein or thereon expose himself or herself to public view." Anyone convicted of violating this ordinance was to be fined up to \$25 or imprisoned in the county jail for up to 25 days, or both. Section 4 provided an alternative to fine and imprisonment. The convicted person with the disability might be "committed to the Almshouse."

In the next several decades, cities across the U.S. adopted statutes that borrowed the San Francisco ordinance's language to bar people with visible disabilities from public places. Many permitted magistrates to waive the fine and jail time if they committed the violator to an almshouse or "poor farm" or "hospital." These laws aimed at more than regulating disabled beggars or looking after destitute people with disabilities. They undertook to cleanse public space of people deemed "unsightly or disgusting" or as Chicago's Aldermen described them "unsightly and unseemly." Unseemliness entailed an accusation of indecency. Disgust expressed

both moral revulsion and social contempt. The attribution of unsightliness declared that some things, some people, must be kept hidden. This regulatory campaign, backed by progressives and conservatives alike, enforced the bias that anyone with a visible disability threatened social disorder.

The provisions authorizing incarceration in an almshouse, poor farm, or hospital helped pave the way for locking up in large-scale institutions many people with developmental disabilities, people labeled in that era as “feeble-minded.” They were blamed for the increases in poverty, vice, and crime that accompanied industrialization and urbanization. Experts warned the public in virtually hysterical terms of “the menace of the feeble-minded.” They asserted that “feeble-minded” men were likely to become paupers and beggars, criminals and sexual predators, while “feeble-minded” women would surely become prostitutes. Society must protect itself by confining them in what became massive, bleak, and brutalizing institutions.

But there were just too many people with developmental and other disabilities to lock them all up. Other segregationist measures, such as the unsightly beggar ordinances, tried to prevent them from contaminating the community. Early in the twentieth century, a main argument for “special classes” was, not that children with disabilities had an equal right to an education, but that their presence in regular classrooms hindered the education and development of non-disabled children. This argument is still heard today against mainstreaming and inclusion.

Some children with disabilities did, at least for a time, attend regular classes though. A 1918 court case in Wisconsin evidences resistance to their presence. A public school expelled an 11 year old boy with cerebral palsy, not because he was unable to keep up academically, but because his teacher and fellow students found him “depressing and nauseating.” The Wisconsin State Supreme Court upheld his expulsion. It would not be until 1975 that children with disabilities in the United States of America gained the right to go to a public school and get an education alongside their non-disabled peers.

Adults with disabilities have historically met with job discrimination in both the private and public sectors. In the early 20th century, they protested exclusionary federal civil service hiring practices as well as New Deal work relief policies that rejected job applicants with disabilities as “unemployable.” But then came the labor shortages of World War II. Adults with disabilities previously turned away as “unfit”

suddenly became a “vast reservoir” of potential workers. People with every sort of disability, including developmental disabilities, went to work. But when the war ended and millions of non-disabled white men returned, workers with disabilities, like women and people of color, lost their jobs.

In the postwar era, some advocates called for legal protections against employment discrimination, but their proposals met stiff resistance. In the 1970s, a new generation of disability rights activists charged that “attitude campaigns” that tried to persuade employers to “hire the handicapped” reduced neither prejudice nor the extraordinarily high unemployment rates among working-age adults with disabilities. Research has consistently confirmed widespread bias among private-sector employers and public-sector agencies against job applicants with any kind of disability, as well as discrimination in wages and access to health insurance. Meanwhile, millions of working-age adults are still kept out of the job market by social welfare policies that provide health insurance, personal assistance services, and payment for assistive devices as long as they stay unemployed and impoverished but penalize them by taking away those vital benefits if they take any job that pays more than meager wages.

In the early twentieth century, eugenicists lobbied for state laws to compel the sterilization of people with many kinds of disabilities, and especially people with developmental disabilities. More than half of the states adopted sterilization statutes. California led the way in this sterilization campaign.

Those who feared the social contamination of people with developmental and other disabilities believed that segregation and sterilization were still insufficient to protect society. So they advocated euthanasia. One of the most powerful arguments for euthanasia of people with developmental disabilities appeared in a best-selling novel now considered a literary classic, *Of Mice and Men*. In this story by the celebrated California author John Steinbeck, the intellectually disabled Lenny is not only unable to control his capacity for violence. He burdens his pal George and destroys the dream of a farm that will rescue George and several other down-and-out farm workers from the ravages of the Great Depression. Hence, George’s “mercy killing” of Lenny eliminates an individual regarded as not only a personal but a social and economic burden. When reread as a pro- euthanasia tract, this story is chilling, especially as it continues to influence the unconscious attitudes of so many current-day students and other readers, and particularly as one encounters similar arguments in the contemporary pro- euthanasia movement.

Throughout this long history, and especially in the decades since World War II, people with disabilities and non-disabled advocates resisted. They fought for educational rights. During the 1950s and 1960s, parents launched a movement for their children's right to an equal and integrated, "mainstream" public education. In the early 1970s, estimates reckoned seven million school-age children with disabilities, with one million completely excluded from public schools and another three million in school but not receiving an appropriate education. In 1975, the movement won passage of one of the most far-reaching pieces of educational legislation in U.S. history, the Education for All Handicapped Children Act. Meanwhile, adults with disabilities demanded access to higher education. In 1962, Edward Roberts, a high school honor student and quadriplegic, sought admission to UC Berkeley. A university official told him, "we've tried cripples before and it didn't work." Refusing to back down, Roberts not only graduated from UC. He became the "father of the independent living movement" and director of the California Department of Rehabilitation.

California advocates also fought for the right of people with disabilities to live in the community. Opponents of institutions that warehoused people with developmental disabilities condemned them as "retarding environments." Said one: "We stick them in institutions. The institutions retard them so that they are unable to function in society. And then we say, 'They're retarded. They can't function in society.'" People with physical disabilities launched the independent living movement. Activists in both campaigns lobbied for programs such as the regional center system and in-home support services. Few states matched California's commitment to community integration.

These efforts were part of the larger Disability Rights Movement. That movement has not been a homogeneous or unitary effort, but an assemblage of campaigns that arose among blind people, deaf people, psychiatric survivors, people with learning disabilities, physical disabilities, and developmental disabilities. Each has addressed issues and pursued agendas particular to their constituencies. But they have operated from increasingly similar principles.

Let me note key elements of the agendas of the developmental disabilities and independent living movements. Both have campaigned for the right of people with disabilities to live in the community. They have demanded: legal protection from discrimination; the right to receive quality treatment or services; the right to

refuse such treatment or services; due process in all professional or governmental decision-making affecting them; equal access to public transportation and accommodations; and, most fundamental, opposition to forced institutionalization and, correspondingly, the right to services to support living in the community. The services include aid with: personal maintenance and hygiene; mobility; household chores such as cooking, cleaning, and child-care; cognitive tasks such as money management; and communications access such as interpreting and reading.

Two important principles underlie these objectives: first, the demand for self-determination. This involves not only individual choices in daily living, but also a collective political voice on the part of disability communities in the formulation of public policies and programs that affect people with disabilities. Both forms of self-determination are expressed in the political demand: “Nothing About Us, Without Us.”

The second principle is the claim that people with disabilities have a right to the means necessary for them to participate in the community. This principle redefines services and assistive devices, accessibility and reasonable accommodations, as, not ways of caring for those who are fundamentally dependent, but alternative modes of functioning and the necessary means for social participation and integration. Disability rights advocates also have campaigned for establishment of these means as enforceable rights, rather than dispensations of public or private charity. Advocates have sometimes argued that funding community-based living and in-home support services is less expensive than institutionalization or nursing home placement. But more important than that pragmatic argument, they have asserted not only the right of people with disabilities “to live in the world,” but also their right to the means to make that right effective.

We stand at yet another turning point in the history of people with disabilities. It is a pivotal moment in which Californians must decide which of these two perspectives regarding people with disabilities the community will adhere to, which of these two sets of public policies the State will follow.

The Supreme Court *Olmstead* Decision

What it Means for Communities,
Individuals and Families



Presented to

by

on

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Background

Dr. Paul Longmore, who was a historian at the University of California, San Francisco, described the history of people with disabilities as a clash of two contradictory public policies:

- 1) Exclusionary and segregationist policies that were supported by conservatives and progressives alike; and
- 2) Democratic and integrationist policies based in civil rights and self-determination, that were fought for and won by people with disabilities themselves.



Historical Treatment of People with Disabilities

- “Unightly Beggar” ordinances barred people with disabilities from appearing in public (the first one instituted in San Francisco in 1867).
- Forced commitment to almshouse, poor farm or hospital, later to large-scale Institutions (to spare society from those who were seen as “unsightly and unseemly”).
- Relegation to segregated education to avoid “hindering” the education of non-disabled children.



- Subject to job discrimination, including federal civil service and New Deal work relief which rejected people with disabilities as “unemployable.”
- Used as labor during labor shortages of World War II, but lost jobs when the war ended.
- Focus of euthanasia policies advocated by leading social activists of the 1930’s.
- Forced sterilization, particularly of those with developmental disabilities, up until the 1960’s.



- And policies that exist to this day that keep millions of working age adults out of the job market by means of social welfare policies that provide health insurance, personal assistance services, and payment for assistive devices ***as long as they stay unemployed and impoverished.***



The Disability Rights Movements Emerged as a Force for Change

- Many Movements of Many Constituencies, But Operating from Similar Principles
- Arose Around the Common Fight against Warehousing People in Institutions
- Founding of the Independent Living Movement in the 1970's



Some of the Key Elements of the Disability Rights Agenda

- Legal Protection from Discrimination
- Right to Receive Quality Treatment or Services
- Right to Refuse Such Treatment or Services
- Due Process in all Professional or Governmental Decision-making Affecting Them
- Equal Access to Public Transportation and Accommodations
- Most Fundamental, Opposition to Forced Institutionalization and Correspondingly, the Right to Services in the Community



Landmark Advancements Won by Disability Advocates

In 1975 the Individuals with Disabilities Education Act was passed by Congress, and children with disabilities gained the right to go to public school and get an education alongside non-disabled peers, ending an era where at least one million children were denied education and four million more were segregated from mainstream schools.



Disability Rights, Cont.

The Americans with Disabilities Act (ADA), the world's first comprehensive prohibition of discrimination on the basis of disability, was passed by overwhelming bipartisan majorities in Congress after two years of extensive hearings detailing the "staggering isolation" faced by people with disabilities. The ADA was signed into law by President George H.W. Bush on July 26, 1990.



Disability Rights, Cont.

And on June 22, 1999, in response to a lawsuit filed by two Georgia women residing in a state psychiatric hospital, the U.S. Supreme Court ruled in *Olmstead v. L.C.* that unnecessary segregation and institutionalization of persons with disabilities is a type of discrimination that violates Title II of the ADA.



The *Olmstead* Decision

In the ruling, the Court wrote,

“Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement and cultural enrichment.”

-Olmstead V.L.C. (98-536) U.S. 581 (1999)



The Court explained,

Unnecessary institutionalization “perpetuates unwarranted assumptions” that people with disabilities “are incapable or unworthy of participating in community life.”



In interpreting the ADA, the Court relied heavily on an implementation regulation promulgated by the U.S. Dept of Justice, referred to as the “integration mandate.”

The ADA’s integration mandate requires a state or local government to “administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”



Who is a Qualified Individual?

A person with a disability who, “with or without reasonable modifications to rules, policies or practices; the removal of architectural, communications, or transportation barriers; or the provision of auxiliary aids or services, meets the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.”



Federal courts have ruled consistently that the *Olmstead* decision’s protections apply to people living in the community, not just to those already institutionalized.



A second important feature of the ADA that the Court relied on in the *Olmstead* decision is the requirement for a state or local government to “make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability.”



Fundamental Alteration Clause

State and local governments are excused from making a modification if it “would fundamentally alter the nature of the service, program or activity.”

What does or does not constitute a “fundamental alteration” is important. Courts have ruled that a state’s claim of inadequate financial resources is not automatically a “fundamental alteration.”



The *Olmstead* ruling required that states must develop a working plan to serve qualified individuals in the least restrictive, most integrated setting.

The Court also required states must maintain a waiting list that moves persons to less restrictive settings at a reasonable pace, not controlled by the state's efforts to keep its institutions fully populated.



In 2000, the U.S. Dept of Health and Human Services Issued Guidelines for Compliance:

- Incorporate consumer input into the state plan;
- Prevent further unjustified institutionalization;
- Ensure ongoing availability of services for people w/disabilities to live in the community;
- Ensure quality, improvement and sound management to implement the plan.



Obama Administration is Enforcing *Olmstead*

- Under the leadership of Assistant Attorney General Tom Perez, the U.S. Dept of Justice Civil Rights Division announced it is “open for business” and has identified *Olmstead* enforcement as a top priority.
- As of late 2011, the DOJ is now involved in litigation on *Olmstead* in over 20 states, and is adding new cases every day.
- By comparison, the previous federal administration filed only one *Olmstead* complaint in eight years.
- State and local governments are often unaware of these enforcement activities as well as their responsibilities under *Olmstead*.



Recent California *Olmstead* Cases

- ***Chambers v. City and County of San Francisco***: Settlement of class action lawsuit against San Francisco on behalf of residents of Laguna Honda Hospital (LHH). San Francisco agreed to create 500 affordable, accessible housing subsidies, provide case management, mental health, and other services for class members moving or diverted from placement at LHH.
- ***Capitol People First v. Dept. of Developmental Services***: Settlement of class action lawsuit against the State and 21 regional centers on behalf of Californians with developmental disabilities residing in, or at risk of placement in, state-run and private institutions. Settlement resulted in protection of funding for community placements from state-run developmental centers (DCs), as well as increased case management for people in DCs and enhanced assessments and information for people in private institutions.



- ***Cota (Brantley) v. David Maxwell-Jolly***: Class action lawsuit against Dept. of Health Care Services challenging cutbacks to Medi-Cal funded Adult Day Health Care (ADHC) services. The first preliminary injunction was issued on September 10, 2009 preventing an across-the board cut in Medi-Cal funding from up to five days to a maximum of three days per week of attendance, regardless of need.
- ***V.L. v. Wagner***: Class action lawsuit against the Depts. of Social Services and Health Care Services challenging significant cuts to the In-Home Supportive Services (IHSS) program based on the use of functional ranks and functional index scores. The cuts, if implemented, would reduce or terminate IHSS services to 130,000 Californians with disabilities.



Napper v. County of Sacramento: Class action lawsuit filed against the County of Sacramento challenging the county's decision to terminate provider contracts serving 5,000 mental health clients and bring all services in-house without adequate transition planning. A preliminary injunction was issued on July 21, 2010 stopping the county from implementing its proposed plan until the Court determines that clients will continue to receive integrated services to avoid institutionalization.

-Adapted from Disability Rights California 9/29/10.



The Department of Justice is using a new framework for *Olmstead* enforcement. Instead of the previous approach of just fixing institutional abuses, they ask, Does the person belong in an institutional setting in the first place?

They are working closely with Centers for Medicare and Medicaid Services, Housing and Urban Development & Health and Human Services to bring federal resources and policies into alignment with the goals of *Olmstead*.



Transitioning from Institutional Settings

Independent Living Centers and other community-based organizations directly assist people to move from skilled nursing facilities and other institutions, back to community settings, utilizing a variety of federal, state and local resources to support the person's needs.



- These resources are known as “Home and Community-Based Services” and they include housing vouchers, In-Home Supportive Services, Home Health, Case Management, Meals on Wheels, Transportation and other essential services.
- For a person to live at home instead of in an institution typically creates substantial savings for the state and federal governments.
- Advocates fight to have these resources re-directed to Home and Community-Based Services to meet people’s needs in the community.



Help with Transition

People who are interested in transitioning from an institution can get information, assistance and support:

www.transitiontohome.org

877-427-0387

800-900-0706 TDD



"Home is
where I live now,
home is where I belong."



Call to Find a Transition Coordinator Near You:
(877) 427-0387 • (800) 900-0706 TDD

Visit Us Online for More Information:
www.TransitionToHome.org



Characteristics of Effective County Long-Term Care Systems That Support Olmstead Implementation

These Principles are Generally Utilized in San Francisco,
and Partially Implemented in Sonoma and San Diego
Counties



Effective County Long-term Care Systems

- Consumer-driven
- Single Point of Entry (allows quality assurance)
Comprehensive Package of Services that are Tailored to the Individual and *Can Change with His or Her Needs*
- Seamless Transitions Between Care Settings



Effective County Long-term Care Systems

- Package Designed on Assessment, with Consumer Choice
- Funding for Services
- Array of Services
- Clear Lines of Responsibility and Oversight
Flexibility to Make Changes



“Disability rights advocates have campaigned for the establishment for establishment of these means as enforceable rights, rather than dispensations of public or private charity.

Advocates have sometimes argued that funding community-based living and in-home support services is less expensive than institutionalization or nursing home placement.



But more important than that pragmatic argument, they have asserted not only the right of people with disabilities ‘to live in the world,’ but also their right to the means to make that right effective.”

-Dr. Paul Longmore



My Contact Information:



Key Messaging Tips: A Quick Reference Guide for Communicating About Olmstead

Effective communication can build public support, motivate leaders to take action and change a debate. When speaking to the press, focus on giving a brief description of the problem, solution and action needed. Include the Who What Where Why When in your description.

Basic Tips:

STAY POSITIVE and talk about what people want from an improved system of care, not about what they don't want. Positive examples include *independence, financial security, choice, health and wellness*. It is especially important to avoid conflict-driven, blaming, crisis, sky-is-falling or overheated rhetoric.

DO use research-tested words and phrases. *Independent, dignity, choice, community, active and home* are words that resonate with the public, and effective phrases include *affordable options, a network of healthcare and supportive services, community networks and community support network*.

AVOID jargon, especially political, clinical and payment systems jargon.

STAY CRISP with short answers. Keep written talking points handy and speak from them. Do not speak extemporaneously or stray from the topic, except on background.

INCLUDE firsthand accounts, accurate facts and data, compelling messages, a local aspect, and good visuals that tell the story.

COMMUNICATE shared priorities and emphasize community values.

KEEP IN MIND that the majority of California voters age 40 and older are worried about not being able to afford long-term services and supports that they or a family member may need in the future. Ninety-five percent of these voters say that it is important to have affordable long-term services and supports available so that people can avoid going into nursing homes.

Tips for Interviews:

PREPARING:

- Practice answering potential interview questions by doing a mock interview with a classmate/friend beforehand
- Jot down notes/facts/talking points before interview, have them on hand
- Prepare and use a Question & Answer sheet to try to “head-off” any tough questions that may come up

DO'S AND DON'TS:

- Try to stay on your main point/message, don't ramble or stray off point
- Do not answer the question if you don't know the answer
- Provide short, crisp answers, if possible
- Go “on background” with reporter to further explain an issue. (On background is when the reporter is allowed to use the information you provide but are NOT supposed to quote/attribute it to you).

MESSAGING:

Avoid: *Overheated language*

- Avoid being negative or bringing up bad stereotypes, even if the interviewer brings them up first. It's OK to go back to your main message.
- Try to be clear and stay on point and use messages and phrases that would be easy for anyone to understand.

Do: *Know your audience*

- Try to talk about the improvements that people want instead of the things that people don't want.
- Focus on core values: Independence, choice, accessibility, health and wellness.

The New Communications Research:

Public Works: the DEMOS Center for the Public Sector has developed new research on communications that is thought-provoking and challenges some of the classic assumptions about what works. Public Works believes that underlying all communications is hidden reasoning that “triggers” powerful symbolic stories. When these stories, or master narratives, are triggered, it doesn’t matter what facts or figures are presented. People intuitively “complete” the stories and arrive at conclusions that are often counter to what you are trying to communicate. These are some of the findings of this research:

- Stories of the “Triumphant Individual” are often used to illustrate success in overcoming hardship and challenges. However, these stories focus on ideas of the “self-made man,” pulling oneself up by the bootstraps, and independence that does not create a sense that community responsibility underlies individual achievement. This research suggests more focus on ideas of a benevolent community that fosters interdependence and collectively values and takes care of all of its members, rather than stories of heroic individual achievement.
- Advocates frequently tell stories of Desperation (“the sky is falling”) rather than Aspiration (“the little engine that could.”) Crisis stories tend to reinforce the public’s belief that government can’t solve anything, and if that is true, the problem is hopeless and so “is not my responsibility.” This finding is a significant challenge. It strongly suggests that crisis communication and messages that undermine the public’s confidence in government, and our ability to solve things together as a community, hurt more than they help.
- Similarly, messages that suggest partisanship and partisan bickering, and messages that reinforce the bureaucratic aspects of government, undermine public confidence that government has anything to offer in solving community problems. The research suggests describing “public systems and structures” rather than “government,” and describing how these public systems work and why they are important to the community.

- Advocates often use “fairness” as a reference point, especially in discussing taxes. This research indicates that fairness is in the eye of the beholder, that Americans have a long and honored history of tax revolts, and that taxes are frequently viewed as a government “taking” (theft) of individual earnings. Fairness arguments trigger these complex narratives and should be avoided. Focus instead on goals and objectives, responsible management, balance, and how taxes are our tool for getting things done together.

Honing Your Communications Skills:

We are indebted to Paschal Roth Communications, The SCAN Foundation and Public Works: the DEMOS Center for the Public Sector for sharing these ideas along with their research and expertise. You can get more in-depth information and training about their communications work and research at our website www.CaliforniansforOlmstead.org under Communications Strategies.

Media Outreach Manual for Promoting Olmstead Implementation

Adapted with kind permission from work of the Central Coast Center for Independent Living and Paschal Roth Communications.

Introduction to Media Outreach

To be successful in implementing Olmstead and increasing home and community-based services, communicating with policy makers and the public through “earned media” is an essential strategy. Earned media refers to publicity outside the realm of paid advertising. It can motivate leaders to take action, and change a debate when important issues are not receiving attention. Earned media typically involves outreach to editorial boards, newsroom staff, assignment editors and journalists to submit or pitch news stories and story ideas. It includes mass media outlets such as radio, television, newspapers, the internet, blogs and social media and may include a variety of formats, such as news articles, TV news segments, letters to the editor, and editorials.

For advocates aiming to expand Olmstead implementation, news stories can get the word out about policy and program issues at both the state and local level that can lead to better understanding and increased support for community living options.

How Do I Reach Out to Media?

A good news story consists of a strong message told by a compelling messenger. To get the story out, there are generally three steps involved. The first is putting together a newsworthy event and inviting media to cover it. This typically includes drafting a news advisory and press release. News advisories include the date of your event, a contact person and phone number, a newsworthy headline, and two paragraphs giving the essential details about your story. It is often useful to include a list of who, what, when, and where at the bottom of your advisory. Advisories usually are written for events happening at a specific day and time, such as a news conference or a rally.

When planning your event, keep in mind the timing of the news cycle – morning events are likely to get more coverage than mid-afternoon events when reporters are headed toward deadline. In addition, consider the proximity of your event to media outlets, and visuals and signage that will help tell your story.

The next step in media outreach is directly contacting newsrooms and journalists to pitch story ideas. One of the best ways to do this is through a targeted search of a newspaper’s archives to find the journalist who covers the topic closest to your issue. You can also speak directly to the news editor to pitch a story idea.

Once contact has been made with the newsroom, the last step is to submit a press release. Press releases are similar to news advisories that are expanded to include additional information and quotes from key individuals. Press releases include a strong headline (or “hook”), easily digestible information with the who, what, when, where and why, recent facts and quotes that tell the story. Press releases are sent to newsrooms and reporters shortly after or a day after the event happens.

The key to generating media interest is having a compelling story and pitch. Every news story has its essential components; you want to incorporate as many of these components as you can into your pitch to make your story idea persuasive to reporters and editors.

Key Elements of a Good News Story

A good news story will have four key elements, outlined below. When approaching a reporter about a program or issue, making sure to have these organized ahead of time will help you get your message out.

- “Hook” - what is timely or urgent about this issue? Why is it important for the reporter to write the story NOW?
- Expert - Have a person lined up who can give data about the issue (how many people are affected? Who are they? Where are they?)
- Human Element - Have a person lined up who can share their personal experience around an issue, to show the program is more important than just numbers.
- Designated spokesperson - It’s always helpful to have someone that is familiar with your messaging and goals for the interview. Make sure this person is prepared with talking points ahead of time.

Some added pointers for drawing earned media attention to your issue include:

- Promote local programs and events - media outlets want to inform readers of what is going on in their community.
- Respond to what’s going on in the news - this will ensure your pitch to news outlets will be timely and relevant.
- Establish relationships—establishing relationships and connecting with journalists will help you get your message across and draw attention to your issue.

To develop an effective news hook, you need to incorporate some or all of these elements into your pitch to news outlets. These points provide a frame of reference and best practices for conducting media outreach.

Finding the “Hook”

Every news story needs to have a “hook” – a compelling reason for people to read or watch the news piece. News hooks can be human interest stories, important legislation that affects a large number of people, or new and interesting studies and

statistics. The hook should answer the question, “Why should I care about this?” or “Why is this important?” Usually, the hook illustrates the scope of an issue, provides readers with context, and tells us who is or potentially could be most affected. To develop a successful news story pitch or draft an effective news advisory, it’s essential to have a compelling news hook.

The uniqueness or significance of an event can be a strong news hook. If a conference you are hosting is the first of its kind, playing that aspect up can be useful in your pitch or news advisory. “News you can use” – stories that provide information readers might find relevant and useful – is another popular hook in news stories. Identifying your target audience can help you in developing your hook – are you trying to reach opinion leaders, the general public, or a specific region? The particular audience you are interested in reaching will help you develop your story’s focus.

A great way to develop a sense of what a strong news hook is to read news articles and consider what the main point of the story was and why the journalist thought it was of interest to readers. As you familiarize yourself more with journalists’ and reporters’ style and writing, you will develop a firmer grasp of what journalists find interesting and what will make a strong news pitch.

Choosing an Expert

Every news story contains at least one quote from an individual. Reporters always expect to talk to a source for quotes, and for stories involving technical subject matter; they will often look to experts to use as sources in their news stories. Journalists look to these experts to provide context, perspective and knowledge on an issue. Experts provide background information and make an issue more understandable to readers and viewers. Having a go-to person to field these questions can be useful for pitching news stories. Ideally this person will be the most well versed person on Olmstead and issues surrounding Olmstead, or the person most familiar with your messaging.

Journalists often look to experts to provide “hard data” such as statistics, numbers and overall trends. Keep in mind that not all statistics need to be negative. If an organization can provide statistics and background on positive outcomes about Olmstead implementation, that can be a strong selling point for a news story as well. In addition, one of the benefits of having an expert in your organization is that

journalists will often come back for comments on related stories. For example, if they have a story about legislation relating to Olmstead, they may contact an expert from a previous story for comment. This can then translate into added visibility for your organization or issue.

Designating a Spokesperson

The designated spokesperson can be an expert, a consumer with a disability, a staff member or others familiar with the issue. These designated speakers can benefit from media training and preparation before speaking to reporters. For those who are speaking to the media as experts on the subject of Olmstead, talking points can be a useful tool for communicating their points effectively and staying focused on messaging. Taking time to craft the right message that resonates with readers and highlights the important aspects of your organization is an important aspect of earned media.

That's why it's beneficial to have a designated spokesperson delivering that message. Who the appropriate spokesperson is depends upon what sort of story it is. For stories providing general information about institutionalization and Olmstead, the most knowledgeable person or the person most familiar with messaging might be appropriate. For consumer-focused stories, someone with a disability who has lived in an institution, or who is familiar with community-living services, might be a better spokesperson.

Designated spokespeople can also be those with a disability who are willing to share their personal stories. For human interest stories, talking points and preparation may not be as necessary, since these stories play up the personal aspects of a story. Providing talking points and over-preparation may dilute the human-interest aspect of the story. However, if there is added information that may be more technical in nature, yet still relevant to the story, talking points can be useful.

Emphasizing the Human Element

Stories that have a human element to them, also known as human-interest stories, are ones that tend to focus on a particular individual and discuss a personal experience. Human-interest stories are a great vehicle for Olmstead because people often know little about it and may miss the importance of the individuals who are

affected. Putting a human face on Olmstead implementation can humanize the story. It can also make what may be an abstract notion more relatable for readers.

However, personal stories can be difficult for people to share. It's important to be sensitive to consumers' feelings when soliciting people to share their stories. Some consumers may not want to be a spokesperson or tell their personal story. Make sure to obtain permission before pursuing a profile story.

When people are willing to speak about their personal experiences, these stories are often much more in-depth than a typical news story. They also create the most memorable impression among readers and can make a strong complement to hard statistics and numbers. While having statistics and numbers to illustrate a point (e.g. the increase in the number of individuals who are institutionalized), human-interest stories tend to leave a strong impression on readers than statistics. For a strong impact, add a quote from someone with a personal story to your press release, for example:

“As the first person with a disability in my community to receive a public education, I can personally attest to the importance family involvement has on educational success,” said Steven Tingus, public policy director of the California Foundation for Independent Living Centers, who has muscular dystrophy. “Without my parents fighting hard for my own education, I would likely be in a nursing home.”

Promoting Local Programs and Events

One of the more recent trends in journalism has been a shift in emphasis towards local, or community, journalism. This type of journalism aims to cover stories that are of interest to residents and better inform readers of news that is happening in their community. This trend works in favor of local grassroots organizations.

Generally speaking, readers and journalists are more receptive to positive local news stories, especially about events or programs that benefit local residents in some way. For example, outlining the programs and services that are provided by an Independent Living Center to people with disabilities living in the community can attract positive media attention.

Aside from news stories, you can also reach out to local newspapers for announcements, news briefs or calendar listings. The main selling point is that the stories are local and relevant to the community.

Responding to Current News

Another quick and easy way to get placed in the media is by commenting on or responding to news stories. This requires keeping up with Olmstead-themed stories. Carol Welsh of St. Jude's Brain Injury Network says, "Following the media is a big part of it *media outreach+... Generally you have to think about how you can get ahead *of the news+... part of it is luck, but a big part of it is also knowing what is going on out there in the community."

There are many ways to go about commenting on a story. One way is to directly call reporters about an Olmstead-related story and offer to get them in touch with an expert or consumer who can speak more on the subject. You can also submit statements by one of your organization's leaders providing comment on a relevant news story, such as Olmstead-related legislation being passed or a new study being published.

Letters to the editor are another opportunity to chime on Olmstead issues. They allow you to educate readers. In doing so, they can also allow writers to make plugs for your organization and your issue. Letters to the editor are generally short and to-the-point, usually no more than 200-250 words in length.

Establishing Relationships with the Media

Making good connections with the media is an important component of media outreach and is one the best ways to generate media interest in Olmstead.

Credibility means a lot when working with the media. Reporters often have a "stable" of go-to sources that they use for different issues. Building a strong rapport with a reporter, editor or TV news assignment planner can help immensely when you're holding an event or pitching a news story. Keep in mind when approaching journalists that you are helping to make their job easier.

The importance of relationship goes beyond the media and extends to forming relationships with other organizations within the region as well. For example, one organization, the Betty Clooney Foundation, receives more media requests than they have capacity for. As a result, they will occasionally refer media inquiries to other local agencies and organizations. Partnering with larger organizations that are more visible can be beneficial and forming a relationship with such organizations can become an opportunity to connect with journalists looking for an expert perspective on Olmstead and a chance to increase your own organization's credibility and profile.

Building a Press Kit

A professional press kit is the foundation of your media outreach strategy. It eliminates the necessity to state all facts verbally in an interview and increases the chances that your message will be conveyed accurately.

A press kit should be complete enough so that a reporter can take it and have all he or she needs to write the story. Press kits should include:

- Press Release
- Fact Sheet
- Fact Sheet about your organization
- Biographies of Key Persons
- Issue Brief (If pertinent)

These documents should be placed in a plain pocket folder. Attach a business card so a reporter may contact you. Press kits should be available at all times, even if there's not a current event or issue. You should have materials ready electronically in order to print them quickly, or to send to a reporter who makes an inquiry.

Messaging

Powerful messages are simple and to the point. Creating messages involves a brief description of the problem, the solution, and the action needed. Jargon complicates messaging and should be avoided.

In the past, messaging was often conflict driven, influenced by polling, was heavily partisan, concentrated on assigning blame and focused on a short-term horizon. However, new research by organizations such as The SCAN Foundation and Public Works: the DEMOS Center for the Public Sector has found that more effective messaging emphasizes shared priorities and values, good stewardship, bringing parties together, the agency of communities working together to solve problems, and a long-term horizon.

When developing messages, consider your audience, and talk about what seniors and people with disabilities want for an improved system of care, rather than focusing only on what they don't want. Emphasize core values such as *independence, financial security, choice, health and wellness*. Some messages have been research-validated as effective; consider using words and phrases such as *dignity, independent, choice, community, active, home, affordable options, community supports, community support network* and *network of health care and supportive services*. Avoid overheated rhetoric, political, clinical and payment systems jargon, and overly partisan messages (The SCAN Foundation, 2010). A message triangle (below) is a simple way to organize your message for any issue or event.

In addition, when developing your message, consumer participation should be discussed. It is very important to have strong consumer sources, and it is also important to plan to help everyone involved in the event be on the same page. It is crucial to provide consumers with the opportunity to understand and articulate the messages that will make the event a success and achieve its goals.

Media Tool: Developing a Message Triangle

The message triangle is a tool that can help in developing effective messages by breaking them down into supporting points based on facts. These facts support each of three main points that answer the question "Why?" and which together can be summed up in one concise central message that conveys: 1) the solution needed, 2) the action to achieve it, and 3) the broadly shared benefit or values.

The message triangle below was developed to communicate the importance and value of Olmstead implementation and community-living options. The first supporting point notes: *People with disabilities are young, old, parents, children – all vital members of our community. Our world is enriched when each person*

can participate in school, the workplace, and community life. Supporting point two is: *Providing services in institutional settings is far more costly to taxpayers. Nursing home care can cost six to eight times as much as community living options.* Supporting point three is: *Access to care in the community settings is the law of the land, affirmed by the Supreme Court in the Olmstead decision.* The central message is: *The freedom for each person to make their own choice about where and how to live is a fundamental part of the American dream. It's time for all of us to come together and hold our elected leaders accountable for making the policy and budgetary decisions necessary to make community living a reality for people with disabilities.* A blank message triangle template can be found in the Appendix..

Olmstead Message Triangle

Central Message:

The freedom for each person to make their own choice about where and how to live is a fundamental part of the American Dream. It's time for all of us to come together and hold our elected leaders accountable for making the policy and budgetary decisions necessary to make community living a reality for people with disabilities.

Supporting Point 2:
Providing services in institutional settings is far more costly to taxpayers. Nursing home care can cost six to eight times as much as community living options.

Supporting Point 1:
People with disabilities are young, old, parents, children – all vital members of our community. Our world is enriched when each person can participate in school, the workplace, and community life.

Supporting Point 3:
Access to care in community settings is the law of the land, affirmed by the Supreme Court in the Olmstead decision.

Tips on Being Interviewed

Even for experienced advocates, being interviewed by a journalist can be an intimidating experience. The best way to combat stage fright is to be thoroughly prepared, to have clear talking points and stick to them. Another strategy to reduce nervousness is to imagine that you are talking one-on-one with the reporter or host without thinking about the viewers or audience; try visualizing yourself as talking with a single individual who is interested in what you have to say.

Here are some specific tips to keep in mind when you are going to be interviewed by the press:

- Ask questions in advance about the format, who else will be on, who goes first, and how long you'll be on. Practice with a walk-through and mock interviews.
- Review talking points and have them on hand. Keep your answers crisp. Long or rambling answers are ineffective. Learn how to estimate time, and try to keep answers concise.
- Prepare and use a question and answer (Q&A) sheet developed in advance to anticipate hard-ball questions. (Your Q&A sheet is just for your reference; don't distribute).
- Prepare and use a fact sheet for specific data and statistics. Include the fact sheet in your press kit.
- Listen and wait before answering questions. Make sure you understand before you answer. If you need to think about your answer for a moment, do so. Control the interview by not letting an interviewer divert you from your talking points.
- Stay calm. Don't let an interviewer make you feel angry. Pause, think and stay on message with your talking points.
- Taped interviews will be edited. Long answers will be cut and pauses deleted, so take your time to think. Themes, however, will be destroyed, so make your points often. If you want to redo all or part of an answer for some reason, ask the interviewer to go back to a specific place; then give your corrected answer starting at the beginning – never in the middle – of a sentence.

- If you need to give further explanation than your talking points, go “on background” with a reporter to further explain an issue. This will keep lengthy explanations from displacing your main talking points in the story.
- If not sure, say so. Don’t try to give information if you don’t know the answer.

Avoiding Common Mistakes

There are a number of common mistakes that organizations make when trying to earn media, often resulting in poor outcomes. The biggest mistake is a lack of preparation. Making sure the right message gets out to the general public takes time and effort; it can’t be done on the fly. Your message and strategy have to be scrutinized and evaluated and prepared correctly in order to put on the right face for the media.

Avoid these missteps in order to get better outcomes from your media outreach:

- Assuming that “If you build it, they will come” – just because you announce an event doesn’t mean that the media will show up. There has to be a real handle.
- Assuming that getting the media there means your job is done - the most straightforward part of the job is getting the media there. It is important to prepare by creating a compelling message – and then articulating that message to the media at the event.
- Assuming that you can interview off the top of your head – unless you prepare, the message will likely not be conveyed as you intend.
- Assuming that the media have prepared for you – reporters, particularly if it’s an event, will not know who you are or what you do. You have to make sure they know the basics of who you are and the issues you are raising.
- Assuming that you will be quoted verbatim –reporters can miss things. To be successful, put facts on paper and add comment and flavor to those facts in the interview. If all information is given verbally is easy to be misquoted. Pertinent facts should be included in a fact sheet, and background information should be provided in written form. The more information you can give the reporter, the less chance they will have to rely on their notes, which might not be as thorough or accurate as you would like.

- Assuming the reporter knows a great deal about the topic – frequently, a reporter may have received the assignment just that day and may not be knowledgeable about disability issues. Disability issues are complex, so it is imperative to start by explaining the basics and work from there.
- Assuming that reporters know where you want to go with a story – reporters have their own agendas. You have to lead them through the story. Be sure to ask if they have further questions or need more information, and be sure to follow up with any information a reporter requests.

Conclusion

Advocates can successfully conduct outreach and “earn” free media coverage for essential issues around Olmstead and community living for seniors and people with disabilities. At its most basic, effective outreach consists of generating a story with a strong message, told by a compelling messenger. Advocates can achieve this by finding a good headline or “hook,” choosing an expert with care, emphasizing the human element and designating an effective spokesperson. To generate interest in their story, they can promote local programs and events, respond to current news and establish relationships with journalists and editors. Building a press kit, developing strong messages with a message triangle, planning and preparing to be interviewed, and avoiding common media missteps will strengthen media efforts. All of these strategies can be productively put into effect to outreach to the media, and ultimately to opinion leaders, policy makers and the public, to promote Olmstead implementation and increase community living options at the national, state and local levels.

Appendix

Sample News Advisory

FOR IMMEDIATE RELEASE

June 29, 2010

Contact: Mike Roth, (916) 444-7170

With Growing Need for Services for Returning Vets, Central Coast Hosts Traumatic Brain Injury Conference in Salinas

Joined by CA Deputy Secretary of Veterans Affairs, Group Unveils Mobile Veterans Outreach Clinic to service the Region

Salinas, CA – As part of a new effort to assist those living with Traumatic Brain Injury (TBI), TBI survivors, families, experts and care providers will gather Tuesday for the Central Coast Center for Independent Living’s conference, “Traumatic Brain Injury Awareness: Connecting Needs and Services.” The day-long event is part of a new effort to reach out to veterans with TBI, and aims to raise awareness of TBI, educate residents on what services are available locally to those with TBI, and introduce the Mobile Veterans Outreach Clinic to attendees.

The event, which will take place at the Northminster Presbyterian Church Conference Center, will introduce participants to the new Mobile Veterans Outreach Clinic which will service region.

As one of 50 mobile vet centers across the country, it will provide readjustment counseling and information resources to veterans with TBI, and help them make the difficult transition between military and civilian life, or for active duty personnel, the transition from a combat zone to a peace time garrison environment.

What: Day-long TBI awareness conference and Mobile Veterans Outreach Clinic showing

Who: TBI care providers and consumers, speakers include Puntillo, Deputy Secretary of Veterans Services of the California Department of Veterans Affairs and Dr. Harriet Zeiner, lead clinical neuropsychologist for the polytrauma center at the Palo Alto Veteran Affairs hospital.

When: Tuesday, June 29, 8:30 a.m. to 4 p.m. Press conference and Mobile Veterans Outreach Clinic viewing from 10:30-11:15 a.m.

Where: Northminster Presbyterian Church Conference Center,
315 East Alvin Drive, Salinas

Visual: Mobile Veterans Outreach Clinic unveiling. Open to viewing by the media from 10:30-11:15 a.m.

Sample Press Release

FOR IMMEDIATE RELEASE

November 18, 2002

Contact: Teresa Favuzzi, 916-444-7280

CFILC PROTESTS CLOSING OF RANCHO LOS AMIGOS

Advocates urge Board of Supervisors to consider impact of rehabilitation hospital's closure on people with disabilities

LOS ANGELES – The California Foundation for Independent Living Centers (CFILC) will join member Independent Living Centers from across Southern California, other disability advocates and union members from SEIU 660 today from 11:30 a.m. to 1 p.m. at Rancho Los Amigos National Rehabilitation Center for a rally to express their dismay over the Los Angeles County Board of Supervisors' proposal to close the nationally-recognized rehabilitation center. Advocates also plan to attend the Board of Supervisor meeting on Nov. 19 to issue statements during public comment on the issue.

The rally will take place today from 11:30 a.m. to 1 p.m. at Rancho Los Amigos (7601 E. Imperial Hwy, Downey, CA 90242), while a large turnout is expected for Tuesday's Board of Supervisors meeting at 500 West Temple Street, LA 90012, room 383.

On Oct. 29, the Los Angeles County Board of Supervisors, in a 4-1 decision, decided to begin the process of closing the down Rancho Los Amigos, the only hospital of its kind in Southern California providing treatment of disabling conditions. Supervisor Don Knabe was the lone dissenting vote. The decision has stunned and outraged the disability community, many of whom live independently in the community because of Rancho Los Amigos.

"For many people with disabilities, closing Rancho Los Amigos would be disastrous," said Knabe. "This so-called cost-cutting decision is not worth the independence and lives that will be put at risk."

CFILC joins many of its member Independent Living Centers in Southern California to take action, including:

- ILC of Kern County (Bakersfield)

- Independent Living Center of San Gabriel/Pomona Valley (Claremont)
- Southern California Rehabilitation Services (Downey)
- Communities Actively Living Independent and Free (Central Los Angeles)
- California Rehabilitation Services (East Los Angeles)
- Westside Center for Independent Living (West Los Angeles)
- Dayle McIntosh Center (Garden Grove)
- Disabled Resource Center (Long Beach)
- Community Access Center (Riverside)
- Rolling Start (San Bernardino)
- Independent Living Center of Southern California (Van Nuys)

Rancho Los Amigos has provided quality care for persons with physical disabilities for more than 50 years. In the 1950s, Rancho made its transition to rehabilitative care with the waning of the polio epidemic, refocusing the team treatment approach developed to address polio on the rehabilitation of persons with disabling injury and illness. Rancho Los Amigos is internationally renowned in the field of medical rehabilitation, consistently ranked in the top 10 rehabilitation hospitals in the United States by U.S. News and World Report. It is one of the largest comprehensive rehabilitation centers in the United States.

Rancho Los Amigos admits spinal cord, brain injury, or other patients from all Los Angeles County trauma hospitals as they become stable enough to be moved from trauma hospitals. From there, Rancho Los Amigos provides quality rehabilitation services for these recently disabled individuals, along with other people with disabilities, allowing them to learn independent living skills to survive in the community.

The closure of Rancho Los Amigos could have a dramatic impact to people with disabilities. Without Rancho Los Amigos, the risk of people with disabilities being forced into nursing home increases. This would make California's plan to implement the Supreme Court Olmstead decision, which stated that people should live in the most integrated setting possible.

Sample Statement

FOR IMMEDIATE RELEASE

November 2, 2010

Federal Government Approves Sweeping Changes to Improve California's Health Care Safety Net

SACRAMENTO, CA – The Service Employees International Union (SEIU) California released the following statement from President Bill A. Lloyd today on news that the federal Department of Health and Human Services has approved sweeping changes that will strengthen California's health care safety net:

"Today's decision is great news for all Californians who count on public hospitals and emergency rooms to be open when they need care. The federal government's approval of our state's waiver application means additional dollars for public hospitals that have struggled to provide health services to all Californians who need care, and builds the funding bridge California needed to implement of federal health care reform.

"The bipartisan coalition that came together to support these changes can be proud that we have strengthened our health care safety net by expanding Medi-Cal, bringing additional dollars to California, and creating a more effective, coordinated system of care for seniors and people with disabilities while reducing costs.

"This victory was only possible because a broad coalition of public and private hospitals, health care advocates, our Congressional delegation, Governor Schwarzenegger, SEIU, and the Obama Administration came together with the goal of improving health care for Californians. Working together, we put California at the forefront of implementing the national health care reform, and that means better health care for all Californians."

Message Triangle

Central Message:

Supporting Point 1:

Fact 1: _____

Fact 2: _____

Fact 3: _____

Supporting Point 2:

Fact 1: _____

Fact 2: _____

Fact 3: _____

Supporting Point 3:

Fact 1: _____

Fact 2: _____

Fact 3: _____

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*A Project of the California Foundation for Independent Living Centers
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