



**PARENTS COORDINATING COUNCIL
AT LANTERMAN DEVELOPMENTAL CENTER**

FEBRUARY -- MARCH 2012

CONTACT

THE NEWSLETTER FOR PARENTS AND FRIENDS

Important Reminder: The PCC Office is staffed by dedicated volunteer family members who donate their time to support the Lanterman families. These volunteers take care of the many organizational and office duties, ranging from sending out the Newsletter to running the fundraiser, to responding to individual family needs and many more activities. The PCC Office is open most but not all days, and may be reached by phone (909-444-7572), fax (909-444-2047), email (ldcpcc@gmail.com), or U.S. Mail: P.O. Box 4408, Diamond Bar, CA 91765.

LANTERMAN DEVELOPMENTAL CENTER POPULATION AS OF JANUARY 25, 2012 — 294

Parents Coordinating Council Meeting

**When: Saturday — March 10, 2012
Start Time — 10:00 a.m.**

**Where: Lanterman Developmental Center
3530 Pomona Boulevard
George DeBell Auditorium**

3 Important Reasons to Attend this Meeting

1. This meeting will focus on how **YOU** can be an effective communicator to your legislator and others who make decisions that affect **YOUR** relative. **YOU** can do this by meeting with your local legislators, writing letters to budget committees, and giving testimony on these issues. Don't miss this opportunity to learn how to become a better advocate!
2. Lanterman Administration will give an update on campus activities – Learn what is going on in your Program – including any consolidation and staffing issues. How are provider visits being handled? How is the campus infrastructure holding up? What recreational activities are available for residents? We have also asked for an update on the issue of the Office of Protective Services and any abuse investigations on campus.
3. We will discuss an important upcoming meeting, where we will ask Regional Centers who are involved with the Lanterman closure to give a presentation to the Lanterman families on the following:
 - **Clients who have left Lanterman** – how are they doing? what types of settings have they been placed in? what other services are they receiving? what are the problems? how are the day programs, health services, dental care, transportation, recreational services, neighbor relations, funding, staffing, training, monitoring??????

- **Lanterman clients who will move in the future** – what is being planned for them? what services are coming on line? when? where are these services? who will be staffing these homes/programs? how is the funding? how are the neighbors? what is the feedback? what can we do to help??????

We would appreciate feedback from YOU on what we should all know about the former and current Lanterman clients so we can work with RCs to make this meeting as informative as possible. (This meeting will be held on Saturday, April 21, 2012).

After the LDC Administration Presentation, the meeting will be for Lanterman Families Only!

Attend PCC Meetings by Phone

If you are not able to attend the PCC meetings in person, but are interested in the topics being presented, please contact the PCC office and we will give you directions to be connected to a teleconference line set up for the meeting. You will be able to listen to the speakers and the presentation from your home. You can contact the PCC office at 909-444-7572, or by email at ldcpcc@gmail.com and we will send you the toll-free number and instructions. Make sure you **contact us at the latest by Thursday, March 8** so we can get back to you in good time for the **Saturday March 10 meeting.**

Co-President's Message – Terry DeBell – Dorothy Juarez Fulco

The past few days we have heard and seen some very disturbing newspaper, radio, and television stories that have focused on some abuses and deaths at the California Developmental Centers and their investigations, including a story related by a family member who describes the tragic and heartrending loss of his brother several years ago. The stories have centered on the Office of Protective Services, located at each DC and mandated to investigate all abuse reports. At this point in time, we do not have much information beyond the original story, but it is most likely that there will be legislative hearings on the systems of protections for DC clients. All work in this area MUST lead to improved protections for our residents, and accountability for anyone involved in any abuse. We hope that any actions taken to examine protections for individuals with developmental disabilities include a review of what safeguards are available in ALL settings, including community placements, family homes, and Developmental Centers.

Legislative Committee Report

ATTEND THE MARCH 10, 2012 PCC MEETING WHERE YOU WILL BE GIVEN THE TOOLS TO MAKE YOUR LETTERS TO LEGISLATORS AND MEETINGS WITH THEIR STAFF IMPACTFUL!

At the PCC meeting on March 10, 2012, the Legislative Committee will be discussing the ABC's of letter writing and ways to make your legislative appointment an educational experience for all.

The Budget Subcommittee Hearing on Health and Human Services is scheduled for Wednesday March 28, 2012. We are looking for individuals who would like to attend and testify at the hearing. Those interested must attend a meeting that is set to take place after the March 10th general meeting.

Please let the PCC office know if you are interested in testifying so that important information can be given to you about the hearing. You can contact the PCC office at 909-444-7572, or by email at ldcpcc@gmail.com

Do You Know Who Represents YOU in Sacramento???

Go to the "Blue Government Pages" in your phone directory! Call your County Registrar of Voters and ask them to provide you with complete contact information for your representatives! Check online at to www.congress.org. Call us and we will help you! Information and tips on writing your legislator on important issues regarding Lanterman and its residents will be sent out after the next PCC meeting. Get ready now by finding out who your legislators are and how to contact them!

State Staff in the Community & the IPP

By Norman J. Fulco, IPP Committee Chair

In most of my emails these past weeks, I've used the words, Big Trouble when referring to reoccurring problems with the Lanterman closure, like State staff working in the community. Yes, those of us wanting LDC staff to follow our relative into the community were led to believe that the program would be just like the Agnews Plan. Well, it wasn't.

Briefly, here's the difference between the two Plans and their accompanying legislation. Agnews had AB 1378 calling for no one to leave Agnews without State staff going with them. Lanterman eventually got SB 853, which created Sections 4474.2 and 4474.3 where both Agnews and Lanterman movers are eligible to have Community State Staff (CSS) become part of the providers rotating staff for two years after the last resident leaves Lanterman. You must read both Bills and the mentioned Sections to get full understanding of the differences. But, to make it simple, Lanterman did not get AB 1378. As we all know, there is no CSS working within the Lanterman Closure. Of the 88 people having already left LDC, only one went to an ARFPSHN in San Jose where three CSS are said to be in rotation. So, CSS for LDC movers will not happen anytime soon, maybe never.

Those of us who are familiar with DDS's Manual on Person-Centered Planning and Sections 4646 and 4646.5 which are the guidelines for IPPs in the community, know that the Objectives within the IPP becomes the basis for funding. In other words, the IPP drives the system's budget. After reading all of DDS's literature, including the Manual, it becomes quite clear that services not listed in the Objectives of the IPP, you can't expect to get them or have the Regional Center pay for it. Per 4646 and 4646.5, the IPP is an agreement between the consumer or conservator and the Regional Center. Sometimes the agreement is really a negotiation between the two parties. Each Regional Center may have their own style for the process; however, families need to know how it is done and how to use their empowerment under the mentioned statutes. Providers such as housing and doctors act as advisors or consultants to the consumer/conservator. Regional Centers will have their own consultants who might challenge any or all aspects of the IPP. If a challenge is raised, a Fair Hearing or lawsuit usually follows. This could mean "Big Trouble" for former DC families not prepared with competent legal council.

Many LDC families have written Preferred Futures for their relatives, which may, or may not, be accepted as Objectives in the IPP. I suggest all of us meet with our Regional Centers and resolve the issue prior to placement. A good example is CSS personnel needed to cope with behavior or nursing concerns. Funding for CSS requires a big chunk of money and Regional Centers may be reluctant to see the need, in which case, you're in "Big Trouble" unless you have a very competent attorney on hand.

In the past, I have recommended that attorneys are not necessary for IPPs. I didn't want the process to become just about the attorneys. However, with the current fiasco going on with the Lanterman Closure Plan not coming close to the Agnews Plan, and massive confusion prevailing about Transition Planning (IPP) and no CSS, a good attorney with plenty of experience dealing with the IPP and Regional Centers will be necessary for at least the first two IPPs during and after transition.

Monitoring and Oversight for Lanterman Residents in a Community Placement

How often are visits made to Lanterman residents who have moved to a community placement? Who is responsible for checking to make sure that they are doing well in their new home? How often are the homes visited by an outside agency, and who is responsible for monitoring the home itself? California regulations include a certain number and type of visit for all placements, but under the Lanterman Closure Plan, there are required extra visits by different agencies to monitor all placements.

The Regional Project staff may be the first to visit the resident in their home. Their monitoring begins on the 5th day of the placement, when the Regional Project, who has worked with the resident, Lanterman staff, and the community staff throughout the entire transition process, makes a call or a visit. At a minimum, the Regional Project returns to see the resident once a month for the first 3 months, then again at 6 months and also at one year. The Regional Project will make additional visits as necessary, depending on the needs of the resident. Since there is often more than one Lanterman resident in a home, the Regional Project may actually see each resident more frequently, as they keep this schedule for each resident.

The Regional Center Service Coordinator visits Lanterman movers in the first, second, and third months, and again at 6, 9, and 12 months. Some of these visits must be unannounced. After the first year, they will visit every 3 months. Regional Center Quality Assurance will review twice a year. For the Adult Residential Facilities for Persons with Special Health Care Needs (ARFPSHN) homes, the Regional Center RN will visit each resident once a month, with at least 4 of these visits being unannounced.

The actual homes are monitored to see if they are in compliance with all the requirements necessary to care for their residents. Regional Centers visit for this purpose twice a year. For ARFPSHN homes, the Department of Developmental Services also visits twice a year. The Department of Social Services checks the home yearly. Day Programs are visited by Regional Centers each year, along with the Day Program accrediting agency, CARF.

The residents and their homes are also monitored through other oversight activities – such as the audit that Regional Centers conduct yearly on each provider, and the annual review of the Client Development and Evaluation Report.

An important oversight activity can be done by YOU! These are the Snap Shots for the Home and for the Day Program, which are short forms available in each setting for family members to give feedback to Regional Centers about residential settings and day programs (NOT for emergency situations!).

Lanterman Family Member Visits the Community

By Jimmy Smith, Board Member

I just left a dental clinic here in the San Diego area. This clinic was identified by a provider in the area! I am very pleased to report this clinic meets all my requirements for my sisters' dental needs and the Doctor is very familiar with dealing with retarded patients. He was also quite shocked to hear of the closure of LDC. His knowledge of state decisions, insurance issues and the current money woes are invaluable!

And yet on another note...last year, I went to visit 2 community homes in the San Fernando Valley and came away with mixed feelings. One of the homes had clients and I certainly felt the staffing was not properly trained to deal with mixed personalities and behaviors. I say this because at the time of our visit one older man was not happy sitting in his chair and the staff was attempting to make him happy when all he wanted was to be left alone...it was, although, a very clean and lovely environment. This home was owned by a number of people (I think 6 in total) all on title as tenants in common.

The second home was only occupied by one older man at the time of my visit. He was celebrating his birthday and was joined by his sister. He was completely void of any ability to make words however his grunts showed me he was in fact happy with his sister's visit...unfortunately there was a caregiver rubbing on his back and asking the man to tell me "how happy he was living at this home!" There was also some serious remodeling done in the bathroom...in other words one of the clients had destroyed it completely....broke all the mirrors, ripped off the towel racks and broke the shower doors. He was not there at the time of my visit however I was pretty concerned about the mix of residents because, as I say the Birthday boy was very dependent on constant care! And there would be no way my sister would have fit in. This property was titled under Easter Seals and in fact there was one room that appeared to be an office for this non profit organization. I hope this information is in some way helpful to any and all.

Not In My Back Yard! -- NIMBY

Not In My Back Yard! This phrase is usually used to describe homeowners who object to some project that may be coming to their neighborhood. It could be a trash facility, a public school, a shopping mall, and it could also be a community home where our family members and others will be residing after leaving Lanterman.

One of the reasons often given for objecting to neighborhood community homes caring for people with disabilities is a perception that such homes will cause a drop in property values for the entire neighborhood. NOT TRUE! In fact, studies show that property values in neighborhoods with group homes increase and decrease at the same rates as those neighborhoods without group homes.

Another reason often given to protest group homes is the idea that the homes are really businesses and therefore should not be in a residential neighborhood. NOT TRUE! In fact, group homes are defined by

law as Single Family Homes, just like the other homes in the neighborhood. State and Federal law absolutely support group homes in neighborhoods.

NIMBY can start to be addressed by educating everyone about the rights of our residents in community placement homes in all neighborhoods.

LantermanPCC.org

Have you visited the website of the Parents Coordinating Council lately? We frequently update the website to include new information, including the **Provider Profiles** that are submitted by providers who will be caring for Lanterman residents. If you have visited a community home, you may find additional information about the provider on the website.

Check the **Resources** section to learn more about monitoring in the community, how to transfer to another Regional Center, how to appeal decisions made about your relative if you do not agree with them, and exactly what a “962” home is. Read about **Life After Lanterman** in some letters about former Lanterman residents now living in the community, sent to us by their families. There is more valuable information available on the website, and we are always working to improve it. So come visit us at lantermanpcc.org!

Message from Cheryl Bright, Lanterman Administration

LDC Tip Line -- Our Lanterman community is a strong one, and as we continue to move forward with closure activities, we continue to face challenges that strengthen our very core.

We are always looking for ways to improve, and recently we have initiated a new hot line that will provide a venue for anyone to share concerns or to report information that warrant Executive follow-up. Messages may be left on an anonymous basis, in order to foster freedom to report.

The hot line was activated as of Thursday, February 16, 2012. This service may be accessed from within the Lanterman Community, as well as from outside the Center.

This line is not intended to replace our current Exec Alert System or 888 Line for client related incidents, but is being provided to add another avenue for reporting concern.

The Tip Line will be reviewed during business hours, Monday through Friday, 8:00 a.m. – 4:30 p.m., so it will be important to continue to **use the 24-hour line via the operator for any emergency situation.**

The Tip Line number is **(909) 444-7349**. The answering machine is up and running and will be accessible 24 hours a day, seven days a week.

Rustic Camp Animals

Lanterman’s Rustic Camp is home to two horses, two goats, three geese, three ducks, three chickens and a partridge in a pear tree! All of these animals will need new homes sometime soon (with the exception of the partridge which became a gift to someone’s true love in December.) These animals can move to another Developmental Center, certainly, but if you have any other suggestions, please contact the Lanterman Administration with your recommendation.

**Parents Coordinating Council & Friends
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Diamond Bar, CA 91765
(909) 444-7572
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www.lantermanpcc.org**

The PCC welcomes interested residents, families and Lanterman staff to attend all meetings. Contact the PCC office for information on meeting dates and times.

The Contact, PCC Post, and the Website -- The Parents Coordinating Council communicates regularly with all Lanterman families and others who have shared their contact information with us, regardless of whether or not they are PCC members. We honor the privacy of all families and do not share any contact information given to us. The Communication Committee greatly appreciates everyone who helps us with the following methods we use to distribute information:

The PCC POST is a one-page emailed update sent out on most Fridays that gives condensed information on what has happened in the past week and what is coming up. This format allows us to get information out on a regular (and inexpensive) basis without waiting for the Contact to be published. People who do not have email or who do not get the **PCC POST** by email receive the past issues with their mailed **Contact**.

The Contact newsletter is mailed every 4 to 6 weeks. It contains articles and information on prior and upcoming meetings, important issues facing Lanterman, and updates on resident activities. It is designed to help family members who may not be able to visit Lanterman or attend meetings regularly keep in touch with what is going on.

www.lantermanpcc.org is our website address, where past issues of the Contact and the PCC POST may be found, along with meeting minutes, family resources, important links, newspaper articles, etc.

Parents Coordinating Council & Friends at Lanterman Developmental Center

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Co-President	Dorothy Juarez Fulco
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**The PCC is a 501 (c) 3 non-profit organization. Financial statements are provided upon request.
The PCC newsletter is meant to educate families. All articles herein are the opinion of the authors.**