

**Assembly Committee on Human Services  
Jim Beall, Jr., Chair  
Assembly Select Committee on Disabilities  
Wesley Chesbro, Chair**

**Joint Oversight Hearing  
Final Report on the Closure of Agnews Developmental Center:  
Keeping the Promise of the Lanterman Act  
April 27, 2010**

**Testimony of Joanie Pepper**

Good afternoon Chairman Beall, Chairman Chesbro, and Members.

Thank you for this opportunity to speak to you today from a parent's perspective about the move of a loved one from a Developmental Center into a home in the community.

My story began on March 30th, 1958 when my son Brucie Rosenfeld was born. I lived in Japan at the time and, unfortunately, due to a difficult birth he entered the world with brain damage. This resulted in him developing a serious seizure disorder and equally serious learning disabilities. He lived at home for thirteen years before entering the Stockton Developmental Center where he resided until he was twenty years old. We were finally successful in having him moved to Agnews which was close to our home. Brucie was an Agnews resident for thirty years, and in that time he received excellent care and our family could sleep well at night knowing that he was in loving and capable hands.

When the Agnews families realized that the rumor of a closure was a reality we were, of course, very concerned about what the future would hold. A major portion of these worries centered around medical care. For many years we have had an active family group at Agnews known as AMRA. When the closure became inevitable, the parent group banded together to become advocates for our loved ones.

A great deal of thought went into the closure plan for Agnews, resulting in the passage of several important pieces of legislation. This created a plan unlike any previous closure of a Developmental Center and should serve as a model for the rest of California, and perhaps for the nation. We now have the 962 homes for the medically fragile, the SRH homes for the behaviorally challenged, Family Teaching Models, AB2100, to establish houses that would be the clients' homes in perpetuity, and AB 1378 providing state employees the ability to work in these residences and maintain their state salaries and benefits. In addition, there was a Quality Management System put in place by DDS to oversee the care of our loved ones after they left Agnews and were situated in the community. I feel fortunate to be a member of this Commission. And, very importantly, careful planning has gone into the transition of the medical and dental care.

In anything we endeavor in life I think it's important to keep our sense of humor. A few weeks ago I attended one of the QMS quarterly meetings and one of the Commissioners told us a little story that made us all chuckle. She went to visit one of the new homes and she spoke to a former Agnews resident who had been known to have a problem with frequent cursing. She asked the client if she was happy in her new house, and the lady replied, "Yes, I like my home. I don't curse anymore, damn it!"

But, back to my story. I honestly feel confident in saying that our parent advocacy played an important role in the successful passage of this important legislation. With the leadership of Brian Boxall and Steve Johnson, dozens of parents bombarded Sacramento with hundreds of phone calls, e-mails, and faxes supporting this new legislation, and in addition many parents appeared numerous times before the legislators in Sacramento to voice their desire to see these bills passed.

The actual transition of clients into their new homes was well thought out, and it went very smoothly. The closure plan enabled families to choose a home close to where they live. A great deal of credit must go to DDS and to the San Andreas Regional Center, who helped immeasurably. Prior to the actual move, the family attended a CLO meeting at which the needs and services for the client were addressed. The client had the opportunity to go to his or her new home for lunch and dinner visits and for a sleep over before actually moving in.

Since mid October of 2007, Brucie has been living in a lovely 962 home in Morgan Hill, less than a half hour from our house. About 50% of the staff are former Agnews employees and the other 50% come from the community. They are extremely caring and loving people. I feel as if they are part of my family.

Brucie was very happy during his first visits and has made a wonderful adjustment to his new environment. I had been concerned that when he lived in the community he would feel isolated compared to having so many people around him at Agnews. Was I ever wrong! He has an in-home day program, which includes many weekly field trips that he greatly enjoys. I would estimate that in these past two and a half years he has gone out at least 325 times. He has been to movies, shopping malls, a model airplane club, church, parks, museums, restaurants, the light rail, ice skating shows, parades, bowling, and the list goes on. I think that he and his housemates go to more places in a month than many of us in this room. He even went swimming for the first time in 30 years and is now enjoying trips to the pool at least once a month. Recently, as he was floating around I asked him how he liked it, and he looked up with a big grin and said, "Wonderful".

There are weekly visits from a dietitian, an occupational, physical, and recreational therapist. His house mates were on his unit at Agnews and are therefore familiar faces. The staff is able to give Brucie and the other four residents a great deal of one-on-one attention. He is also enjoying delicious home cooked meals. Brucie, his roommates and the staff are truly a family. I had the pleasure of being able to decorate Brucie's room with the things that I know have special meaning to him. Our Regional Center case

worker has been very attentive to our needs, questions and requests. We continue to have our IPP Meetings which take place in his home.

When Brucie was young, he could walk, talk, ride a bicycle, etc. But, about 14 years ago he had broken a bone and during his recovery he aspirated food into his lungs and was in intensive care for 10 days. The doctors didn't think that he would survive. He came out of the incident unable to walk, talk, use the bathroom or feed himself. Then, in October of last year, a miracle happened. The neurologist who serves Morgan Hill clients has turned out to be an unbelievable asset. I had been taking Brucie to Stanford, but I heard such wonderful things about the Morgan Hill doctor that I decided to meet him and see what he might suggest. Well, it truly was as if he waved a magic wand over Brucie. He made some changes in his meds and within two weeks I received a call from the staff asking us to come over as soon as we could because Brucie was doing all sorts of things he had never done before. We rushed over and saw a brand new guy. He was pushing his own wheelchair, which he had never done before, he was feeding himself, he could shred paper, throw and catch a ball, and, wonder of all wonders, he was talking again! We now have a speech therapist contracted by the Regional Center. She is just marvelous and Brucie has been saying the most amazing things. Although not all of the words are spoken clearly, many are quite understandable.

The other day his House Manager was sending me an e-mail and she asked Brucie if he wanted to say something to me. He replied, "Tell my mom that I love her big as the wide world". Because he can now feed himself he has recently gained some weight. The dietician said, "Maybe Brucie should go on a diet", to which he replied, "That's crazy!" Now when I visit I get hard hugs and juicy kisses. When we went to see "Disney on Ice" recently, he kept looking at me and saying, "Thank you" and "I can't believe it." He is saying intelligent things with no prompting and most importantly, he is enjoying life. His language skills are like many a young child, but to me it's as if he has been awarded a PHD. My visits to him are so delightful. He has blossomed and so have his housemates. It is wonderful to see and experience what can happen in a well run home that is served by a caring provider.

Medical care is provided by the Santa Clara Family Health Plan. They have contracted with a doctor in Morgan Hill as well as a neurologist. There is a hospital nearby and recently an Urgent Care Center has opened as well. And, in addition, medical care is also provided by an outpatient clinic that is still operating at Agnews. A dental surgical center has opened in San Jose that is providing care to the residents. Brucie had a very successful treatment at this facility.

Earlier I said that I could sleep well at night when Brucie was at Agnews. Now that he is in his beautiful home I am sleeping even better. He has really become a part of the community. I have learned a lot through this experience. I have learned that a small group of individuals--in this case, parents--can play a significant role in helping to create a new kind of community for their disabled family member. I have learned that sometimes when we fear change, that change can surprise you by creating a situation that is better--better than you ever imagined. I have learned that being a parent of a special

needs child has made me a stronger person. I have found strengths I never knew I had and I have seen first hand what determination and incentive can accomplish. Having our children in the community is obviously a whole new ball game and there will be a learning curve as we move forward. But, hopefully, with all of the professional oversight and diligent parental involvement, our children will flourish in the community.

The thought that went into the Agnews closure plan was an exercise in humanity, and as we all know, the more we exercise the healthier and stronger we become. I would trust that the lessons learned in the Agnews closure will result in an even smoother transition for any clients who may be leaving a DC in the future. Hopefully, they too will be able to experience a successful outcome.

Thank you for listening to my story. And thank you to DDS, the Regional Centers, the legislators and all the hard working wonderful people who helped make the closure of Agnews such a success.