

November 10, 2009

Board of Directors
Alta California Regional Center
2135 Butano Drive
Sacramento, CA 95825

Dear Board of Directors:

Families for Early Autism Treatment (FEAT) is a non-profit organization of parents, educators and other professionals dedicated to providing best outcome education, advocacy and support for the Northern California Autism Community. We have been the trusted voice for thousands of families since 1994 when, in partnership with Alta California Regional Center (ACRC), effective autism treatment programs became the standard of service.

FEAT has learned that Alta has informed some social skills training providers that their programs will no longer be funded or utilized. FEAT estimates at minimum 100 consumers will be affected. This group of consumers includes children, adolescents and adults. Families of children as well as adult consumers are currently being notified by ACRC that their social skills training/socialization programs which fall under vendor code 028 will be discontinued because the trailer bill amendments (ABx4.9 Chapter 9 Statutes of 2009) prohibit the regional center from purchasing services that "...Have not been clinically determined or scientifically proven to be effective..." This is a misrepresentation of the programs in question, and is based on an erroneous interpretation of the intent of the trailer bill language.

This categorical decision to cut a service as well as discontinue the utilization of the 028 providers fails to follow Lanterman Act guidelines mandating that the individual's needs shall be considered by the IPP team when decisions for services and supports are made. This unilateral decision is being presented to consumers with no effective alternative service being offered. Furthermore, after lengthy litigation to restore these services, the providers of these programs may no longer exist within the regional center system, which will leave the consumer with NO OPTIONS.

The first criterion in the DSM-4-TR for a diagnosis of an autism spectrum disorder (ASD) is “qualitative impairment in social interaction”. Countless studies support the need for social skills training for persons with ASD as improving this deficit is critical to the successful progress for these consumers. A fundamental tenet of the Lanterman Act is that consumers remain in the family home where the Legislature “finds and declares that children with developmental disabilities most often have greater opportunities for educational and social growth.”¹ Also woven throughout the Lanterman Act and clearly stated in the Welfare and Institutions Code is language that supports the inclusion of developmentally disabled persons in their communities among the non-disabled, in social opportunities as well as employment. *SEC. 9. Section 4571 is added to the Welfare and Institutions Code, to read:*

4571. (a) It is the intent of the Legislature to ensure the well-being of consumers, taking into account their informed and expressed choices... (3) Include outcome-based measures such as health, safety, well-being, relationships, interactions with people who do not have a disability...employment, quality of life, integration, choice, service. “ Without social skills training, consumers with autistic spectrum disorders have no chance to achieve these goals. In addition, social skills are a prerequisite for personal safety skills.

There are many consumers for whom the 028 social skills training/socialization programs are their only intervention provided by the regional center. This is not a duplication of any skills training either provided or required to be provided by public education. Rather, they are focused programs with individualized participant goals, taught by experienced staff in a group setting with participants matched for a variety of factors to address their unique needs. These are the very challenging skills needed for these consumers to function successfully in the dynamic real world into which it is the stated intent of the Lanterman Act that they remain and thrive.

FEAT has led the call for the use of individualized evidence based services. The social skills training/socialization programs that have been discontinued meet the intent of the language in the amended Lanterman Act because they do collect data and interpret and integrate this information into the treatment plan for the individual client. The trailer bill language states that “(3) ‘Evidence-based practice’ means a decisionmaking process which integrates the best available scientifically rigorous research, clinical expertise, and individual’s characteristics. Evidence-based practice is an approach to treatment rather than a specific treatment. Evidence-based practice promotes the collection,

interpretation, integration, and continuous evaluation of valid, important, and applicable individual or family-reported, clinically observed and research supported evidence.”

The Lanterman Act is civil rights protection for the disabled for which the intent is to empower the consumer or the family in a leadership role, while fully participating on the IPP team in all decisions about the services and supports provided for families and family members through the regional center. Decisions are to be based on assessment of that individual’s unique needs. The categorical elimination or modification of social skills training and socialization programs completely defies the intent of the Legislature. *“It is the intent of the Legislature that regional centers provide or secure family support services that do all of the following: (1) Respect and support the decision making authority of the family. (2) Be flexible and creative in meeting the **unique and individual needs of families as they evolve over time... (emphasis added)** (5) focus on the entire family and promote the inclusion of children with disabilities in all aspects of school and community.”²*

The categorical discontinuation of services without reviewing the individual needs of these consumers, and without offering a realistic, timely and effective alternative is in violation of the very trailer bill language that ACRC cites as justification. Many of the consumers for whom 028 programs are being discontinued are adolescents and young adults who have no alternative programs to which they can turn. Given the recent tragedy at CSUS in which the victim, a young adult with Autism did not have the social skills to recognize danger, the teaching of social skills should be mandatory for persons with ASD as they are absolutely necessary for a consumer to maximize their independence in and allow safe access to the community in which they live. These are fundamental rights guaranteed by the Lanterman Act.

The categorical discontinued utilization of social skills training and socialization programs is not in the language of the Trailer Bill nor is it the intent in any section of the Lanterman Act. Without social skills training, persons with ASD will not be able to remain within their homes, will require more restrictive housing options, are at risk in the community including school of becoming a victim of violence, will not be able to form and maintain social relationships that are essential for their quality of life, will be at greater risk of depression and suicide, and will not be able to work in a group which will make obtaining and keeping employment very unlikely. All of these situations will compromise the quality of life for the consumer and cost the state far more than the provision of these social skills training services now.

FEAT asks the ACRC Board of Directors to immediately correct these mistaken actions and order the cessation of this categorical discontinuation of the 028 social skills training and socialization programs.

Sincerely,

The Board of Directors
Families for Early Autism Treatment

1. Sec. 17 Sec. 4685 Welfare and Institutions Code
2. Sec. 17. Sec. 4685 Welfare and Institutions Code