

# **DISABILITY, ABUSE AND PERSONAL RIGHTS**

A Project of

## **SPECTRUM INSTITUTE**

**A Non-Profit Corporation Promoting Respect for Human Diversity**

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## **8<sup>th</sup> Conference on Abuse of Persons with Disabilities:**

### **A Think Tank**

June 11, 1997

Mr. Thomas Coleman  
Director  
SPECTRUM  
P.O. Box 65756  
Los Angeles, CA 90065

Dear Mr. Coleman: *Tommy*

This is a personal invitation to you to participate in this Think Tank. The meeting is scheduled for Wednesday, October 8, 1997 at the Burbank Airport Hilton Hotel, from 9am to 4pm.

The purpose of the Think Tank is to design the California State Model for assuring effective abuse response services to children and adults with disabilities. Directors of Agencies whose work is directed towards either abuse or disability issues are needed to be present together to discuss the development of a plan that will work towards coordination of efforts between these two areas. We will need recommendations for policy, procedure, legislative, service and training modifications. We are seeking a commitment from these and other agencies to work together.

This Think Tank process is limited to approximately 20 participants. The outcome will be a plan for initiating implementations of recommendations that emanate from the participants. Participants are all persons who are leaders in their field and have the authority to create change. Each participant has been carefully selected so that the Think Tank includes only those individuals whose representation for this effort is critical. As a part of your participation in this Think Tank Process we ask that you make a commitment to read the reading materials that will be sent to you at least 2 months in advance of the Think Tank.. This will ensure that all participants are working from the same information base, saving important meeting time to the purpose of the Think Tank. A description of the reading materials is

attached.

At the present time, abuse of children and adults with disabilities is a problem of major proportion recognized within the disability community, and under-recognized in the abuse and neglect response agencies. The national incidence study conducted by Westat under NCAAN demonstrated that children with disabilities are abused at twice the rate of generic children. No State in our nation has developed a coordinated plan to address this problem. California has the opportunity to develop a model that can be used by other States, again taking a leadership role in a new area.

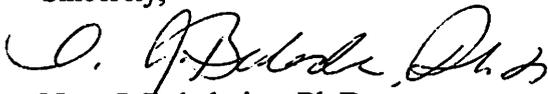
Following the Think Tank, a Proceedings & Recommendations Report will be developed and distributed to all Think Tank participants.

We need to hear from you by 7/15/97 regarding your ability to attend and participate. We do not have funding to pay for hotel or transportation expenses. We will pay for the meeting room, morning coffee and lunch for a working lunch time.

Please respond by returning the attached Participant Response Form by Fax or using the self addressed envelope we have enclosed.

Thank you, in advance, for your consideration of participation in this pioneering effort.

Sincerely,



Nora J. Baladerian, Ph.D.  
Conference Chair

Dan Sorenson  
Conference Vice-Chair

Conference Co-Sponsors and Coordinators:

Office of Criminal Justice Planning  
ICAN - InterAgency Council on Child Abuse and Neglect

Enc. Participation Response Form  
List of Reading Materials  
List of Invited Participants

Appendix A - Advance Think Tank Reading Materials (list)  
Appendix B - On Site Additional Reading materials (list)  
Appendix C - All written materials sent to Invitees  
Appendix D - National Survey on State Inter- Departmental Collaboration for Abuse of Victims  
with Developmental Disabilities  
Appendix E - Roster of Think Tank Members

Proceedings Report

Day of the Program

Registration:

Each participant completed the registration process and received additional reading materials. These are contained in Appendix B. The consents for the videotaping process were collected at the time of registration. The entire proceedings were videotaped. The tapes will be available separately.

It is of note that all who were invited accepted the invitation and all of them attended or sent a high level agency representative.

The meeting began with welcoming remarks from the Chair of SPECTRUM INSTITUTE, Jay Kohorn. He provided a visionary presentation, setting the stage for the day to be an opportunity to begin the building of a coalition of agencies that can develop a working relationship to specifically address the problems of children and adults with disabilities who become victims of abuse or perpetrators (real or accused) of crimes, including abuse. He offered the analogy of the care that is put into the manufacture of the Volvo. He informed us that the Volvo company is careful in every detail, functional, aesthetic and creature comforts. The company hires individuals who are the best in their field for each aspect of the construction. Then all of these experts share their knowledge so that, together, the best possible outcome can occur. This takes time, working together to work out conflicting purposes to arrive at a model of excellence. So, today's Think Tank should be considered as the first meeting of such an endeavor.

Today we will not leave with a finished product as a result. Today we will leave with the beginning foundation in the form of a plan of action, with each Think Tank participant having taken on a responsibility for either a large or small activity to do. The presence of each individual signifies the fact that each believes that the problem of abuse of children and adults with disabilities is a significant problem that is not yet adequately, or perhaps is poorly managed at this point in our history in California. This is also true for individuals with disabilities who commit or accused of reporting crimes, and those who may inappropriately be reported for suspected abuse when in fact the individual was acting within her or his own autonomy.

He provided the example of a case on which he collaborated by Dr. Baladerian. In this case an adult woman 22 years of age, conserved by her 24 year old sister, was found to have engaged in sexual intercourse. Although she had been informed, through the sex education classes as the

ICF-DDH where she lived that she was allowed to be sexually active, when she was discovered to be sexually active she was immediately taken to the hospital for rape crisis treatment, and her partner arrested for statutory rape. The question posed by the District Attorney was that of her ability to understand the nature and consequences of the act of sexual intercourse. Interestingly this case resulted in establishing exactly what are the nature and consequences of the act, and an assessment tool designed to determine her perspective in these areas. It was concluded, based on both her ability to understand the criteria that had been developed regarding the nature and consequences of the act, as well as her overall ability to understand her part in making decisions to participate in a sexual relationship with her partner, that this was not a rape. One of the problems to address in this case was that of the dishonesty of the facility staff. They had informed her that she was allowed to be sexually active, yet when she acted in accordance with this information, essentially she was treated like a criminal and someone unable to make such judgements and decisions.

He concluded by welcoming the awesome array of individuals who had taken the time from their busy schedules and huge responsibilities to attend to this serious problem for individuals with disabilities and their families.

Next, Thomas F. Coleman, Executive Director of SPECTRUM INSTITUTE, welcomed the gathering. He provided the perspective of balancing the rights of all individuals with disabilities. He focused on the question of the individuals' involvement in the legal system as a victim of abuse. He advised us to be cautious to assure a balance of the individual's right to self determination, privacy, autonomy, freedom of choice. The importance of assuring the patient's rights to dignity, privacy and humane care when living in licensed residences. The importance of assuring an adult's right to make decisions about his/her well being without the imposition of their parent's "orders", in particular when the parent has no legal authority with the adult.

Further, the legal rights of the individual in matters of freedom of association, rights to sexual expression, rights to confidentiality of medical information should remain intact. He reminded us that there have been egregious behaviors on the part of professionals in an effort to help an individual with a disability who have, perhaps inadvertently, engaged in behaviors or comments of "benign control" that disempower the person with a disability.

This would include punishing individuals with disabilities for behaviors that are both legal and socially acceptable for individuals who do not have disabilities. He gave examples in the area of sexuality and sexual expression. This applies precisely in the areas of sexual activity for residents of licensed residences, and issues of sexual orientation and thus partner selection. These illuminate a conflict between personal and religious beliefs and attitudes of care providers with their legal and regulatory responsibility to assure civil rights (legal) and dignity, privacy and humane care (regulatory) in service delivery. There may also exist within the State Departments who have a responsibility to monitor licensed residential programs for adherence to and assurance of access to these rights to service consumers, a reluctance to assure that these areas of the individual's life are protected.

So, abuse may include not only the willful infliction or trauma or pain, but also the *voluntary* or

unwitting infliction of trauma through chronic ignoring or unfamiliarity of the professional or agency that is the source of the individual's trauma or distress. In some states, including California, individuals living in licensed residences are more often than not denied their constitutional rights with no recourse, where the responsible Departments have responded to this problem by noting that it is complex and they need more time to resolve conflicting issues, these being the right of the tenant with the presumed right of the service provider (to impose their attitudes and beliefs on the tenants).

He concluded his remarks welcoming all of the members of the Think Tank, noting that each was specifically chosen to participate both as a result of their personal and professional commitments that have been demonstrated over time. He was enthusiastic that today's efforts will result not in some document that will sit on a shelf somewhere, but rather an active working plan to achieve completion of the goals to be selected by the group during the first half of the day. In addition, the videotaping results are planned as 3 products: a 5-10 minute "Preview", a one hour informational program, and a full (edited) version of approximately 4 hours that can be used by other States or entities who wish to replicate California's Think Tank Model.

The next speaker was Nora Baladerian, Project Director of SPECTRUM INSTITUTE's Disability, Abuse and Personal Rights Project. As coordinator for the Think Tank, she expressed an enthusiastic welcome for each of the participants as well as the grouping that had been convened. She reviewed some of the most salient issues for the Think Tank, including the facts that abuse and neglect of children with disabilities occurs at a level of least twice the rate of the generic child population and that in fact the data on this problem is infrequently and inadequately collected. The same is true for adult crime victims who have disabilities.

She noted that today's gathering is not limited to the population of individuals with developmental disabilities, but rather the greater population of individuals with disabilities whose vulnerability to crime or abuse is increased due to the disability.

She supported the comments of Tom Coleman that the purpose of the day was to develop an action plan that would later be written up in a Proceedings Report, and that the activities committed to today would be followed up with supportive monitoring and subsequent meetings to follow up. She also emphasized the comment by Jay Kohorn that this was an elite and powerful group that had the ability to make real changes in the system that can positively impact on abuse victims with disabilities and offenders with disabilities as their case is managed throughout the criminal justice system.

She referred to the extensive reading material that had been sent to each of the participants (great laughter ensued) and described its rationale as an effort to avoid reinventing already existing "wheels" and to assure that each participant would have a common informational basis for today's discussion. The intention of this was to avoid wasting any time in reviewing background information and to maximize the potential result of the day's gathering. In preparation for the Think Tank, a national survey was conducted to assess State of the Art nationally on State-level Inter-Departmental Collaborative efforts similar to this ThinkTank. The report was disseminated, with the primary finding being that no State has done such a comprehensive effort, and only 12

\*\*\*\* States have held any meeting at all. Of these 2\*\*\* have developed written reports and inter-departmental agreements and collaborative activities.

The meeting was then turned over to Michael Borunda, Governor's Appointee to the Office of Criminal Justice Planning. He described how the day would be spent, with a description of the purpose and desired outcome of each portion of the day. The first order of the day, then, was to conduct personal introductions, by identifying one's name, agency, and reason for choosing to attend the Think Tank. Next would follow a discussion of the major recommendations and issues that the members had identified in their reading or professional experience. Lunch would be served in this common room without an agenda. Following lunch, content groups that will have been identified prior to lunch would gather to discuss the issues that had been listed for each issue, with the mission to create specific activities that would further realization of the recommendations. Finally, a plenary session would occur during which reports from each group would be shared, resulting in a list of planned activities that will be undertaken in the near future.

To begin with the introductions, the following are the members with their name and reason for attending the Think Tank. See Appendix E for the Roster with the names of Think Tank members and their professional affiliation and position.

As a facilitator, Mr. Borunda sought agreement from the group on the plans for how the day would proceed. At that point, two individuals who had chosen seating in the public audience area rather than at the meeting table identified themselves as official Think Tank invitees. They had declined to complete the registration procedure. One of them stated that she had been surprised to see the professional videotaping equipment and operation professionals and that she had not known prior to the meeting that it would be videotaped, even though the original invitation and each written correspondence had included a statement informing the reader of the fact that professional videotaping had been planned and special funding secured. The other person seated in public seating agreed. Thus ensued, with cameras shut off, a discussion on the videotaping, the purpose of the taping. The two individuals in public seating (Director of the State Department of Mental Health and the Deputy Director of the Department of Social Services) requested that no taping occur.

There was discussion of the purpose of the tape, who would control the actual tape once produced, who would have a say in final editing and dissemination. The purpose of the videotaping was reviewed again, as an effort to demonstrate a model for other States or agencies as well as to inform those unable to attend the meeting, and to create a unique product that would be a singular contribution to the field. Much time was taken up with this discussion, with a stated reluctance of these two individuals to have any of their comments and their image electronically recorded. (\*\*indeed their physical presence recorded ) They feared both having any statement being recorded as well as taken out of context during editing or misuse as well as a possibility of technologically altering their comments!!! Needless to say, both the stated fear that SPECTRUM INSTITUTE would maliciously alter comments as well as possibly misuse a recording of the proceedings was extremely distressing to the Think Tank coordinator who had spent a great deal of time acquiring financial backing for the videotaping, and hiring the appropriate professional videotaping crew. Nonetheless, an agreement was finally made. The two invitees and anyone else

The activities planned by Group Four (Policy) are:

Summary comments were then solicited from the group, and final comments were made by Michael Borunda, Nora Baladerian, Tom Coleman and Jay Kohorn.

Nora gave thanks to the members, most of whom stayed to the conclusion of the proceedings. She remarked that this has been a landmark event for the State of California, and can serve as a model to other States who wish to enhance services to abuse victims with disabilities and disabled offenders. The plans are to issue a proceedings report on today's meeting and develop the videotapes. Anyone who wishes to participate in the development of either of these products was invited to contact her. Additionally, dissemination of these products beyond the Think Tank members will be decided by SPECTRUM INSTITUTE and other Think Tank members with participation of OCJP. Further, the next step that is planned is to assure implementation of the action plans that were developed today. Each member will be contacted by Nora within 6 months, to assist with implementation plans and to document progress with the action plan. A return meeting of this group is not planned at this time, although there was discussion of meetings with representatives of all or some members, and the possibility of meeting only with selected members who either have expressed a desire to participate in the follow up activities or are members of the group being served by Nora with monitoring and support services. Nora gave her thanks to all members for their contribution today and to the field.

Tom Coleman also thanked the members for their participation, and noted that already some new linkages had been made and plans for collaboration that were not part of the official program. He suggested that those who wished to have more participation with this process contact SPECTRUM INSTITUTE.

Jay Kohorn also expressed his appreciation and also stated that he was impressed with both the caliber and enthusiasm of the members regarding this topic. He noted that he had learned a lot today, and that in fact the proceedings far exceeded his expectations. In fact, he had thought he may not have a significant contribution to make, but found that his expertise was valuable to the discussions. He had fun! He reminded the group that today's mission was to begin the procedure for building a Volvo, and that it was clear from the discussions that exactly the right people had been present, and that the foundation had indeed resulted from the gathering. He noted that today should be viewed as a success by all of those present. Additionally, he recognized the excellent work of Michael Borunda in facilitating the meeting and assuring that our goals were realized due to his extraordinary ability. Additionally the work of Cheryl Mouras Ashby, Chief of the Family Violence Branch of OCJP was acknowledge as being both overtly and "behind the scenes" of great importance and contributed to the success of the meeting. Without her efforts, the meeting would not have experienced the high level of success.