



# MTARS COMMITTEE NOTICE/AGENDA

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<b>PARTICIPANT CODE:</b>	<b>2982825</b>

**DATE:** June 25, 2015

**TIME:** 10:00 a.m. – 11:30 a.m.

**LOCATION:** State Council on Developmental Disabilities  
1507 21<sup>st</sup> Street, Suite 210  
Sacramento, CA 95814

**TELECONFERENCE SITE:**

Tarjan Center at UCLA  
760 Westwood Plaza  
58-217 Semel Institute  
Los Angeles, CA 90095-1759

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	<u>Page</u>
1. <b>CALL TO ORDER</b>	A. Lopez
2. <b>ESTABLISH QUORUM</b>	A. Lopez
3. <b>WELCOME/INTRODUCTIONS</b>	A. Lopez
4. <b>PUBLIC COMMENTS</b>	
<i>This item is for members of the public only to provide comments and/or present information to the Council on matters <b>not</b> on the agenda. Each person will be afforded up to three minutes to speak. Written requests, if any, will be considered first. The Council will provide a public comment period, not to exceed a total of three minutes, for public comment prior to action on each agenda item.</i>	

For additional information regarding this agenda, please contact Thomas Johnson, 1507 21<sup>st</sup> Street, Ste. 210, Sacramento, CA 95811, (916) 322-8481. Documents for an agenda item should be turned into SCDD no later than 12:00 p.m. the day before the meeting to give members time to review the material. The fax number is (916) 443-4957.

5.	<b>APPROVAL OF MARCH 24, 2015 MINUTES</b>	A. Lopez	<b>3</b>
6.	<b>AIDD/MTARS UPDATE</b>	A. Carruthers	<b>6</b>
7.	<b>REVIEW ADVOCACY AND DIRECT INDIVIDUAL ADVOCACY SERVICES PAPER</b>	A. Lopez	<b>9</b>
8.	<b>ADJOURN</b>	A. Lopez	



**DRAFT**

**MTARS COMMITTEE  
March 24, 2015**

**Members Present**

April Lopez (FA)  
Sarah Greenseid  
Janelle Lewis (FA)  
Kristopher Kent  
Sandra Smith (FA)  
Nancy Clyde (SA)

**Members Absent**

Olivia Raynor  
Catherine Blakemore

**Others Attending**

Mike Clark  
Aaron Carruthers  
Thomas Johnson  
Benita Baines

**1. CALL TO ORDER**

The meeting was called to order at 10:12 a.m.

**2. ESTABLISH QUORUM**

A quorum was established.

**3. WELCOME AND INTRODUCTIONS**

Everyone present introduced themselves.

**4. PUBLIC COMMENT**

There was no public comment

**5. APPROVAL OF October 20, 2014 MINUTES**

It was moved/seconded (Smith [FA]/Lewis [FA]) and carried to approve the October 20, 2014 MTARS meeting minutes as presented. Council members April Lopez (FA), Janelle Lewis (FA), Sandra Smith (FA), and Nancy Clyde (SA) voted 'Aye'. There were no "nays". Sarah Greenseid and Kristopher Kent 'abstained'.

## 6. AIDD/MTARS COMPLIANCE UPDATE

Executive Director Mike Clark reviewed the AIDD/MTARS Compliance task chart with committee members. He reports that 49% of the required submissions have been made. He also notes that the next call with AIDD will be on April 27<sup>th</sup> and that the Membership Committee has done amazing work in recruiting new members for the Council and Regional Advisory Committees. Members also thanked Sarah Greenseid and the Governor's office for their assistance.

## 7. CALIFORNIA MODEL

Chief Deputy Director Aaron Carruthers discussed the California Model, which describes California's unique structure among the developmental disability council system in the United States. However, California's uniqueness has prompted some skepticism. He expressed confidence that SCDD will fulfill the ideals of the Americans with Disabilities Act and AIDD's expectations with our unique model and structure.

As a result, Chief Deputy Director Carruthers notes that he and Executive Director Clark met with SCDD staff and the regional office managers for two days to brainstorm ideas on how to make sure that our organizational structure best meets the needs of Californians with developmental disabilities and/or their families. This group looked at what other state councils do, as well as other substantive subjects. What the group determined is that California's regional model is the best model to meet the needs of California's large and diverse developmentally disabled community.

## 8. INDIVIDUAL ADVOCACY

Committee members discussed the role and value of individual advocacy. Members then reviewed a handout on individual advocacy, titled, "Advocacy and Direct Individual Advocacy services. This document can be accessed at the following website hyperlink:

<http://scdd.ca.gov/res/docs/pdf/MTARS/2015/HQ-%20Advocacy%20and%20Direct%20Services%20Paper%20March%2023%202015.pdf>

It was generally agreed that there will always be a necessary role and need for individual advocacy, for issues like education, available services, housing, and legal issues. However, it was also emphasized that SCDD needs to build a strong structure and model that ensures capacity building, statewide advocacy, and that fulfills the expectations that AIDD has placed on SCDD.

Committee members then made a few edits to the document.

It was moved/seconded (Kent/Lewis [FA]) to approve the edits to the document and move it forward to the Executive Committee for further discussion. Council members Nancy Clyde (SA), Janelle Lewis (FA), April Lopez (FA), Sandra Smith (FA), Kristopher Kent, and Sarah Greenseid voted 'aye'. There were no 'nays' or 'abstentions'.

## **9. REIMBURSEMENT UPDATE**

Chief Deputy Director Carruthers updated that committee on SCDD's reimbursement status. Mr. Carruthers notes that AIDD is a full quarter behind in reimbursing funds we have already spent. However, constant communication with AIDD regarding the cash flow problems with reimbursements and expenses, along with SCDD's work in completing its corrective action plan, has resulted in the positive result that AIDD has agreed to deposit funds each month once the council spends it, then reconcile that amount with the 270-packet of receipts.

## **10. ADJOURNMENT**

The meeting was adjourned at 11:56 a.m.

## AIDD/MTARS - Compliance Status- At a Glance – As of 6/10/15

CAP ITEM	Task Description	Date of Submission	Status
A-1	AB 1595, Bylaws	12/1/14	MET Compliance
A-2	Executive Director Job Description	1/1/15	Compliance NOT MET- requires continuous monitoring.
B-1	Bylaws	12/1/14	MET Compliance- additional clarification requested
B-2	Membership Committee meeting minutes & report to Council, list of organizations on distribution list, recruitment materials.	4/1/15	MET Compliance
C-1	Bylaws	12/1/14	MET Compliance
C-2	Demographic analysis of Governor's appointees to the Council	12/1/14	Compliance NOT MET – requires continuous monitoring
D-1	AB 1595, Bylaws	12/1/14	MET Compliance
D-2	Council roster showing membership and changes for 2015	12/1/14	MET Compliance
E-1	AB 1595, Bylaws	12/1/14	MET Compliance
E-2	Council roster showing membership and changes for 2015		
F-1	Bylaws, administrative procedure	12/1/14	MET Compliance
F-2	Membership Committee reports to Council	4/1/15	MET Compliance
G-1a.	Orientation binder, welcome letter	1/1/15	MET Compliance
G-1b.	Annual Councilmember training	4/1/15	MET Compliance
G-2	Welcome letter for agency reps	2/1/15	Compliance NOT MET – requesting additional information
G-3b.	SAAC packets and materials for 2015, evidence of facilitator attendance for 2015		
H-1a.	State Plan development process		
H-1b.	Documentation of public outreach, meetings, surveys, use of available data sources (NCI, ICI, CDER, etc). Copies of staff products submitted to committees and Council to support integration of data and public input. Various other documents showing committee work and council review and revisions of state		

<b>CAP ITEM</b>	<b>Task Description</b>	<b>Date of Submission</b>	<b>Status</b>
H-2	Documentation of public outreach, meetings, surveys, use of available data sources (NCI, ICI, CDER, etc). Copies of staff products submitted to committees and Council to support integration of data and public input. Various other documents showing committee work and council review and revisions of state plan.		
I-1	MOU		
I-2	MOU		
I-3	DSS Invoices	2/1/15	MET Compliance
I-4	DSS Invoices	2/1/15	MET Compliance
I-5	AB 1595, Bylaws	12/1/14	MET Compliance
I-6	Bylaws, Form 700, Gov't Codes 1090 and 87100	1/1/15	MET Compliance
I-7	Bylaws	12/1/14	MET Compliance- additional clarification requested
I-8	Breakdown of staff by funding source, training materials, staff orientation binder		
I-9	See A (Staff), H (Five Year State Plan), and M (Fiscal Requirement)		
J-1a.	State Plan work plan		
J-1b.	Evidence of periodic meetings and joint activities.		
J-2	Amended plan and supporting documentation.		MET Compliance
J-3	Approval of new state plan.		
J-4	PPR		
K-1	Documentation of TA received and products based on TA		
K-2	Evaluation plan		
K-3	PPR		
L-1	State accounting policies, budget development directives	2/1/15	Compliance NOT MET – requesting additional information
L-2	Month's expenditures by object code for entire budget	2/1/15	Compliance NOT MET – requesting additional information
M-1	State accounting policies, budget development directives	2/1/15	Compliance NOT MET – requesting additional information
M-2	AB 1595	12/1/14	MET Compliance

CAP ITEM	Task Description	Date of Submission	Status
M-3	Council reviews of monthly budget projections, Council votes on resource allocation, including cost-reductions		
N-1	Contract Manual	12/1/14	MET Compliance
N-2	RFP, Overview of RFP process, summary pages of selected vendor		
O-1	State Accounting policies	2/1/15	MET Compliance
O-2	DSA Annual Evaluation		

## **MTARS COMMITTEE AGENDA ITEM DETAIL SHEET**

**ISSUE:** Advocacy and Direct Individual Advocacy Services

**BACKGROUND:** In January of 2013, a team from the federal Administration on Intellectual and Developmental Disabilities (AIDD) visited the State Council on Developmental Disabilities (SCDD) and found several issues of concern around California's implementation of certain requirements of the Federal DD Act. These areas of concern were largely similar to areas noted by AIDD in its 1994, 2001, and 2006 visits. In November of 2013, AIDD issued its findings that California was not in compliance with a number of provisions of the DD Act. AIDD made it clear that if SCDD could not comply with the Federal DD Act, the federal government would withdraw its financial support of SCDD. They implemented a Monitoring and Technical Assistance Review System (MTARS) to move a correction process ahead.

**ANALYSIS/DISCUSSION:** One area of concern was a finding that SCDD was providing direct services in the form of individual advocacy. This often took the form of attending an Individual Education Plan meeting or Individual Program Plan and advocating for the individual's needs. During 2014, the Council ended providing this direct service, however, the need remains among individuals with and intellectual and/or developmental disability and their families.

January 2015, the Council directed the MTARS Committee to discuss how SCDD can assist clients and families with individual advocacy need while still staying in alignment with the Federal DD Act. This paper was largely to give guidance to SCDD staff on how to respond to request for assistance and give direction on acceptable advocacy versus direct services that are not funded through SCDD's federal grant.

May 2015, the Council reviewed the draft paper. Council Member Blakemore advocated that the council could do more, especially as it relates to monitoring to identify system issues. Council Member Blakemore offered:

"While I agree that the primary purpose of the Council is not to provide direct individual advocacy services but rather to engage in "advocacy, capacity building, and systemic change" I don't think the line is quite as bright as suggested in the policy. I say this both because there is not an explicit prohibition in the DD Act against direct advocacy particularly if it is a strategy to implement a Council State Plan objective and because a limited direct advocacy function can be a strategy to fulfill other important Council functions such as systemic advocacy or barrier elimination.

“For example,

“An effective strategy for training, might be individual training to assist the individual/family to prepare for an IEP meeting. Sometimes this could be done as an IEP training and clinic. SCDD would provide training about educational rights and then individual assistance in reviewing IEPs or other documents and helping the consumer/family identify individual strategies to access the services he/she needs. It isn't clear if this type of individual assistance would be considered to be direct service advocacy

“Barrier removal, another allowed Council activity, might require the following strategies. The Council receives input that the local regional center is not providing copies of IPPs in the consumer's/family's native language. The Council decides to ask the regional center for copies of the consumer's IPP, verifies that IPPs were providing in English only and then meets with the regional center to address concerns about the regional center not meeting language access requirements. The definition of direct service advocacy includes “attending meetings for agency based supports and services”. In this scenario the SCDD contacted the agency to obtain records for individuals but for the purpose of removing a barrier. The SCDD then went to a meeting, not to obtain individual services, but to resolve a barrier. I think both would be considered direct advocacy but done for a barrier removal purpose.

“System Advocacy

“The Council receives reports that a local school district is not providing individuals with both developmental disabilities and mental health disabilities access to behavioral services during the school day. As part of its review of this concern the Council engages in the following activities: review of individual student records, reviews applicable law regarding the district's obligation, attends IEP meetings to observe how the local district provides access to behavioral services; meets with the district and/or files an administrative complaints (e.g. a special education compliance complaint not an individual administrative hearing) on behalf of individuals to address a systemic problem, assuming one was identified. These are likely direct advocacy services but done for the purpose of system's change and I think an appropriate strategy for resolving systemic change.

“Given these gray areas, I think the Council policy should recognize the distinction between providing direct advocacy for the sole purpose of assisting an individual family or consumer obtain access to services versus providing direct advocacy to fulfill the Council’s other responsibilities, particularly those related to barrier removal and systems change activities. To say that Council staff can never engage in direct advocacy, when that strategy helps resolve a systemic barrier seems short-sighted.”

Council Member Blakemore suggested changes to the paper, which the Council referred the MTARS Committee for review. Chair April Lopez asked that the paper with Council Member Blakemore’s comments be sent to ITACC for technical assistance.

**COUNCIL STATE PLAN GOAL:** NA.

**PRIOR COUNCIL ACTIVITY:** Following action from the Council on January 22, 2015, to reconvene the MTARS Committee to discuss how the Council's Regional Offices, in alignment with the Federal DD Act, can assist families and consumers with individual advocacy needs, the MTARS Committee met on March 24, 2015. The Committee discussed the draft paper, made revisions and referred it to the Executive Committee. Staff incorporated those changes and on April 14, 2015 provided the March 26, 2015 version of the draft paper to the Executive Committee. The Executive Committee acted to refer the paper to the full Council for consideration. On May 20, 2015, the Council acted to refer the draft paper back to the MTARS Committee to redraft and authorize the Committee to bring others into that process if needed.

**RECOMMENDATION(S):** Review and provide input on the attached Advocacy and Direct Individual Services paper.

**ATTACHMENTS(S):** Advocacy and Direct Individual Advocacy Services draft paper with suggested changes by Council Member Catherine Blakemore. Advocacy and Direct Individual Advocacy Services draft paper with comments by Sheryl Matinee, Director of Technical Assistance, Information and Technical Assistance Center for Councils on Developmental Disabilities (ITACC).

**PREPARED:** Aaron Carruthers, Executive Director (A), June 15, 2015



## **ADVOCACY and DIRECT INDIVIDUAL ADVOCACY SERVICES**

### **Introduction**

State Councils exist to provide advocacy, capacity building, and system change activities that contribute to a comprehensive system of supports and services that is centered around and directed by clients and families. This system is to include needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families. Councils are to promote self-determination, independence, productivity, integration, and inclusion in all facets of community life, through culturally competent programs. (Developmental Disabilities Assistance and Bill of Rights Act of 2000 [DD Act] Section 101[b], 101[b][1], and 101[b][1][B].)

The federally funded network serving people with intellectual and/or developmental disabilities (I/DD) and their families also benefits from the protection and advocacy systems, which protect the legal and human rights of individuals with developmental disabilities. (DD Act Section 101[b][2].) In California, Disability Rights California is the federal developmental disabilities network partner who is responsible for providing direct advocacy services and other legal supports and assistance to ensure that individuals with I/DD are able to exercise their rights to make choices, contribute to society and live independently. The federally funded network also benefits from the University Centers for Excellence in Developmental Disabilities Education, Research, and Service as well as from the Parent Training and Information Centers.

Given the focus on advocacy in the I/DD network, this paper clarifies advocacy activities that are and are not allowed to be provided by the State Council on Developmental Disabilities (Council). Such clarification may be issued as a departmental policy. The following addresses issues specific to the role and activities of the Council as authorized under the Developmental Disabilities Act. (Public Law 106-402).

### **Types of Advocacy**

Advocacy involves promoting the interests or cause of someone or a group of people. An advocate is a person who argues for, recommends, or supports a cause or policy. Advocacy is also about helping people find their voice. (West Virginia University Center for Excellence in Developmental Disabilities.)

For the purposes of Council activities, there are two types of allowable advocacy: systemic advocacy and self-advocacy.

Systemic advocacy is about changing laws, rules, or agency practices that will improve outcomes for Californians with developmental disabilities and their families. The Council is directly responsible for systemic advocacy. In this capacity, the Council is responsible for conducting a comprehensive review and analysis of the state disability system, which informs the State Plan. This work assists individuals with I/DD by addressing barriers at the local, state, or national level. The focus can be changing laws or changing written or unwritten policies. Activities supporting systemic advocacy include outreach, training, barrier elimination, system design, system redesign, and informing policy makers.

Self-advocacy refers to an individual's ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights. Self-advocacy means understanding one's strengths, needs, personal goals, legal rights, and legal responsibilities. It also means communicating these to others. Self-advocacy is speaking up for oneself. The Council facilitates and supports self-advocacy for people with I/DD and their families.

Facilitating and supporting family and self-advocacy focuses on empowering individuals to create change in their lives. The Council supports and facilitates self-advocacy by informing individuals of their rights, instructing individuals on how to make complaints, providing information about the correct organizations to help create change, and encouraging individuals and families to speak for themselves.

### **Direct Individual Advocacy Services**

As stated above in the background section, State Councils engage in advocacy, capacity building, and systemic change activities that contribute to a coordinated, comprehensive system that includes needed community services and individualized supports. The Council does not directly provide these services and supports to consumers and their families. The intent is for State Councils to impact the service delivery system, not become part of the delivery system. (Information and Technical Assistance Center for Councils on Developmental Disabilities.)

Speaking or acting on behalf of an individual or family to obtain or access services is a may be a form of direct service and should not be a primary an allowable activity for the State Council with federal funds. However, engaging in individual advocacy when undertaken as part of another Council activity, such as system advocacy is an allowable activity for the State Council with federal funds. Some of these unallowable State Council activities, such as include attending meetings for agency based supports and services (e.g. Regional Center, schools or school districts, Social Security, Department of Rehab) or making calls to these agencies on an individual's behalf, may not be allowable when done solely for the purpose of assisting an individual consumer or his or her family. However, the activity may be allowable if it is undertaken for as part of a

system advocacy strategy. For example, it may be appropriate to call an agency to request consumers' service records when needed to obtain the records to verify a systemic issue regarding a failure to translate documents into a consumer's native language. It may also be appropriate to file a systemic compliance complaint following the Council's receipt of information that an entity has a policy or practice of not providing services authorized by law. The Council acknowledges that direct individual advocacy services are a critical need in the system. For example, parents need support when meeting with schools to discuss an individual education plan. Nationally, the perspective is that Parent Training and Information Centers (PTIC) are to provide this service. A review of the PTICs in California and assessing whether they meet the needs of families would be an allowable Council activity. Advocating for funding or better services is the role of the Council as are other direct individual advocacy services when used as a strategy to fulfill the Council's other responsibilities, particularly those related to barrier removal and systems change activities. ~~providing these services is not.~~

### **State Council Advocacy Activities**

There are many activities that are effective and consistent with the DD Act when working with individuals who are seeking advocacy support: information and referral, technical assistance, and training. These activities provide a benefit beyond helping individuals and families seeking advocacy supports. It leverages the strength of the California Council, with its headquarters in Sacramento and regional offices throughout the state, to provide an ongoing comprehensive review and analysis of the service system. Additionally, staff may conduct surveys to collect information on problems that are emerging within their regions, which helps identify statewide trends, and communicate their findings to the Council for action.

Staff typically does not need to personally attend direct service meetings to collect this type of information. The mere presence of staff at these meetings brings the State Council into the room, which can have the effect of direct individual advocacy services and make the Council a party to the action, also a direct service.

### **Conclusion**

While this paper focuses on the division between advocacy activities that are allowed and not allowed, there is a large universe of advocacy activities that fulfill the State Council's purpose. Systemic advocacy marshals the Council's limited resources to serve the greatest number of people. Focusing on activities that impact the greatest number of individuals is a responsible and efficient way of changing the system of supports and services for people with I/DD and their families. With its headquarters and regional offices, the Council is structured to identify and change systemic issues at local, county, regional, and state levels.



## ADVOCACY and DIRECT INDIVIDUAL ADVOCACY SERVICES

### Introduction

State Councils exist to provide advocacy, capacity building, and system change activities that contribute to a comprehensive system of supports and services that is centered around and directed by clients and families. This system is to include needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families. Councils are to promote self-determination, independence, productivity, integration, and inclusion in all facets of community life, through culturally competent programs. (Developmental Disabilities Assistance and Bill of Rights Act of 2000 [DD Act] Section 101[b], 101[b][1], and 101[b][1][B].)

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Given the focus on advocacy in the I/DD network, this paper clarifies advocacy activities that are and are not allowed to be provided by the State Council on Developmental Disabilities (Council). Such clarification may be issued as a departmental policy. The following addresses issues specific to the role and activities of the Council as authorized under the Developmental Disabilities Act. (Public Law 106-402).

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**Comment [A1]:** As written, it appears that the PTIC's are part of the federally funded network – Recommendation: end this sentence after the word Service. You may want to explain what the UCEDD does?

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Self-advocacy refers to an individual's ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights. Self-advocacy means understanding one's strengths, needs, personal goals, legal rights, and legal responsibilities. It also means communicating these to others. Self-advocacy is speaking up for oneself. The Council facilitates and supports self-advocacy for people with I/DD and their families.

Facilitating and supporting family and self-advocacy focuses on empowering individuals to create change in their lives. The Council supports and facilitates self-advocacy by informing individuals of their rights, instructing individuals on how to make complaints, providing information about the correct organizations to help create change, and encouraging individuals and families to speak for themselves.

**Comment [A2]:** This is specific to what the CA Council provides? If this document serves as departmental policy, will this statement hold true going forward? (next 5 year plan, etc)

### Direct Individual Advocacy Services

As stated above in the background section, State Councils engage in advocacy, capacity building, and systemic change activities that contribute to a coordinated, comprehensive system that includes needed community services and individualized supports. The Council does not directly provide ~~these services and supports to consumers and their families~~. The intent is for State Councils to impact the service delivery system, not become part of the delivery system. (Information and Technical Assistance Center for Councils on Developmental Disabilities.)

**Comment [A3]:** So...the DD Council indirectly provides services? Might want to rephrase.

**Comment [A4]:** The further clarification would be – unless the direct service was part of a demonstration project within a larger systems change initiative (but, that would be on a time-limited basis) Section 125(c)(5)(K)(i) – oh I see this in the next paragraph -

**Comment [A5]:** The deleted wording is better – it is a form of direct service – (rather than may be) – it is...or it is not.... Again...you may want to rephrase – this statement gives one the impression that as long as it's not a primary activity it is okay....(and no...it is not... remember the MTARS findings).

Speaking or acting on behalf of an individual or family to obtain or access services is a may be a form of direct service and should not be a primary an-allowable activity for the State Council with federal funds. However, engaging in individual advocacy when undertaken as part of another Council activity, such as system advocacy is an allowable activity for the State Council with federal funds. Some of these unallowable State Council activities, such as include attending meetings for agency based supports and services (e.g. Regional Center, schools or school districts, Social Security, Department of Rehab) or making calls to these agencies on an individual's behalf, may not be allowable when done solely for the purpose of assisting an individual consumer or his or her family. However, the activity may be allowable if it is undertaken for as part of a

**Comment [A6]:** There is a big "it depends" here... I would caution the CA Council on supporting these types of individual advocacy activities when you are engaged in addressing a MTARS finding that cites the Council for providing direct services. I'm wondering what the intent was for striking the original wording?

**Comment [A7]:** I would suggest reverting back to the stricken words – and not include the rest of the sentence beyond the word behalf, - see next comment.

system advocacy strategy. For example, it may be appropriate to call an agency to request consumers' service records when needed to obtain the records to verify a systemic issue regarding a failure to translate documents into a consumer's native language. It may also be appropriate to file a systemic compliance complaint following the Council's receipt of information that an entity has a policy or practice of not providing services authorized by law. The Council acknowledges that direct individual advocacy services are a critical need in the system. For example, parents need support when meeting with schools to discuss an individual education plan. Nationally, the perspective is that Parent Training and Information Centers (PTIC) are to provide this service. A review of the PTICs in California and assessing whether they meet the needs of families would be an allowable Council activity. Advocating for funding or better services is the role of the Council as are other direct individual advocacy services when used as a strategy to fulfill the Council's other responsibilities, particularly those related to barrier removal and systems change activities.; providing these services is not.

**Comment [A8]:** I do not view this as a DD Council role or responsibility; however, according to the DD Act, Title C this is appropriate for the protection and advocacy entity in the State. Councils are not given authority to request service records, but I understand the P&A are given the authority to do so. You guys may want to check with the P&A

**Comment [A9]:** I'm not sure this would be "defensible" – If you are referencing my viewpoint – it would not be representative of the national perspective. However, you would be safe in stating – Other federal funds support a national network of PTIC's to provide these types of services.

**Comment [A10]:** Isn't this what AIDD cited the DD Council about – direct individual advocacy SERVICES... take great care with that language – DD Councils do not provide direct services.

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While this paper focuses on the division between advocacy activities that are allowed and not allowed, there is a large universe of advocacy activities that fulfill the State Council's purpose. Systemic advocacy marshals the Council's limited resources to serve the greatest number of people. Focusing on activities that impact the greatest number of individuals is a responsible and efficient way of changing the system of supports and services for people with I/DD and their families. With its headquarters and regional offices, the Council is structured to identify and change systemic issues at local, county, regional, and state levels.