

APPROVED ON 09/09/09

**STATE INTERAGENCY COORDINATING COUNCIL  
EXECUTIVE COMMITTEE MINUTES**

**Thursday, May 7, 2009  
10:00 A.M. - 5:00 P.M.**

**Welcome and Introductions**

Theresa Rossini called the meeting to order at 10:10 a.m. She announced that Mac Peterson, ICC Chair, is attending the Senate hearings dealing with the proposed budget cuts to DDS and the provision to narrow the focus for entry to services into Early Start for speech services. His concerns are that many children with autism begin with a speech pathologist and are referred from there to other services, hence, the possibility of delay of services. The Assembly has already passed the bill. Mac is speaking as a private citizen since the ICC has not discussed this.

Arleen Downing said many pediatricians also are concerned about the bill and are attending the hearing this morning. She said many children with speech delays are being assessed; however, social emotional delays are not as easy to assess so children with autism may be missed.

The main goal of this ICC meeting is to discuss current affairs and to see how involved the ICC would like to be.

Theresa introduced Madaline Journey-Lynn as the new representative for the Department of Alcohol and Drug Programs.

Self-introductions were made by ICC members and the audience.

*ICC Members Present:*

Madeline Journey Lynne

Rick Ingraham

Toni Doman

Debbie Sarmiento

Theresa Rossini

Arleen Downing

Beverley Morgan Sandoz

Jim Bellotti

Kevin Brown

Marie Poulsen

Susan Burger

Elaine Fogel Schneider

Hallie Morrow

Linda Landry

Cheryl Treadwell

Theresa said she had hoped for a discussion by ICC members on the issue of the bill before the Senate; however, due to the lack of a quorum, the discussion would not take place since

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Mac needed information by 10:30 a.m. The language of the bill will be handed out this morning and also will be discussed this afternoon as part of the "Current State of Early Start" presentation as well as during the panel meeting tomorrow. (Note: additional ICC members arrived later, making a quorum; however, it was too late to provide input to Mac.)

### **Review of Agenda**

The agenda was approved with no additions.

### **Approval of February 2009 Strategic Planning Notes**

The February 2009 Strategic Planning notes were approved with no changes.

### **2009 Priorities Discussion/Approval**

Theresa asked for the pleasure of the group to discuss the four priority areas:

1. Data Collection and Analysis
2. Child and Family Outcomes
3. Issues: Transition, Natural Environments, Surrogacy
4. Comprehensive System of Personnel Development

Beverley Morgan Sandoz requested a summary of the issues and it was noted that a summary was on pp.8-9 of the February meeting minutes.

Kevin Brown noted that the priority areas are up for approval, not the specific comments noted under each topic, which were part of the February brainstorming workgroups. Detail will be added as a result of further discussion. Rick Ingraham noted that the February discussion also was about how to keep the ICC relevant in light of both OSEP requirements as well as items that are important to ICC members.

The four priorities were approved.

### **ICC Committee Structure/Membership**

Theresa noted that this subject would be discussed in further detail at the September meeting based on how the ICC organized the priorities. Rick said there is a longstanding history with current committees. As new priorities are being identified, the question is, "Do these committees, as presently structured, serve these priority areas" or, "Do the committees need to look and operate differently?"

Arleen suggested that people self-designate first and second choice of committees and whether they are willing to serve as chair/co-chair and then have the ICC Chair appoint membership. Marie Poulsen suggested operationalizing the work of these committees according to the priority areas in order to identify the skill set needed. She suggested the ICC as a whole discuss what each committee will work on and that the focus should be narrow and focused rather than global and broad. Rick noted that DDS would put forth what it would like each priority area to focus on and email ICC members before September. ICC members should decide prior to the September meeting on which committee they would like to serve. Theresa asked about the Executive Committee structure and whether it would remain the same. Rick recommended that it remain the same.

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### **Review of May 2009 ICC Agenda**

Theresa noted that Friday's panel discussion includes Bob Baldo (Association of Regional Center Agencies), Tony Anderson (ARC of California), Julia Mullen (DDS Deputy Director), and Michelle Doty Cabrera (staff to Senator Denise Ducheny). There will be no Family Resource Centers Network of California (FRCNCA) report, ICC Staff report, or other reports to accommodate the agenda. Debbie Sarmento suggested that because we're serving families, she would like to do a quick report. ICC members approved.

Marie is concerned about the lack of a Department of Mental Health (DMH) designee. The current representative retired and Rick noted that DMH is undergoing reorganization and is looking at a replacement.

Public Input will return to the 10:00 a.m. time slot in September.

Jim Bellotti asked about the "ICC Priorities and Committee Structure" Action Item. Kevin said it could be a consensus, not an Action Item. The vote is not about a committee structure (which will be decided on in September), but about the priorities. The second Action Item, "Communication with Policy Makers," will be based on the day's discussion and may also be a consensus item. Theresa said it was added as an Action Item in case something was developed to vote on, i.e., writing a letter.

Jim also noted that Mac wanted to discuss the role and responsibilities of the ICC. Theresa preferred to review the agenda prior to discussing this item.

### **Other Business**

*2009 Parent Leadership Award:* This year's recipient is Linda Neimeyer. She is not able to be present tomorrow so the presentation will be in September. She was notified by Mac. Elaine described the selection process and noted that the Public Awareness Committee (PAC) is looking at some changes to the procedures. There were three candidates under consideration. Debbie Sarmento said that Linda is the director of a Family Resource Center (FRC) in San Bernardino/Riverside, the only Early Start-funded FRC that is still a network due to its size. She is also a parent.

### **Current State of Early Start, Part 1**

Budget information was distributed and Rick said decisions about the process were made at high levels and will be used to identify where budget reductions will take place. The regional center budget for next year was reduced by \$100 million and DDS was charged with covering that money. DDS' director embarked on a stakeholder input process with 25 people. The two people on the work group with the most knowledge of Early Start were Bob Baldo (Association of Regional Center Agencies) and Linda Landry (Family Resource Centers Network of California and a parent). Other work group members were associated more with adults. The invitation list was generated at the director's level. There were creative brainstorming sessions with a range of proposals—everything from eliminating programs to selling electricity. DDS was charged with creating concept papers for 10 of the ideas. Then it was reduced to five, with three pertaining to Early Start. These concerned eligibility, increased use of neighborhood preschools as an early intervention service, and use of private insurance to pay for services. Serving high-risk infants is

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discretionary for all states and at this point, only eight states serve this population with California being one of

them. In addition, Part C is not a federal mandate—states can choose not to participate. The South Carolina governor said he was considering having his state pull out. With funding staying flat and the number of children entering the system increasing, they didn't have the resources. Then the stimulus package emerged and states decided not to be so hasty since Part C was specifically mentioned. Some states are not going to meet their maintenance of effort requirement and Rick doesn't know the impact of that. There was not a lot of time to develop the concept papers and Rick doesn't know how decisions were made to keep or drop specific proposals.

### Discussion

*Ed Gold:* What is the regional center's entire budget? DDS' budget is \$4 billion with much of it going to developmental centers. Regional centers receive about \$2 million; however, they've endured several cuts and rate freezes during the past four or five years.

*Shane Nurnberg:* Eight states are still serving at-risk kids—how many have opted out of Part C? South Carolina is considering it but Rick hasn't heard about any other states. Arizona shared a letter with states about draconian cuts to its Part C program. Many states are very concerned about being able to meet their maintenance of effort requirement due to state cuts. Maintenance of effort can be waived for Part B. Jim said there are declining revenues and redirected revenues based on policy maker decisions. For local school districts/SELPA's, it's based on compliance determinations—those SELPA's that meet requirements of IDEA via the State Performance Plan. Most do, but some don't so they will have to do something with the stimulus funding to meet the maintenance of effort requirement.

*Daniel Shaw:* A trailer bill was introduced Tuesday night. The delay category was different than indicated in the handout— 50% delay in one area and 33% in another. DDS did not have information about the numbers that would be impacted. In his area (Tri-Counties Regional Center), eligibility would be reduced by 37%. Rick said trailer bill language is the same in concept; however, sometimes the language is changed or edited to introduce a nuance. The concept is that the regional centers receive a lot of late entry kids with mild speech delay, i.e., at 28-29 months, which means that transition occurs right after intake so regional centers are spending a lot of resources for a child who may not be eligible.

Daniel also had another point of clarification. Kids will transition to Part B, not Lanterman. Many kids will still go on to IDEA services, which is the point of the transition language. Kevin has been working with the California Department of Education (CDE) to track kids from Part C to Part B. Both DDS and CDE have an interest in knowing how kids perform over time. Data is not yet available. The Departments collect different data elements so it is difficult to collect. Kevin said transition is a problem nationally and in California. The Early Start Report has been drastically changed and much of the data DDS will be collecting will help. Rick said additional data to be reviewed was transition data and then children who re-enter the system at 4 or 5 years old.

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Daniel also wanted to know if DDS has looked at the idea of looking at Early Start as a consult model. It's going to be harder and harder to adequately serve kids. A more appropriate way to serve kids might be a consult model. He noted the Kendall School in Modesto for children with a diagnosis of Autism Spectrum Disorder. The empirical data for progress is better than any school district or regional center. Rick asked for an operational definition of consult model.

*Theresa Rossini:* How many children were identified as speech delay and later diagnosed with another condition? Many kids were referred to Early Start for speech in order to attain eligibility but there may be other conditions. Marie said an assessment is needed to see if speech delay was a factor in autism. If we have appropriate assessment, improved diagnosis will occur. Rick noted that on November 3<sup>rd</sup>, ARCA sent a letter to DDS recommending that California pull out of Part C because of costs. Rick said that when looking at the survival of the program at all— recognizing only eight states serve high risk— what can we give up to maintain the program? Until now, with the different eligibility categories for Part C, it didn't matter because the kids would be served. A definitive diagnosis was only needed at 36 months to determine Part B eligibility. In other states, where Part C is restricted, clinicians have done greater due diligence to determine kids who really need to be served. The regional centers will need to be more precise regarding eligibility. DDS is looking at recording the area of eligibility.

*Laurie Jordan:* Didn't California get in trouble for not serving enough kids but now we want to serve less? Rick said it wasn't that we weren't serving enough kids, but that we were "below the national average." He added that the national average would be impacted by what all states will do.

*Susan Burger:* What is the status of the proposals? Rick said trailer bill language is under development now. The bill is on its way to statute with the legislature to weigh in. She said that the Department of Managed Health Care, on March 9<sup>th</sup>, sent a letter to managed health care plans about improving services for kids with autism and to ensure they are providing basic health care service for individuals with autism, in particular that plans have processes for screening and evaluation. Regarding delivery of services, the letter said basic services, i.e., speech, OT, and PT, should be provided when medically necessary.

*Julie Kingsley:* What kind of savings would be gained by eliminating the high-risk category since you still have to assess the kids. Rick said savings are estimated at \$13 million statewide. Theresa said costs to the system are greater if the kids have to return to the system. Rick encouraged people to look at autism data report currently posted on the DDS website.

*Marie Poulsen:* Is this trailer bill fete complete? Two needs to address: can something be done to not have it happen and what is the safety net for kids with other needs? Rick said because serving high-risk kids is discretionary, proposals are put forth annually about whether to serve this population; however, these are different times. What other cuts will happen? What about the May 19<sup>th</sup> election? Rick said there would be a 7% payment reduction across the board for vendors if the ballot initiatives don't pass.

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*Arleen Downing:* When the Senate committee met, they already had the proposals in trailer bills—it's a done deal. This is not really a 'proposal' anymore. It makes the community think it's something different than what it is. In addition to eligibility, children will not attend an infant development program, which is a serious issue—how will community programs serve children who have real delays and disabilities? Rick said the IFSP process remains intact. He estimated is that 1 in 20 kids could be served in a community preschool rather than an infant development program.

*Beverley Morgan Sandoz:* What is the impact for children served by Early Head Start and the requirement that the programs meet their 10% requirement but by meeting the requirement, the children have to have an assessment? Rick said DDS has no monitoring system to enforce the 10% requirement. Perhaps some collaboration is necessary.

*Elaine Fogel Schneider:* She agreed with Arleen that the language needs to be reviewed. We will put ourselves in a 'box' when we find ourselves using words like what 'should' or 'shall' take place. Being in the field, this is not what takes place, i.e., services are not always IFSP driven. In many cases, services revolve around a DDS description. In looking at the idea of preschools, there are no statistics around that but there are other alternative programs that have data of success. Rick encouraged all comments to be brought forth tomorrow.

*Sandra Suitor:* Why, with so many cuts to Early Start and people with disabilities, why has DDS said that it is off the board to take anything from Development Centers? They are closing and the money isn't going anywhere else. Rick asked the same question at a managers' meeting and all that was noted was that \$100 million was taken out of the regional center budget and development centers also have been cut. There was no real understanding of why. Rick said much could happen over the next few months when the ICC is not meeting. What role should Mac have as a spokesperson? How will you have a voice as the situation rapidly changes?

### **Current State of Early Start, Part 2**

Kevin noted that much of his presentation (Attachment B) was debated in the morning session with some suggestions made to address questions to tomorrow's panel.

A theme that runs through the various newspaper headlines that deal with the economy, state budget, DDS budget, and the Federal stimulus is crisis—and OSEP requirements. Kevin noted that this presentation is about bringing past and present events into focus, and to provide information and lay the foundation for an Executive Committee discussion on possible future actions and to formulate ideas for tomorrow's panel. The ICC has a difficult task ahead of it. Its mission is to provide advice and technical assistance to DDS. It is difficult to walk the tight rope regarding proposals since the governor appoints the ICC Chair.

*Agenda for presentation:* Economy and the budget: Many things have happened nationwide in the past year. People have different reasons for the financial crisis: mortgage market, lack of credit, lack of consumer confidence, corporate financing, other forms of debt, and unemployment figures.

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All states have been impacted. Actual public debt is \$11.2 trillion. Federal government can spend money it doesn't have, unlike California.

In California, the budget is highly dependent on income/sales tax. In January 2009, there was a projected \$40 billion budget shortfall for current/subsequent years. \$42 billion solution package passed in February, including spending reductions, tax increases, federal funds (stimulus), borrowing, and six California budget-related propositions:

- 1A. Rainy day reserve fund
- 1B. Education supplemental payments
- 1C. State lottery
- 1D. Early childhood development program, funds (specific to Early Start)
- 1E. Mental health program funds
- 1F. Elected officials salary increases  
(\$6 billion in revenue if passed; deficit if not)

Regarding propositions that deal with education and early childhood education funds (First 5 funding), \$265 million of that \$600 million that is planned to be redirected is looking at Early Start purchase of service. The March Legislative Analyst's Office analysis said that in the short term, there will be an \$8 billion shortfall and in the long term, a \$26 billion shortfall by 2013-14 because revenue increases and spending reductions are of a short-term nature. As of March, California's unemployment rate was 11.2%.

Department's proposals: DDS savings target of \$334 million (real number is how can DDS come up with \$100 million to cut). Assembly Bill ABX3 5: DDS to develop cost containment measures for \$100 million general fund reduction in 2009-10 and work with stakeholders on a plan for the legislature. ("X" means extraordinary session—thus far there have been three extraordinary sessions.)

Vendor rates have been frozen for some time; temporary 3% rate reduction that will be permanent for 2009-10; additional 7.1% rate reduction if DDS does not demonstrate \$100 million reduction or if ballot initiatives are not approved by voters; and impact of further economic decline on budget and additional reductions are unclear.

Stakeholder work group input was it's important to have the least impact on consumer while ensuring program and service integrity; maximize the use of generic resources; and maximize receipt of federal funds. The result was 15 proposals were adopted; reductions distributed throughout RC system; and three proposals specific to Early Start.

See handout for proposals. Projected savings to General Fund: \$102.8 million

Three Early Start proposals:

1. Expand availability and use of neighborhood preschools as a natural environments service setting. Impacts children 18 months and older. Estimated general fund reduction for 2009-10 approximately \$8.9 million.
2. Use of private insurance. Estimated general fund reduction for 2009-10 approximately \$6.5 million.

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3. Eligibility criteria. Eliminates “at risk” eligibility for those 24 months or older. Estimated general fund reduction for 2009-10 approximately \$13.4 million. Also eliminates services for metabolic disorders.
  - Total Savings for these three proposals: \$28.8 million.

Current status is that the Assembly Health Committee met to here DDS proposals. No action expected until after election.

Federal stimulus package: \$787 billion part of the stimulus package. Eight broad categories:

1. Tax relief
2. State and local fiscal relief
3. Infrastructure and science
4. Protecting the vulnerable
5. Health care
6. Education
7. Energy
8. Other

Estimated \$46 billion to California in 10 categories:

1. Health and human services
2. Labor
3. Transportation
4. Science and technology
5. Energy
6. Other
7. Housing
8. Water and environment
9. Public safety

California funds allocated thus far:

Part B grant  
Part B preschool grant  
Title I  
Part C grant  
Education technology  
Adoption assistance  
Foster care

Part C stimulus funds: \$500 million available to all states. California share is \$53.2 million over 27 months. Half requested for FY 2008-09/half for 2009-10. Money is applied to purchase of service. Maintenance of effort (as a state, California is spending more on POS every year and it has to maintain the level from prior year) is not an issue.

Annual Performance Report: Submitted APR by 2.1.09. OSEP had a weeklong period asking for clarification with one week to respond. Items targeted:

- Child outcomes
- Family outcomes

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- General supervision
- Complaints/mediation
- ICC Annual Performance Report
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### Future challenges

#### Economy

Limited resource growth

Multiple stakeholders with competing priorities

Vendor frustration

Regional Center frustration

Cuts/furloughs to state agencies/departments

Advocates

OSEP

Dealing with a changing population if eligibility proposal is accepted or defeated (different issues)

Dealing with decreasing pool of vendors

Addressing increasing service demands due to the 'ripple effect'

Addressing OSEP requirements

Looking into the 'crystal ball' to deal with potential, additional cuts

### **Update of Senate Hearing**

The Senate Budget Committee met. Mac was not aware that any of this was occurring until last week. Senator Leno listened to consumers and spent time with them. He said he wasn't going home until everyone spoke. Hundreds of people presented. No decisions were made; however, the Assembly approved everything but this is not a budget bill, it is a trailer bill.

Work group members were invited to the table. Terri Delgadillo responded to questions from the Senator and allowed work group members to respond. Linda Landry was on the work group and she shared her personal story as a parent of a child with a disability. She talked about threats and budget cuts over the years to Early Start. Peter Michael Miller also testified and focused on the eligibility and explained some of the technical knowledge that work group members did not know about.

Peter Michael Miller said that the American Academy of Pediatrics (AAP) has been having discussions and specifically addressed the eligibility issue and how it's not cost effective to change the criteria. He noted one of the concerns of the cutback would be at a time when pediatricians were beginning to perform developmental screenings. As of 2006, AAP has mandated pediatricians to do developmental screenings for kids between 18-24 months. There has also been an increase in autism screening by pediatricians.

Mac advocated that people contact their legislator to tell personal stories.

### *Discussion of ICC Role:*

Mac provided the following information:

Concerns from Regional Centers:

- Caseload ratios
- 45-day timeline
- Lack of resources
- DDS monitoring

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- Lack of communication
- Dumping by other public agencies
- Funding of staff (36–39 months)
- Paperwork

Reductions in place (2008-09):

- Parent participation
- 3% reduction in rates
- 3% reduction of regional center staff

Elaine noted that the ICC should take a stand about the ICC role, especially in light of the fact that the ICC was not invited to be on the work group.

Re Proposition 1D, AAP is against this. Many editorials are also opposed to it. Many are saying the six propositions will not pass.

Audience member noted this is a key time since these 15 proposals were a directive from the legislature to DDS. It is up to the legislature to accept or change the proposals.

Linda said the legislature noted that other experts should be involved in the process. This is an open door for input.

Theresa noted her disappointment about the lack of ICC involvement. This needs to be addressed so that it doesn't happen again. Perhaps the reason for the lack of invitation was that it was not just Early Start, but also all of DDS. She is left questioning her purpose.

Marie reminded members about a vote in February to better promote the ICC in local communities. This could be done by better disseminating concept papers that the ICC prepared.

Beverley asked how possible it is to develop something in writing to respond to the three Early Start issues. Rick said you could make a request of the Chair. Mac responded that he does not have the resources to do this. There was discussion about to whom the letters would be sent, i.e., the Senator Leno or Terri Delgadillo, since state agencies might have to abstain. The letter would include that it is important to sustain this program and that the rates for occupational therapy, physical therapy, and speech and language should be maintained where they were six months ago.

What is the ICC's position on the propositions, especially 1D and 1E (Prop 63—Mental Health Services)? Mac supports 1D while the AAP opposes it. Marie said both issues have been very polarizing. So many unspent dollars that people want to put to use and those who see kids that are benefiting see it differently. There is no consistency of opinion across the board. Theresa asked if WestEd could support the process. Kevin responded yes. Mac said we should have consensus on one sentence about what the ICC believes.

Jim said taking supporting/opposing positions will mean he will have to abstain unless the state Superintendent gives consent. CDE supports the ICC and Early Start and wouldn't want any action taken to reduce or curtail services or cutbacks.

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The consensus was that the ICC will not take a position on the propositions but can support a letter on issues of eligibility and provider rates. Elaine also wanted to add something about services in neighborhood preschools—are we really encouraging a family approach if we support this since it isolates the parent from the services. Kevin responded that the family-centered approach is about participation in the IFSP, not service delivery. Elaine responded that a specific site should not be mentioned. Kevin said that services would be provided where the child can achieve the outcomes—if it's not in a natural environment then it should be in the IFSP.

Letha Sellers expressed concerns about the preschool issue. Her regional center offered preschools to the family and ultimately came full circle and realized it wasn't meeting the needs of the child or providing the needed services. It omits parent training and support. It starts out with the wrong assumption that we send everybody to a center-based program at 18 months. Some schools don't have a reasonable curriculum and there is no way to monitor quality assurance.

Ed Gold noted that if you try to enroll a child with a disability into preschool, you would be told they couldn't be served because the staff isn't trained.

Beverley said the legislation should not be prescriptive and that the key is that parents and programs have options. She does not want the ICC to say preschools don't meet the needs of children. Addressing the concerns that the ICC was not included in the decisions or work groups, she said there is an opportunity to take a position on the proposals, the propositions, and the issues of regional centers (eligibility for high-risk infants 0-3), rate reductions to Early Start providers (a. 3% across the board and 7.1% as of September 2009 if the propositions do not pass); and natural environments/preschool.

Following a discussion about to whom the letter about eligibility should be addressed, a motion was made for the letter to be sent to the DDS director (Terri Delgadillo) with a cc to the Health and Human Secretary (Kim Belshé).

Marie said she would not want to vote on anything before seeing trailer bill language. Children should not be seen without a caregiver involved. These protections need to be built in.

Peter Michael Miller questioned a 19-month old being in preschool and especially a child with special needs. He also mentioned the lack of standards for child care and this might be an opportunity to discuss this issue.

Hallie Morrow confirmed that she would have to abstain.

The following motions were discussed for further discussion and voting at the Friday meeting:

*Eligibility:* "The ICC is opposed to any change in eligibility to restrict eligibility for Early Start services for low-risk infants/toddlers entering Early Start at 24 months of age or older."

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*Rate Reduction:* Robin Millar said rate reduction has already happened retroactive to February. She said the ICC could say they are concerned about an additional rate reduction and would advocate for the sustainability of current rates. No further discussion.

*Neighborhood Preschools:* The legislature believes 5% (1,535 kids) of Early Start children would be able to thrive in neighborhood preschools with supports (doesn't say all children). There is concern that it says, "*Shall* consider neighborhood preschools *in lieu of* infant development programs [emphasis added]." It also violates the IFSP process because it's not the IFSP team making the decision, it is the regional center. Daniel Shaw said you would be out of compliance since there is no multidisciplinary team making the decision.

Motion to be included in tomorrow's action item: "The ICC opposes the DDS proposal on neighborhood preschools as currently stated."

### **Adjournment**

Meeting adjourned at 5:05 p.m.