Should Part C Early Intervention Services be Extended to Children, Ages 3-5?

HAEYC Leadership Conference
Hawai`i Convention Center
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Background

- IDEA 2004
- Parents
- Legislative hearings
- Opposition from DOH and DOE
- Act 289
Purpose of ACT 289

To study the feasibility of expanding eligibility, pursuant to Part C of the Individuals with Disabilities Education Act, for services from the Department of Health’s Early Intervention Section to children between 3 and 5 years old who have developmental disabilities.
Tasks

- Identify the potential number of children annually who may benefit from a longer transition period.
- Identify the number who were served by Part C, but not eligible to be served under Part B.
- Identify the number with delays, ages 3-5, who were not served by Part C.
Tasks (continued)

- Research evidence-based practices for service models
- Define the array of services required
- Based on projected numbers, derive resources and cost projections
- Conduct a needs assessment of families, focusing on their transition experiences
The Task Force Shall Also:

- Project the timeline to develop resources
- Develop indicators for evaluation to assess outcomes
- Submit a report to the Legislature 20 days prior to the convening of the 2008 Session (report due December 27, 2007)
Funding

- Appropriation of $120,000
- Governor allowed House Bill No. 531 to become law as Act 289 without her signature
- DOH initial funding $15,000 to begin
To Begin

The Department of Health to enter into a Memorandum of Agreement with the Center on Disability Studies for $15,000 to do the following:

- Facilitate two meetings of the Task Force
- Complete the needs assessment of families, focusing on their transition experiences from Part C. [(7) in Act 289]
Background (National)

Prior to 1975 – Parental Lawsuits

1975 – Education of All Handicapped Children’s Act

1986 – PL 99-457 – Part C

2004 – IDEA Reauthorization
Background (Hawai`i)

- 1949 - Exceptional Children’s Law
- 1972 - Early Intervention Began
- 1974 - Silva Consent Decree
- 1975 - Federal Legislation
- 1980 - Preschool Special Education Began
- 1987 - Part H
- 1990 - Preschool Task Force
- 1997 - STEPS Project
- 2000 - Preschool Study under Felix
# Children Served under Part C in Hawai`i, 2005

<table>
<thead>
<tr>
<th>Ages</th>
<th>Developmental Delay/ Biological Risk</th>
<th>Environmental Risk</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>0-1 years</td>
<td>431</td>
<td>18.6%</td>
</tr>
<tr>
<td>1-2 years</td>
<td>773</td>
<td>33.3%</td>
</tr>
<tr>
<td>2-3 years</td>
<td>1,162</td>
<td>50.1%</td>
</tr>
<tr>
<td>Total</td>
<td>2,320</td>
<td>100%</td>
</tr>
</tbody>
</table>
### Hawai`i Part C Exit Data, 2005

<table>
<thead>
<tr>
<th>Category</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exited prior to age 3; developmentally age appropriate</td>
<td>519</td>
<td>33%</td>
</tr>
<tr>
<td>Part B eligible (unknown how many enrolled)</td>
<td>501</td>
<td>32%</td>
</tr>
<tr>
<td>Not Part B eligible</td>
<td>274</td>
<td>18%</td>
</tr>
<tr>
<td>Part B eligibility not determined</td>
<td>264</td>
<td>17%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>1,558</td>
<td>100%</td>
</tr>
</tbody>
</table>
## Hawai`i Part B Indicators, 2005

<table>
<thead>
<tr>
<th>Child Status Following Referral/Evaluation</th>
<th>Part C Children Referred</th>
<th>Indicator Measurement</th>
<th>Completed PRIOR to 3rd Birthday</th>
<th>Completed AFTER 3rd Birthday</th>
</tr>
</thead>
<tbody>
<tr>
<td>IDEA Ineligible</td>
<td>86 (14.80%)</td>
<td>B</td>
<td>44 (51.2%)</td>
<td>42 (48.8%)</td>
</tr>
<tr>
<td>IDEA Eligible</td>
<td>479 (82.44%)</td>
<td>C</td>
<td>317 (66.2%)</td>
<td>162 (33.8%)</td>
</tr>
<tr>
<td>No Evaluation Conducted</td>
<td>16 (2.76%)</td>
<td></td>
<td>15 (93.8%)</td>
<td></td>
</tr>
</tbody>
</table>
Background on Funding

- Concept of “unfunded mandate”
- Part C based on state poverty formula
- Hawai`i is a minimum allocation state
- Part B is based on a child count formula
Unfunded Mandate

The federal dollars for educating preschool children with disabilities in Hawai`i ($437 per child in 2005) cover only about 2% of the approximately $21,000 in annual costs of educating a preschool child with disabilities.
Part C Funding Issues

- Approximately 90% of the funding comes from State funds
- Part C has been chronically under-funded
- Emergency appropriations have been required for many years
- For the current year, funding is inadequate to serve the number of children referred for services
Part C Policy Issues

- Part C has been described as a “flawed national policy”
- No research exists to show that early intervention should end at age three, regardless of the needs of the child and family
- Decisions were driven by the compromises to get the legislation enacted rather than best practices
“For many families, transition means the unwilling severing of a therapeutic relationship with their service providers.”

“No wonder many families endure a sharp sense of loss in spite of everyone’s best efforts to make the transition smooth.”

--Talbot Black, 2000
“I am suggesting that the national policy that emerged from that compromise needs to be examined, even though it has been in effect all these years. And, if the policy does not prove itself to be in the best interests of children and families, then it’s time to think about what needs to be changed.”

--Talbot Black, 2000
“Thinking about what needs to be changed” succinctly summarizes the charge to this Task Force.
Caveats

- First, do no harm!
- Design a system responsive to needs, not to birthdays
- Do not design another UNDERFUNDED system
- Work within other initiatives (Act 259)
- Include children with 504 eligibility
Parents have always been the guiding force in policy, whether in the lawsuits that preceded the initiation of the Education of All Handicapped Children’s Act, the Silva Consent Decree, the Infant and Toddler Program, and this Task Force.
Family Survey

What do we need families to tell us that will help the Task Force decide on policy recommendations to the 2008 State Legislature?
“Not everything that can be counted counts, and not everything that counts can be counted.”

Albert Einstein
Work of Survey Committee

- Reviewed all previous preschool surveys and results in Hawai`i
- Identified items to be included
- Delegated to a sub-committee responsibility for developing survey
- Reviewed drafts by email
- Approved final survey and process
- Obtained IRB approval for survey
# Teacher Response Rates

<table>
<thead>
<tr>
<th>County</th>
<th>Response Percent</th>
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</thead>
<tbody>
<tr>
<td>Kaua`i</td>
<td>37.5</td>
</tr>
<tr>
<td>O`ahu</td>
<td>50.7</td>
</tr>
<tr>
<td>Hawai`i</td>
<td>32.4</td>
</tr>
<tr>
<td>Maui</td>
<td>41.9</td>
</tr>
<tr>
<td>State</td>
<td>47.1</td>
</tr>
</tbody>
</table>
## Return Rate for Surveys

<table>
<thead>
<tr>
<th>County</th>
<th>Surveys Distributed</th>
<th>Surveys Returned</th>
<th>Return Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kaua`i</td>
<td>20</td>
<td>47</td>
<td>??</td>
</tr>
<tr>
<td>O`ahu</td>
<td>555</td>
<td>363</td>
<td>65%</td>
</tr>
<tr>
<td>Hawai`i</td>
<td>81</td>
<td>32</td>
<td>39%</td>
</tr>
<tr>
<td>Maui</td>
<td>60</td>
<td>17</td>
<td>28%</td>
</tr>
<tr>
<td>State</td>
<td>716</td>
<td>459</td>
<td>64%</td>
</tr>
</tbody>
</table>
# Surveys Returned by whether Served by Early Intervention

<table>
<thead>
<tr>
<th>County</th>
<th>Number of Surveys Returned</th>
<th>Number Surveys for Child Served by EI</th>
<th>Percent Surveys for child Served by EI</th>
<th>Number Surveys for Child not served by EI</th>
<th>Percent Surveys for child not served by EI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kaua`i</td>
<td>47</td>
<td>37</td>
<td>79%</td>
<td>10</td>
<td>21%</td>
</tr>
<tr>
<td>O`ahu</td>
<td>363</td>
<td>265</td>
<td>73%</td>
<td>95</td>
<td>26%</td>
</tr>
<tr>
<td>Hawai`i</td>
<td>32</td>
<td>25</td>
<td>78%</td>
<td>6</td>
<td>19%</td>
</tr>
<tr>
<td>Maui</td>
<td>17</td>
<td>10</td>
<td>59%</td>
<td>7</td>
<td>41%</td>
</tr>
<tr>
<td>State</td>
<td>459</td>
<td>337</td>
<td>73%</td>
<td>118</td>
<td>26%</td>
</tr>
<tr>
<td>Island</td>
<td>Sent</td>
<td>Returned</td>
<td>Rate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------</td>
<td>------</td>
<td>----------</td>
<td>------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>O`ahu</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>696</td>
<td>177</td>
<td>25%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>287</td>
<td>115</td>
<td>40%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>294</td>
<td>163</td>
<td>55%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>555</td>
<td>363</td>
<td>65%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maui</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>32</td>
<td>12</td>
<td>37%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>18</td>
<td>17</td>
<td>94%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>60</td>
<td>17</td>
<td>28%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kaua`i</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>6</td>
<td>2</td>
<td>33%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>12</td>
<td>8</td>
<td>67%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>20</td>
<td>47</td>
<td>??</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Big Island</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td>23</td>
<td>7</td>
<td>30%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td>33</td>
<td>26</td>
<td>79%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>81</td>
<td>32</td>
<td>28%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>State Total</td>
<td>348</td>
<td>136</td>
<td>39%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2005</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>State Total</td>
<td>357</td>
<td>214</td>
<td>60%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2006</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>State Total</td>
<td>716</td>
<td>459</td>
<td>64%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Ages of the Children

(Birth years)

2003 – 235 (51%)  
2004 – 204 (44%)
Description of Child Needs

Speech-Language 142 (31%)
Health-Medical 8 (2%)
Developmental Delay 144 (31%)
Autism 35 (8%)
Missing Data 130 (28%)
Age When Early Intervention Services Began

Average age: 19 months
Median age: 24 months
Range: 0-35 months
Question 6

How did you feel when you learned your child could not have early intervention services after your child’s third birthday?
Comments – Question 6

Positive: 28 (10%)
Negative: 140 (52%)
Uncertain/Mixed: 99 (37%)
Sample Positive Comments

- It was fine and worked out well because she got to start the Head Start-DOE.
- I was feeling ok and I was happy she was moving forward to new stage.
- Disappointed at first, but I like the special education program very much.
- Happy because he would start school.
- Transition services provided non-interrupted therapy for my child.
Sample Negative Comments

- I was disappointed because she only had 6 months of early intervention.
- I was shocked and worried that he might not receive the help he needed.
- I was sad because services were about to end just as he was making progress.
- Wondered why services were limited to 0-3 in age, felt frustrated.
Question 7

When your child turned three years old, did you want your child to stay in early intervention longer instead of starting DOE preschool?
At age 3 – wanted continued early intervention services

Yes: 22%
No: 46%
N/R: 31%
If “yes,” why?

- I was not ready to be without her for 6 hours every day.
- My daughter’s development was only 9 months, she had excellent services and was not ready to transfer, I thought.
- Because I felt early intervention takes more care about my child.
- I felt he was not ready to be in a school setting.
If “no,” why?

- Because he would be around other kids.
- He would receive more hours of learning and therapy and interaction with his peers.
- I felt preschool would help her with speech and socialization.
- I thought he was ready so I’m glad.
- It helps me get a break when he is in school.
Question 8

Now, after your experiences, would you have wanted your child to stay in early intervention longer instead of starting preschool?
Now think staying in early intervention services would have been better:

Yes: 11%
No: 57%
N/R: 31%
If “yes,” why?

- She wasn’t ready, and the school wasn’t ready for her.
- He’s a special case, he needs more services.
- I still feel he is too young to attend an all day, every day program.
- I would still prefer him to start preschool at 4 years and enjoy him at home where young children belong.
If “no,” why?

- Preschool helped her much more because of the everyday reinforcement.
- The DOE teachers are way more proactive and engaged, interested in her.
- He loves school and wants to learn.
- He is learning so much more and in a great atmosphere with other children – he is very happy.
Site of DOE Preschool Services

- DOE Classroom for children with disabilities: 78%
- Head Start or Community Preschool: 17%
- Missing data: 4%
Transition Experiences

Had transition conference: 85%
Visited PS classroom: 73%
Evaluations explained: 96%
Positive IEP meeting: 90%
Welcomed by DOE staff: 98%
Liked amount of services: 91%
### Question 12

**Please tell us about the IEP meeting for your child.**

<table>
<thead>
<tr>
<th>Response</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I went to the meeting and people listened to my ideas.</td>
<td>86%</td>
</tr>
<tr>
<td>I went to the meeting but people did not listen to my ideas.</td>
<td>4%</td>
</tr>
<tr>
<td>I did not go to the meeting.</td>
<td>5%</td>
</tr>
</tbody>
</table>
Sample Positive Comments

- Everyone took me step-by-step, that’s great because it makes a nervous parent comfortable, was positive, encouraging.
- Everyone seemed very concerned for my son’s needs.
- Everyone was very helpful and made transition go smoothly.
- They showed concern and support.
Sample Negative Comments

- My ideas were seen as coming from a Mom who didn’t know what she was talking about.
- I felt insulted.
- The whole transition process was bad, mishandled, the meeting was very tense.
- I felt everyone against me.
- We wanted an inclusion class and there was none available in the complex.
Question 13

Did you feel welcomed by DOE Staff?

Yes: 94%

No: 2%

N/R: 4%
Sample Positive Comments

- They were so pleasant and helpful.
- They truly care about the child and family.
- They helped our family and put us at ease.
- Extremely welcomed and satisfied.
- They are great!
- The entire staff were friendly, informative.
- Not only welcoming, but also encouraging.
- DOE staff has been wonderful.
Sample Negative Comments

- The principal and SSC were very rude.
- I had to fight with them for certain services. They wanted to base everything solely on my son’s evaluations with strangers that had seen him once.
- Administration does not make parents feel welcome on campus.
- 1st IEP meeting was overwhelming. DOE staff used lingo, acronyms I was unfamiliar with.
Question 16

Below is a list of some ways DOE preschool may help children and families.

Comments:
Sample Positive Comments

- My child has progressed so much in the past 11 months.
- I like the individualized attention each child receives.
- The change I’ve seen is unbelievable – all the teachers and staff do an amazing job.
- She loves her class and enjoys going to school every day.
Sample Negative Comments

- Families don’t talk much to one another.
- My child needs more services.
- Quality and quantity of services are 50% of EI (0-3). No family involvement.
- Believe my son needs more services, but they are fighting me.
- We would like him to be exposed to other children his age without disabilities.
Question 17

Compared with your feelings when your child started DOE preschool, how do you feel now?
Current Feelings

- Less satisfied: 3%
- Feelings unchanged: 9%
- More satisfied: 84%
- No response: 4%
Sample Positive Comments

- I was nervous about him going to school, but now, I’m so glad he is in school.
- My child is improving and I see that my child enjoys school and other kids.
- I was a little nervous in the beginning, but he loves his school.
- He gets more services through DOE.
- I feel my child will be ready for kindergarten.
Sample Negative Comments

- Concerned with speech more now than before.
- Need better support for my son with autism. After school care is also needed.
- The teacher is SPED certified, but does not have any ECE credentials. Not the best learning environment for my child.
- I was optimistic at first, but there’s no communication with parents.
Question 18

Is there anything else you want to share?
The DOE teachers and therapists are out of this world – they are just great!

I really appreciate the amount of communication there is between myself and my son’s teacher – she writes us daily.

Being in a school for my child is much better because she gets to interact with other children.
Sample Negative Comments

- I do recommend that our children in 0-3 should continue the program until age 5.
- ...even our EI care coordinator did not advocate for him.
- Early intervention needs to be provided in private preschools to encourage inclusion.
- I would like to see more screening of preschool teachers.
- Why doesn’t DOE have after school care for preschoolers with special needs?
Summary

- The response rate was excellent in terms of the number of surveys distributed.
- However, for reasons that are not clear, the responses probably represent less than one-fourth of the number of children enrolled in preschool special education.
- Families feel strongly about the issues as evidenced by the great many comments.
Families are initially apprehensive about the transition to DOE pre school.

But at age three, less than one-fourth of the families wanted more early intervention services.

Then, after experiencing DOE preschool, a majority of families do not think further early intervention services would have been better for their child.
What wasn’t counted …

- How the other three-fourths of families might feel.
- Whether all families understand the importance of inclusion for young children with disabilities.
- Data on the small percentage of families who felt their child would benefit from a longer transition period with continued Part C services – and how they would “benefit.”
No data are available...

- On the number of Part C/Part B-eligible children who may benefit from a longer transition period with continued early intervention services.
- On the number of Part C/Part B non-eligible children who still may benefit from early intervention services.
- On the number of non-Part C children ages 3-5 who might benefit from early intervention services.
Summary Statements

- Resources were inadequate to complete the work outlined for the Task Force.
- However, the work completed provides valuable information for policy formation.
- Available data do not support a change in policy regarding provision of services to preschool children with disabilities.
- Available data do suggest significant areas for improvement in early intervention and preschool special education.
Recommendation from Study Authors

Make no changes in current policy unless there is significant further study and adequate funding to support any changes in policy.
Recommendations from Task Force

1. Continue the Task Force work and request the Governor to release the $120,000 to complete the Task Force activities.
Recommendation

2. Ask the Early Intervention Coordinating Council to review the data and family comments to determine how early intervention services could be more responsive to family needs.
3. Ask the Special Education Advisory Council to review the data and family comments to determine how preschool services could be more inclusive and responsive to family needs.
4. Ask the STEPS Team to review the data and continue to work to make the transition process as seamless and supportive of families as possible.
Final Message

Blend the skepticism of a scientist,
With the passions of an advocate,
The pragmatism of a policy maker
The creativity of a practitioner,
And the devotion of a parent,

To create a decent quality of life
for all children with disabilities.
www.cds.hawaii.edu/3to5

- Task Force Members
- Information on all meetings
- Copies of all presentations
- Resource materials