

## Report on Infant Learning Program Parental Rights and Procedural Safeguards

*“I think it’s great that you’re even calling and doing this kind of research. It will get me to review that booklet that I hand out but haven’t read in years.” - ILP coordinator*

### Summary

Fifteen of Alaska’s 17 Infant learning Program (ILP) provider agencies responded to brief telephone interviews about procedural safeguards and parental rights procedures with the Research Analyst at the Governor’s Council on Disabilities and Special Education. These interviews with ILP coordinators revealed several important facts and recommendations. There is a lot of variation in training, attitudes, comfort levels, and practices among Alaska’s ILP providers regarding rights and safeguards. Overall, agency staff are concerned that parents do not understand their rights but are unsure of what they should be doing differently. These inconsistencies and concerns could largely be eliminated if there were established best practices communicated to agencies on a regular basis, a more “family-friendly” summarizing document to go over with parents, a self-led online training module for staff on the history of parental rights and past abuses, training videos for staff to see best practices in action, and videos for parents depicting families expressing their rights and/or talking about *how* procedural safeguards are important to them. It has been suggested that the state ILP office provide more frequent, useful, and consistent messaging about rights and safeguards. Below are the summary findings for each question in the interview.

### 1. What training does your staff receive on parental rights and procedural safeguards?

- All 15 agencies reported new staff orientation as the main form of training. This training varied from informally covering all the documents and procedures with new staff (most agencies), to shadowing experienced staff (several agencies), to formalized mentorship programs (only one agency).
- 7 agencies reported training or reviewing the rights and safeguards with staff periodically, but the remaining 8 agencies do not train staff again after their new-employee orientation.
- Only 2 agencies reported teaching staff about the *importance* of rights and safeguards with a lesson on the history of the law and past abuses.



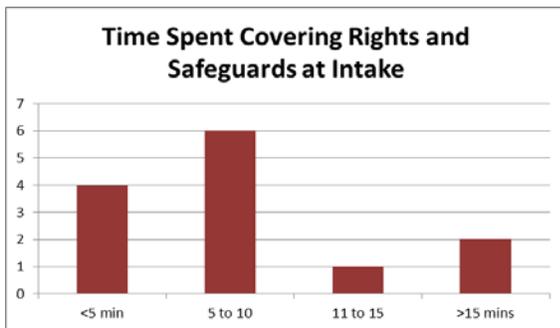
**2. What training does your staff receive on how to address the issue of parental rights and procedural safeguards with parents or primary caregivers?**

- 12 agencies reported no specific training on how to address rights and safeguards with parents.
- 3 agencies indicated specific training on how to give this information to parents as part of their staff training, including role-playing and practicing delivering rights and safeguards to parents before going out on their own.

**3. How much time does your staff devote to outlining parental rights and procedural safeguards with parents or primary caregivers? (e.g. do staff bring it up with parents just once, or periodically? How long does this conversation usually take?)**

All agencies reported covering rights and safeguards at the first intake meeting with parents and that the time spent covering them varies depending on the family.

Some families are engaged, asking questions, so the conversations would last longer, however, this is not the norm. All agencies reported that parents rarely seem interested in this part of intake and get “glassy-eyed” as rights and safeguards are covered. One coordinator stated,



*“I know that parents are saying they don’t know their rights and safeguards, but we ARE going over this with them. What else can we do?”*

The majority of agencies reported that rights and safeguards at intake takes less than 10 minutes. Although most agencies reported that parent’s “don’t want to hear” rights and safeguards at every meeting, 4 coordinators indicated that parents interrupt and try to stop them from going over rights and safeguards again. According to one coordinator,

*“It’s pretty brief because parents stop us. They don’t want to hear it again and again, because we do it in all our meetings. Sometimes it feels like we’re reading them ‘their rights’ and parents get freaked out. They stop us when they hear that legal-ese and say, never mind, these services sound more intense than I was thinking. They decline services when we go through the rights and safeguards!”*

- Although all agencies have to update parent signatures annually, not all providers are actually reviewing the rights and safeguards with parents; they are just getting new signatures.



7 agencies indicated that they cover rights and safeguards periodically after intake. Eight agencies reported that they usually do not bring rights and safeguards up again after intake unless initiated by the parent. As one rural provider put it,

*“I’m thinking, Oh God, the plane’s here, and I rush through it. I sometimes just dump the booklet and paperwork on them all at the end and I do not feel good about that. But sometimes I just have to do it.”*

2 agencies specifically stated that most of what they explain are parental rights like confidentiality and record-sharing; procedural safeguards is the briefest topic covered. Although the other agencies may not have been explicit about this, they often made statements to indicate that they also conflate rights and safeguards as the same thing. For example, many coordinators referred to the rights and safeguards process with parents as “the signature page” or “prior written notice,” which is not the same thing as covering procedural safeguards. One coordinator stated,

*“About 90% of the information I give them is on their rights to confidentiality, though. The exchange of information, records, and notes with doctors is basically what all our conversations are about, not what to do if they are unhappy about services.”*

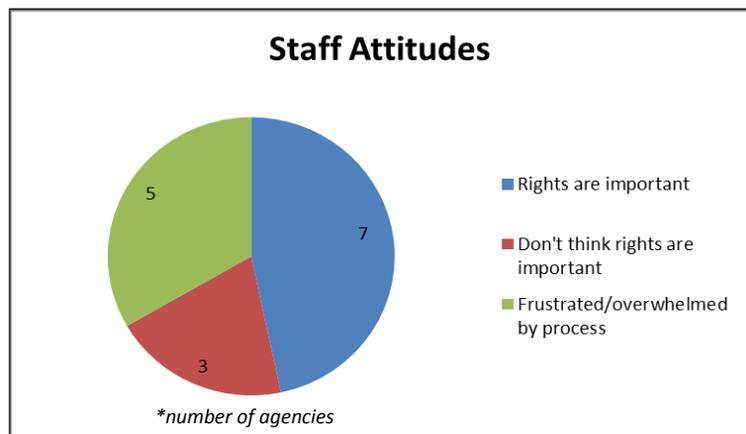
#### 4. Does your agency have a grievance procedure for when parents call to complain?

- All agencies except 2 reported grievance procedures at some level, either in their ILP program or the native corporation.

#### 5. How would you describe the general attitude of your staff about the process of notifying parents or primary caregivers of parental rights and procedural safeguards?

Coordinators report different attitudes to rights and safeguards, ranging from understanding the value of rights to being completely frustrated by them.

*“We know these are very important. I was an ILP parent, I’ve been in those shoes. Parent rights were not explained to me and the documentation they give you is confusing to everyone. I had a college degree and came from the dominant culture, and still didn’t know what my rights were.”*



Some agencies view the rights and procedures as integral to the process, while others do not seem to value it much. For example, one coordinator referred to rights and safeguards as “mind-numbingly boring and has no value.” She went on to state that the attitudes of her staff are also negative,

*“General attitude? Dislike. Two thumbs down. We have talked about the history of these rights with staff but they still think it’s just more paperwork. [Staff] also think we cover it too often, especially because families don’t want to do it again. [Parents] ask us to stop, mention that they’ve already got the booklet, whatever. Even the families say this is too much paperwork and that we cover it too often in meetings.”*

## **6. Relatedly, how comfortable do you think your staff feel about raising the issue of parental rights and procedural safeguards when meeting with parents or primary caregivers?**

8 agencies reported that staff are relatively comfortable going over rights and safeguards with families. This seemed to be related to:

1. Rates of staff turnover. Staff that have been doing this the longest seem most comfortable with it, and
2. Supervisors review the material periodically with staff, annually or in staff meetings. Those that reported being uncomfortable also reported having little training.

7 agencies reported being somewhat uncomfortable with this part of their work. For example,

*“Not very comfortable. It is habitual at intake, they do not put much thought into it. But otherwise it’s uncomfortable to keep broaching with parents that don’t care.”*

*“Not comfortable. I’m actually afraid a parent will ask be a thoughtful question because I might not be able to answer it.”*

## **7. Is there a process for your staff to check that parents understand these rights?**

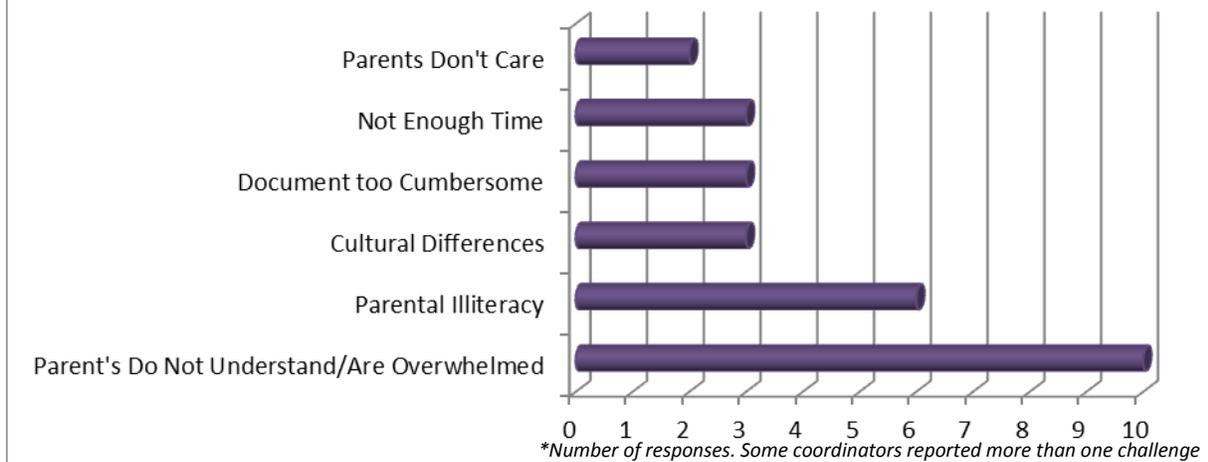
Although all agencies said that they ask the parents if they have any questions after going over rights and safeguards, agencies reported that parents rarely, if ever, have any questions. 13 agencies have no explicit way that they check for understanding.

- Only 2 agencies do knowledge checks with parents, asking them questions later in the session like, “Now, where would you go if you have a problem with your services?”

Most coordinators indicated that they were concerned that parents did not understand their rights fully due to the following challenges:



## Challenges with Rights and Safeguards



*“Well I was not comfortable yesterday because I had to use a language interpreter. The state ILP has documents in only three languages, I had a [foreign] family the other day. So far it’s just basics that we’re covering, but I’m concerned about getting into more in-depth material, including rights and safeguards, with an interpreter. I did it just briefly yesterday with them, and gave them the booklet, but it’s in English. I did not feel good about doing that.”*

### 8. What further training would benefit your staff on this issue? (e.g. videos, tutorials, other materials?)

Results from the ILP coordinator interviews resulted in 4 recommendations for improvement:

1. All agencies recommended that the **state ILP office produce a summarizing document** for ILP staff to cover with parents. Several coordinators reported that the current document is not “family-friendly” and does not take into account different reading / comprehension levels of families. Most agencies reported being more comfortable with the shorter, bulleted document. Some are even still using their old documents, despite being “told not to.”

*“We used to use a one-page summary that was much better, it never scared anyone off. Now ILP tells us we can’t use that simplified version. Parents may not understand this newer format, it sounds scary, and I think it’s a problem.”*

Another provider in a different area of the state agreed, stating,



*“[Staff] laugh about the booklet, it’s like 15 pages long and has so much information. We hand it to parents but it is overwhelming. Some parents don’t even take it home with them. I think it’s good to have available but the booklet is not right for all families in our region.”*

**2. State ILP office communicates best practices to agencies on a regular basis.** The most commonly reported way to do this, was with a training video for staff to see an ideal family interaction about parental rights and procedural safeguards. However, roundtable discussions and role-playing exercises at ILP conferences were also suggested.

**3. State ILP office provides an online training module for staff** that covers the history of parental rights, procedural safeguards, and past abuses, to provide context for the importance of this material for families.

**4. Culturally-appropriate videos for parents and caregivers** that shows families expressing their rights and talking about how procedural safeguards are important to them. Just as staff need context to understand these complicated procedures, so do families need to understand why these rights exist and how they can be useful or important to them.

*“Maybe culturally-appropriate videos for parents would help? It would be nice to give parents something to take away, to watch or review later in time, when they’re ready for the information. Something not written, like a video. And something that recognizes that [ethnic minorities tend to] avoid conflict, maybe something that portrays procedural safeguards not as conflict, but as something else??”*

**9. Is there anything else you can think of that ILP can do to improve staff’s understanding and comfort with addressing parental rights and procedural safeguards with parents or primary caregivers?**

ILP coordinators had three other suggestions:

1. Training on how to interact with parents with disabilities, especially parents with intellectual/developmental disabilities.
2. Get more consistent, useful, and frequent communications from the state ILP office.
3. Get AILPA involved with implementing some of these recommendations.

*“I think this research study is very positive. That the Governor’s Council is doing this, is great. I like that we’re going to improve.” - ILP coordinator*

