

## **A Parent's Guide to Asking Questions: Parental Rights and Procedural Safeguards (Kansas Version)**

### **Promises to Families**

As a parent or family member of a young child with a developmental delay or disability you may have experienced someone on the early intervention team reciting your parental rights to you. Perhaps you received a brochure with your parental listed. Maybe you experienced both. This is a first step. However, the law actually says that you can expect much more. The law says that the early intervention program staff has a responsibility to help you to *know and understand* your parental rights. When parents, such as you, know and understand your rights, these rights can become a part of the everyday interactions of early intervention.

A law, The Individuals with Disabilities Education Act (IDEA), guides the early intervention staff in which your son or daughter is enrolled. The majority of the rules and regulations that guide the program are listed under Part C of the IDEA. This law outlines your rights as parents, and gives explicit guidance as to processes designed to protect your parental rights. This guidance is named procedural safeguards. Procedural safeguards must be in place in every program to protect your rights. The parental rights and procedural safeguards of IDEA are *promises to your family* about how things should go while your and your child are receiving services from the early intervention program.

The most important thing to know is that these promises should result in you receiving the type of support you want and need for your child, and for your family, from the early intervention program. You should experience this support from the first phone call to the day your child exits the program.

One of the best ways to receive support and to feel supported is to be able to ask questions and to expect answers. This is where your program staff comes in. They should be open to questions from you and be able to give answers that tie directly to the promises made to your family through Part C of IDEA.

Parents often report that they have many questions, however, they may not know when, how or if they can ask their questions. Parents sometimes worry about offending the early intervention providers or of asking questions that make them sound like less than a perfect parent. Sometimes parents hesitate to ask questions for fear of losing some of the program supports and resources that are already in place for their child and family. In other instances, parents ask questions and are either not given the answer or are given a less than satisfactory answer.

This document offers a series of short stories written from the perspectives of families. Each story is followed by a short summary of the rights and roles of the family according to IDEA. After the summary a list of suggested discussion questions

follow. These discussion questions are intended to offer samples for the types of questions families might ask during different activities and processes of the early intervention program.

It is not the intent of this document to offer every possible story or question but to offer a model for families and providers in how, when, and why questions should or could be asked and answered.

The resource is written primarily for parents, but also for their early intervention providers, so that everyone has a chance to explore questions that are sometimes considered but never asked. The hope is that parents begin to ask these and other questions and that providers begin to anticipate such questions, and find ways to make sure parents get the answers they need and in a way that is understandable.

We are going to group the stories under the following ten categories:

Promises to Families:

1. Confidentiality,
2. Family Decision Making,
3. Partnership,
4. Comprehensive Evaluation and Assessment,
5. Family Capacity Development,
6. Individualized Services,
7. Natural Environment,
8. Transition,
9. Service Coordination, and
10. Dispute Resolution Options.

The stories shared in this document are not designed to cause you worry or to put your guard. The majority of the time early intervention services go smoothly. Parents, in general, report high levels of satisfaction with Part C services. The stories are intended to acknowledge that we are all human and sometimes providers misunderstand or just do not know the answer to a question. Sometimes parents misunderstand what is being said by providers. Sometimes parents and providers simply disagree. However, we believe that the more information parents and providers have about parental rights and procedural safeguards, the more smoothly the process and services will go. Our intent is that these stories help to open up the communication between providers and parents.

## 1. Promise to Families: Confidentiality

### **Family Story: How do I protect the confidential details of my family's daily life?**

My daughter, Marja was born very early, three months early. Since the day she was born, people have asked questions and I have answered questions, some of which I consider very personal. It seems like that I have to share every detail of my life. Sometimes I just plain feel violated. When I left the hospital, I thought that all of that was over and today, when the person from the early intervention program called to schedule our first appointment, she asked for 2 hours and said, it's an intense discussion about our day-to-day life. She said I could share as much or as little as I wanted to about our family and activities of our day. She said it would help to identify the priorities for the plan we will develop. I can tell you my priority! Right now, I just want to be left alone to get to know my daughter. My plan is to get some sleep. I know there are things Marja needs and that I may need help to figure it all out. I just do not understand why helping Marja means telling these strangers all about my life; it is my life we are talking about! Marja is too little to have a life!

### **Rights and Roles of Family**

You have the right to protect information about your family. Generally, when this right is explained to families, the focus is on having control over who sees the information or how it is stored or eventually destroyed. However, confidentiality also gives you protection during collection of information. You have the right to share as much or as little information as you want and you have the right to ask why the information is being collected or why they need to know.

### **Suggested Discussion Questions**

Help me understand more about why you need to know the details of my day? How will this help my daughter?

What do you mean when you say I can share as much of my day as I want to tell you? Would there be a reason for not sharing certain parts of my day?

What if I shared something with you that I do not even want my doctor to know? Will this remain confidential between us? How will you protect my information?

Social services has an open case with our family. How is what I say shared with social services? I know I have to give you permission to share the information you gather, but exactly what do you share? Is it facts? Your perception? Can I see what is shared before you share it? Will you share my information over the phone? In writing? If over the phone, how will I be informed of what was shared?

### **Family Story: How do I make sure that my son's involvement in early intervention does not show up in his high school records?**

I know it may sound silly since my son is only two years old, but what I really want to ask is if it will show up on my son's records that he was enrolled in early intervention. The minute Maddie, the person from the early intervention program said the words, special education, I have been worried about this. I do not want to make decisions now that will negatively impact my son later. I do want some help with his speech but if it means that being enrolled in special education stays on his record, I would rather go without services or find someone private. Then I worry, have I already gone too far just by letting the people from the program come to my house? I signed some papers that said they could evaluate him. Do I have the ability to make sure his information is protected?

### **Rights and Roles of Family**

You have the right to control who sees your child and family information outside the early intervention program. Before anyone can access information about your family, you must give your permission in writing.

However, there is one exception to this rule. When a child is close to age three, if they are enrolled in early intervention, the team would typically look at the need for services after their eligibility ends with the early intervention program. The process is usually referred to as transition (or your child's team may use the word notification or referral). Each program submits the child's name, date of birth, and the parent contact information (names, addresses, telephone numbers) to your local special education program serving children at age three. This does not require parental consent and Kansas does not have an opt out option for parents. This information must be shared with your local school district no later than 90 days before the child's third birthday and as early as nine months before the third birthday.

### **Suggested Discussion Questions**

I am worried that my son's enrollment in early intervention will show up on his high school record and I do not want that to happen. Can you explain to me if there is a process for preventing it?

I understand that at age three, you send information about my family to the school district. I do not want my child's information sent to the school district. Can you explain if there is a process for preventing my child's information from being shared?

How long does the early intervention program keep the records they have on my child and family? Where do they keep these records?

When my child leaves the early intervention program can I ask that all the records be destroyed?

## **2. Promise to Families: Family Decision Making**

### ***Parent Story: They keep asking me to sign a Prior Written Notice (PWN)***

Since day one, it seems my service coordinator, Janelle, has been intent on my signing a form called “Prior Written Notice”, but in my opinion that is all it is to her, just a piece of paperwork to sign. She often asks me to initial that I agree to waive my ten day notice before the meeting or action that is being proposed and it is pretty clear she expects that I will waive the ten days as we are usually right at the timeline limit that she has to complete the paperwork. I like Janelle but I will have to say I get frustrated every time she asks me to sign the form. It seems to not make much of a difference to the process. I mean sometimes I don’t feel like I completely understand what we are doing or why. For example, the other day she had me sign a notice saying we would have a meeting to update our outcomes but I don’t see why we need a meeting. I am o.k. with what we are working on. Sometimes I want more time to think about things than I am given or time to talk to my husband first, but it seems really important to her that the paperwork is in line, completed, and on time. regardless. So often, I just don’t ask. I wonder how to get her to slow down when I need her to, skip the paperwork when I don’t think we need it, either take it all seriously, or just skip it all together.

### **Rights and Roles of Family**

You are right. The purpose of a prior written notice is more than just getting the paperwork done. The prior written notice is intended to make sure you have enough information about a meeting or a proposed change and assure that you feel like this is the right decision for your family. The intent behind this prior written notice is to give you enough time prior to the meeting to plan, to organize your thoughts and questions, or to invite family, friends or other advocates that might be able to assist you in making the best decisions for your family.

The Prior Written Notice form you receive is about much more than the date, time, and place of the meeting (which should be acceptable to you). Prior Written Notice should include an explanation of who will attend, what their roles are, what the purpose of the meeting is, or what the proposed change is. The form’s intent is to engage your family in a thorough discussion of the process. It is a time to answer any questions or concerns you might have. It is a time for you to express differences of opinion or conflicts and to prepare for the discussions around these differences and conflicts. The notice is not just about your agreement and acknowledgement as part of participation, it honors your right to disagree as part of participation. The

prior written notice should tell you and help you understand the what and why of a meeting.

### **Suggested Discussion Questions**

I feel like the paperwork is sometimes just something we are doing to get done or to meet a timeline. I would like to slow the process down a bit, so that I am comfortable and sure that I have all the information I need to make decisions, or I have time to get feedback from everyone I need to talk to. Is there a way we can change how we are doing things so that if I need the whole ten days, then I am allowed the ten days, but at the same time, we make sure you have enough time for you to meet your timelines?

Can you help me understand the purpose of the paperwork? Sometimes it does not make sense to me. Why do we need to do paperwork about a decision we just both agreed to during our face-to-face in discussion? Seems like busy work. Is it all really necessary?

### ***Parent Story: Can I just choose to quit?***

Angela, Joey's teacher just left. As usual, I am left wondering why I have her come. All she does is sit on the couch and ask me a million questions I don't know the answer to. If I knew how to help him gain weight, I would not have called her. I would love to just quit the program, but I am not even sure I can. I know that the program is through the school district, and when I was trying to decide if I wanted to send Amy to kindergarten when she had just turned five, they said I could wait, but once I started, she had to keep going. There was no turning back. I wonder if Joey's program has the same rules. Angela is nice enough but it just isn't helping me. She says she is a coach, but doesn't a coach teach the players how to play?

### **Rights and Roles of Family**

Services for families enrolled in programs under Part C of IDEA are voluntary. You have the right to withdraw or decline any service. If you decline, the program staff has the responsibility to make sure you are fully aware of the evaluation, assessment, and early intervention processes. The staff also needs to assure that you understand that your child will not be able to receive evaluation, assessment, or early intervention services unless consent is given. So, bottom line, you can choose to quit. There is no mandatory attendance involved.

With that said, it sounds like you might be more concerned with how services are being offered rather than what services are being offered. Evidence based practice (EBP), which providers are required by IDEA to practice, is sometimes misinterpreted by providers. In this instance, you might want to ask for more information about what coaching with parents involves according to EBP. For example, the research around coaching with parents indicates that five key characteristics need to be in place for coaching. These characteristics are joint planning, observation, action/practice, reflection, and feedback. If your provider is

only asking questions then it sounds as there may be a misunderstanding by your provider about coaching and that would be a point of conversation.

As a parent, you have the right to ask questions and request alternatives if what is happening does not match what you believe needs to happen in terms of support for your family. There are many options available for you to bring your questions to the table. Generally, the first step is to discuss your concerns with your coach, Angela. If you are not comfortable doing this or you have done this and she does not seem to be listening, you can call her supervisor and ask for an IFSP review. If no one at the program level seems to be listening, there are informal and formal complaint and dispute options available to you. These options range from calling to talk to someone at the state agency, mediation, or due process. It is generally in everyone's best interest to work things out at the local level if possible. However, there are times this is not possible without outside help. Getting outside help is not always the easiest thing to do, but often results in services being changed so that you feel you are getting what you need for yourself and your son.

### **Suggested Discussion Questions**

Angela, I have some concerns about how our visits are progressing. I would like to discuss how things are going from my perspective. I feel like you are asking a lot of questions but I don't feel I am also being offered solutions for the questions. I need some suggestions for what I can do to help Joey. Sometimes I will need you to show me what to do as well as tell me what to do. These are some of the issues I want to discuss.

Angela, I would like to request an IFSP review to discuss Joey's progress. I don't feel like I have the information I need to help Joey, and I would like us to work together so that I have what I need.

(To Angela's supervisor). I would like to discuss some concerns I have with my services. I don't feel like I am receiving strategies that help me with my son. I spoke to Angela and it didn't change the situation. I would like to schedule an IFSP review meeting with the three of us to discuss my concerns.

I am have been thinking about how my services are going. I am thinking about quitting. If I decide I don't want services any more will you turn me into child welfare?

I know you have talked to me in the past about medication and due process. Can you remind me what those terms mean and what is the difference?

(To state lead agency). I would like to discuss some concerns I have with services in my hometown. I spoke to my direct service provider and her supervisor but I don't like any of the solutions. I would like to request support for all of us to work through this issue. I would like to share my story with you.

### **3. Promise to Families: Partnership**

***Parent Story: I am not sure that the primary service provider is going to meet his needs.***

My son Larry and I just moved to Kansas to live with my sister. Wow, things are different. In the last program, we had an occupational therapist, a teacher, and a speech language pathologist working with Larry. They came one or two times a week, usually in teams of two. Now they tell me that that one person can meet all of Larry's needs. Honestly, I just don't see how. They said the one person has access to other team members if she needs them. That doesn't seem to make sense to me. First of all, what do they mean by access and why can't I have access directly to the other staff instead of going through someone? I have lots of questions. I am not sure what they are suggesting is wrong, because working with so many people in the last program was so very hard, but it seems like we are drastically reducing the help Larry will receive. I wish I had someone to talk to.

#### **Rights and Roles of Family**

You have the right to ask questions about the service delivery model that is utilized by the program. Asking questions is part of your right to fully participate in all decision making about your child and family's services. You always have the right to give consent before any service. Also, you may decline a service after accepting it without jeopardizing other early intervention services. Sometimes it is very helpful to talk to other parents about early intervention programs. The program you are enrolled in will be able to help you find a support group or a parent training and information center in your area. Many programs have parent-to-parent programs in which you are matched with a parent that will help you work through your questions.

#### **Suggested Discussion Questions**

I have a lot of questions about the service delivery model you are proposing. It is drastically different from the one we had where we lived before. Could you provide me with the information that shows the effectiveness of this model?

I have many questions and concerns about what you are proposing for Larry. I would like to talk to other parents that have been in your program about their experiences with your service delivery model. Can you help me connect to an experienced parent?

What are the steps I need to take if I want more services than what you are proposing?

If we try these recommendations and Larry doesn't make progress, how long will we wait before we change things? What is the timeline and criteria for assessing whether progress is being made?

If I disagree with the recommendations, or decline all or part of the services, can you explain the next steps to me?

#### **4. Promise to Families: Comprehensive Evaluation and Assessment**

##### ***Parent Story: Does Caleb have autism?***

Does Caleb have autism? I have asked myself this question a million times over the last few weeks. The early intervention team is coming tomorrow to do an evaluation for Caleb. I am so worried. I have so many questions. The doctor thinks he might have autism. I don't really know what that means, except I know it isn't good. I asked them if they would be able to tell me for sure if he had autism and they said they did not do the work to provide a diagnosis. I don't understand that. If my doctor is worried about autism, and they can't tell me if that is what is going on, then why did he send us to this program? If they can't diagnose, who can?

##### **Rights and Roles of Family**

The program's evaluation is completed first to establish eligibility. The staff will also look at Caleb's strengths and needs and your families' resources, priorities and concerns concerning Caleb's development. Once the evaluation and assessment are complete, the team will work with you to find services and supports to meet those needs and how you can build everyone's strengths. Eligibility for early intervention in Kansas does not require a diagnosis. This is why the staff member is telling you that they don't do the work to provide diagnosis. If your team suspects that Caleb does have autism, they can work with you to schedule an evaluation with a diagnostic team to determine if he has autism. Some programs have this expertise on their team; others will need to help you find someone outside the team to provide this service.

##### **Suggested Discussion Questions**

I am interested in finding out if Caleb has autism. I would like your help setting up a diagnostic evaluation, in addition to, or in conjunction with, the evaluation, your program is conducting.

I would like to connect with another parent whose child was evaluated to see if he or she had a diagnosis of autism. I have a lot of questions about this process and would like to talk to someone who has been in my shoes.

##### ***Parent Story: I need to know who is going to evaluate my daughter.***

I have so many concerns about Valarie's development. She is way behind her twin sister Vicki. I thought that she would catch up but it isn't happening. The twins were born six weeks early, but they were a decent weight and the doctors were not worried when we left the hospital. Still, they turn six months old tomorrow and there is a big difference between them. One thing I am really worried about is Valarie's vision. I am not sure she can see. The program staff said they are sending

two people out. They called them early interventionists. I am wondering what their credentials are.

### **Rights and Roles of Family**

You have the right to ask questions during the evaluation and assessment process and should be an active contributor of information. The evaluation must be comprehensive and multidisciplinary. This means that the team must look at all areas of Valarie's development. This includes things like how she uses her words, how she plays, and how she moves. They will also ask questions about her health and will assess her vision. The evaluation and assessment must involve staff from at least two separate professional disciplines (i.e. occupational therapy, physical therapy or education) who are qualified to evaluate all areas of your child's development. The IDEA law outlines the qualifications you should expect.

### **Suggested Discussion Questions**

I would like to know more about your qualifications as an evaluation and assessment team. Would you share with me your credentials and experience? I also want to know what areas of Valarie's development you will be looking at and what the process looks like. I want to be sure we evaluate Valarie's vision. I am concerned that she is having trouble seeing. I want to be involved as much as possible. I am with her every moment of every day. I know Valarie.

## **5. Promise to Families: Family Capacity Development**

### ***Parent Story: Should I have the other kids out of the house during the time Zachary has therapy?***

The provider from the early intervention program is going to be here on Wednesday. When they came to the house to do the evaluation for Zachary, it was pure chaos. With five kids under seven, it is always chaos. We made it through the evaluation but I am not sure they got the information they needed. It is tough when I am trying to answer questions and attend to the kids. They said that if Zachary qualifies, all the services would be at my house. I wonder if I need to get a sitter for the other kids. I don't know how I could swing that financially or who would do it, everyone I know is crazy busy or working during the day.

### **Rights and Roles of Family**

The beauty of this program is that the providers you are working with have, as part of their mission, a responsibility, and a belief in meeting the needs of the whole family as they relate to Zachary. That means that not only can the other kids stay for the visits, but you can expect your team to help you figure out what needs done for Zachary while at the same time meeting the needs of your other children during the visit. Sometimes it might mean pulling the other kids into the activities of the visit and also the activities of the week. Other times you might have a question about your other children, and the team can offer support or help you find resources.

### **Suggested Discussion Questions**

I need some help structuring our visits so that I can focus on what Zachary needs but at the same time meet the needs of my other children.

I want some information about how to talk to my other children about Zachary's needs and why extra people come to our house to see him.

I want some information and support around meeting the needs of all my children, not just Zachary. I would like to have our conversations take into account the needs of the whole family. I want to meet Zachary's needs but not less so than those of the other children. All are equally important.

### ***Parent Story: We are just trying to survive and schedule.***

It's time for the IFSP review. Tara, my service coordinator, told me to be thinking about our conversations and activities over the last few months and what our families' priorities are so we can think about next steps. My real answer is... surviving and scheduling. Timothy has been so sick since he was born. It never ends. There are so many doctor appointments, meds to give, work demands, taking care of Samantha, she is only three, and she still needs so much. Then there is trying to find time for Joe and I. Sometimes I wonder if our marriage will survive. There's nothing left to give each other at the end of the day.

### **Rights and Roles of Family**

You have the right to expect Tara to focus on the concerns of your whole family in relation to Timothy not just in relation to his development.

The early intervention law or IDEA and best practice guidance recognize that support to the family, as a whole is one of the most important things that can be done in support of Timothy. Therefore, having conversations about the well being of your family fits perfectly with meeting Timothy's needs. Sharing your stories and priorities are important. Sharing the fact that right now your focus is on surviving and scheduling is perfectly legitimate. In meeting Timothy's needs, you also need to meet your own needs in terms of your quality of life and your family's quality of life. Having conversations with Tara and letting her know what is going on behind the scenes will enhance her ability to support your family and to make recommendations that fit with all that you have on your plate. Tara could also help connect you to another parent. Sometimes talking to an experienced parent who has had similar experiences can help you think about the needs of your family, and how to effectively convey what your family needs to Tara.

### **Suggested Discussion Questions**

Tara, in addition to talking about what we want to achieve in terms of Timothy's development over the next six months, I want to talk about adding in some outcomes that help us focus on support for me and the rest of the family.

Tara, to be honest, the last six months has been about surviving and scheduling. I want to be sure that what we plan for Timothy fits with what we need to do as a family. I would like your help doing that.

I would like to talk to another parent who has already survived the first year! Can you connect me with someone you think would be a good fit for me?

***Parent Story: I am so depressed. I asked Jen, my early intervention provider, if that is why my son Ben doesn't talk.***

I asked the big question. I have been debating asking it for a while. Did I want the answer? I haven't had the energy to get off the couch most days. It has been so hard since Ben and I have been on our own. I worry about taking care of Ben, and paying the bills. Now that Ben is two and he isn't talking I worry every day. He makes a few sounds, maybe they are words, but he isn't anywhere close to where he should be. Jen has been coming once a month for two months and things aren't getting better. One of the problems is that she really doesn't work directly with him. She talks to me and shows me things to help me know what I should do during the day to work with him. It seems easy enough but what she doesn't understand is that most days, I don't have the energy to do much talking at all. I don't know how to get the things done she suggests when I feel this way. I realize that in order to help Ben, she has to understand this. So, I asked. Am I the reason that Ben can't talk? She got really quiet and didn't really give me an answer. Her silence gave me my answer. Then she said something like all we need to concentrate on now is that he is in early intervention. However, that's the point, that's why I asked. I know it is important for him to get early intervention but if I am the key, then the key is broken. We need a different plan.

### **Rights and Roles of Family**

You have the right to ask for help for yourself. Sharing what you are thinking and how you feel is critical to Jen being able to provide support for your family. The services provided by early intervention can range from those directly related to Ben's development to services to support both you and Ben, such as individual or family counseling. The recommendations should support Ben and also be made with your well being in mind. Letting Jen know that you need support and that Ben might need support beyond what you can offer right now is o.k. That said, sometimes early intervention providers are not sure how to help. Jen's silence might likely be an indicator that she was trying to figure out how to help and what words to say. It is important to realize that Jen is not the only person on the team who might be able to assist your family. She should have additional team members, such as social workers, who may have more experience with issues of depression. Both Jen and yourself could seek out extra support from others on the team.

Your concern about the connection between your well being and Ben's progress is a question that has high priority for you. It will also be important to assure that Ben's lack of progression is not due to a developmental diagnosis or other medical issue that has not yet been uncovered. Sometimes lack of progress is connected to a need

for different strategies or recommendations. Making sure the team is looking after your needs, and at the same time, carefully looking at what might be going on with Ben are equally important..

Finally, another option to consider might be for Jen to come more often. Frequency of services should be a decision made that is connected to both Ben's needs and your needs. If you need visits more often in order to get the support you need for Ben, than this is something to discuss with Jen. In addition, you might think about other places Ben spends time and other people he interacts with on a regular basis. Are there others Jen can be working with to add to the support you provide for Ben?

### **Suggested Discussion Questions**

Jen, I am struggling. I need some help to meet Ben's needs. I don't feel well enough most days to carry out the strategies we have talked about. Is there someone we can talk to in your program that can help me figure out how to get the help I need in order to help Ben?

I need someone to help me stay on top of what Ben needs. It would be helpful to me if you came weekly to help me really problem solve how I can best help Ben learn to talk. I would like to discuss this.

Ben is at my mother's house quite a bit. Can you do visits with her or can she come to our visits? My mother is a huge support to both Ben and I.

### ***Parent Story: As the father, I feel invisible.***

I love our coach Tammy. She has brought hope into our home! My wife, Cristina, loves when Tammy comes, it is so helpful to her. I want Cristina to have support. She is with Michael all day, everyday and he keeps her constantly busy. She does everything Tammy suggests and then some. They have great conversations about what Cristina can do to help Michael. More than that, Tammy provides emotional support to Cristina. Tammy and Cristina have discussed evaluating Michael to rule out autism; many tears have been shed during these and other discussions. I can't say enough about what Tammy has done for our family. I feel selfish for even thinking this, but Tammy does such a great job supporting Cristina, I am often left out of the picture. If I am there, Tammy does a great job of including me but to be honest, most of the time I feel invisible. Sometimes, Tammy asks questions of Cristina about me while I am in the room. For example, the other day she asked, 'Is Chad able to help on Saturday afternoons so you can get some you time'. I was sitting right beside Cristina. And it isn't just that. I have questions, lots of questions, and they aren't always the same as Cristina's. But most of the time the visits are scheduled when I am at work. I have asked on several occasions for the visits to be scheduled when I am home, but it is rare.

### **Rights and Roles of Family**

You have the right to ask to be more actively involved and to have your questions answered. You have the right to have the early intervention meeting scheduled at a

time that works for yourself and your wife. Early intervention parental rights extend to both parents. The evaluation, assessment, and intervention should include all who elect to participate and should reflect the resources, priorities, and concerns of yourself and your wife. In addition, research supports the inclusion of every family member and highlights the unique contributions only father's can make to the development of their child.

### **Suggested Discussion Questions**

I appreciate all you do for our family. However, I want to talk about how I can be more actively involved in how and when information is shared. I have many questions. Some are the same questions that Cristina has but some are different. I also want to talk about some different options for scheduling.

### ***Parent Story: Are you here for me or for my child?***

I called the early intervention program so that they could come and help Trevor learn to talk. My wife and I have tried everything we know to do and would like more ideas on how to help Trevor. During the visits Susan, the early intervention teacher, spends at least the first fifteen minutes doing what I would call visiting. She asks how I am doing, and about how my week went. I understand when the questions have to do with our daily routines, activities and how I can carry out the strategies, they recommend. That makes sense, but that is where the focus should stay...on Trevor and strategies I can learn to help him.

### **Rights and Roles of Family**

You have the right to let the program staff know which services and supports your family wants and needs. Many families find it helpful to use the early intervention program as a resource as they seek additional support for themselves in relation to their well being; because they believe it will help them meet their child's needs. Often providers have been trained to ask questions as a way to make sure the whole family is receiving the support they need and want from the early intervention program. Providers have also been trained to use informal conversations as a way to develop trust and build a working relationship that is needed to partner with parents. However, if these strategies do not fit what you need and want from early intervention, you can let your providers know what you need in order for the early intervention process to be successful for you.

### **Suggested Discussion Questions**

I appreciate that you care about my well being. However, during our visits, I would prefer to focus only on Trevor's needs in relationship to moving his development forward. I don't mind spending a minute or two visiting at the beginning of the visit but I really want to spend the majority of our time talking about what Trevor needs or trying out different strategies while you are here.

## 6. Promise to Families: Individualized Services

### ***Parent Story: I want more services!***

My wife, Betty is way more patient about this than I am. Our daughter, Candice is one year old and has a diagnosis of Down syndrome. She isn't walking yet. She isn't making a lot of sounds. Even though Betty and I work with her constantly, we are not seeing much progress. I have talked to other parents and I have read everything I can get my hands on, and from what I can put together, the more services the better. Our doctor agrees. He thinks Candice should be seeing a speech and language pathologist, a physical therapist, and a teacher. Our early intervention program doesn't agree. We have one person that comes out, Adam, the teacher. That made some sense to me when she was little but now it is time to get to work! There are 17 services listed in the law, and I can see that Candice and our family could benefit from almost every one of them. I have asked for a meeting to review the IFSP. I need to figure out a way to impress upon them how important I think it is that Candice and our family has access to every possible service so that Candice has the best possible life.

### **Rights and Roles of Family**

You have the right to ask for an IFSP review at any time if you feel like the current IFSP is not meeting the needs of your family. IDEA, Part C lists 17 services and you have a right, along with your IFSP team, to consider which of these services and related supports are needed to meet the outcomes included on your IFSP. That said, not every need might equal a service. Some of the services can meet a broad array of needs. There is research that supports what your doctor told you, that more is better. However, discussions with your early intervention team can help you determine who can most effectively deliver the "more". Research shows us that support in teaching parents to embed intervention into daily routines and activities is one way to achieve more. The research also tells us that a productive way to support parents is in the context of a primary service provider model. There is research to support the primary service provider model which is most likely the model your program is using from your description. In the end, the services and

supports must be appropriate to meet both your needs and your daughter's needs. Additionally, services must be provided by those qualified through credentials and/or experience. Also know that you have the right to have an advocate, or person outside the family, participate in the IFSP meeting. Many families find it helpful to bring in an advocate or perhaps someone with expertise specific to a certain diagnosis, such as autism. Other parents request that their physician be included in the IFSP meeting.

### **Suggested Discussion Questions**

I would like to schedule an IFSP review. I believe that there are some services we are not currently accessing that would help Candice and our family. I realize that services must be related to outcomes we hope to achieve so I would like to review our outcomes to make sure we have the services in place to help Candice grow and develop. I believe that Candice has some needs that are not being appropriately addressed.

How do we know when enough services are being provided? How do we know if the early intervention staff are coming often enough to help Candice?

I would like to schedule an IFSP review to discuss our outcomes for Candice and to make sure we have all the supports and services in place needed to assure the best outcomes. I would like to invite someone from our parent support group. In addition, I want to include our doctor in the IFSP meeting

## **7. Promise to Families: Natural Environment**

### ***Parent Story: I want my daughter to go to a preschool for children with vision loss.***

There is a preschool in our city that serves only kids with vision loss. They take kids as young as two years old. The people there are experts in helping kids like my Heather. She is getting close to two and there is so much she needs to know. I have talked to the center, and they are willing to work with us, but they said that Part C funds would not cover the preschool services because they are not considered by the state to be a natural environment. The center said this is because only kids with vision loss attend the preschool. In my mind, this is a perfect place for her. I am not talking forever; I would like to see her back in our neighborhood by kindergarten. However, I think this is a good solution for now, until we get a better handle on what it means to have so little vision.

### **Rights and Roles of Family**

It sounds like you have a good understanding of the concept of natural environments. The law states that you have the right to participate in home and community settings in which children without disabilities participate. The law also uses the words 'to the maximum extent appropriate'. Services can be implemented in settings other than the natural environment, if more appropriate, as determined

by the parent and the IFSP Team. However, this only applies when early intervention services cannot be achieved satisfactorily in a natural environment .

### **Suggested Discussion Questions**

I would like to request an IFSP review to discuss Heather's services. In particular, I would like to review the possibility of enrolling her in a preschool that specializes in meeting the needs of children with vision loss.

I believe we are not able to satisfactorily meet all of Heather's needs within our home and community environment. I believe that a preschool specializing in meeting the needs of children with vision loss will be valuable in meeting her early skills in orientation and mobility. Our stated outcomes of increasing her ability to move and play are not progressing and I believe that may be because she is so hesitant to explore her environment. I would like an IFSP review to discuss how our current resources fit this priority.

### ***Parent Story: Why does it matter where services are offered?***

I guess I am missing something about this whole natural environment thing. Debbie, my early intervention coach, is adamant that we meet at my house. I work full time and by the time we get home, it is time for supper, bath, and bed. I would love to have her meet me over lunch near where I work, or maybe we could meet at my mother's house. My mom watches Christopher while I work, so I could meet her there before we get home and get into our night routine. Anything would be better than visits as soon as I walk in the door!

### **Rights and Roles of Family**

The intention of meeting in your home is to meet the requirement in IDEA to provide services in the natural environment, which is the place where Christopher would be typically during the day. In addition to the natural environment being a place, it means that the parents, other care providers and early intervention providers have a chance to discuss everyday learning opportunities that occur during the daily routines and activities of life. In order to truly support the natural environment, to provide intervention recommendations and to individualize strategies, providers need to discuss and observe Christopher and yourself involved in the activities of daily living.

Given all of that, it does seem that some of these conversations could take place in other places such your mother's house. From your description, your home is not Christopher's only natural environment. It sounds like he spends much of his day at his grandmother's house while you are at work. Requesting visits in this setting where Christopher spends a significant amount of his time is an appropriate request. However, as a part of these discussions it will be important to talk about how the intervention strategies fit within your evening routines, what supports are needed for home, and how progress will be evaluate.

## **Suggested Discussion Questions**

Scheduling visits when I am just getting home is not working for our family. Actually, it is adding stress. I would like to consider other options such as Saturday visits or having some or all visits at my mother's house.

## **8. Promises to Families: Transition**

### ***Parent Story: Thoughts during a surprise IEP meeting***

Our family just started early intervention at the beginning of December. I have been so concerned about my son Ethan's behaviors that it was wonderful to find someone willing to help me instead of judge me. I love the person who comes out to visit us, Kelly. But nothing good lasts forever. Kelly told me when we started, that she could only work with my Ethan and until he turned three; and his birthday is February 13. Right after Christmas, we started talking about preschool options and then things started moving fast! We had a meeting in my home and the preschool teacher attended. She seemed nice but she did NOT say the same things Kelly said. Kelly and I had talked about Ethan attending preschool only two days a week until he got used to it because change is so difficult for him. The preschool teacher, Janet, said that wasn't how it worked. He would have to go all four days. I told her I didn't want him to be upset or cry and she said 'Oh, he will. He might cry all day, everyday for a month.'

Oh my gosh! I have been upset ever since! That is not in line with my thinking of parenting nor my belief about how parents and children connect to each other. To top it off, they talked about my BABY riding a bus! NO WAY! Still, I need the help especially with a new baby at home and because Ethan's behaviors are escalating! So I consented to the this meeting which they said was an evaluation, but now, out of the blue, they want me to sit down and write what they are calling an IEP and they are talking about Ethan starting preschool in two days! I feel like a tornado just ripped through my world! My son and I have never been apart except for him to go to grandma's house. I haven't even had a chance to think. I am not sure this is what I want. I feel like they are not listening to me! I wonder how to slow all of this down and have them listen to me without risking not getting help. I also wonder if he goes to preschool, how is that going to help me figure out what to do at home and how is it going to help me with figuring out how he can accept his baby sister so I can keep them both safe? I thought I had help at home from the early intervention teacher at least until his birthday. I am so confused!

### **Rights and Roles of Family**

You have the right to slow everything down. One of the things that might be going on is that the team is worried about some of the legal timelines around transition. You and Ethan got started a little late in the process. However, there are legitimate reasons for slowing down if that is your choice.

Transition is the term used by providers to describe the process of moving from one program to the next. By law, this transition should go well for your family. The law

uses words like smooth and seamless to describe transition. You can expect your early intervention service coordinator, Kelly, to be by your side answering questions and facilitating the process during all the stages of transition.

During this process, you always have the right to have all of your questions answered and to have a say in any part of the process. Kelly's role is to help you understand what your choices are during this transition process.

All of the parent rights that have been in place since you enrolled in early intervention are still in place. This includes the right for you to be the ultimate decision maker for your family.

### **Suggested Discussion Questions**

We need to slow everything down. I would like to discuss a timeline that meets my family's needs.

Somewhere I remember something about 10 days before meetings and changes, remind me of those rules.

I would like more time to think about how I want all of this to go for my family. I think a week would give me time to talk to my husband, and to think carefully about what is best for our son and our family before we move ahead.

I would like to reopen the conversation about how many days per week Ethan would go to school. I think it is in Ethan's best interest to go only three days per week.

Could you help me understand what interventions would be used to help Ethan adjust to the classroom if crying does occur?

What type of support can I get to help me to handle Ethan's behavior at home?

**Parent Story:** What happens when Al turns three and services end? What if he is not fine by then? How am I going to get information to help Al?

### **Rights and Roles of Family**

Before Al turns three and services end, your service coordinator should work with you to develop a transition plan. This plan must be in place not less than 90 days, but not more than 9 months, before Al turns three. This timeline is at the your discretion and working with your early intervention team. Therefore, if you are worried about transition, and it is between 9 months and 90 days before Al's third birthday, you can request an IFSP review to get started on this plan. This plan will have all the information you need for making sure Al receives services and supports he needs at age three. An early childhood special education preschool or some other appropriate service in the community may be considered. It will also include a plan for how you will continue to receive support. As in all aspects of early intervention,

transition should include plans to meet the needs of all family members around supporting Al's development

### **Suggested Discussion Questions**

I know Al doesn't turn three for six more months but I am getting worried about what happens next. I have a lot of questions. I would like to schedule an IFSP review to develop our transition plan at this time.

(At the transition plan meeting) I would like to look at options for Al when he turns three, and I also want to be sure that the supports I need are in place as well.

## **9. Promises to Families: Service Coordination**

### ***Parent Story: Can Kelsey come to Quinton's appointments?***

Quinton is scheduled to go back to the Spina Bifida Clinic at the children's hospital next month. Even though it is a month away, I am already dreading it. We see so many people and they offer so many suggestions. English is not my first language and the day is long when I am trying to understand everything that is being said and trying to answer all of the questions. One of the questions I can never answer is why we are not getting more services from our early intervention program. The doctors at the clinic think we should be seeing the speech therapist more often. In fact, they have referred me to a private speech therapist. This is one more appointment for me to keep track of and one more set of recommendations to add on to everyone else's. It is hard to keep it all straight and to decide which direction to go when what one provider tells me differs from what another provider tells me. I wonder if Kelsey, my service coordinator, could come with me to Quinton's appointment at the clinic or if she can help me set up the private therapy. She could help me explain why we don't see the early intervention speech therapist more often. She could help me explain how things work at the program Quinton and I are enrolled in. I also wonder if she can help me make sense of all of the recommendations.

### **Rights and Roles of Family**

You have the right to ask for the support you need to help pull together, into one plan, all of the different aspects of Quinton's intervention. This is what the IFSP is designed to do and what the service coordination is all about. It is Kelsey's responsibility to help you access, coordinate, and monitor the delivery of services and supports for Quinton and yourself. Requesting Kelsey's support during visits to the clinic is certainly an appropriate request. Requesting support to help schedule the private clinic, and making sure information from all is shared in a way, you can understand, is something that Kelsey can assist with. Sometimes it might be Kelsey that can directly support you or it might be another member of the early intervention team. Some parents find it helpful to ask an experienced parent to

accompany them as they try to navigate the service maze. You mentioned that English is your second language. You have the right, in all aspects of early intervention, to request that things be explained in your native language.

### **Suggested Discussion Questions**

Kelsey, I am having difficulty understanding all of the information and recommendations shared at the Spina Bifida clinic. It would be really helpful if I had someone with me at those appointments, will you go with me. I would like us to brainstorm some possible solutions.

I think it would be really helpful to meet another parent of a child with a diagnosis of Spina Bifida. Would you help connect me? Or is there a parent group in town that might assist me in finding someone to go to appointments with me?

I think I need a translator when I go to the appointments at the children's hospital. Would you help me find this resource?

I would like for everyone who works with Quinton to be on the same page. It would be helpful to me. Is there a way for you, the early intervention team, the clinic, and the new private therapist to communicate better? I get recommendations that do not fit one with the other. I need help navigating through all of the different agencies and providers that work with us!

## **10. Promises to Families: Dispute Resolution Options**

### ***Parent Story: I am just plain unhappy and no one is listening. What are my options?***

O.k. I am done. I keep saying the same thing over and over, and no one is listening. I talked to my early intervention coach Paula. I talked to her boss. They keep saying they hear me, but nothing really changes. My son, Gerald, has a diagnosis of autism and they are only sending one person out once a month, well, twice a month since I complained. However, more than that, when she does come out, it seems she knows less about autism than I do and she can't answer my questions. I want the intensity of services increased and I want someone who is trained in working with kids with autism. Paula says she has only worked with two children with autism, but that is two more than anyone else on her team. I know they mean well, but from what I have read, if I do not do as much as I can right now while his brain is still developing, then we have missed our chance. My son and I cannot wait. I think it is time we all have someone else come in and figure out what needs to happen.

### **Rights and Roles of Family**

It sounds like you have exhausted all of your avenues in your local program to have your voice heard. You have the right for your voice to be heard when you believe your rights are not being protected by your local program.

There are process at the state level that exist to protect you and your child's rights. These processes are mediation, informal and formal complaints, and due process. All of these can be explained by someone at the state level agency (lead agency) that is responsible for the program you are enrolled in. Paula should be able to give you a website or a telephone number to call for more information. It is fine to ask Paula for the number for the state agency or if you are more comfortable doing so, you may want to call Paula's supervisor for this information.

### **Suggested Discussion Questions**

I believe we need some additional support to help us to come to a satisfactory solution around the areas we disagree about in serving Gerald's needs. I would like to call the state (lead) agency level for that support. I will need the number or website address for the agency.

### **Summary**

As we stated at the beginning of this document, these stories are not meant to worry you. They are meant to provide examples of times parental rights and procedural safeguards have potential for misinterpretation or misuse. We believe that providing stories about what it doesn't look like will help both parents and providers to understand what correct interpretation would look like. We hope that the message that comes thorough is that only through open and honest communication with everyone involved in asking and answering questions/providing information, can true partnerships grow. The beauty of being human is our ability to communicate with one another. We hope that when things do not make sense or when you are not comfortable, please view your early intervention provider as an equal partner and share your perspective.