

### **Box 1: Context of Limited Empirical Evidence**

**[1a] Parent participant (10016):** *“The most difficult part, I guess, is the unknown....I think the most difficult piece of it was just the lack of information in one location. We had to go through so many avenues to get the information that I needed to feel better about the decision that we were making. I needed all the information, and we had to go everywhere.... That’s the hardest part. It’s so hard to make the decision when you don’t have all this data.”*

**[1b] Provider participant (20001):** *“I think just the uncertainty of what is going to give their child the better long-term outcome is really hard...The fact that I can't totally resolve that uncertainty”.*

**[1c] Provider participant (20026):** *“Lack of us knowing what we're doing [is most challenging] ...we need to get more data to know what we are doing. Are we really helping them or are we doing more harm? Do we need further stringent criteria to decide on this or is what we're doing okay? I think those are the questions that we need to answer...I think it's lack of data and knowing if we are doing the right thing for this child or if we are actually harming them more than we are helping.”*