# **Chapter 1: Lived Experience**

**Introduction:** Working with professionals to address your child’s disability, education, and needs can be stressful. Meetings can cause fear and anxiety if you don’t understand the process or don’t feel your team is understanding you or your child. You can learn from other parents who have gone through the process. Reading about other’s experiences can help you feel less alone and you can learn about what helped them be successful in team meetings.

## Definitions:

* **Lived Experience:** Lived experience is the things that someone has experienced themselves, especially when these give the person a knowledge or understanding that people who have only heard about such experiences do not have. For families raising children with disabilities, lived experience can mean you have feelings of guilt, loss of opportunities, maternal sacrifice, worrying about the future, social isolation, lack of socioeconomic support, and stigma. It can also mean your family is strengthened by the challenge, or you are happy and fulfilled when your child reaches an important milestone like talking or walking.
* **Family:** Families provide support, love, and care, and a sense of belonging by providing social, emotional, physical, and other support to each other.  Family includes parents, brothers, sisters, children, grandparents, aunts, uncles, foster parents, and others who share responsibility and support for each other.
* **Professional:** A professional is a member of a profession who has special experience and expertise in their area of practice. A professional is someone whose job requires special education, training, and skill and who is subject to standards and ethics in their field.
* **Team:** A team is a group of diverse individuals, all working together for a common purpose. The individuals on a team should have common goals and objectives and work together toward achieving those goals.

## What Families Should Expect:

Your lived experience is important and should be valued by professionals working with you and your child. Your lived experience has taught you so much about your child and their strengths and challenges, and your team members should use your knowledge to help make good decisions about services and supports for your child. Make sure you share your lived experience with your child’s team as you work to address your child’s needs. Find a way to share information that works for you. If you are not comfortable speaking up at meetings, share your information in writing, or ask a trusted friend or advocate to attend meetings with you to help you feel supported and able to share information.

## What Families Want Their Team Members to Know:

* Sharing personal information about my child or family can be hard, especially in a large group of people at a team meeting. I may be sharing intimate details about my family life. Creating a welcoming environment at meetings will help me to share important information. You can make me feel welcomed by introducing yourselves, making sure I understand the meeting agenda and information, and scheduling enough time so that the meeting is not rushed and all of my questions can be answered.
* Raising a child with a disability is very stressful. Listening to professionals focus on my child’s limitations or problems is hard to hear and adds to the stress. You can make my lived experience better if you strike a balance in discussions during meetings. Remember to also focus on my child’s strengths and abilities when planning for my child’s services and supports.
* I know my child better than any professional can. The information I have about my child’s abilities and challenges can help you make better choices about services and supports and will help you to understand my child’s likes and dislikes. Please listen to what I have to say about my child and use it to better serve my child.

## What Professionals Want Families to Know:

* We know that what is happening with your child at home or in the community impacts how your child will do at school. You can help us meet your child’s needs by communicating with us about your child’s morning or evening. If your child struggled to sleep or had a bad morning, let us know so that we can provide more supports that day, and if your child had a great experience in the community, let us know so that we can reinforce that experience at school.
* Sometimes as professionals, we don’t know how to provide the right supports to you as a parent. We don’t know everything that is going on in your life. If you need extra support, let us know so that we can work to find that support. On-going communication about your family stressors and needs can help us be a better team.

## Family Checklist:

* Have I shared my lived experience with my team?
* Have I found a way to be comfortable in speaking up at my child’s team meetings?
* Do I share ideas with my team about how to best support my child based on my personal experiences about what works and doesn’t work for my child?
* Have I found ways to feel supported as a parent, and have I shared that information with my team?

## Professional Checklist:

* Has our leadership provided professional learning opportunities for staff to learn to support family needs?
* Have we organized our meetings to be welcoming to families, including creating agendas, introducing participants, diversifying participants, and cultivating a nurturing environment?
* Do we encourage team members to focus on the child’s strength as well as challenges in all that we do?