

Privacy and Confidentiality

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Privacy and confidentiality are concepts with which all First Steps providers are familiar. Provider contracts, contracts with agencies for whom providers may work and licensing requirements all carry with them obligations to follow various laws and regulations surrounding the protection of privacy and confidentiality for families served in the First Steps system, most notably FERPA and HIPAA.

Because the First Steps system is governed under the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA) it falls under the auspices of the Family Educational Rights and Privacy Act. Also known as FERPA, this act passed in the mid 1970's explains families' rights, opportunities and responsibilities when participating in educational programs such as First Steps, preschool and school. FERPA is generally described as having more stringent requirements than the Health Insurance Portability and Accountability Act (HIPAA) which many are now familiar with through interactions with the health care community.

Commonly referred to as FERPA, but also known as the Buckley Amendment, this law has critical importance to our work as early intervention providers. It makes sure that information about individual children and families is kept confidential. This law requires us to obtain a family's permission in writing before we share any information about them or about their child. Practically speaking, it is why we do not discuss families or their children in public, or with friends and colleagues or with our significant other. Information that is included in the child's early intervention record is to be kept confidential and not shared without the family's written permission to do so. If the family gives their consent, the information to be shared and the person with whom it is to be shared must be named specifically in that written permission. It is not possible for a parent to give a general overall permission to anyone nor can an agency ask that they do so. Families may also revoke their consent or permission at any time.

The First Steps early intervention system expects that all providers become familiar with FERPA and fully comply with the rules and regulations of this law. Providers confirm their understanding of this expectation when signing their Provider Agreement to participate in the First Steps system. Many providers have found it helpful to have a print copy of FERPA in their working files to have handy.

You can find a copy of a helpful brochure that describes the basic rights, opportunities and responsibilities of families on the First Steps Website under the Publications tab. Titled *Families Always Have Rights* the brochure describes these basic rights in clear, understandable language. These rights include:

1. Families have the right to an evaluation.
2. Eligible families have the right to a coordinated plan.
3. Families have the right to consent.

4. Families have the right to prior notice.
5. Families have the right to privacy.
6. Families have the right to review records.
7. Families have the right to participate.
8. Families have the right to understand.
9. Families have the right to an advocate.
10. Families have the right to disagree.

Visit the First Steps Website at http://www.state.in.us/fssa/first_step/pubs/index.html to access this brochure for more details about each of these rights. To review more information about FERPA and HIPAA and to access copies of these laws for your own review, visit these Websites.

Family Educational Rights and Privacy Act (FERPA)

<http://www.ed.gov/policy/gen/guid/fpco/ferpa/index.html>

Health Insurance Portability and Accountability Act (HIPAA)

<http://www.hhs.gov/ocr/hipaa/>

It is valuable to remind ourselves of these responsibilities and to consider how to ensure the appropriate protection of privacy in situations that we often encounter as First Steps providers. The critical nature of this issue as it affects families is often only apparent when there has been a breach of a family's confidentiality and privacy. A breach can be emotionally traumatic to a family and can complicate their lives in many ways. It is useful to think about how a breach of confidentiality might occur. Consider these examples.

NO NAMES

It is clear to all providers that they should not speak about a child or family using their name(s) outside of the provision of services. It is also important to consider the many other characteristics of a child or a family that, when shared, do in fact identify the child and their family members. Sharing an anecdote about a family and including an unusual sibling group or family size may inadvertently but clearly reveal the identity of the child or family about whom you are speaking; similarly, sharing information in terms of a child's diagnosis, particular medical equipment used or unique behavior may reveal who that family is.

WHO IS IN THE ROOM

Having a conversation with a parent about their child within their home would appear to meet all requirements of privacy. However, homes that include visitors, additional caregivers, helpers and other individuals may be settings that do not allow for private and confidential conversations. Parents have the right to decide how much information others will have about their children, even if those present are regular participants in the child's care and seem to be a part of the "team" in that family's life. If providers do not have permission to do so, speaking about a child's diagnosis, development and other issues in the presence of others is a violation of confidentiality.

Often conversations about families take place between providers outside of official IFSP meetings. This may be necessary to serve a family appropriately and to communicate effectively with a family's team of providers. It is vital that the setting of such conversations is considered. Using Local Planning Coordinating Council, Transition Committee and other meetings (or the time immediately before or after) as a chance to touch base may be an efficient use of time. However, if community partners, parents or other providers are present, such conversations can and do violate privacy. If you choose to engage in a conversation about a family before or after these meeting, it is critical that you find a private space to do so or arrange a different meeting time and place to have these discussions.

Similarly, we often meet in public places, such as restaurants to catch a quick bite between appointments, churches and schools where our personal connections bring us together. When others overhear conversations in these settings, privacy is violated. Discussing details about a child or family is never appropriate in a public space.

THE ELECTRONIC AGE

Much of the communication we have in this modern era is electronic in nature. It is vital for us to consider that such communication can often take on a "life of its own." Emails can easily be forwarded beyond their intended recipients, breaking confidentiality. The "reply all" buttons both on email and on listservs can instantly and irretrievably send information to multiple recipients. Messages left on voice mail can be retrieved or heard by someone other than the intended recipients. It is a requirement that provider electronic and voice mail communications are protected to the maximum extent possible. Email accounts and access codes can not be shared with spouses or others; providers must maintain private accounts. Messages left in families homes should be considered unsecured and should not contain personal and private information. Information about diagnosis, services plans, eligibility and other similar details should never be left on a message. It is also critical to be mindful of where we are when having phone conversations that discuss confidential information about a family. Having "your side" of the conversation overheard while you talk at the grocery store would constitute a breach of privacy.

NO EXPIRATION

During the period that we serve families, we often develop close relationships with families that include extensive knowledge about their lives. It is natural to want to check in on families months or years after we stop serving them. While many families welcome and appreciate this continued communication, when it comes in a setting other than direct contact with the family, we are risking breaching their privacy either by disclosing a previous professional relationship or by receiving updated private information about them. Providers must be diligent about not putting others in position of violating confidentiality. Asking a colleague how a family who you once served is doing now is asking them to breach that family's privacy.

THE STORY BELONGS TO THE FAMILY

Parenting a child with special needs is often a unique and powerful experience, one from which many lessons are learned. Often as providers we seek, with good intentions, to share those lessons for the betterment of others. Perhaps we are passing along encouragement to one family in the form of another's story, illustrating the importance of early intervention by sharing stories of its impact, or putting intervention techniques into context with an anecdote about another family's experience. It is important to note that intentions do not shade the degree to which we are bound to protect a family's privacy. A family's story is its own; as providers we may have access to a part of that story, but in sharing the story we are taking something that belongs solely to the family. Families are often happy to have parts of their story shared if it would be of benefit or support to other families. As providers, we simply need to ask permission before sharing a family story with others.

SETTING EXPECTATIONS HIGH

Appropriate practice in support of privacy protection within a family's First Steps experience can serve not only to support a family's positive relationship with providers but also assist a family in gaining knowledge as to their rights and what to expect as they navigate the many systems their child will encounter throughout their lives. Often First Steps providers are "setting the stage" for a family's expectations of the professional conduct, an expectation that will extend across environments.

No doubt all First Steps providers strive to maintain and preserve the confidence of families who participate in the system. Given the importance of confidentiality it is critical that each provider regularly review the rules and regulations regarding FERPA and HIPAA. It is also important for providers to support each other in maintaining the highest level of confidentiality as required by these laws. As such, sharing questions and concerns about confidentiality is encouraged. Discussing confidentiality during IFSP meetings and with each other regularly helps to keep everyone informed and reminded about this most basic component of a successful early intervention experience. Do you feel comfortable with your understanding of confidentiality and the law? What will you do next to ensure you and your colleagues completely understand and support these concept