

CHILD CARE

plus +

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Supporting Inclusion in Early Childhood Settings

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+ Maintaining Confidentiality in Your Program

Effective partnerships with parents and families are grounded in mutual respect. As you build relationships with parents of children in your care, you may be told or given information about them or their child that is not shared with everyone. A child's disability, medications, therapies, educational goals, or what is happening at home are examples of information that you should keep confidential out of consideration for the family's right to privacy and your goal to establish trusting relationships with families.

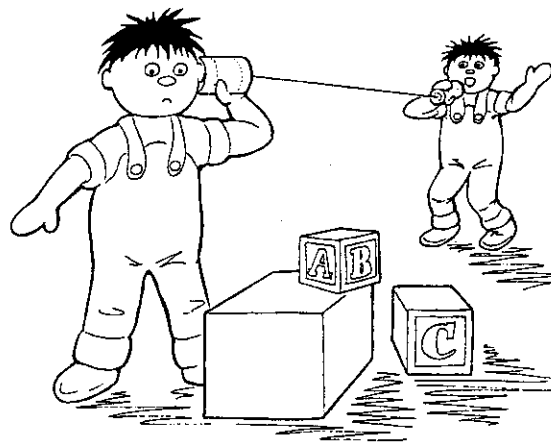
Showing respect for a family's privacy is often referred to as **maintaining confidentiality**. Maintaining confidentiality essentially means that individuals and agencies—including early childhood professionals—may not give or receive records or other information about young children or their families without written permission from the parents or legal guardian. Permission is voluntary; parents have the right to change their minds and revoke their permission at any time. In addition, parents must be given the opportunity to review records about themselves and their children upon request. If team members or others ask for your caregiving reports or observation notes, they must also present written permission from parents for you to give information to them.

Many everyday situations can challenge your ability to maintain confidentiality. Here are a few tips:

- ▶ Observations and caregiving notes about specific children should be kept in a closed notebook or folder.
- ▶ Daily plans related to children's IFSP or IEP goals should

also be kept concealed or the child's name erased.

- ▶ If you put up lists to remind you of medications, new words, or skills a child is practicing, do not put the child's name or any other identifying information on the list.



In addition to records and other written information, it is important that you maintain confidentiality when it comes to talking about children and their families. It is natural to want to share events of the day, progress a child has made, or concerns you may have. Whenever you begin to describe a child to someone other than the child's parent(s), confidentiality may be jeopardized.

For a variety of reasons, a few parents may be reluctant to allow the release of records or information to you. They may be unsure

about how the information will be used, for example, or fear that if you know everything about their child's disability, you will treat the child differently. Remember that this is their right, and in fact, many parents feel obligated to protect their child's records. As you develop a collaborative partnership, it is likely that parents will eventually recognize your need for more information about their child. If not, this is a decision you must respect and accept without judgment.

The one exception to getting parental permission before releasing information to other professionals or agencies is when you have a reasonable concern that a child may be neglected or abused. In this instance, you are required by law to report your concern to the proper authorities whether or not you have parental permission to share this information. This serious situation demands that your primary concern be for the welfare of the child.

Unless you have already developed a philosophy which includes the principle of maintaining confidentiality, the whole idea may come as a surprise to you. While confidentiality takes effort to maintain, responsible providers willingly make the effort to safeguard the privacy of the children and families in their programs. + SLM

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+ FROM THE SOURCE

Should I or Shouldn't I?

Maintaining confidentiality requires a commitment on the part of all members of a child's early intervention or special education team. Just as another professional must have received a signed and dated request form from the parent before sharing any information with you, **you** may only disclose records or exchange information with other individuals or agencies with written permission from parent(s). It is very important that you never give out any records or information that you received from another individual or agency (a copy of the child's IFSP, for example). You can only release records which you generated in your program. If agencies need other records, they must go to the original source of the record.

Most parents are cooperative when the information you are seeking benefits their child and improves the care you offer; they will either give you the information themselves or the written permission you need to seek information from other professionals. The only person(s) who can share whatever information they wish, when they wish, and with whom they wish are the parent(s).

Without written permission, you cannot obtain the child's records, but you can still gather general information from the local library, professionals such as your own pediatrician, or agencies familiar with children with disabilities such as United Cerebral Palsy. Although not specific to an individual child, this kind of information will be helpful as you learn more about the care a child needs while in your program and formulate specific questions to ask the child's family. + KMG



+ MAKING IT WORK

Developing a Request for Information Form

In order to do your job as an early childhood professional, you need to develop a way to get parent permission to gather information from other members of the team working with a child. While there is no special form that you need to use, there are essential pieces of information you must include. You can develop your own form to request information as long as it includes the following elements:

- ▶ the name and address of your program and/or the individual who is requesting the information
- ▶ the name and address of the individual or agency from whom information is being requested
- ▶ the type of information requested (IFSP, IEP, medical records, resource list)
- ▶ the child's full name
- ▶ the child's birth date
- ▶ a parent's (or legal guardian's) name and signature
- ▶ the date signed
- ▶ a simple paragraph describing your program and any specific requests (optional)

This form is your request for information from the particular individual and/or agencies designated by the parent as important to their child's inclusion in your program (physician, occupational therapist, nutritionist, etc.). You need a separate form for each individual or agency. It is important that the parent date the request form because a signed request is only valid for one year from the date of signing. You can use this form to request copies of records, summary reports, a phone consultation, or permission to attend a therapy session. + KMG

+ NOTES FROM HOME

Parents Want To Know Why

Before we enrolled our daughter, Karen, in child care, we looked at different programs trying to find the one that offered the best early childhood experiences and the best teachers. I was adamant that Karen have at least one setting where she was treated like a "typical" kid. Because she has spina bifida, we see a lot of specialists. I wanted the child care program to be a place where we could escape from the disability focus. So when the program director asked me to sign an information request form so she could get a copy of Karen's Individualized Family Service Plan (IFSP) and other records, I refused. I wanted the child care program staff to treat Karen like all of the other kids—this was the one setting where I hoped her disability wouldn't be the primary concern.

A few months later, Karen's teacher asked again if I would be willing to share the IFSP. She explained that it would help her develop better lesson plans if she knew more about what Karen could do and which skills we were working on. That was the first time I realized that Karen's special needs could be incorporated into the games and activities that happened in child care. Although still a little reluctant, I signed the form to give my permission.

Now I wish that at the very beginning, the director had explained why it was important for them to have Karen's IFSP and how they were going to use it. You can't blame parents for wanting to protect their child's (and their own) privacy. I would suggest that before child care providers ask parents to sign a request for information, they are sure the parent understands how it will be used. I remember being offended when asked to release Karen's records, and I am sure that other parents feel the same way. I refused to sign the request the first time because I thought it would turn child care into one more "special" service, and I never thought that having more information about Karen's needs could actually make the child care setting a better place for my daughter. +

+ SPOTLIGHT: NAEYC Code of Ethical Conduct

The National Association for the Education of Young Children (NAEYC) *Code of Ethical Conduct and Statement of Commitment*—adopted in 1989 and amended in 1992—was created by NAEYC's Ethics Commission. Often called the *Code of Ethics*, it provides guidelines for responsible behavior and establishes a common ground for early childhood professionals to resolve ethical and moral issues encountered in daily practice. The foundation for the *Code of Ethics* is a commitment to quality early childhood practices, including providers' goals to:

- appreciate childhood as a unique, valuable part of the human life.
- base program practices on knowledge of child development.
- appreciate and support the child/family bond.
- understand children in the context of their family, culture, and society.
- respect the uniqueness and worth of children, family members, and colleagues.
- develop helpful relationships based on trust, respect, and positive regard.

The *Code of Ethics* is presented in four sections which describe professional relationships with *children, families, and early childhood colleagues*, and responsibilities to the larger *community and society*. Each of these sections begins with a brief, clear description of primary ethical responsibilities and then lists both ideals and principles to consider. The ideals describe "best practices" written as goal statements. The ideals help you to develop and express your own goals for creating and maintaining effective professional relationships. The principles provide specific examples of practice that can guide your actions in the resolution of ethical dilemmas.

The *Code of Ethics* provides a useful guide to help you address complex questions that are not answered by early childhood research or laws. In some cases, the *Code of Ethics* provides specific direction such as encouraging the development of "written policies for the protection of confidentiality and the disclosure of children's records." However, the *Code of Ethics* is not intended to provide a formula for resolution of ethical dilemmas. Rather, it offers guidance in the problem-solving process to enhance ethical and responsible decision-making in early childhood programs. NAEYC suggests a three-step approach for using the *Code of Ethics*:

1 Decide what makes a challenging situation an ethical dilemma. Perhaps the goals of the program are conflicting with a parent's goals for the child or there is conflict between staff members about program practices.

2 Consider all of the people involved in the dilemma and sort out the issues each person must examine. The players might include parents, the program director, early intervention specialists, staff members, or even public policy-makers.

3 Refer to the *Code of Ethics* to consider priorities and responsibilities as you work toward the ethical resolution of the dilemma.



The usefulness of this problem-solving approach is enhanced by a regular feature called *Using NAEYC's Code of Ethics: A Tool for Real Life* in the organization's journal *Young Children*. This feature presents an ethical dilemma and solicits solutions developed by practitioners using the *Code of Ethics*. These examples may be helpful as you work toward solving ethical dilemmas in your own program.

As you consider issues surrounding confidentiality, you may find the NAEYC *Code of Ethical Conduct* and the problem-solving approach useful in clarifying policies and actions in your program. The *Code of Ethics* establishes a professional ideal "to develop relationships of mutual trust with families we serve." Two supporting principles from the *Code of Ethics* describe the practice of maintaining confidentiality with families in your program.

We shall develop written policies for the protection of confidentiality and the disclosure of children's records. The policy documents shall be made available to all program personnel and families. Disclosure of children's records beyond family members, program personnel, and consultants having an obligation of confidentiality shall require familial consent (except in cases of abuse or neglect).

We shall maintain confidentiality and shall respect the family's right to privacy, refraining from disclosure of confidential information and intrusion into family life. However, if we are concerned about a child's welfare, it is permissible to reveal confidential information to agencies and individuals who may be able to act in the child's interest.

A copy of the *Code of Ethical Conduct and Statement of Commitment* can be found 1) in the March 1996 issue of *Young Children*; 2) in a brochure (#503) available in Spanish and English from NAEYC, 1509 16th Street, Washington, DC 20036-2460 (1-800-424-2460) for 50¢ per copy or 100 copies for \$10; and 3) on the Internet at www.america-tomorrow.com/naeyc/index.html. + SHW

+ WHAT DO I DO WHEN . . . ?

QUESTION: *I understand the importance of maintaining confidentiality, but I'm confused about what I can and cannot tell families in my program. For example, can I tell a parent that a child has Down syndrome? What do I say when they ask if a child will ever be able to walk? What if they ask about how often or why a child has seizures?*

ANSWER: Sounds like you have discovered that maintaining confidentiality is not always easy. There are no simple answers as to what can and cannot be revealed. This is an ethical dilemma you will continually face even when you already understand why maintaining confidentiality is so important and are doing everything you can to ensure that private information remains confidential.

Here are some guidelines that might help you. 1) When parents of children with disabilities enroll their children in your program, explain how important privacy is to you. Ask for their input about what to say about their child if there are questions. You might ask if you can tell inquisitive parents that the child has Down syndrome. This helps parents learn more about this disability. Or you might ask how they would prefer that you explain seizures to other children and parents if the child should happen to have a seizure in the program. If parents understand why information might need to be shared and feel comfortable with the plan, you gain a valuable tool for teaching other children and adults.

2) Try to discover why parents are asking about a child. Have they observed a behavior they have never seen before? Are they concerned that their child might be hurt or "catch" something? Are they simply asking for help understanding the importance of inclusion? Knowing their purpose

Child Care plus+ staff are available to answer questions, brainstorm, problem-solve, and provide resources and training regarding maintaining confidentiality.

Call 1-800-235-4122

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for asking the question will help you respond appropriately. 3) Try to anticipate questions that might be asked about a particular child. You could even brainstorm suitable responses with other providers. (Be sure to do this without identifying the child.) Maintaining confidentiality is a great topic for a staff meeting, child care association meeting, or early childhood conference session. + SMG

+ RESOURCE REVIEW

Because child care providers and other early childhood professionals may be unfamiliar with getting parents' written permission and exchanging confidential information with other professionals, therapists, and specialists, *Child Care plus+* has developed a sample **Request for Information** form. This sample gives you a guide to create a form to fit your own program's needs. To receive a free sample form and instructions, write: *Request for Information Form*, Child Care plus+, 052 North Corbin Hall, The University of Montana, Missoula, MT 59812, or call 1-800-235-4122, (406) 243-5467 (voice/TT), or FAX (406) 243-4730. +

CHILD CARE plus+ is designed to support inclusion of children with disabilities in early childhood settings by supporting child care providers, parents, and community service providers including social workers, therapists, physicians, teachers, and administrators.

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