ASSOCIATION OF
Child Life
Professionals

SOCIETY OF
PEDIATRIC NURSES

Pediatric Bill of Rights

INTRODUCTION

The Pediatric Bill of Rights is a statement of the rights to which children and their families are entitled as recipients of care in healthcare settings. Children and their parents/legal guardians are responsible to engage and work in partnership with their healthcare team in the planning and delivery of care.

Pediatric Bill of Rights

In this healthcare setting, you and your parents or legal guardians have the right to:

Respect

- Have people tell you their names, what is going on, and why.
- Be called by the name and pronouns you prefer to use.
- Feel lots of different feelings, and for people to understand that sometimes you may need to cry if you feel afraid or hurt.
- Express emotions.
- Cope in ways that are unique to you.
- Receive care without judgement because of race, ethnicity, origin, religion, mental or physical ability, sex, gender expression, etc.
- Respect for your personal space in the exam room.

Privacy

- Have people honor your privacy.
- Have your information shared only with people who need to know so they can assist in your care.

Information

- Learn about the reason you are here and receive information in a way you understand.
- Learn about what is happening to you with people who you want present to support you.
- Ask questions so you understand your treatment plan and care.
- Know the names of the people taking care of you and what they do.
- Be prepared for procedures ahead of time.
- Have an adult, including a qualified interpreter if needed, help you and your family or legal guardian understand health related information.
- Tell us about yourself, what you need and how you feel.

Support

- Talk to or engage in play with caregivers who know how to help when you have questions or problems.
- Explain any wait times and help you go home as soon as possible.
- Receive care that lessens your pain or discomfort.
- Receive care that respects your need to grow, play and learn.
- Have access to people and things that help you feel safe and comfortable, like your favorite toy from home or your own clothing when it is okay.

Patient & Family-Centered Care

- Take part in shared decision making to plan your care with your family and health care team.
- Receive support and comfort from your parents/family members or legal guardian.
- Have your family help take care of you, stay near you, and be with you, especially when things about your care are explained to you.
- Receive care that values your cultural, and religious and personal customs and beliefs and supports your medical, physical, and emotional needs.
- Feel safe both physically and emotionally and receive care that is free from verbal, physical, sexual, and emotional harm.

Choices

- Make your own decisions when possible and have us support your choices.

Flexibility

- Have your interests considered and needs met, not just those related to illness or ability.
- Have time to rest, to play and to learn in ways that help you feel your best.
- Have your home routine maintained whenever possible.

Bill of Rights for Parents/Legal Guardians

In this healthcare setting, you and your child have the right to:

Respect

- Treatment without judgement because of age, race, religion, sex (including pregnancy, childbirth or related medical conditions), gender identity, sexual orientation, national origin, or disability, genetic information, marital status, military status or any other legally protected class. Be called by the name and pronoun you prefer to use.
- Request care that supports your child’s quality of life and is consistent with your values, religious beliefs, and customs.
- Ask your providers to introduce themselves and explain their role in your child’s care.
- Expect your providers to listen and recognize your needs and your expertise in what is best for your family.

Privacy

- Expect the things you tell your providers in confidence will be kept private as long as it is consistent with the law and is safe for you and your child.
- Know that information about your child and your family will only be shared with members of the healthcare team who need that information.

Information

- Be informed of any patient safety issues and action taken.
- Have the services/treatments explained to you in detail by someone who speaks your language, including a certified medical interpreter.
- Ask questions about your child's care and treatment plan.
- Ask to review your child's medical record with healthcare personnel.
- Access detailed information about your child's medical bill.
- Know the process for taking care of your concerns or complaints.
- Expect caregivers to understand and adjust care to your child's developmental level.

Support

- Ask to have someone from your family or another support person with you when receiving information and explanations.
- Stay with your child during most medical treatments if you choose.
- Have at least one family member stay near your child when they are hospitalized.
- Talk with the healthcare team about your feelings, questions, problems, or concerns.
- Receive resources to equip you with providing care for your child.
- Collaborate with the healthcare team to address your child's pain and fear.
- Receive help to connect with community resources and/or other families who have had experiences like yours.

Patient & Family-Centered Care

- Know the people who take care of your child in the healthcare setting, and what they do.
- Expect the members of your child's care team (e.g., doctors, nurses, child life specialists, etc.) to know how to care for children and youth.
- Coordinated care across teams.
- Expect all healthcare providers to make patient safety and quality care their priority.
- Participate in the planning for and care of your child at whatever level is most comfortable to you, to achieve mutually agreed upon treatment plan and goals.
- Receive education and the skills training you will need to take care of your child at home before you leave the healthcare setting.
- Receive appropriate follow-up information and who to call in case of an emergency.
- Transfer your child to another healthcare setting.
- Be notified before your child is moved to another department.
- Receive a list of possible primary care physicians, if you currently do not have one, before being discharged from the hospital setting.
- Access a team member/specialist to assist with concerns and/or conflict resolution.

Choices

- Work in partnership with your healthcare provider to:
    - Make decisions about your child's treatment options and care.
    - Include your child in decisions related to their care.
- Refuse treatments as permitted by law.
- Change your mind about care for your child even if you have already given permission.
- Ask for a second opinion from another doctor. You can ask for a specialist to see your child.
- Access to an ethics consultant to clarify and resolve ethical issues in decision making.

Flexibility

- Expect your healthcare provider to consider your child’s interests and needs, not just those related to illness or disability.
- Expect your healthcare provider to adjust the treatment plan based on your child's physical and emotional response to care.
- Expect your healthcare provider to keep your child’s schedule and activities as normal as possible.

Responsibilities of Patients, Family Members or Legal Guardians

Patient Responsibilities

- Ask questions to fully understand what we are telling or showing you.
- Talk with the healthcare team and your family about your fears and pain to help you feel more comfortable.
- Show respect and be kind with your behaviors and words.
- Talk to your healthcare team and family about your thoughts and concerns.
- Do your best to adhere to the treatment your care team recommends for you.

Family/Legal Guardian Responsibilities

- Ask questions to fully understand what we are telling or showing you.
- Contribute to the development of a plan to address your child’s fear, manage pain and provide comfort.
- Show respect for the knowledge and skills of the healthcare professionals you encounter.
- Tell your healthcare providers your concerns in a clear and kind way.
- Participate in the planning and care of your child at your level of comfort.
- Show respect for the rights of other children and families in the healthcare setting.
- Engage in education and learning skills necessary for the medical care of your child.

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