

---

# Introduction

---

Your child with special health care needs faces challenges in many areas: medical, social, educational and vocational. Professionals in each of these fields can provide assistance within their own areas of knowledge, but you, as your child's parents, cannot leave the management of your child's care totally in the hands of the professionals. You must also become a part of the team caring for your child. This Coordinated Care Record has been designed to help you become a full member of your child's special health care team.

As parents, you know your child best. You live with your child and see him or her in all areas of life, at home, at school, at the doctor's office, etc. Also, as parents, you have only your child's interests at heart, so you are in a good position to advocate for your child. The services and providers of service will change throughout your child's life, but you will most likely remain as the constant in his or her life, the ones most familiar with your child and his or her history.

Health care and other services for your child will be most helpful when these services are made available in such a way that you have the maximum possible involvement. You can achieve this level of involvement only by becoming an equal partner with the professionals who are offering the services required by your child.

In order for you to become equal partners with professionals in caring for your child, you need to become educated consumers of whatever it is your child is receiving. If it is medical care, education, financial assistance or any other type of service, you need to learn about that service, who provides it, how you get it, and what your responsibilities are. The purpose of this workbook is to give you some guidelines to use as you become educated consumers. Another purpose is to supply you with a framework to help you gather information and coordinate care for your child.

You will be learning about different kinds of programs and services throughout your

child's life. You will meet people from many agencies, with a variety of backgrounds: doctors, nurses, teachers, social workers, etc. You will learn to ask the right kinds of questions to get the information you need to make decisions about your child's care. You will learn how to be a member of a team working for the betterment of your child. Skills you will learn include communicating, negotiating, coordinating, and coping, just to mention a few. This workbook will give you guidelines in the form of "Tips," worksheets to help organize information about your child, and a place to keep specific reports or papers important to your child's care.

The titles and order of the workbook sections were recommended by our parent advisers. They told us that parents worry first about what is wrong with their child and how to treat it. Therefore, the first section is a place to keep health and medical information. The worksheets reflect questions most often asked by health professionals or information most often required.

The next thing parents worry about is "how am I going to pay for this?" The second section addresses funding. The "Tips" discuss types of funding available to help pay for bills. The worksheets will help you identify your child's specific insurance coverage. There is also space for you to keep information about your eligibility and funding from the state's Division of Specialized Care for Children.

The third thing parents worry about is their child's education and whether they will be able to support themselves as adults. "Tips" include some general information about educational and vocational programs in Illinois. The worksheets are designed to help you identify and record the educational or vocational programs your child is involved in. A space is included for you to keep copies of important educational plans or school reports.

While we hope children will receive the services they need and parents and professionals will be able to work together as

teams, we realize this is not always the case. The section titled "Rights" contains information about your rights and what to do to assert those rights.

The last section is entitled "Other" because there was a lot of information the committee wanted to share with parents but it did not fit neatly into any of the other sections. So this section is just that - "Other."

Each section of the Coordinated Care Record includes pages for notes you may wish to

make. Also, you will be able to add pages to any of the sections, if you like. Use the Coordinated Care Record in the manner that you feel will make it the most helpful in meeting your personal needs.

The Division of Specialized Care for Children is committed to supporting the principles of family-centered, community-based, coordinated care. This workbook is a result of that commitment. We hope it will help you in your endeavors to obtain the best possible care and services for your child.