

delAware – Summer 2010 – Transition

The Care Notebook: A Record-keeping Tool

A care notebook is a valuable organizational tool for families of children and adolescents with disabilities and special health care needs. It is the place to keep track of – and maintain an organized record of – important information about a child's health care, services, and providers. The care notebook is designed to help organize the information in a central place to assist both families and providers. This is a perfect compliment for the medical home model, which promotes coordinated care between the health care team and the family.

Care notebooks have a variety of uses and benefits. Caregivers can share the notebook with health professionals and educational staff to provide continuity and assure the best care possible for their child. The notebook can be used to track changes in medicine or treatments, list contact information for providers and community organizations, file information about health history, and help families prepare for appointments. It serves as an easy-to-access reference for families and professionals.

For teenagers who are increasing their independence and preparing to transition out of child-centered services, the care notebook can be an additional way to understand and participate in their own care. Keeping a care notebook encourages adolescents to be more engaged in their health care, provides information about their condition and health history, and helps them prepare for emergency situations. The notebook is a valuable resource when teens are developing a care plan for the future.

Delaware Family Voices Family to Family Health Information Center periodically offers training for families and providers on how to put together a care notebook. Please call Michelle Lamers at 302.831.6608 to learn about future training sessions, or visit **www.delawarefamilytofamily.org**.

The following websites are valuable resources for learning more about care notebooks and the steps to take to construct them; they include examples and blank forms.

- Build Your Own Care Notebook, National Center for Medical Home Implementation, American Academy of Pediatrics: **http://www.medicalhomeinfo.org/tools/care_notebook.html**.
- Planning and Record Keeping, The Center for Children with Special Needs, Seattle Children's Hospital, Research and Foundation: **<http://cshcn.org/planning-record-keeping>**.