

Agenda

12:00 Welcome

12:05 Electronic Care Notebook –
Yvette Baptiste & Fran Goldfarb

1:05 Questions & Answers

1:30 Conclude

Yvette Baptiste, MA is the Executive Director of the Family Resource Library in Alhambra, CA. She is the mother of 3 children with special needs.

Fran Goldfarb, MA, CHES is the mother of a young adult who has Asperger syndrome. She is the Director of Family Support at the USC University Center of Excellence in Developmental Disabilities (UCEDD), Childrens Hospital Los Angeles (CHLA) and serves as Parent Faculty in the Interdisciplinary Leadership Education in Neuro-developmental and Related Disabilities (LEND) program.

Electronic Care Notebook

For Children with Special Needs





Presenters



Funded by California Consumer Protection Foundation



Electronic Care Notebook

Learning Objectives

- The concept of EMR and how healthcare organizations are making them user friendly
- Parent care notebooks get an electronic makeover
- Top 10 reasons it is important to keep copies of medical records about your child



ELECTRONIC MEDICAL RECORDS (EMR)



Electronic Medical Records

- What are EMRs?
- Why are we concerned about them?
 - Industry trend
 - Healthcare reform
 - Consistent with Medical Home
 - **Accessible**
 - **Family centered**
 - **Comprehensive**
 - **Continuous**
 - **Coordinated**
 - **Compassionate**
 - **Culturally competent**⁷



Electronic Medical Records

■ Benefits

- Test results are available more quickly
- Easier to share information with other providers
- Reduces error by having up to date information
- Allows patients more control of and understanding of their own medical information – more transparent
- The more you know the more you can be involved in the decision making



Examples of EMR systems

- Healthcare Partners-
<https://mypop.healthcarepartners.com/>
- Kaiser –
https://members.kaiserpermanente.org/kpweb/toc.do?theme=myhealthmanager_members
- Healthnet –
<https://www.healthnet.com/portal/member/selectRegion.do?forward=member.home®ion=CA>



By any other name it's still the same

ELECTRONIC CARE NOTEBOOKS



How can the Care Notebook help me?

- The Care Notebook is simply a filing system, but it is also a way to get to know your child's issues in an organized way, makes it easier for you to tell others what you want for your child



How can the Care Notebook help me?

- It is tempting in a parent's busy day to day life to use the "pager bag system" of filing. However, inevitably when you want to put your hands quickly on information necessary to get services and help others understand your needs, you will be grateful to yourself for having filed the information in an easy-to-find order.



Cardinal Rules

- Give it in writing. Get it in writing.
Know where it is.
- If it isn't in writing, it didn't happen.



How is the notebook organized?

Table of Contents



How can the EZ Access Notebook help me?

- Track changes in your child's medical care and needs
- Keep phone numbers handy
- Track status of action steps and communications



How can the EZ Access Notebook help me?

- Add new information and documents
- Keep track of and prepare for appointments
- Take the notebook with you to appointments or the ER so you will have information easily available



How to put together your Notebook

Many generic and disability specific notebooks are available, don't really need an example, just put things on a flash drive even...the organization is up to you!

AAP -

http://www.medicalhomeinfo.org/for_families/care_notebook/

- UCEDD – All About Me
- Local Early Start FRCs



How to make it work for you?

- Trading information with your doctor
 - Protocol for sharing
 - Privacy
 - Viruses



How to put together your ECN

Family Resource Library ECN example

- Piloting with prevention program
- Will be available in Spanish, Chinese next?
- Will be posted on the website soon:
www.familyresourcenetworklac.org



How to put together your ECN

Family Resource Library:

[ECN sample](#)



Top Ten Reasons

10. Allows you to track your child's progress.
9. Makes it easy to share information with other service systems and providers.
8. Helps you feel more "in control"



Top Ten Reasons

7. Aids participation as a member of your child's care teams.
6. Allows you to advocate more effectively for your child because you have documentation for your requests.
5. It sends a positive message



Top Ten Reasons

4. If you have to appeal decisions, you have documentation of what has occurred.
3. It helps you prepare for appointments and meetings
2. It is empowering



Top Ten Reasons

1. It gives your memory a break.

Adapted from the Los Angeles Medical Home Project



Finally

- Setting an example
- Transferring ownership to your child...you are the caretaker of this information but just for a while 😊