

REFLECTIONS ON SUPPORT SYSTEMS



For parents living with children diagnosed with epilepsy

FOCS SESSION 2 - OCT 2021

FOR PARENTS

SOCIAL MEDIA



- FACEBOOK online groups do exist, and can be valuable for reference and sharing.
- Parents can join, search and review information for free.
- The best groups offer ASYNCHRONOUS discussion threads and are clearly monitored, for appropriate and reliable contributions, and are void of personal information.
- Limitations include:
 - absence of local content and connections
 - must have social media account
 - not actual interactive, safe spaces from trusted source



OTHER FAMILIES

- Families connect through shared experiences with their kids
- Casual meetings from clinic visits or word of mouth
- Kids connect and become closer, through fluid and organic experiences - even across age groups

ONLINE RESOURCES



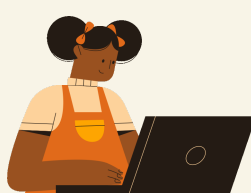
- Research information online
- Be careful about factual information, access to trusted sites



EEA

- EEA offers trusted, factual resources
- Families connect through Families Online Conversations since 2021(FOCs)
- EEA can engage families through a number of activities and projects
- EEA live events (when they resume) become an opportunity for support for families
- Families Summer Camp idea - would allow families and kids to live memorable experience together, and build lasting bonds with one another

FOR KIDS



SAFE ONLINE SPACES

- Limited access to safe online spaces for kids of all ages
- Key reasons for reluctance to join (or allowing to join)
 - unmonitored environments could be damaging and confusing
 - many families do not have access to social media or online spaces

KIDS' GROUPS



- Could be in person or online, monitored and supervised.
- Kids could share hobbies and passions, through group projects or adventures
- The simple fact that these groups would be joined by kids sharing the experience of living with epilepsy, it can bring the sense of NOT BEING ALONE.
- EEA offers mentorship opportunities, also for youth to connect on a one-to-one relationship and share experiences
- EEA can support this idea with online and in-person initiatives

SHARED PATHWAYS



- Families connect through a variety of ways and share their experiences
- There will always be someone who is newer to the path of living with epilepsy, and someone else who has gone through that experience in the past
- By sharing stories, challenges and coping strategies, everyone feels less alone and more hopeful for their kids