

What's Out There?

Overview of publicly-funded services and supports that exist for families of children with special health care needs, developmental disabilities, and/or chronic illnesses.



Presented by O. Sophia Johansson for the MA21 Alliance

"MA21"

Massachusetts Alliance for a 21st Century Disability Policy
To advance full participation for individuals with disabilities.



Presented by O. Sophia Johansson
o.sophia.johansson@gmail.com

What is out there?

Overview of publicly-funded services and supports that exist for families of children with special health care needs, developmental disabilities, and/or chronic illnesses.



What is out there?

Overview of **publicly-funded** services and supports that exist for families of children with special health care needs, developmental disabilities, and/or chronic illnesses.



What is out there?

Overview of publicly-funded **services and supports** that exist for families of children with special health care needs, developmental disabilities, and/or chronic illnesses.



What is out there?

Overview of publicly-funded services and supports that exist for families of children with **special health care needs, developmental disabilities, and/or chronic illnesses.**



How will we talk about this?

- Comprehensive overview
- Tools & techniques for describing what you need
- Initial resources that will lead you to others



Where money and laws intersect with families.

rights - best practice, what we should expect
should not expect funding or legislation is in place to protect these

eligibility - meets criteria, but services may not be offered
usually partially funded, based on state and federal budgets

entitlement – services are guaranteed
advocacy for funding is still necessary



Where money and laws intersect with families.

rights - best practice, what we should expect
should not expect funding or legislation is in place to protect these

eligibility – meets criteria, but services may not be offered
usually partially funded, based on state and federal budgets

entitlement – services are guaranteed
advocacy for funding is still necessary



Where money and laws intersect with families.

rights - best practice, what we should expect
should not expect funding or legislation is in place to protect these

eligibility – meets criteria, but services may not be offered
usually partially funded, based on state and federal budgets

entitlement – services are guaranteed
advocacy for funding is still necessary



Where money and laws intersect with families.

rights - best practice, what we should expect
should not expect funding or legislation is in place to protect these

eligibility - meets criteria, but services may not be offered
usually partially funded, based on state and federal budgets

entitlement – services are guaranteed
advocacy for funding is still necessary



What does this mean in practice?



What does this mean in practice?

- always ask for what you need



What does this mean in practice?

- always ask for what you need

- believe you, your child(ren), your family deserve what you are asking for



What does this mean in practice?

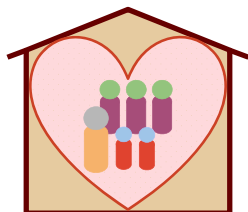
- always ask for what you need

- believe you, your child(ren), your family deserve what you are asking for

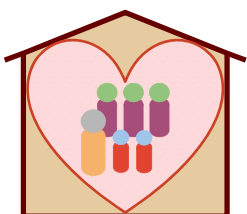
- be persistent



It all starts with the family home.



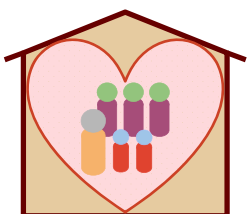
It all starts with the family home.



Children with disabilities have a right to live in a family home with loving parents.



It all starts with the family home.

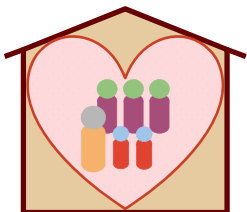


Children with disabilities have a right to live in a family home with loving parents.

Children have a right to services and supports in the most natural setting.



It all starts with the family home.



Children with disabilities have a right to live in a family home with loving parents.

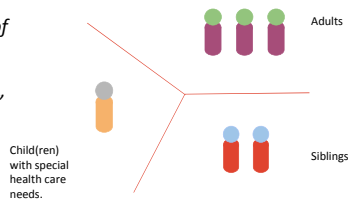
Children have a right to services and supports in the most natural setting.

Families have a right to access all the services and supports they need to keep everyone in the home as happy and healthy as possible.

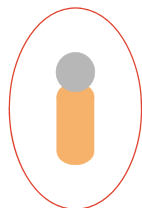


How to assess need.

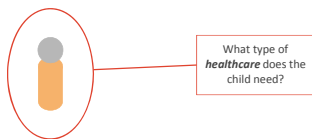
"If things feel out of control more than 50% of the time, they probably are."

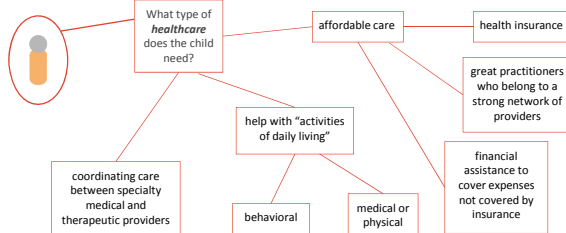


Considerations for the child(ren) who led you to watch this webinar.

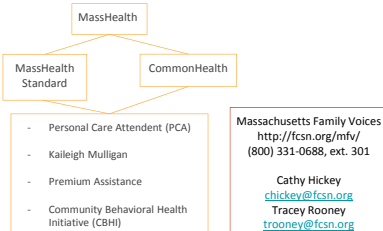


Considerations for the child who led you to watch this webinar.



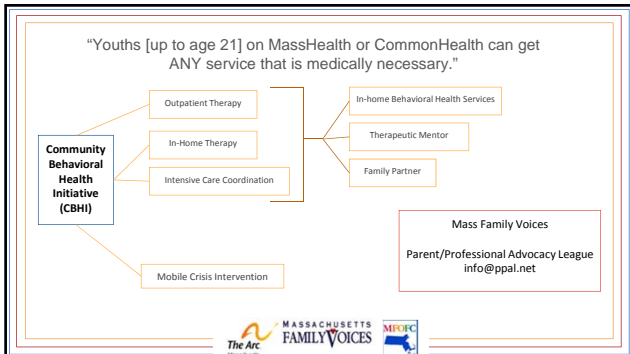


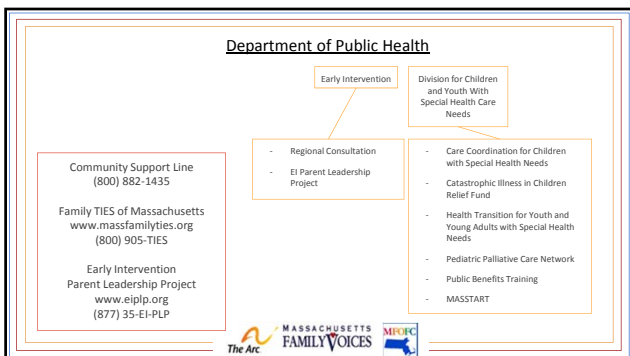
MassHealth

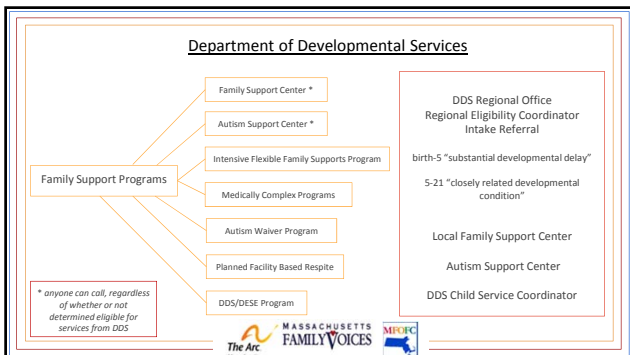


- Complete application
- Complete disability determination form.









Considerations for the child who led you to watch this webinar.

What type of *healthcare* does the child need?

What does the child need to be able to access *school*, learn, and be a part of the school community?

The Arc MASSACHUSETTS FAMILY VOICES MFPC

What does the child need to be able to access *school*, learn, and participate in the same activities that the other kids do?

physical access

extracurricular activities

support to stay healthy

modifications to the curriculum

language access

social emotional support

summer camp!

The Arc MASSACHUSETTS FAMILY VOICES MFPC

Department of Education

Early Education & Care

- Coordinated Family & Community Engagement Grants
- Preschools

Elementary & Secondary Education

- Elementary School & High School
- Transition Services

Higher Education

- Inclusive Concurrent Enrollment

Special Education: IEPs, 504s

Mass Rehabilitation Commission

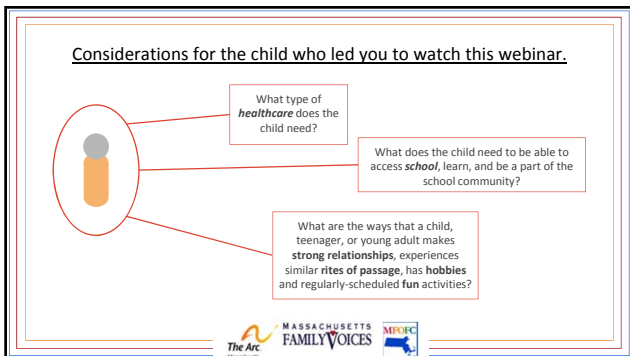
Job Readiness

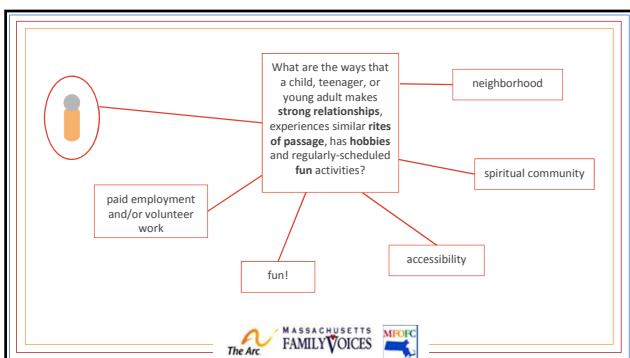
Federation for Children with Special Needs
www.fcsn.org
(800) 331-0688

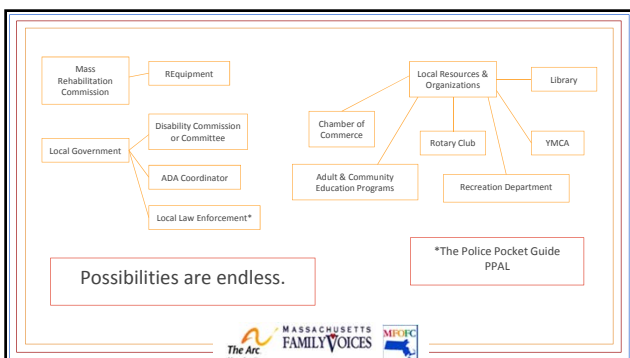
Program Quality Assurance
www.doe.mass.edu/pqa/
(781) 338-3700

Mass Advocates for Children
www.massadvocates.org
Helpline: (617) 357-8431

The Arc MASSACHUSETTS FAMILY VOICES MFPC







What do siblings need to be happy and healthy?

The Arc MASSACHUSETTS FAMILY VOICES MFOFC

What do siblings need to be happy and healthy?

- Mass Sibling Support Network
- CBHI
- Family Support Center
- Local Resources and Organizations

The Arc MASSACHUSETTS FAMILY VOICES MFOFC

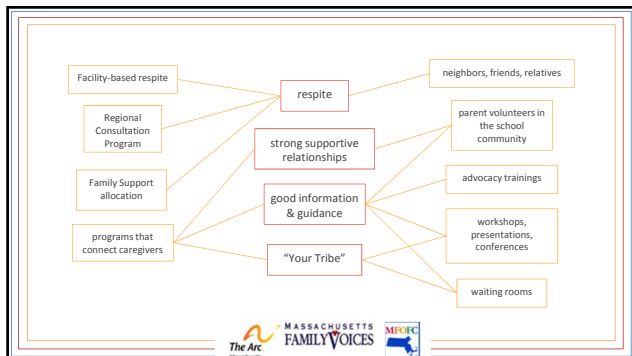
What do parents need to sustain their health and well-being?

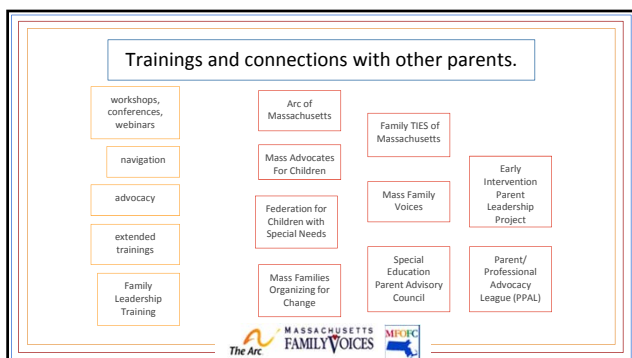
- respite
- strong supportive relationships
- "Your Tribe"

What do relatives need to sustain their involvement?

- access to good information & guidance

The Arc MASSACHUSETTS FAMILY VOICES MFOFC





Questions? Feedback? Want to share a resource?
 o.sophia.johansson@gmail.com
