Leveraging Community Connections
For Sustainable Respite And Caregiver Support

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National Lifespan Respite Conference
Presenters

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Advocates Inc.

- Private, Non-Profit Agency
- 70 million dollar budget
- Meeting the unique needs of elders, families and individuals with a broad range of abilities for over 35 years
- Employs over 1,000 staff members and serves 20,000 individuals across eastern and central Massachusetts
Increasing the Reach

- Family support centers: 2,000 families
- Supported Home Care: 400 families
- Visions, trainings, fun: 300 families
- Diverse communities:
  - African-American
  - Chinese
  - Haitian
  - Latino
  - Portuguese
  - Vietnamese
Family Services & Caregiver Support
Supports to Caregivers

Respite: A Broad Perspective

• Behavioral health services
• Emotional support
• Culturally sensitive and multi-lingual staff
• Training and informational sessions
• Individualized respite
• Resource navigation
• Stipends and grants
Family Supports
Respite: A Broad Perspective

- Advocates supports entire family across the lifespan
- Community, Recreational and Social Supports
  - *Fun, Friends, & Family!*
- Facilitating family connections
- Family leadership training
- Family empowerment through training and informational sessions
- Visioning
Supporting the Individual
Respite: A Broad Perspective

• Culturally sensitive supports
• Individualized respite
• Meaningful day and work supports
• Stipends and grants
• Social and recreational activities
Putting the Pieces Together

- Community organizations
- Department of Developmental Services
- Fundraising
- Grants
- Human service agencies
- Mass Health (Medicaid)
- Private pay
Advocates Family Alliance

• A group of family stakeholders whose loved ones receive services from Advocates.

• Collaborate with Advocates staff and administrators to improve services, advocate for their loved ones, plan social and recreational activities and provide mutual support.

• Serves as the selection committee for the Fred Gaspari Fund, a fund specifically reserved for those who care for loved ones with disabilities living at home.
Connections Newsletter
  - Reaches families every month providing families with the perspective of a family member with a special needs child.

Advocates Family Services Team
  - Provides personalized service navigation to families looking to Advocates for support and resources
    • Family Coordinator
    • Family Services Liaison
    • Senior Vice President
    • Advancement

www.AdvocatesFamilyServices.org
Family to Family Blog

- Featuring perspectives of family caregivers, professions and families.

Family Programming

- *Building a Meaningful Life Series* - workshops designed for the community to provide information and resources to families looking to develop their families members future.

- *Fun, Friends, & Family!* Events designed to provide respite and networking opportunities for families while enjoying a fun activity.

Family Support Centers

Autism Alliance of MetroWest
Offers resources, programs and support for families with children and young adults diagnosed with autism/pervasive developmental disorders.

Project Able
Provides culturally competent family support services to Chinese and Vietnamese individuals with intellectual and developmental disabilities and their families in the Greater Boston area.

South Coastal Family Support Center
Provides trainings, workshops, case management, information and referral services to families caring for loved ones with intellectual and developmental disabilities in the MA South Shore area.
Autism Alliance of MetroWest
Autism Alliance of MetroWest

• Connections to Resources
• Consultation Services
  • Free call in educational consultations with a former Special Education Director.
• Support Groups
  • Coordinate monthly support groups with guest speakers relating to sexuality, special needs specific financial information, housing, technology, human rights and more. Other groups include: Just for Dad’s group, Grandparents Breakfast Group, Corporate Lunch Support Group.
• Awareness
  • Annual Kite Day - Brings over 1,600 people to grow autism awareness and provide a fun family “day out” filled with information about autism and community support.
Friday Nights
Provides people on the autism spectrum a chance to develop friendships and have some fun. Families drop off their loved ones and are able to have a short respite.

Sibshop
Provides ten to twelve siblings with a safe place to express themselves, share experiences and have fun with peers.

Sunday Open Gym
Provides children of all ages and their siblings with suspended swings, balancing games, group activities, and much more.
South Coastal Family Supports
Family Support on the South Shore
South Coastal Family Supports
Family Support on the South Shore

Adult Mentoring
• Weekly small group sessions in the local community and Quincy YMCA under the direction and guidance of an adult mentor. Areas of focus include wellness, fitness and independence.

Alternative Communication Device Loan Program
• iPads and alternate communication devices are available for use on a trial basis.

Handbell Choir
• Learn about this beautiful musical art form using color coded bells. Great for improving focus, processing speed and coordination. Performances are scheduled throughout the year.

Sibling Support Group: It’s All About Me!
• Meet and share your experiences, feelings and concerns while participating in a fun group activity such as art, bowling and movie nights.
South Coastal Family Supports
Family Support on the South Shore

Social Groups
- Adult and Children Focused
- Adventure Sports
- Friday Fun Night
- Free Family Swim
- Recreational outings and gatherings for adults and children to foster social skills
- Sports and Game Nights
Project Able
Support for Chinese and Vietnamese Families
Project Able
Support for Chinese and Vietnamese Families

- Accessing health care and emergency services
- Community resources
- Communication support
- Family training
- Government benefits, housing
- Individual Education Plan (IEP) and Individual Support Plan (ISP) participation
- Multi-lingual support groups
- Recreational and social activities
Family Support Programs
Far Reaching Across the Lifespan
Supported Home Care
In Home Support for Families

- Support over 400 families in Central and Eastern Massachusetts.
- Enables individuals with disabilities and elders to live in their own home or in the home of a loved one.
- Individuals served are 16 years or older.
- Certified Medicaid funded Adult Family Care (AFC) service.
Supported Home Care
In Home Support for Families

Case Manager and Registered Nurse

- Actively engaged in each family’s journey and vision
- Caregiver stress management and self-care for caregivers
- Educates families on medical questions
- Emergency on-call 24/7
- Ensures families maximize government benefits through assistance with applications and recertification
- Facilitates communication between the family and outside resources/agencies
- Person-centered approach to work collaboratively with families

Culturally competent approach

- Staff understand and respect clients' own cultures.
- Staff speak Cantonese, English, French, Haitian-Creole, Lithuanian, Mandarin, Portuguese, Russian, Spanish and Twi.
Supported Home Care
In Home Support for Families

Cultural Knowledge Starts with Our Staff
Supported Home Care
In Home Support for Families

Caregiver Support
Caregivers receive monthly case management and nursing support from qualified staff.

Caregiver Compensation
Provides a tax-free monthly stipend paid directly to the caregiver. Two tiers of stipends depending on the complexity of needs.

Community Placement Services
Family Placement Specialist and Supported Home Care staff work collaboratively with individuals and families to help them design and choose supports uniquely suited to their needs and wishes.

Respite Services
Supported Home Care
In Home Support for Families

Respite Services

Recruitment
- Respite providers can be identified by families or the Family Placement Specialist.
- Once qualified by staff, providers are able to provide respite for any Supported Home Care individual.

Compensation
- Tax-free stipends are provided to respite providers through MassHealth funds.

Training and Screening
- Person-specific trainings are provided by Supported Home Care staff in conjunction with families.
- Supported Home Care staff complete CORI, TB Screening and collect documentation of Respite provider’s good health.
Counseling Services
• Working with older adults, their caregivers and support networks to enhance dignity and independence
• Languages spoken: English, Portuguese, Russian, and Spanish

Caregiver Telephone Connections
• Telephone Support Group for Family Caregivers of Older Adults
• Provided in English and Spanish
• Promotes creating connections between caregivers
• Provides materials and information to help caregiver build their ‘care team’
Fred Gaspari Fund
Supporting Families Needs and Dreams

• In memory of Alfred Pasquale Gaspari, a longtime advocate for the former South Middlesex Association for Retarded Citizens (SMARC).

• Provides financial support through grants to families caring for a loved one with an intellectual or developmental disability.

• Family member must live at home with the family or independently in their own home in the community.

• Eligible families may apply for up to $500 for any ‘family need’ which is broadly defined.
Fred Gaspari Fund
Supporting Families Needs and Dreams

Examples of past awards received:

- Buy an Intellikeys keyboard for family member
- Pay for therapeutic horseback riding classes
- Convert a bedroom of family's home into a therapy room for family member
- Fence in backyard for the safety of family member
- Purchase shoes and leg braces for family member
- Hire someone to take family member with active seizure disorder out into the community for social activities
Family stories

Eleftherakis Family
Questions?

THANK YOU!