



MassFamilies

Annual Open Meeting

December 14, 2024

www.massfamilies.org | hello@massfamilies.org



Board of Directors 2024-2025

Rania Kelly, co-chair
Keila Torres, co-chair
Priscilla Bessa, clerk
Lauri Mederos, treasurer
Amy Peters
Ann Berbue
Brian Sullivan
Jaya Pandey
Lesla (Lee) Anto
Lisa A Sims
Melanie Zoltan
Nicole Desnoyers
Paloma Fernandes
Ruchi Mendiratta Khanna
Stacy Limperis
Sue Crosby
Symbia Rose Barnaby



[Link to board members](#)



Grants Received In 2024



\$15,000 from *Massachusetts Developmental Disabilities Council (MDDC)* for indigenous families that support loved ones with disabilities.



\$10,000 grant from the *Doug Flutie Foundation* to support BIPOC Family Leadership training.



Financial Update

Current bank balance is \$35,702.67



Since 1990, MassFamilies has provided the **Family Leadership Series** to empower families and individuals to live and engage in their communities.

But we do so much more than FLS...



Events & Collaborations in 2024



MassFamilies

webinar series

WORKING TOGETHER

November 2023 – April 2024

A free 6-part webinar series that covered key aspects of special education post-pandemic COVID-19. Presented to English-speaking and Spanish-speaking audiences.

Partners

MassFamilies

The Arc of Greater
Haverhill-Newburyport

Massachusetts Advocates for Children

WORKING TOGETHER

A FREE Special Education Webinar Series for Families
2023-2024

NOV 7	Navigating the IEP	DEC 5	Anti-Bullying
JAN 16	Autism Parent Training	FEB 6	Transition Training
MAR 12	Navigating the IEP	APR 23	Basic Rights

Training sessions will be held via Zoom from 6:30-8:00pm.

View session descriptions and register at massfamilies.org/training/working-together-series/

Hosted By: MassFamilies The Arc
In Partnership With: MASSACHUSETTS ADVOCATES for CHILDREN

TRABAJANDO JUNTOS

Una serie gratuita de la educación especial para las familias
2023-2024

9 NOV	Navegando el IEP	7 DEC	Anti-Bullying
18 JAN	Taller para Padres de Estudiantes con Autismo	8 FEB	Taller de Transición
14 MAR	Navegando el IEP	25 APR	Derechos Básicos

Talleres tendrán lugar por Zoom de 7:00-8:30pm.

Ver las descripciones de las talleres y registrarse en massfamilies.org/training/working-together-series/

Hosted By: MassFamilies The Arc
In Partnership With: MASSACHUSETTS ADVOCATES for CHILDREN



MassFamilies

legislative advocacy

49TH ANNUAL LEGISLATIVE RECEPTION AT THE MASSACHUSETTS STATE HOUSE

March 6, 2024

This year's theme was "Reaffirming Our
Commitment to Those in Need."

Nearly 400 Individuals attended, including 45
legislators and officials from EOHHHS.

Our Partner

The Arc of Massachusetts





MassFamilies

webinar

SPECIAL NEEDS TRUSTS AND FUTURE PLANNING

May 7, 2024

The Western Mass Family Leadership Program produced a webinar presented by Attorney Gina Barry. The webinar focused on providing key information on special needs trusts and other legal arrangements which can help families effectively plan for the future.

Partners

MassFamilies

Massachusetts Department of Developmental Services

Multicultural Community Services (MCS)

The flyer features a header with social media icons and a quote: "For tomorrow belongs to the people who prepare for it today." – African Proverb. Below this, it invites participants to join the Western Mass Family Leadership Program in partnership with MCS Family Support Centers for a training titled "Special Needs Trusts and Future Planning". The training is presented by Attorney Gina Barry from Bacon\Wilson P.C. The flyer includes details on the date (Tuesday, May 7, 2024), time (6:00 PM), and location (Zoom). A QR code is provided for registration, along with a link to the registration form: <https://forms.gle/riX8czjWz7Uhw67o9>. The footer contains logos for the Western Mass Family Leadership Program, the Massachusetts Department of Developmental Services (DDS), Multicultural Community Services (MCS), and the Commonwealth of Massachusetts.

For tomorrow belongs to the people who prepare for it today." – African Proverb

Join the Western Mass Family Leadership Program
In Partnership with MCS Family Support Centers for:

Special Needs Trusts and Future Planning
A training for families and caregivers

Presented by: Attorney Gina Barry, from Bacon\Wilson P.C.


Long term planning is important for our family members, But it can be challenging and confusing...

Where do we begin??


This training will provide key information on special needs trusts and other legal arrangements which can help families effectively plan for the future.

Date: Tuesday, May 7, 2024
Time: 6:00 PM
Location: Zoom
Register online: <https://forms.gle/riX8czjWz7Uhw67o9>

Or scan here:



Serving Berkshire, Franklin, Hampden and Hampshire counties, the Western Mass Family Leadership Program at MCS is funded by the Massachusetts Department of Developmental Services, collaborating with MassFamilies and family support programs in Western Massachusetts and beyond.





MassFamilies

webinar series

SOCIAL MEDIA SKILLS FOR FAMILY LEADERS

May – June 2024

A three-part free series to learn Facebook Mastery, Effective Engagement, and Integration & Support

Partners

Multicultural Community Services (MCS)

Empowered Social Media

MassFamilies

FREE VIRTUAL TRAINING OFFERED BY Western MA Family Leadership Program

SOCIAL MEDIA SKILLS FOR FAMILY LEADERS

a Three-Part Series presented by the team at Empowered Social Media

Learning how to network, share stories, and raise awareness with social media



May 22

Facebook Mastery: Effectively using Facebook Groups to find and interact with like-minded individuals

May 29

Effective Engagement: Engaging with others in social media platforms and leveraging these connections based on shared interests.

June 5

Integration, Support, and Q&A:

Wrapping up the skills learned in Trainings 1 and 2, providing a platform for participants to ask questions, share experiences, and receive additional support to optimize their social media presence.

REGISTER NOW

Questions? Call (413) 200-7563 or email sue@massfamilies.org

Serving Berkshire, Franklin, Hampden, and Hampshire Counties, The Western Mass Family Leadership Program at MCS is funded by the Mass Department of Developmental Services, collaborating with MassFamilies, and family support programs in Western Massachusetts and beyond





MassFamilies

online documentary screenings & discussions

UNSEEN

August 2024

The Western Mass Family Leadership Program presented a film dedicated to the caregiver crisis, followed by a discussion about the challenges families face. It was offered three consecutive days to make it accessible to many people.

113 people attended throughout the 3 screenings!

Partners

Massachusetts Department of Developmental Services

Multicultural Community Services (MCS)

MassFamilies

THE WESTERN MASS FAMILY LEADERSHIP PROGRAM
PRESENTS A FILM DEDICATED TO THE CAREGIVER CRISIS:

UNSEEN

How We're Failing Parent Caregivers
& Why It Matters

FREE FILM SCREENING

Join us for a FREE screening of Unseen, followed by a discussion about the challenges families face, how caregiver supports can be truly supportive, and how we can start conversations about possible solutions.

THREE DATES AVAILABLE!
Monday, August 19, 2024 at 1:00pm
Tuesday, August 20, 2024 at 6:00pm
Wednesday, August 21, 2024 at 6:00pm

RSVP

Serving Berkshire, Franklin, Hampden and Hampshire counties, the Western Mass Family Leadership Program at MCS is funded by the Massachusetts Department of Developmental Services, collaborating with family support programs in Western Massachusetts and beyond.

[Watch movie trailer](#)



MassFamilies

online workshop series **IMAGINANDO MEJOR**

(Imagine Better)
September 2024

Free multilingual workshop series Family Vision and Planning Family Counseling and Mentoring Family Leadership Development Charting the LifeCourse.

Partners

MassFamilies

Riverside Community Care

MassFamilies busca líderes familiares
y auto-defensores BIPOC para

IMAGINANDO MEJOR

Sesión de 2024

Imaginando Mejor es un programa con el objetivo principal de abordar el acceso, la equidad y la pertenencia de BIPOC dentro del Movimiento de Apoyo a las Familias con Discapacidad.

Imaginando Mejor enfoca en 3 áreas centrales:

- La visión y planear de la familia
- La consejería y tutoría de la familia
- El desarrollo de liderazgo familiar

Los participantes desarrollaran habilidades de autodefensa utilizando la planificación centrada en la persona, las herramientas de Charting the LifeCourse y el liderazgo familiar para crear una visión y un proceso viable para que su familiar lleve una vida plena y productiva a lo largo de su vida dentro de su comunidad.

Ofrecemos Imaginando Mejor virtualmente y en varios idiomas.

Para mas informacion o registrarse,
favor de contactar a

imaginebetter.program@gmail.com
413-419-8008



**! REGÍSTRATE
HOY!**

"Siempre pensaba que todos los demás eran 'los expertos,' estas sesiones abrieron mis ojos al hecho que YO soy el experto de mi querido y que nadie puede hacer un mejor trabajo planear, apoyar y abogar por mi hijo que yo. Que no debo tener miedo hablar ser sincero cuando viene a las necesidades y los deseos de mi hijo. Gracias por hacer este entrenamiento posible."

- 2022 Participante de Imaginando Mejor

Presentado por



Riverside
Community
Care



MassFamilies

charity event

Flutie 5K for Autism 25th Anniversary

October 2024

MassFamilies' members walked, rolled, and ran to raise more than \$500 which was matched dollar for dollar to collectively raise more than \$1,000.

Our Partner

Doug Flutie Jr. Foundation for Autism





MassFamilies

celebration representation

THE ARC'S LEO SARKISSIAN RETIREMENT CELEBRATION

October 17, 2024

The Arc of Massachusetts invited MassFamilies to be part of celebrating Leo Sarkissian's 33 years of leadership as Executive Director. The gala was held at The prestigious Edward M. Kennedy Institute for the United States Senate.

[Read more about Leo's legacy as an advocate and leader.](#)



MassFamilies' board members doing their "Power Pose" with Massachusetts's State Representative Sean Garballey.



MassFamilies

online workshop series

ADVOCACY BOOTCAMP IN SPANISH

October – December 2024

MassFamilies created "advocacy camp" designed to teach family members fundamental skills of advocacy so that they can empower their children and loved ones with disabilities to lead meaningful and exciting lives. The series focuses on the early years of children and the many things we need know.

Our Partners

Metro Family Leadership
Riverside Community Care

**DÉ
EL SALTO**

El Campamento de Abogacía de MFOFC fue diseñado para enseñarle las habilidades fundamentales de defensa para que podamos empoderar a nuestros niños para que puedan llevar una vida significativa y emocionante

Mas información en massfamilies.org/advocacy-bootcamp/



MassFamilies

event

ADAPT & TASTE 2024

MassFamilies enabled this pioneering initiative that started in 2023 to continue to provide adapted cooking classes tailored for autistic children.

Partners

Andressa Dias Costa

MassFamilies

Riverside Community Care





MassFamilies

activism & contributor

**MASSACHUSETTS ALLIANCE
FOR 21ST CENTURY
DISABILITY**

Year round meetings

MassFamilies role with MA21 is our substantial consultation to give feedback to Massachusetts DDS to protect the right of people with disabilities to self-direct, and through its efforts helped pass the Real Lives Law in 2014.

[Learn more about MA21 Alliance.](#)





MassFamilies

active partnership

MASSACHUSETTS DEPARTMENT OF DEVELOPMENTAL SERVICES (DDS)

Year round 2024

MassFamilies continues to partner with DDS, who provides numerous statewide trainings. They often tap MassFamilies to help DDS find family members for advisory boards and consultations. They continually seek the family voice for our “Substantial Consultation” around the work that affects families throughout the entire state. DDS is grateful for the statewide notices MassFamilies shares for the department.

Our Partner

Massachusetts Department of Developmental Services (DDS)





MassFamilies

active participation

MASSACHUSETTS SPECIAL COMMISSION ON STATE INSTITUTIONS

Fall 2024+

MassFamilies was invited to be part of the only statewide commission led by persons with disabilities, along with scholars, educators, and advocates. The Special Commission takes stock of what is known about the history of state institutions in Massachusetts and how that history is relevant for understanding policies and services for persons with disabilities today.

Lauri Medeiros, Metro Regional Coordinator and board member represents MassFamilies, following in the footsteps of MassFamilies Co-chair, Rania Kelly.

[Read more about this Special Commission.](#)





MassFamilies

Calendar

January 2024: launched Working Together special education webinar series

February 2024: annual Legislator "Love Note" Campaign

March 2024: attended The Arc of Massachusetts annual Legislative Reception

Spring 2024: Western Mass Family Leadership Series

Spring 2024: Metro Mass Family Leadership Series

May 2024: Special Needs Trusts and Future Planning webinar

May 2024: launched Social Media Skills for Family Leaders webinar series

August 2024: "Unseen" documentary online screenings & discussions

September 2024 Indigenous Documentary film

September 2024: Imaginando Mejor workshop series

October 2024: Flutie 5K for Autism 25th Anniversary charity event participant

October 2024: The Arc's Leo Sarkissian's retirement celebration

October 2024: launched Advocacy Boot Camp in Spanish

Fall 2024: Started as member of Massachusetts Special Commission on State Institutions

Year round 2024: active contributor to Massachusetts Department of Developmental Services (DDS)



MassFamilies continues to be actively and continuously engaged with many of our partners.

MassFamilies involvements in 2024

Community of Practice for Supporting Families' innovation roundtables meetings

LifeCourse in Action Series meetings

National Collaboration for Supporting Families meeting

Pathways to Friendship Metro and Northeast

The ARC of Massachusetts MA 21 meetings

The ARC of Massachusetts Legislative priorities meetings

LifeLines Indigenous support Center in West Roxbury MA, community meetings

Disability Law Center focus groups and priorities meetings

Center of Public Representation priorities

Mass Advocates for Children legislative partnership meetings



**Many more
organizations have
partnered with
MassFamilies in 2024.**

MassFamilies partner orgs 2024

Boston University's Center for Autism
Research Excellence (CARE)

Center of Public Representation

Circle of Vietnamese Families

Conexiones Latinx-MA

Disability Law Center

Doug Flutie Jr. Foundation for Autism

Empowered Social Media

Federation for Children with Special
Needs

Institute for Community Inclusion

Lawrence Partnership for Transition to
Employment (LPTE)

Massachusetts Advocates for Children

Massachusetts Commission on the
Status of Persons with Disabilities

Massachusetts Commission on the
Status of Women

Massachusetts Department of
Developmental Services (DDS)

Massachusetts Office on Disability
(MOD)

MassHealth

Multicultural Community Services
(MCS)

National Collaborative for Supporting
Families

Native American LifeLines Boston

Parent/Professional Advocacy League
(PPAL)

Plugged In Band Program

Riverside Community Care

The Arc of Massachusetts

The Community of Practice

Tufts University School of Medicine

UMass Chan Medical School

Wellesley College



Member Success Stories in 2024



Rania Kelly, Mass Families Chair contributed to an article published in the Journal of Educational and Psychological Consultation.

The article: *Equal Ground: Meaningful Collaboration with Culturally and Linguistically Diverse Families of Children with Intellectual and/or Developmental Disabilities.*

The screenshot shows the article page on the journal's website. The title is "Equal Ground: Meaningful Collaboration with Culturally and Linguistically Diverse Families of Children with Intellectual and/or Developmental Disabilities" by Zach Rossetti, Oanh Bui, Nancy Figueroa, Rania Kelly, Manuel Angel Ramirez, Ruchi Mendiratta Khanna, and others. The article is categorized as a "Research Article" and was published online on 24 Aug 2024. The page includes navigation options like "Full Article", "Figures & data", "References", "Citations", "Metrics", and "Reprints & Permissions". There is also a section for "Related Research" with a "Recommended articles" button.

Home ► All Journals ► Journal of Educational and Psychological Consultation ► List of Issues ► Latest Articles ► Equal Ground: Meaningful Collaboration w...

Research Article

Equal Ground: Meaningful Collaboration with Culturally and Linguistically Diverse Families of Children with Intellectual and/or Developmental Disabilities

Zach Rossetti ✉, Oanh Bui, Nancy Figueroa, Rania Kelly, Manuel Angel Ramirez, Ruchi Mendiratta Khanna & ... show all

Received 16 Feb 2024, Accepted 14 Aug 2024, Published online 24 Aug 2024

🗨️ Cite this article 📄 <https://doi.org/10.1080/10474412.2024.2393855> 🔍 Check for updates

📄 Full Article 📊 Figures & data 📄 References 🗨️ Citations 📊 Metrics 📄 Reprints & Permissions 📄 Read this article 📄 📄 📄 📄 📄

Sample our Education Journals
➔ Sign up here to start your access to the latest two volumes for 14 days

ABSTRACT

Despite increased attention and research during the past three decades, systemic barriers continue to hamper meaningful collaboration between school personnel (e.g. teachers, consultants) and culturally and linguistically diverse families of children with intellectual and/or developmental disabilities (I/DD). In this critical review of recent research, we address both the ideal of culturally responsive family-professional partnerships and the frequent reality of persistent systemic barriers, adversarial interactions, and the expectation of advocacy (rather than participation) by families. We highlight the cultural mismatch and inherently hierarchical nature of formal interactions with school personnel. Framed by a life span approach and drawing from our research and first-hand experiences shared as testimonios, we provide descriptive examples and make recommendations for

Related Research

Recommended articles

Cited by

Perspectives of culturally and linguistically diverse families in the management of children with type 1 diabetes in Western Australia >

Sabrina Binkowski et al.
Ethnicity & Health
Published online: 19 Mar 2023

Innovative Cultural Care for Culturally and Linguistically Diverse Children in Out-of-Home Care >



Rania Kelly, MassFamilies Chair, created a workshop that was accepted by the 2024 Vision of Community Conference.

The topic was *Empowering Nonverbal Communicators & Medically Complex Roundtable*.

Co-presenters

Rania Kelly, MassFamilies Co-Chair

Jennifer Bertrand, Disability Policy Specialist (MDDC)

 **2024**
**Visions of
Community**
Conference
Where *You* Matter.
March 9, 2024

**Tickets on
Sale Now!**



To register, visit: fcsn.org/voc



Lisa Sims and her son, Jevon Okundaye, are both Family Leadership Series graduates; Lisa is also currently a Board Member.

They were invited to be part of LifeCourse in Action Series on May 8, 2024. They spoke about the value of using the Charting the Lifecourse framework and tools as self-advocates—how those tools empowered Jevon to help him organize and communicate what he wants for the future, and how Lisa was able to support Jevon using the framework.

Partners

Department of Developmental Services
The Arc of Massachusetts
Institute for Community Inclusion

The Department of Developmental Services,
The Arc of Massachusetts, and
the Institute for Community Inclusion present:

LIFECOURSE IN ACTION SERIES

**REGISTER FOR
THE LIFECOURSE
IN ACTION
WORKSHOP
SERIES.**

The Charting the LifeCourse framework is based on the core belief that all people and their families have the right to live, love, learn, work, play, and pursue their life aspirations in their community. Individuals, families, and professionals can use the Charting the LifeCourse framework and tools to envision and chart a course toward a good life.

WHAT IS THE LIFECOURSE IN ACTION SERIES?

The *LifeCourse in Action* series is a virtual educational forum where you will hear inspiring stories and learn first-hand how these tools and resources may benefit you, your family, or your organization.

SHOULD I REGISTER?

Yes! The *LifeCourse in Action* series is for you, your family members, service providers, advocates, self-advocates, and anyone who wants to learn more about the Charting the LifeCourse framework and tools.

SESSION 9: (MAY 8, 2024):

The Value of Using the Charting the Lifecourse Framework and Tools from a Self-advocate
Join us **Wednesday, May 8 at 12pm** for our next LifeCourse in Action session to hear from self-advocate Jevon Okundaye and his mother Lisa A. Sims. Jevon and Lisa will share how Jevon was empowered by using the framework and tools to help him organize and communicate what he wanted for his future. They will also talk about how Lisa was able to support Jevon using the framework.

Presenters:



Jevon Okundaye

Program Assistant for Massachusetts Advocates for Children's Racial Equity and Access Program (REAP), LifeCourse Ambassador

As part of this role, Jevon writes blog posts, conducts research about the intersection of race and disability, and helps the REAP Program Lead with projects relating to the advancement of racial equity in Boston Public Schools.



Lisa A. Sims

Board Member for MassFamilies

Lisa is a LifeCourse Ambassador, Family Leadership graduate, disability advocate, and single mother of an adult son with disabilities. Lisa also her own disability challenges.



For more information or questions, or to access recordings from previous sessions, contact:

Elizabeth.Wike@umb.edu

Our next LifeCourse in Action session (#10) will occur on Wednesday, June 12 at 12pm.



Andrew Carr and Consuelo Perez, both Metro Family Leadership Series graduates, established *Access 2 Community and Friendships*.

Cambridge Foundation awarded a \$5,000 innovation grant for this grassroots group of young adults with disabilities to host social events and fun activities throughout Greater Boston.





Lesa Antonie, Valeska Toledo, Lisa Sims, and Amy Peters—all 2023 Metro Family Leadership graduates—were accepted into the prestigious LEND fellowship. Lisa's son, Jevon Okundaye, is also a Fellow.

The LEND Fellowship aims to develop academic and leadership skills and substantive knowledge in the area of disability-related health policy.

[More about LEND Boston here.](#)





Rania Kelly, co-chair of MassFamilies, assisted with sourcing and writing a sizeable grant, and connected them with indigenous families who have a loved one with disabilities.

The grant: The John Hopkins Bloomberg School of Public Health for Indigenous Health in Albuquerque, New Mexico was awarded \$85,000 for *Ask Grandma: A Culturally Responsive Early Developmental App.*





Board member Lisa Sims and her son, Jevon Okundaye, presented at 5 statewide conferences and webinars, including two for DDS.

Lisa and Jevon discussed the impact of “Charting the LifeCourse” tools. Lisa talked about how she supported Jevon and how she let him go. Jevon talked about how he has changed his perspective and is now able to view his own Vision of a good life.



Lisa Sims and Jevon Okundaye_with
Massachusetts' Congresswoman Ayanna Pressley



Lisa Sims and Lauri Medeiros had coffee with Congresswoman Pressley.

They thanked her for her commitment to families like ours and Medicare's long-term services and support.





Lisa Sims, Family Leadership graduate, met Governor Maura Healy at the 2024 Academy of Women Achievers luncheon.

Lisa and Lauri Medeiros spoke with Governor Healy about supporting families, DSP rates, and the DDS budget.





Lisa Sims and Lee Antonie, Family Leadership Series graduates and current board members, and Lauri Medeiros, Program Director for MassFamilies Metro Family Leadership attended the *2024 Pathways to Friendship Community Inclusion Summit*.

They learned strategies and techniques to support inclusion within programs, as well as connect with like-minded people and organizations.





Would you like to volunteer?

Get involved as little or as much as you want.

A few hours here and there is great.

Volunteer more for committees, events, activism, outreach.

Ex: MassFamilies' Legislative Committee

Offer to help! hello@massfamilies.org



Got photos?

We'd love to see photos you have of MassFamilies' events!

Email photos to bill@massfamiles.org

If you rather we don't use certain photos publicly, just let us know!



Mass Families

leadership training for a world where everyone belongs

Questions? Suggestions? Praise!

Email us anytime:
hello@massfamilies.org

More about us at www.massfamilies.org