The Role of Family Organizations in Advancing Supported Decision-Making: Parent Centers and Family to Family Health Information Centers Leading the Way!

Panelists

- **Bev Baker**, Co-Director, Leadership in Family Professional Partnerships; Associate Director for Programs, Family Voices
- **Dylan Campbell**, Youth Coordinator, Maine Parent Federation
- **Dawn Monaco**, Co-Director, REACH for Transition @ SPAN Parent Advocacy Network (F2F & PTI)
- **Carrie Woodcock**, Executive Director, Maine Parent Federation (F2F & PTI)

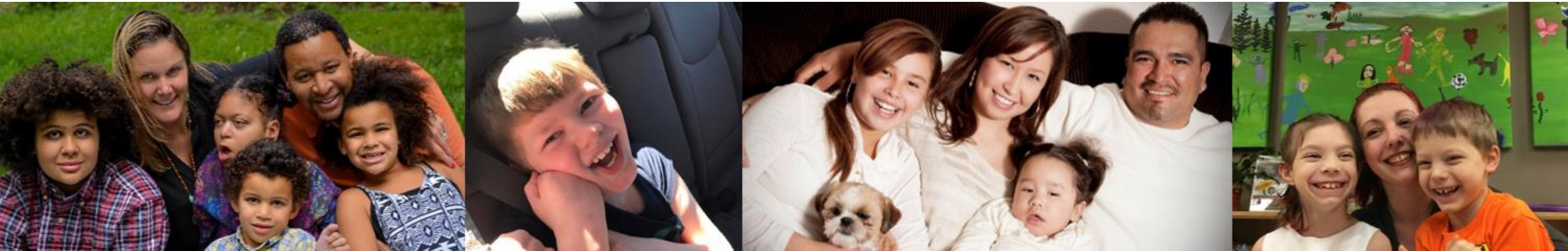
Bev Baker

- Co-Director, Leadership in Family Professional Partnerships (LFPP) & Associate Director for Programs, Family Voices
- Family Voices Representative on National Resource Center for Supported-Decision Making Advisory committee
- Parent and daughter using SDM

"I use Supported Decision-Making strategies to support my son with autism and my aging father. As my son grows older, he needs less of this kind of support. As my father grows older, I find that he needs more support."

FAMILY VOICES®

- Family Voices is a national family-led organization of families and friends of children and youth with special health care needs (CYSHCN) and disabilities.
- We ***promote partnership with families at all levels of health care***–*individual* and policy decision-making levels—***in order to improve health care services and policies for children*.**
- We connect a network of family organizations across the United States that provide support to families of CYSHCN.



FAMILY VOICES®

Leadership in Family Professional Partnerships (LFPP) Program

- Funded by HRSA Maternal and Child Health Bureau (MCHB)
- Serves as a national leader and resource for **promoting and increasing family engagement at all levels of health care for CYSHCN**.
- Special attention to engagement of families from diverse and underserved communities

Family Voices & Supported Decision-Making

KASA

National grassroots project of FV created by youth with disabilities & health care needs for youth

- Serve on national and state advisory boards, councils and committees
- 3 part webinar: Starting a Youth Advisory Board
- FV Leadership conference 2019

www.fvkasa.org

Family Voices & Supported Decision-Making

- FV & P2P distributed a survey to F2Fs, FV State Affiliate Organizations, and P2Ps

- Two-part webinar:
  1. *Introduction to NRC-SDM and Website.*
  2. *Building Partnerships and Educating Families and Professionals about Supported Decision-Making.*

F2Fs Working on SDM: Engaging Families in Making Changes

- FV of WI (Waisman Center) provides professional education to health care providers, trainings and resources on SDM for families, and participates on the Wisconsin Interdisciplinary Network of Guardianship Stakeholders (WINGS) that encourages state courts to partner with community stakeholders.

- Raising Special Kids (AZ F2F) developed training for parents, caregivers, and professionals to explore alternatives to guardianship.

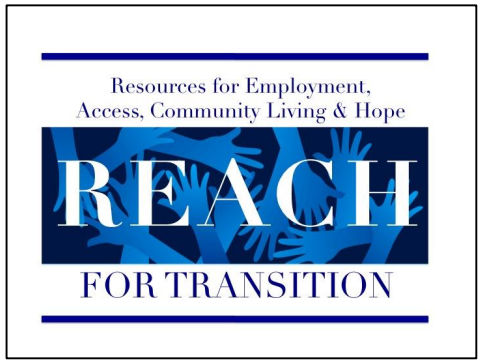
F2Fs Working on SDM: Engaging Families in Making Changes

- Virginia F2F partners with their Protection & Advocacy agency on cross-referrals of families and co-training.

- Missouri F2F incorporates SDM information in their “Charting the LifeCourse” materials, especially around transition.

FAMILY VOICES®

When you engage a family to get input on topics like SDM, you hear the perspective of one family. When you engage a family-led organization, you get the voices of many families.



- The SPAN Parent Advocacy Network (SPAN) is a one-stop family-led organization in Newark NJ
  - PTI, F2F, FV SAO, NJ affiliate of P2P USA & FFCMH
- SPAN houses two national TA centers
  - Center for Parent Information and Resources
  - National RAISE Transition TA Center
- SPAN houses two regional TA centers
  - NE-PACT Region A Parent TA Center
  - REACH for Transition Regional Transition Parent Center

RAISE Transition Parent TA Center

The National Resources for Advocacy, Independence, Self-determination and Employment (RAISE) Technical Assistance Center (www.raisecenter.org) provides assistance to parent-led organizations including:

- The 7 Rehabilitation Service Administration (RSA) grants engaging parent centers in 15 states
- The 94 Parent Centers funded by US ED OSEP in collaboration with the national Center for Parent Information and Resources @ SPAN (CPIR, www.parentcenterhub.org)

RAISE Partners

- Autistic Self-Advocacy Network
- Branch Military Parent TA Center
- EPICS (former Native American Parent TA Center)
- Institute for Educational Leadership
- National Black Disability Institute
- National Federation of Families for Children's Mental Health
- National TA Center on Transition
- TASH
- TransCen

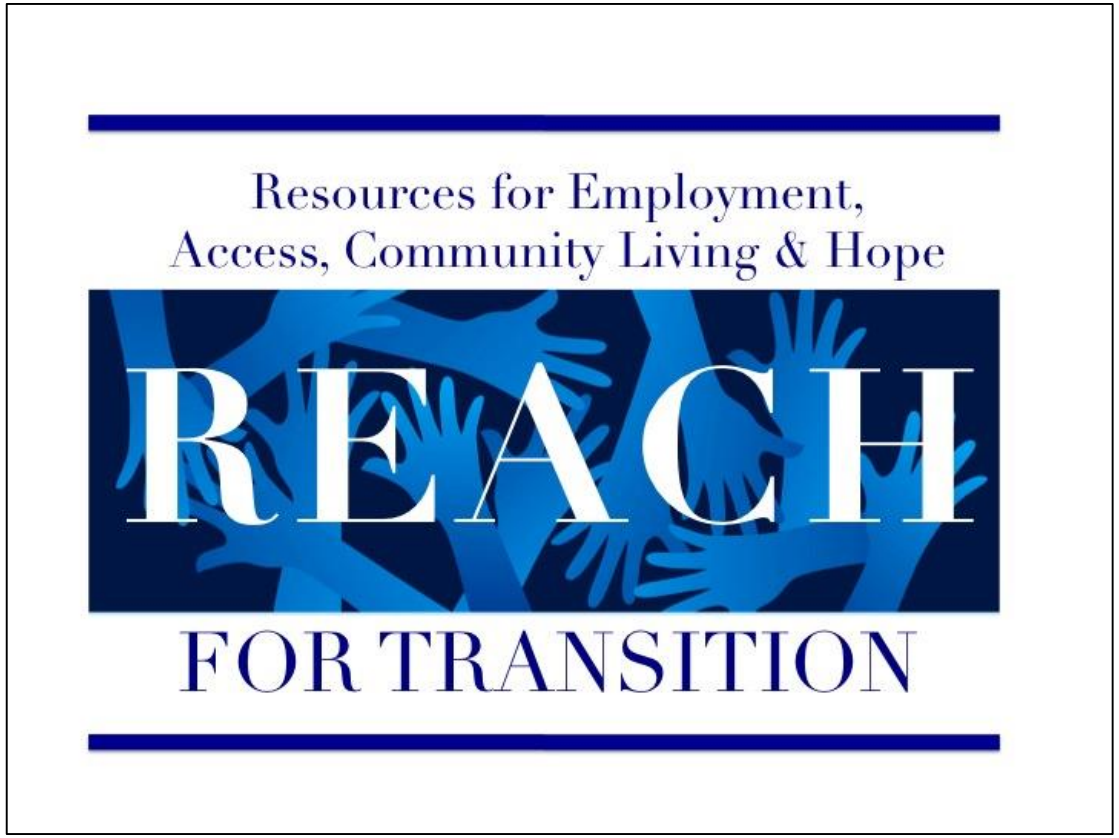
RAISE Parent Center Partners

- Federation for Children with Special Needs LINKS Center (MA)
- NYS Transition Partners (INCLUDEnyc, Parent Network of WNY, Starbridge)
- Open Doors for Multicultural Families (WA)
- Project Launch (PACER Center-MN and IND, KY, Ohio parent centers)
- REACH for Transition (Resources for Employment, Access, Community Living, and Hope) (SPAN-NJ and 8 other funded parent centers; a Community of Practice with 26 parent centers)
- SHIFT Transition Project (PEAK Parent Center-CO, NM PRO, and 4 other parent centers
- STELLAR (Supporting Transition to Engaged Lives by Linking Agency Resources) (MPACT-Missouri Parents Act)

RAISE

RAISE Partners

- The RAISE Standard articles
  - March 2018 Issue
- You Tube videos
  - Gabby Castro, www.youtube.com/watch?v=duyJJkZ2mIQ
  - Timberly Mouat, www.youtube.com/watch?v=DwnJ1nRR0Hs
- Dissemination of Support My Decision guide by ACLU, www.SupportMyDecision.org
- Annual RAISE Summits in collaboration with the National TA Center on Transition to share resources from national RAISE partners and RSA-funded parent centers
- Getting Ready for the Age of Majority Parent Guide and suite of resources: www.parentcenterhub.org/?s=Getting+Ready+for+the+Age+of+Majority&fwp_paged=1



A Community of Practice of Region A Parent Centers

Core Components of Community of Practice

- Facilitation of Governance/Advisory Board
- Face to face convenings (2x/year)
- Webinars & Virtual Train-The-Trainers
- Resource Repository
- Action Plans & Mini-Grants for Funded Partners

Governance Board

- Representative from each funded Parent Center & an Adult Service Provider/agency from each funded Parent Center's state

- Meets quarterly to:
  - Make recommendations
  - Review results of project activities and events
  - Discuss current & emerging needs including SDM

Face to Face Convenings

- REACH/Youth Pre-Conference Forum & REACH/Youth Pre-Follow Up Forum
  - Resource sharing
  - Presentations on activities & accomplishments
  - Youth participation
    - Youth Panels (KASA, Eye to Eye, Youth MOVE, ASAN)
    - Youth Leader Facilitation of Table Discussions
    - Youth Leader Participation

Resources for Employment, Access, Community Living & Hope

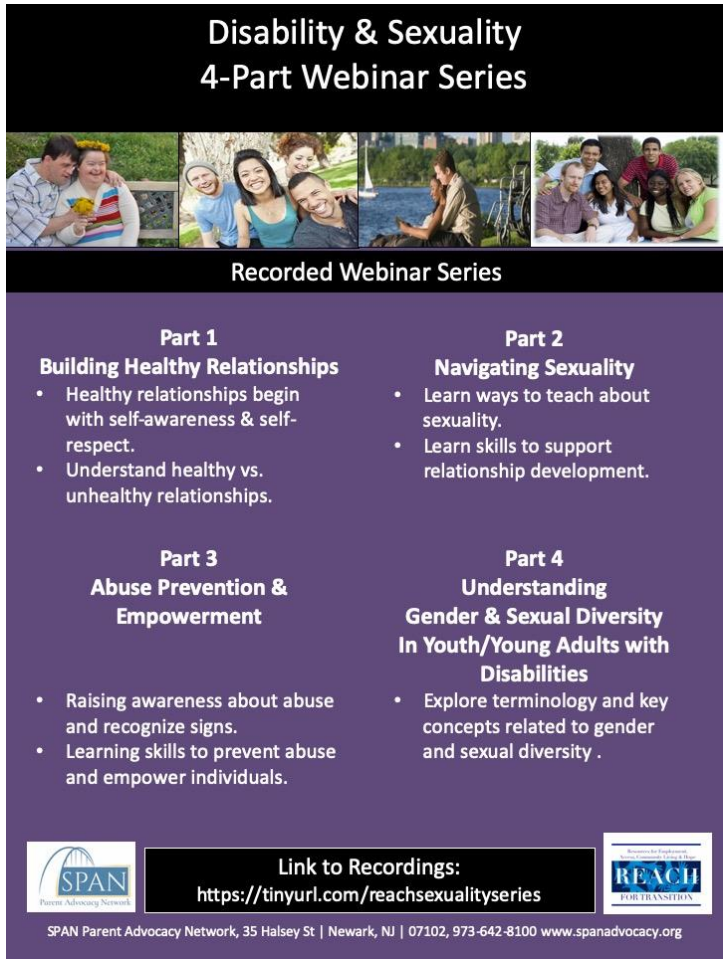
REACH FOR TRANSITION

Webinars & Train the Trainers

- **Four webinars & two virtual Train the Trainers each year**

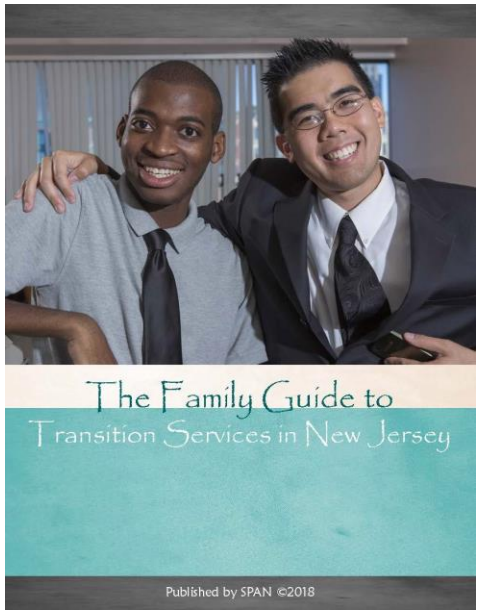
REACH Webinar Series

Link to webinar recordings:
www.spanadvocacy.org/content/reach-transition-webinars-0



Resource Repository

- A growing repository of over 150 transition-related resources from all Region 1/A Parent Centers available for easy access
  - All Region 1/A Parent Centers can add to repository
  - Reduces need to “recreate the wheel”
  - Permits “state personalization” of resources
    - The Family Guide to Transition Services



Action Plans & Mini-Grants

- Each funded partner (9 parent centers – 7 PTIs & 2 CPRCs - in 7 states) develops an Action Plan each year
- Each funded partner receives $7,000/year in 2 installments toward implementation of their action plan, including disseminating information/tools/resources on Supported Decision-Making

Outcomes/Impact

- Qualitative outcomes for REACH Partners
  - 95.6% of survey respondents indicated that the assistance was of high quality, relevant and useful
  - 92% of family, professional, and youth surveyed reported an increase in knowledge, awareness, and confidence

REACH Funded Partners

Resources for Employment, Access, Community Living & Hope
REACH FOR TRANSITION

AFC

Maine Parent Federation
Since 1984 . . . because every family matters

SPAN
Parent Advocacy Network

ASCF

Parent Information Center

United We Stand
OF NEW YORK

CPAC
Connecticut Parent Advocacy Center

PEAL CENTER

Vermont Family Network

Examples of 2 REACH Partners' Activities: New Jersey and Maine (PTIs & F2Fs)

SPAN
Parent Advocacy Network

Maine Parent Federation
Since 1984 . . . because every family matters

SPAN State Activities

Parent, Professional & Youth Development

- Strong emphasis on self-advocacy & self-determination incorporated into all workshops
- Transition Mini-Conferences - separate strands for parents/families and youth concentrating on SDM and self-determination.
- Youth Empowerment workshops for at risk youth.
- Supported Decision-Making webinar, website landing page, and “postcard” disseminated at all transition-related events

SPAN State Activities

Individual Assistance to Families, Youth, and Professionals

- Strong emphasis on self-advocacy & self-determination in individual assistance
- Redirecting parent requests about guardianship toward SDM
- Focus on including supported decision-making in conversations by SEVA volunteers (Special Education Volunteer Advocates) with parents
- Fact/tip sheets for families and youth on SDM

SPAN State Activities

Policy Advocacy

- Discussing and advocating for Supported Decision-Making with:
  - State “DD Act” funded agencies (DDC, P&A, UCEDD)
  - Family Support Planning Councils
  - NJ State Agencies
  - Other Disability Organizations

Maine Parent Federation

Dylan Campbell, Youth Coordinator

Carrie Woodcock, Executive Director

Maine Parent Federation State Activities

Parent, Professional & Youth Development

- In Response to:
  - Maine's new Probate Code – effective July 1, 2019, and
  - Feedback from families of youth approaching 18 they were feeling pressured to obtain guardianship from schools and providers.
- Funding Provided by Maine's Developmental Disability's Council
  - Two years for $20,000 includes:
    - For families training participation stipends of $100, mileage reimbursement, accommodations, & lunch,
    - Staff time, and
    - Resources and supplies.

Maine Parent Federation State Activities

Individual Assistance to Families, Youth, and Professionals

- First Year – Development & Implementation of Parent & Youth Training
  - Parent Training includes:
    - Self-Advocate Presentation w/activity,
    - Education on Probate Code Changes,
    - Education on all available guardianship and least restrictive options,
    - Education on how to be a supporter w/ activity, and
    - 1 to 1 assistance with MPF employee drafting SDM plan and IEP goals.
  - Youth Training includes:
    - Finding Your Voice Self-Advocacy workshop,
    - Self-Advocate Presentation w/activity, and
    - Education on how to be a decider w/activity.

Maine Parent Federation State Activities

Individual Assistance to Families, Youth, and Professionals

- Second Year – Continuation & New Development
  - Full day workshop for parents & youth,
  - Implementation of SDM within our peer to peer support program,
  - Develop 2 hour trainings for parents & youth,
  - Develop live and recorded webinars,
  - Develop brochures, one sheeters, and informational packets, and
  - Develop training and outreach for schools & providers.

Maine Parent Federation State Activities

Policy Advocacy

- Working with Disability Rights Maine, (protection and advocacy) on promoting to families and professionals,
  - SDM User's Guide,
  - Maine AAP Newsletter, and
  - Collaboration within trainings.
- 129th Legislative session amendment to the probate code,
  - Providing parent voice at public hearings, and
  - Providing updates to our parental community about changes.

Successes/Accomplishments

- Changing the attitudes and trajectory of our own staff away from guardianship and toward supported decision-making
- Helping families see the benefits of supported decision-making and restrictive aspects of guardianship
- Reaching out to and supporting youth more directly to support them in advocating for supported decision-making in their own lives, empowering self-determination and independence
- Helping policymakers understand the importance of supported decision-making

Challenges

- “Over-protectionism” fostered by doctors, providers, schools, (and even other parents!) leading to over-segregation, and limited opportunities for inclusion and decision-making
- Many disability organizations, schools, and state agencies encourage families to start the guardianship process, even very early on
- Hard to change long-held myths, stereotypes, and beliefs about the “need” for guardianship

Recommendations

- Discuss importance of EI providers working with families to focus on “my child can” instead of “my child can’t”
- Start talking about supported decision-making and the drawbacks of guardianship early on – from birth!
- Work to build decision-making into curriculum early and for all students, including students with disabilities
  - DC Public Schools’ detailed description of what can be worked on at each age and grade is useful resource!
- Integrate SDM into ALL workshops, individual assistance, etc.
- Target youth and young adults directly with training, TA, etc.

Conclusion

“For anyone who has been told you can’t do something, you can’t make your own decisions, I give you Jenny Hatch — the rock that starts the avalanche.” Jonathan Martinis in The Washington Post

“Just because people have a disability does not mean they need a guardianship…many times they may need just a little help.” Jenny Hatch, http://jennyhatchjusticeproject.org/jennys_words