

# Family Organization-State Agency-Provider Collaboration that Makes a Difference

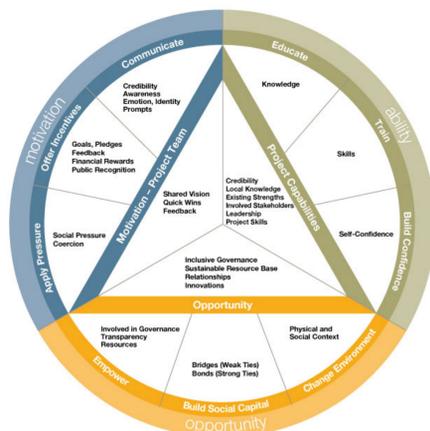
## Family-Led, Family-Centered, and Family-Empowering Systems of Care

### Statewide Parent Advocacy Network

Diana MTK Autin, Executive Co-Director for Health and Family Support

#### INTRODUCTION

Children with Special Healthcare Needs (CSHCN) have improved outcomes on core outcomes (early and continuous screening, medical home, community-based services, adequate healthcare financing, and transition to adult systems of care) when their families report greater partnership at all levels. Family organizations, led and staffed by parents with direct experience navigating systems of care, have the knowledge, expertise, and commitment to advocate for systems change and improvement across all six of the core outcomes for CSHCN, yet too frequently are seen by state agencies and providers as useful partners only regarding family involvement. Family organizations are also often only accepted as partners when they “go along to get along,” and are viewed negatively when they serve their invaluable role as “critical friends.” Yet the most powerful and meaningful improvements in systems can only be made when family organizations, state agencies, and providers work together even in the face of differing histories, experiences, perspectives, perceptions, and chains of command.



#### BARRIERS

- Lack of understanding about the knowledge, experience and expertise that family-led organizations bring to the table across issues
- Limited capacity on the part of family-led organizations and state and provider agencies
  - Insufficient knowledge about how to partner effectively
  - Insufficient financial resources to partner meaningfully
  - Insufficient time to partner deeply
- Misunderstanding about the varied roles of family-led organizations
  - How can a family-led organization be a (funded) partner and an advocate that questions state policies and provider practices and engages families in advocacy for change?
- Taking the professional, personally
  - How can you be my partner if you are attacking me?
- Unaligned missions, visions, values, and/or chains of command
- Lack of knowledge about how systems change actually happens and the role of “critical partners” in that process

#### ADDRESSING THE BARRIERS

- Engage in collaborative mission, vision, value, action, and evaluation planning on targeted areas for improvement
  - Facilitated if necessary!
  - Address areas of disagreement honestly
- Focus on mutual trust, respect, and “creating agreement”
- Make the time and take the time
- Don’t overpromise, don’t under-deliver
- Don’t assume!
- Really LISTEN...with the heart...for the heart...from the heart
- Be honest
- Have high expectations – for yourself, for your partners

#### METHODS

- Engage family organizations at the start and throughout:
  - Identifying the problems
  - Developing the proposed solutions/interventions
  - Identifying the needed resources
  - Implementing activities – with a meaningful, financially supported role!
  - Evaluating results
  - Celebrating successes – and getting the credit!
- Have a parent co-leader at every stage and every level
- Recognize – and publicly acknowledge – that family organizations are the experts in engaging, supporting, and empowering families!

- Understand your own conflict resolution styles and their impact on:
  - How you perceive others with similar and different styles
  - How others perceive you and how it affects them
  - How you respond to disagreement
  - How your conflict resolution styles differ – personal or professional, internal or external partner, etc.
  - Your ability to partner with others different from you
  - The outcomes of your efforts
- Understand your own cultural beliefs and biases
- Let family organizations advocate for the right thing even where you cannot, instead of trying to limit their advocacy

#### OUTCOMES

##### What does NJ Title V say about our partnership?

- Over 90% of Special Child Health Services Case Managers say that SPAN’s Family Resource Specialists:
  - Help families partner with their child’s health, education, and other service providers
  - Help families more effectively navigate community services
  - Build parent confidence & competence in getting needed services for their child



“Our collaboration-partnership is possible and effective because we have trust in each other, equality and a balance of power, a shared vision and commitment to the same goals; we highly value the contributions made by each agency; and we see the benefits to our respective agencies, but most importantly to the families and children we serve.” *Gloria Rodriguez, Assistant Commissioner, Family Health Services, NJ Department of Health and Senior Services*

- ✓We engage each other in our stakeholder groups
- ✓We co-lead systems change initiatives
- ✓We give credit where credit is due
- ✓We let each other know when things are – or aren’t – working
- ✓We seek to give the other recognition and support
- ✓We find the places where we can work together, and give each other space when we cannot
- ✓We act on the assumption that we are each doing our best within the confines that are placed upon us
- ✓We presume positive intent
- ✓We follow through on our word

#### Community of Care Consortium Partners

