

# FABRIC NOT FRINGE: WEAVING FAMILY INVOLVEMENT STRATEGIES INTO LENDS AND OTHER PROFESSIONAL DISABILITY RELATED TRAINING PROGRAMS

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# INTRODUCTION

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Mark Smith

# Introduction

- Family as Discipline
  - First “officially” recognized in a meeting co-sponsored by AUCD and MCHB in 2005, but involving family members as trainees started earlier
  - The LEND Family Faculty Work Group emerged
  - From the beginning, the Work Group was (and remains) focused and active. Some examples:
    - Developed original guidance documents for LEND Family Faculty
    - Collaborated with other MCHB-sponsored training programs on family involvement
    - Developed other guidance, including scholarly articles and technical assistance documents
    - Presented at national meetings on family as discipline and related topics
  - Today we’ll be talking about results from our recent survey on family involvement in LEND programs leading to the development of a white paper, both of which will be discussed, but
  - The central goal of this session is that we want to hear from you

# LEND FAMILY INVOLVEMENT SURVEY

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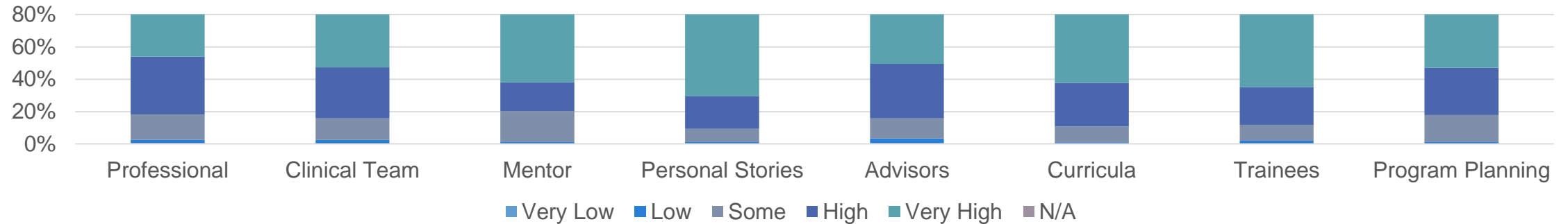
Fran Goldfarb

# Overview

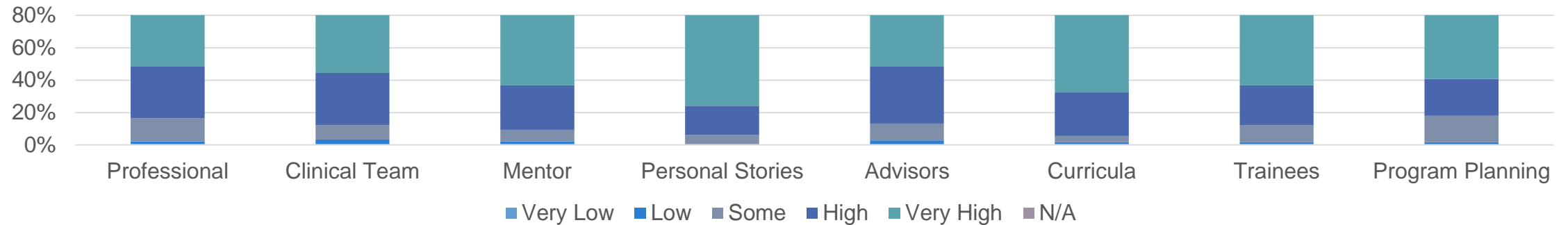
- Graduating Fellows from Any Discipline
- Endorsed by AUCD and MCHB
- Impact and Importance of Family Involvement in LENDs
- Identified 8 types of Involvement.
- Responses
  - 2014 – 213 responses (24 LENDs)
  - 2015 – 194 responses (23 LENDs)
  - 2016 – 241 responses (26 LENDs)

# Impact

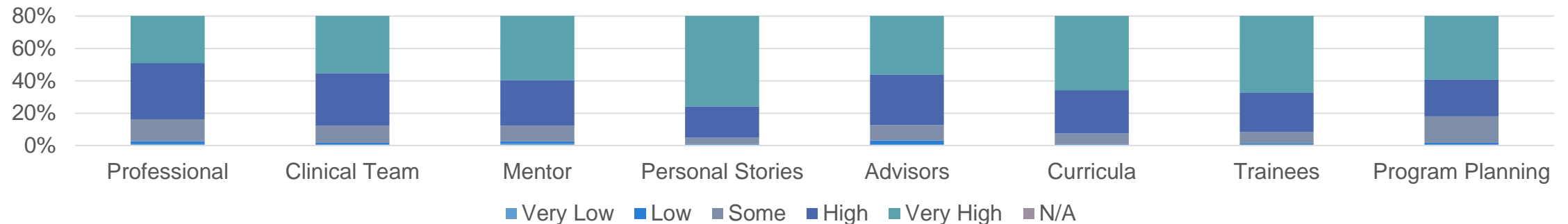
2014



2015

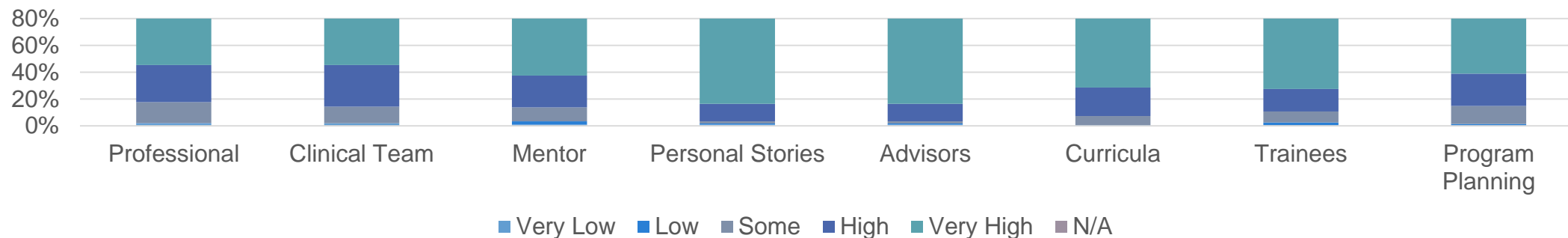


2016

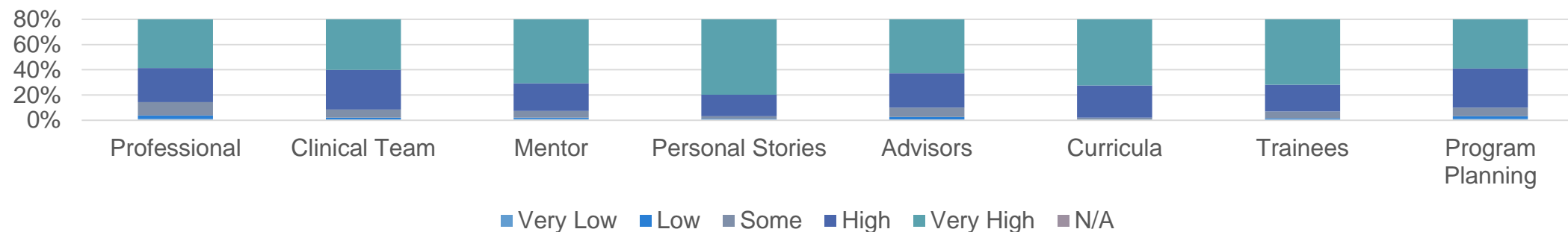


# Importance

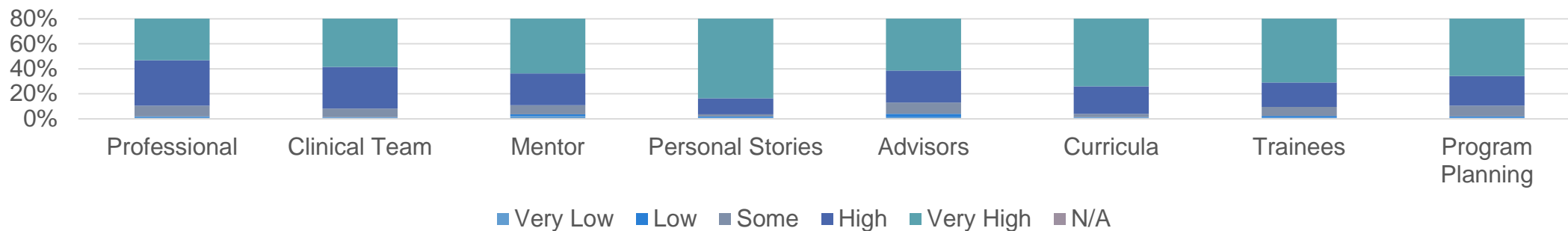
2014



2015



2016



# TYPES OF FAMILY INVOLVEMENT IN TRAINING

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Barbara Levitz



# Types of Family Involvement in Training

- **Families as professionals:** employed as program and university faculty and staff
- **Families as interdisciplinary team members** in clinical settings
- **Families as mentors for trainees** during home and community visits
- **Families as guest presenters** for training sessions

# Types of Family Involvement in Training

- Families as program advisors participating in community councils, research projects...
- Families as trainees (representing the family discipline)
- Families as participants in program planning, implementation and evaluation
- “Families” as a component of training curriculum

# SHIFTING THE PARADIGM

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Julieta Hernandez

## **Quick question for the audience**

- What other disability-related training programs are represented here today?

# Healthy People 2010—Family Centered Care objective

- “families of children with [developmental disabilities and] special health care needs will partner in decision making at all levels, and will be satisfied with the services they receive.”

(Kuhlthau et al. 2011)

# Family-Centered Care Principles

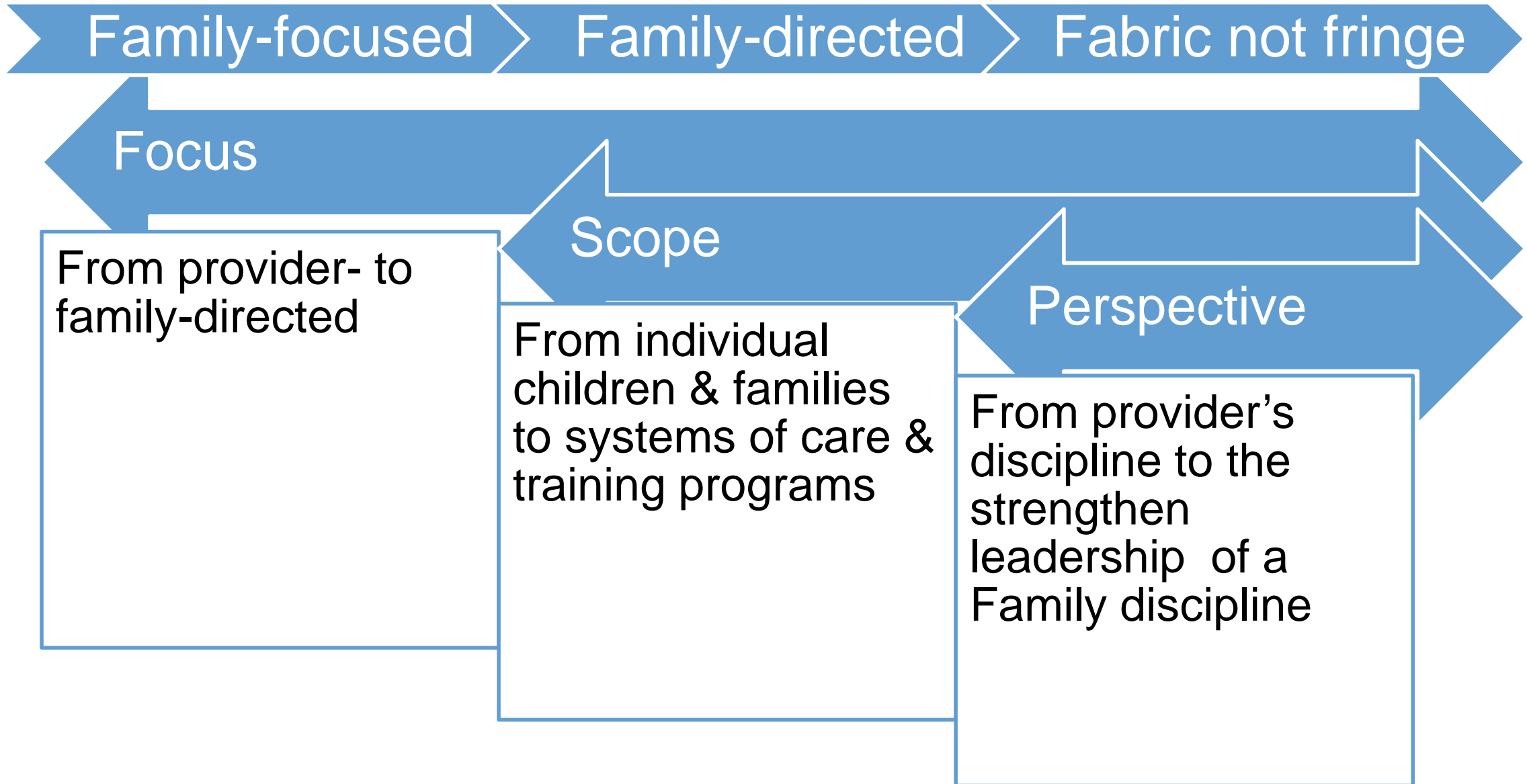
- recognizing the family as a **constant** in the child's life;
- facilitating parent-professional **collaboration** at all levels of health care;
- honoring the racial, ethnic, cultural, and socio-economic **diversity** of families;
- recognizing family **strengths and individuality** and respecting different methods of coping;
- **sharing** complete and unbiased **information** with families on a continuous basis;
- encouraging and facilitating family-to-family **support and networking**;
- **responding** to child and family **developmental needs** as part of health care practices;
- adopting **policies and practices** that provide families with **emotional and financial support**; and
- designing **health care** that is flexible, culturally competent, and responsive to family needs

(Institute for Family-Centered Care 2007)

# The paradigm shift

	Provider-driven	Family-driven
Source of solution	Professionals & agencies	Child, family, their support team
Relationship	Dependent client expected to comply	Partner/Collaborator in decision making, service provision, and accountability
Orientation	Isolation approach: Fix the problem which resides in the child or family	Ecological approach: Enable child & fam to do better in the community
Assessment	Deficit oriented	Strengths based
Expectation	Low to modest	High
Planning	Agency resource based	Individualized for child & family
Access to service	Limited by agency's menus, funding streams, staffing schedules	Comprehensive, provided when and where the child & fam require
Outcomes	Based on agency function and symptom relief	Based on quality of life and desires of child & family

# The evolution of FCC – an emerging paradigm

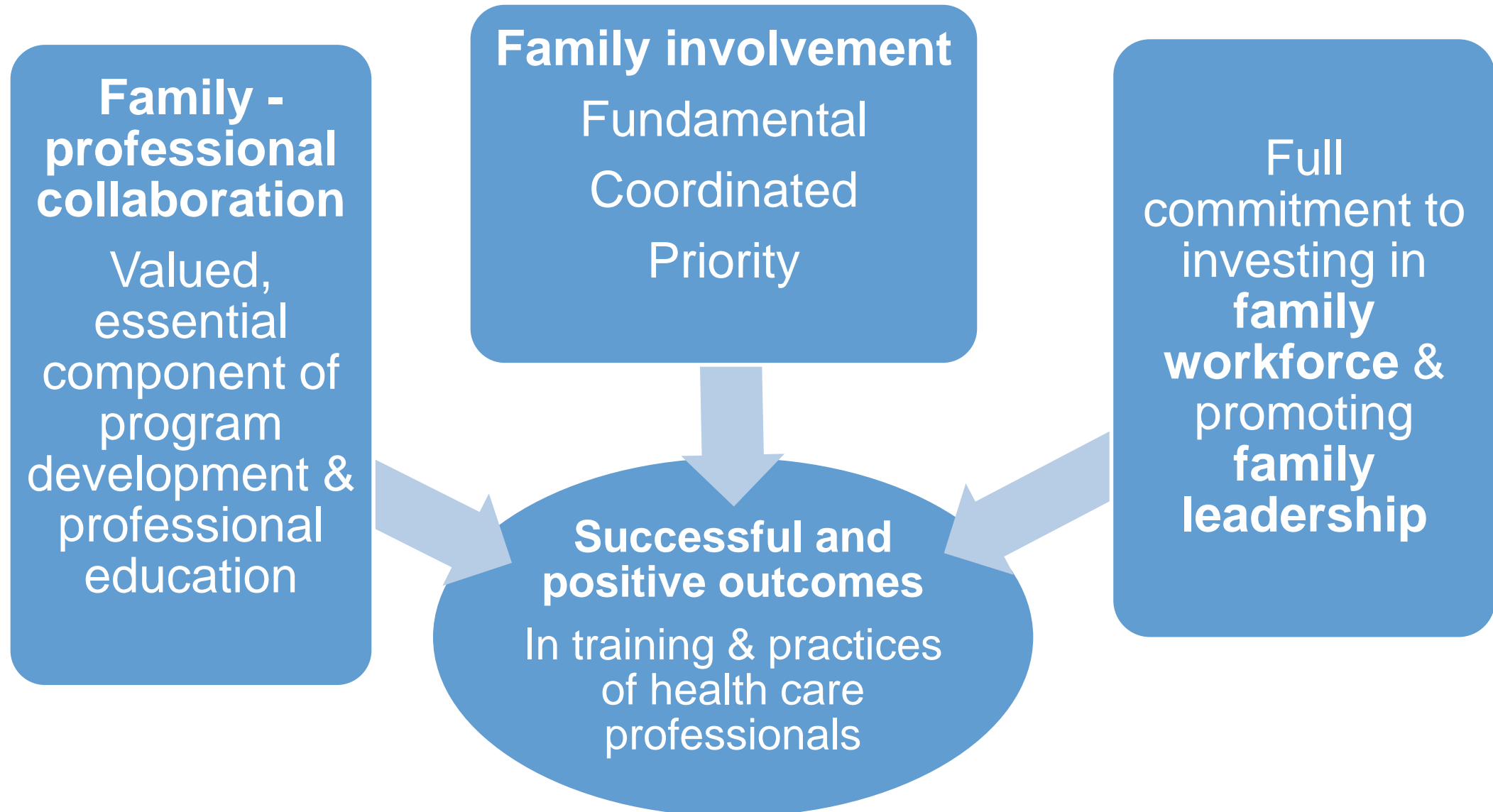




# Family involvement roles

Family-Focused	Family-Directed	Fabric Not Fringe
Cheerleading	True partners	Leadership
Participants in debriefing of evaluation findings	Advisors	Substantial partnerships
Participants in developing child's service plan of care/education	Service planners	Substantial contributions
Optional family involvement in isolated program activities	Providers	Define and affect child outcomes
Add-on family involvement requested by administrators	Evaluators	Define and affect system outcomes

# Fabric Not Fringe



# Objectives

- Increased awareness of the value of family involvement in all types of professional disability related training programs.
- Identification of new ways to involve family voice into professional disability related training programs.
- Development of a plan to introduce and/or increase family involvement into professional disability related training programs.
- Opportunity to contribute to a network-wide white paper on Family Involvement.

# DISCUSSION

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Amy Carlsen