

CREATING A VISION FOR THE FUTURE

**It's Never too Early (or too late!) to
Begin**

**Barbara Katz and Liz Hecht, Co-Directors, Family Voices of
Wisconsin**

ABOUT THIS SESSION

- **Creating a Vision:** What lives of people with disabilities can look like
- **Building Blocks:** What tools and strategies need to be used to support youth
- **Community Support and Inclusion:** How our formal system of support is transforming
- **Moving Forward:** Strategies for Supporting Families
- **Selected Resources**

CREATING A VISION

ROLE OF FAMILIES

- Families are the core unit in our society, serving as a source of support for all of its members.
- Values about work, community and contribution come from families.
- The role of family is unique and often central in the support and care provided across the lifespan.
- Families play key roles in identifying and securing opportunities.
- Families often provide medical, behavioral, financial, and other daily supports beyond what most families provide.

ROLE OF FAMILIES

Families who are well supported, with all of their complexity and diversity, are able to use their capacity, strengths, and unique abilities to support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.

www.familysupportagenda.org/FSNA/

CHILDREN GROWING UP

- **Families do the best they can to raise and support their children based on:**
 - Strengths and resources
 - Cultural beliefs and values
 - History and experience
- **Typical families and children have access to everyday experiences that prepare them for self-determined lives.**

SHAPING A VISION FOR THE FUTURE

- Dreaming and imagining
- Role models
- Experiences and opportunities
- Safety and tolerance for risk
- Self Advocacy and Self Determination

GROWING UP WITH DISABILITIES or SPECIAL HEALTH CARE NEEDS

- How does disability change the way families and children think about the future?
- Families and children with disabilities may have fewer opportunities to have visioning experiences.
- Families and youth need information and experiential opportunities to develop skills.

WHAT FAMILIES WORRY ABOUT

- Tolerance for risk
- Vulnerability
- Who is the voice for people who need support to communicate choices?
- Shifting roles of families, professionals and community
- And...
 - **WHAT ARE YOU WORRIED ABOUT?**

BUILDING BLOCKS FOR ACHIEVING YOUR VISION

SETTING THE STAGE FOR SELF-DETERMINATION

- Self-determined individuals come from knowledgeable, empowered families who transfer this knowledge and skills to their children.
- Families and children move along a developmental continuum towards self-determination, regardless of disability, with each step building on the last.
- For families of individuals with a disability the opportunities to experience success and failure with self-determination can be limited

SETTING THE STAGE FOR SELF-ADVOCACY

- Self advocacy progresses along a learning path beginning with the family and moving to the individual.
- Families who have children with disabilities may need help teaching self advocacy skills.
- Critical for families and service providers to work in partnership in skill development

OPPORTUNITIES TO BUILD SKILLS

- Using “teachable moments” and role playing to support self-advocacy skills
- Involvement in extra curricular activities
- Community connections and experiences
- Use of “formal” planning tools:
 - Discovery Process
 - PATH
 - MAP, and more!

YOUNG CHILDREN

- Families teach and model their values and beliefs about work, contribution, community, and independence to their children starting early.
- **Challenges and Opportunities:**
 - Previous experience and values about disability
 - “Deficit model” vs. “Assets model”
 - Family and professional skills to teach choice and decision-making to young children
 - Begin by thinking about long-term outcomes

SCHOOL YEARS

- **Challenges**
 - Fewer opportunities
 - Natural supports
 - Expectations
 - Success after school is increased by parent involvement
- **Opportunities**
 - Inclusion
 - Access to opportunities
 - Natural supports
 - Typical development
 - Youth Leadership

IMPORTANCE OF SCHOOL EXPERIENCES

- **Success after school is increased by parent involvement, early work experiences, and self advocacy skills** (*Turner 1995, Field & Hoffman 2002*)
- **Self-determination skills improve student outcomes** (*Carter et al. 2006*)
- **Parent education and socio-economic situation impact student development of self-determination skills** (*Zhang 2005*)
- **Parents of special education students engage their students less often in self-determination practices than parents of non special education students** (*Zhang 2005*)
- **Teacher beliefs about students' limited capacity to engage in self advocacy** (*Carter et al.2006*)

FORMAL SUPPORTS: A MOVEMENT TO COMMUNITY INCLUSION AND CONTRIBUTION

MOVE FROM SEGRATION TO INTEGRATION

We are seeing this in schools, work and community

- **Early Childhood:**
 - Birth to Three move from a “medical model” to “coaching”
 - Community based integrated opportunities
- **School Years:**
 - Inclusive classes
 - Peer to Peer support
- **Transition:**
 - Community based learning
 - Focus on employment
 - Post secondary education

MOVE FROM SEGRATION TO INTEGRATION, continued

- **Employment:**
 - Integrated and competitive employment
- **Community Living:**
 - Fewer congregate settings
 - Community contribution; living a “full life”
 - Natural supports

MOVING FORWARD

STRATEGIES FOR SUPPORTING FAMILIES

Information and Navigation	Networking and Community Connections	Services and Goods Directed to Family Unit
<ul style="list-style-type: none"> • Best practices and values within and outside of disability services • Accessing and coordinating community supports • Advocacy and Leadership skills • Useful information 	<ul style="list-style-type: none"> • Family-to-Family Support • Self-advocacy organizations • Sib-shops • Support Groups • Professional Counseling • Non-disability community support 	<ul style="list-style-type: none"> • Planning for current and future needs • Respite/Childcare • Adaptive equipment • Crisis prevention and intervention • Systems navigation • Home modifications • Health and wellness management

QUESTIONS TO CONSIDER...

After today's session, you might want to think about:

- **What are your child's talents, gifts and interests?**
- **What makes your child smile?**
- **If your child was living the best life imaginable, what might that include?**
- **What needs to happen for your child to have a great life?**

SELECTED RESOURCES

Information and Navigation:

- **Core of a Good Life**
<http://www.waisman.wisc.edu/cedd/products.php>
- **PACER Parent Brief on Person Centered Planning**
http://www.pacer.org/publications/parentbriefs/ParentBrief_Feb04.pdf
- **Family Voices Trainings, Newsletters and Fact Sheets**
www.fvofwi.org
- **Regional Centers for CYSHCN**
<http://www.dhs.wisconsin.gov/health/children/RegionalCenters/index.htm>
- **Fostering Self Determination Among Children and Youth with Disabilities – Ideas from Parents for Parents**
<http://www.waisman.wisc.edu/naturalsupports/pdfs/FosteringSelfDetermination.pdf>

SELECTED RESOURCES, continued

Networking and Community Connections:

- **Parent to Parent of Wisconsin**
<http://www.p2pwi.org/>
- **DPI Opening Doors Series**
http://sped.dpi.wi.gov/files/pubsales/pdf/opening_doors.pdf
- **WI Board for People with Developmental Disabilities**
www.wi-bpdd.org
- **People First of Wisconsin**
<https://www.facebook.com/peoplefirstwisconsin>
- **Youth Leadership First**
http://wiyouthfirst.org/youth_leadership.html

SELECTED RESOURCES

Services and Goods:

- **Children's Long Term Supports**
<http://www.dhs.wisconsin.gov/children/>
- **Adult Long Term Supports – Family Care**
<http://www.dhs.wisconsin.gov/LTCare/>
- **Adult Long Term Supports – IRIS**
<http://www.dhs.wisconsin.gov/bdds/IRIS/index.htm>
- **Department of Public Instruction – Special Ed**
http://sped.dpi.wi.gov/sped_tm-spedtopics
- **Medicaid**
<http://www.dhs.wisconsin.gov/forwardhealth/>
- **Division of Vocational Rehabilitation**
<http://dwd.wisconsin.gov/dvr/>

CONTACT US!

Family Voices of Wisconsin

www.fvofwi.org

Check us out on Facebook!

Liz Hecht, liz@fvofwi.org

608.239.1364

Barbara Katz, barb@fvofwi.org

608.220.9598