Each family has a voice. Together, our voices will be heard.
Family Voices supports families who have children with disabilities and special health care needs. We empower families to navigate health care and community support and services.

As a family-run organization, we guide families on their own leadership and advocacy journeys. We promote family-centered care and family/professional partnerships.

Visit our website to view our fact sheets, newsletters and online learning.
Overview and Getting Started

Living and Working in the Community

Decision-Making

Long-Term Supports and Health Care

Education

Family and Youth
• **Individual Child**
  • Building self-determination and self-advocacy; daily-living skills; social skills; dreaming and imagining, checking out new and different experiences

• **School**
  • Transition IEP and planning for life after high school

• **Health Care**
  • Insurance and providers

• **Public Benefits**
  • SSI, DVR, Medicaid, Long-Term Support Waivers

• **Community**
  • Volunteering, trial work experiences, social life, recreation, fun stuff
Getting Started

- How old is your child?
  - This will help you think about where to begin

- Talk with your child about:
  - Their dreams and interests
  - Their likes and dislikes
  - Things they do well and things that are difficult

- Is your child’s IEP addressing transition goals?
  - Skill development, including social skills
  - Building on interests
  - Planning for what to do after high school
  - Self-determination, advocacy, community connections

- Have a notebook (electronic or print) to stay organized

- Track important dates (we talk about this next)
AGES 14 - 21
- Individuals with Disabilities Education Act (IDEA) requires transition activities to start at age 16 (age 14 in Wisconsin)
- Services end school year youth turns 21

AGE 17 ½
- Connect with Aging and Disability Resource Center (ADRC)
  - Access to Disability Benefits Specialists
  - Public benefits, assistance, referrals and support

AGE 18
- Legal changes
  - Responsible for all actions and decisions
  - End of parent rights and decision making
  - Supported-Decision Making options
- Apply for Supplemental Security Income (SSI) after 18th birthday
  - Cash benefit and access to Medicaid
- Register to vote
- Register with Selective Service (males)
Overview and Getting Started

Living and Working in the Community

Decision-Making

Long-Term Supports and Health Care

Education
With legal status changes at age 18, youth may need assistance making informed decisions

- This is sometimes called “supported-decision making”
- There are multiple tools that can be used, including:
  - Supported Decision Making Agreements
  - Family Voices Supported Decision Making Training
  - BPDD Supported Decision Making Toolkit
  - Powers of Attorney
  - Guardianship
- Supported-decision making builds on choice-making opportunities youth have had throughout their childhood
  - It's never too late to start
  - Family Voices "Early Choices Matter" toolkit
Our laws presume people are competent to make their own decisions

• Making an “informed” decision means:
  • Understanding information needed to make decisions
  • Understanding the outcomes and consequences of decisions
  • Having a way of expressing your decisions

• It does not mean:
  • The decision is what others, including parents, would choose or approve
Decision Making is a Continuum

Person remains “the decider”
- Release of information/consent
- Supported Decision-Making Agreements

Someone else is “the decider”
- Power of Attorney (POA)
- Guardianship

Financial Safeguards
- Social Security Representative Payee
- Joint checking/savings accounts
- Limits on debit cards

* For the purpose of this publication, the term "individual" refers to an individual with disabilities and/or an aging adult.

Courtesy of Wisconsin Board for People with Developmental Disabilities, “Supported-Decision Making Toolkit”
How Do I Know Which Option is Best for My Youth?

- Talk with your youth about their preferences for assistance with decision making
- Talk with other families about the choices they made
- Keep learning about the different tools to help with decision making
- If unsure, start with the least restrictive tools first
- At the very least, have your youth sign a Release of Information at the bank, school and the doctor’s offices so they can share information with you after they turn 18
- Most importantly... **TAKE YOUR TIME** so an informed choice is made
Overview and Getting Started

Living and Working in the Community

Education

Decision-Making

Long-Term Supports and Health Care
Paying for Health Care

Private Insurance

- Affordable Care Act (ACA)
  - Coverage on a parent’s plan up to age 26
  - Marketplace options
- Employer or University Coverage
- Disabled Dependent Provision
  - Some private plans, allows a child with a disability to stay on parent’s plan as long as parent has that plan

Public Insurance

- Medicaid: BadgerCare, SSI and Long-Term Support
- Medicare: SSDI
- MAPP (Medicaid Purchase Plan): Buy into Medicaid for those with disabilities and higher income and assets
  - 250% of the Federal Poverty Level (FPL), and assets under $15,000
Medicaid Home and Community Based Waivers

- Children’s Long-Term Support (CLTS)
- Family Care (managed care) or IRIS (self-directed)

- Supports
  - Living, working and playing in the community
  - Personal care and activities of daily living

- Based on Individual Outcomes
  - How do I want to spend my days?
  - Where and with whom do I want to live?
  - What do I want to do for fun?

- Need to apply (or reapply)
  - Aging and Disability Resource Centers (ADRC)
  - CLTS Support and Service Coordinator and ADRC
  - Based on “functional screen” and financial need
  - ADRC offers “options counseling” and benefits specialists
Transition from pediatric to adult health care providers
  • Primary care
  • Specialists
  • Different hospital
  • Dentists and eye doctors too

Portable medical information including:
  • Emergency plans
  • Medical summary
  • Medical alert bracelets or other tools
Increased Independence
- Understanding and talking about disability/health needs
- Filling prescriptions and making appointments
- Directing caregivers and expressing needs
- Using technology
- Asking for information in a way they can understand

Role Playing Examples
- What would you tell a new doctor about yourself?
- How would you tell the doctor that you’re not feeling well?
- If you choose to talk about your disability, what would you say?
IEP Transition planning begins at age 14

• IEP requires a Postsecondary Transition Plan (PTP)
  • PTP is federally mandated for all public schools

• Transfer of rights from parent to student at age 18
  • Release of information to parents
  • Decision making options

• Identify objectives for life after high school
  • Advocate for community-based opportunities
  • Extra-curricular, social and recreational opportunities
  • Daily living skills for independence

• Course selection
  • May depend on what diploma youth will get
Continuing high school after senior year

- Transition programs for 18 to 21-year-old students
- Participate in graduation with peers
- Special education ends with diploma or certificate of completion
- If there are still unmet IEP goals, what can occur after 12th grade?
  - Taking a college class
  - Exploring different jobs
  - Job Shadowing
  - Volunteering in the community
  - Life skills training
  - Social opportunities
  - Learning about and using transportation
Applies to Anyone of Transition Age with No IEP

Transition planning must be initiated by the family

• Parents can start working on transition and independence-building activities anytime
  • Important for these families to be working on building early choice-making skills
• Proactively call DVR to get connected to pre-vocational programs

Social Networks

• Interesting field trips and gatherings with local homeschool co-ops
• Library activity clubs
• Some public school after-school programs
The Division of Vocational Rehabilitation Services (DVR) in the Wisconsin Department of Workforce Development

- Starts when youth is 16, but usually begins when student has one to two years left of high school
- DVR counselor can participate in IEP meetings
- Supports people throughout their lifetime as needed
- Provide support for:
  - Career guidance and counseling
  - Interest inventory
  - Skills assessment and development
  - Work incentives benefits counseling
  - Job search and placement assistance
  - Additional training and education after high school
  - Support to keep jobs
  - Individualized supports related to jobs
IDEA does not apply to colleges, universities or technical schools

- Colleges and technical schools have offices for disability services
- Need to have a disability determination that is acceptable to the school to get accommodations
- Student needs to seek out services or accommodations
  - Accommodations may include tutors, extended test times, note takers and assistive technology
Overview and Getting Started

Living and Working in the Community

Decision-Making

Long-Term Supports and Health Care

Education
Integrated Employment
• Competitive employment
• Supported employment
• Self-employment

Segregated Employment
• Workshop employment for sub-minimum wages

Day Services
• Community-based or facility-based
• Can serve as “wrap-around” support for part-time workers who need full-day support

★ Jobs can be full-time or part-time
★ Mix and match jobs
DVR plus Family Care or IRIS Vocational agencies

- Job developers – finding jobs
- Job coaches – support on the job
- Adaptive equipment – assist to do job
- Trial job experiences
- Transportation to and from work
- Workplace personal assistance

Work Incentives Offered Through Social Security

Work Incentives Benefits Counselors
Will my adult child continue to live at home or move out?

- Learn What's Available in Your Community:
  - Aging and Disability Resource Center (ADRC)
  - Family Care case manager or IRIS consultant
  - Independent Living Centers
  - Disability-specific Organizations
  - Talk with other families

An individual and family decision
Community Supported Living: individual hires supporters
- Owning or renting a house or an apartment
- Roommates or living alone
- Supports can be a few times a week or 24/7
- Use of technology to support independence (alerts, scheduling apps)
- Use of public assistance (Foodshare, Home Energy Assistance, Section 8/Section 42 subsidized housing, home purchase incentives)

Regulated Settings: agency-owned, managed and staffed
- Adult family homes/group homes
- Residential Care Apartment Complexes (RCACs)
- Community-based Residential Facilities (CBRFs)
Community Participation: What does this mean?

• Friendships and social connections
• Things to do for fun and recreation
• Voting and political advocacy
• Building community networks
  • Volunteering
  • Religious/Spiritual opportunities
• Stretching oneself to continue to build on self-advocacy, self-determination, social and independence skills
NEXT STEPS

Which piece will you take on first?

Which partners will you bring on to help you?

What information will you need?
Thank You!
familyvoiceswi.org
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