

# It Starts with Families...



## Introduction

We believe that families are an important asset in the equation of ensuring people with disabilities have the opportunity to live their best lives for their whole lives. And, we know when families have access to information and resources, they are more empowered to support and care for the family member with disabilities.

### Did you know?

- Approximately **119,000** or **65% of Ohioans with intellectual or developmental disabilities (I/DD)** live with their families? And in most cases, the support provided does not end when the family member turns 18.
- Over **58% of parents/caregivers spend more than 40 hours per week** providing support to their loved one with I/DD beyond typical care.
- **52%** of families caring for children with disabilities **experience difficulty paying medical bills.**

### Across agencies and across the lifespan

Extensive research on people with disabilities and their families recognizes that supports are most effective when provided to the family so they have the capacity and knowledge to provide assistance. Strategies to support the family unit must be a fundamental consideration across all agencies, at all levels of each agency, and in all aspects of planning.

As partner agencies and organizations that support people with disabilities, you play an important role in helping to build families' confidence and encourage a vision for the possibilities and opportunities for the whole family. To do this, we must connect families to important information, research, and resources and support effective family engagement strategies.

### About this guide

The Ohio Employment First Taskforce and its member agencies are developing a cross-agency professional learning experience designed for local professionals working to prepare, involve, and empower families of students with disabilities as they transition from secondary education to adulthood.

To help you get started before the training in spring 2022, we want to share *It Starts With Families*, a guide designed to support local professionals serving individuals and their families to become familiar with the research around family engagement and understanding their unique needs.

Ultimately, the guide and training are designed to support local professionals serving individuals and their families to:

- become familiar with the research around families,
- learn how to better design family engagement strategies to reach all families, and
- build trust, rapport, and successful partnerships with families through culturally responsive practices.

*We hope that this guide helps you to commit to Ohio's mission of developing and implementing universally designed approaches that will ensure all families have the necessary knowledge and skills regarding transition education and services and are involved in all aspects of transition planning.*

Parents and other family members of people diagnosed with intellectual and developmental disabilities (I/DD) often provide medical, behavioral, financial, and other daily supports beyond what most families provide. Yet, the vital role of families is not fully recognized or supported in disability policy and practices.

**65%** or approximately **119,000** people with I/DD\* in Ohio **live with their families**<sup>1</sup>; For many families, the support provided is not short term and does not end when the family member turns 18 years old.

## Contributing Factors

Families often are faced with emotional, social, physical, and economic demands that they may not have experienced had their child not been diagnosed with a disability.

**28%** of children with I/DD\* **live below federal poverty levels** as compared with 16% of children without disabilities<sup>2</sup>.

Over **58%** of parents/caregivers spend **more than 40 hours** per week providing support to their loved one with I/DD\* beyond typical care. **40%** spend **more than 80 hours** a week<sup>4</sup>.

*“Because I work, I have medical insurance, but my minimal income is just enough to exclude me from other public assistance. We struggle to survive.”*

**52%** of families caring for children with disabilities\*\* **experience difficulty paying medical bills**, compared to 32% of families with children without disabilities. Of those who care for children with disabilities and report having this difficulty<sup>11</sup>:

- **71%** report having **used up** most of their savings
- **50%** report being **unable to pay** for basic necessities such as food, heat, or rent
- **43%** report having **incurred large credit card debt** or having to take out a loan to cover medical expenses

Parents of children with disabilities\*\* have lower rates of, and diminished opportunities for, employment and advancement than parents of children without disabilities<sup>3</sup>.

## Impact on Families

Families caring for children with disabilities\*\* are more likely to have<sup>5</sup>:

- less self-reported annual family income
- greater personal financial strife
- less employment security
- elevated levels of emotional stress
- greater use of health services by their children

**28%** of families caring for children with disabilities\*\* spend **11 or more hours** per week providing or coordinating health care for the children<sup>6</sup>.

Siblings of people with disabilities\*\* experience the following<sup>7</sup>:

- at least one and a half times as **likely to have behavior problems** in all settings
- one and a half to twice as **likely to have emotional behavior** and activity engagement problems

<sup>1</sup> [State of the States in I/DD](#)

<sup>2</sup> [Wingspread Report: Supporting Families](#)

<sup>3</sup> [Caring for Children with Disabilities in Ohio: The Impact on Families](#)

<sup>4</sup> [Wingspread Report: Supporting Families](#)

<sup>5</sup> [Caring for Children with Disabilities in Ohio: The Impact on Families](#)

<sup>6</sup> [Caring for Children with Disabilities in Ohio: The Impact on Families: Policy Brief](#)

<sup>7</sup> [The Social Interaction and Behavior Effects on Siblings who Reside in a Household with a Child with Disability](#)

Families caring for a child with disability\*\* earn, on average, between **\$7,000 and \$22,500 less** than families not caring for a child with disability<sup>8</sup>.

**26%** of families **cut work hours** to care for children with disabilities\*\*<sup>9</sup>.

*“We need people to pay attention and not give just lip service – you people should spend one long day in our shoes.”*

Many parents of children with disabilities\*\* experience one or more of the following employment problems<sup>10</sup>:

- **Time stress:** Parents work fewer hours because of increased time needed to provide and coordinate care.
- **Employment proximity:** Parents take lower-paying jobs closer to home, limiting employment opportunities to be available to help with care-giving needs.
- **Job lock:** Parents take lower-paying jobs, limiting employment opportunities, because health insurance benefits are better for their children.
- **Fatigue:** Parents are less available to work and are less productive due to physical and emotional exhaustion related to care-giving duties.

*“Finding caregivers is difficult...We are looking for a group home for our daughter due to the fact we cannot find caregivers. We do not want to do this, we HAVE to do this.”*

Families caring for children with disabilities\*\* frequent the health care setting at a much higher intensity than parents of children without disabilities. Among families of children with disabilities, **those with Medicaid waivers** have higher levels of primary care visits but **less intensive levels** of mental health and physical therapy visits<sup>12</sup>.

**Interventions to aid siblings** in households with a child with a disability\*\* **may be cost-beneficial to Medicaid** from the potential mental health cost savings alone<sup>13</sup>.

## Addressing the Challenge

The overwhelming amount of research on people with disabilities and their families recognizes that supports are most effective when provided to the family so they have the capacity and knowledge to provide assistance when necessary over time. Strategies to support the family unit must be a fundamental consideration across all agencies, at all levels of each agency, and in all aspects of planning.

The Ohio Employment First Taskforce and its member agencies are developing a cross-agency professional development plan designed for local professionals working to prepare, involve, and empower families of students with disabilities to transition from secondary education to adulthood. We encourage these local professionals serving individuals and their families to become familiar with the research around families, learn how to better design family engagement strategies to reach all families, and build trust, rapport, and successful partnerships with families through culturally responsive practices.

To learn more about the professional learning opportunity, contact [ItStartsWithFamilies@dodd.ohio.gov](mailto:ItStartsWithFamilies@dodd.ohio.gov).

<sup>8</sup> [Caring for Children with Disabilities in Ohio: The Impact on Families](#)

<sup>9</sup> Ibid.

<sup>10</sup> Ibid.

<sup>11</sup> [Caring for Children with Disabilities in Ohio: The Impact on Families: Policy Brief](#)

<sup>12</sup> Ibid.

<sup>13</sup> [The Social Interaction and Behavior Effects on Siblings who Reside in a Household with a Child with Disability](#)

<sup>14</sup> [An Issue Brief from the Family Support Council](#)

## Definitions

### \*Intellectual and developmental disability (I/DD)

The term “intellectual and developmental disability” means a severe, chronic disability attributed to a mental/cognitive or physical impairment or combination of mental and physical impairments diagnosed or that become obvious before the age of 22. The condition is likely to continue indefinitely and limits the individual in three or more of the following areas:

- self-care
- receptive and expressive language
- learning
- mobility
- self-direction
- capacity for independent living
- economic self-sufficiency

### \*\*Disability

A child with disability is defined as a child that is limited or prevented in any way in his or her ability to do the things most children of the same age can do as identified on the children with special needs screener (CSHCN Screener®).

## Resources for Information

[The Social Interaction and Behavior Effects on Siblings who Reside in a Household with a Child with Disability Brief](#)

[The Social Interaction and Behavior Effects on Siblings who Reside in a Household with a Child with Disability](#)

[Evaluating Services that Support Families with Children with Disabilities](#)

[An Issue Brief from the Family Support Council - 2006](#)

[Caring for Children with Disabilities in Ohio: The Impact on Families](#)

[Caring for Children with Disabilities in Ohio: The Impact on Families: Policy Brief](#)

[Autism Minority Outreach Initiative - 2015](#)

[Wingspread Report: Supporting Families](#)

[State of the States in I/DD](#)

## In partnership with:

