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Balancing Work & Family Responsibilities: A Guidebook for Parent Support Providers

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Balancing Work & Family Responsibilities: A Guidebook for Parent Support Providers

February 2015

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Balancing Work & Family Responsibilities: A Guidebook for Parent Support Providers

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Organization and Suggested Use of the Manual and Workbook

This training manual and guidebook for Parent Support Providers has been adapted from *Children/Youth with Disabilities: Their Parents are YOUR Employees*, a workbook for human resource professionals originally produced by the Work-Life Integration Project at Portland State University. The research behind the manual comes from over two decades of federally funded studies focused on understanding the work-life experiences of parents with children challenged by behavioral health disabilities. Supplemental materials to the manual for group training purposes include a slide presentation, and a training script.

The survey at the end of this manual may be used as a pre/post evaluation of knowledge and attitudes with a group; or simply as an evaluation by individual Parent Support Providers of their learning after working through the modules.

The seven modules are structured to include a brief introduction, objectives, salient information, and a summary of key points. At the end of each module is a Notes and Reflections page. These pages are designed specifically for the Parent Support Provider to highlight what has been most meaningful to learn about the module's topic, keep track of additional questions about the material, and to personally reflect on the content's relevance. Parent Support Providers are in a unique position because of their lived experiences, to give support and guidance to other parents facing similar challenges. Reflecting on one's own work-life experiences and workplace support needs strengthens the Parent Support Provider's knowledge in this area and associated advocacy skills.

Module 7, *Accessing Workplace Support*, is a set of conversations and planning activities that may be initiated by Parent Support Providers with parents. The foundational information for the suggested dialogues and potential plans in Module 7 is covered in the preceding modules.

Throughout the modules are concepts in **bold** type, indicating that further explanation can be found in the Glossary. In addition to the Glossary, The Appendix includes a brief list of website resources, the Parent Support Provider Knowledge Check, and a Workplace Support Resources Inventory.

If you have any questions, suggestions or comments please contact us.

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Introduction and Acknowledgments

We are grateful for the opportunity to share our knowledge about the the work-life integration experiences, needs, and strengths of employees who are parents of children and youth with disabilities. During the past twenty years, we have talked with family members caring for children and youth with disabilities and workplace professionals, including human resource staff, work-life specialists, and workplace supervisors, to better understand the dynamics on both sides of the work-life equation. We are grateful to all those who have shared their experiences and generously given of their time so that we could learn from them. Many of the findings from our research are discussed in a recent book, *Work, Life and the Mental Health System of Care*, but we were convinced that the key insights from the studies also should be shared through training publications.

The material included in *Balancing Work & Family Responsibilities: A Guidebook for Parent Support Providers* synthesizes much of what we have learned. It is our hope that the information presented will help Parent Support Providers respond to the needs of employed parents of children and youth with disabilities and serve as a personal guide to attaining a better fit between their own work and family responsibilities. Moreover, we believe that the manual will assist all stakeholders, including policy makers and employers, to become better informed about what it takes to construct an integrated work-life that maximizes the well-being of all family members.

Writing and producing this manual and its associated training materials would not have been possible without encouragement, support, and advice from many individuals. Thanks to family support specialists Conni Wells and Sandy Bumpus, who encouraged us to develop training materials for the use of Parent Support Providers. We are also grateful to Lynda Gargan of the National Federation of Families for Children's Mental Health for her assistance in planning the contents of this manual, and in reviewing drafts of the materials. We also wish to thank Debora Bubb and Linda Roundtree who patiently guided us in our learning about the human resource profession and its perspectives on work-life issues, and shaped an earlier version of this manual designed for human resource professionals, *Children/Youth with Disabilities: Their Parents are YOUR Employees.*

We hope that the training materials facilitate successful partnerships between employed parents of children/youth with disabilities and the Parent Support Providers who assist them.

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1 Definitions and Prevalence

- Terms used: *disabilities, special needs, special health care needs*.

- Various categories: e.g., physical, behavioral health, developmental.

- Chronic conditions with acute episodes.

- Rates of occurrence vary by definition used for data collection.

- Rate of employees parenting children/ youth with disabilities.

- 23% of households have children/youth with special health care needs.

- Public health crisis: only 1 in 5 children/ youth receive needed behavioral health care.

- 9% of employees are parents of children/youth with disabilities.

Definitions and Prevalence

Introduction

Disabilities affecting **children/youth** take many forms and significantly shape the way families live in their communities. It is likely that there are family members you are supporting who are striving to meet their job responsibilities while also caring for children/youth with disabilities. But what are the different types of disabilities that children/youth may experience, and how widespread is their experience? To better address the needs of employed parents of children/youth with disabilities, it is necessary to understand what policymakers and service providers mean by the concept of "disability" and related terms, and to be aware of the extent of employed family members raising children with disabilities.

Objectives

By the end of Module 1, you will be able to:

1. Describe the different terms used in reference to the concept of disability.

2. List the broad categories of disabilities that affect children/youth.

3. Identify some of the most common types of disabilities affecting children/youth.

4. Discuss the prevalence of children/youth with disabilities in households in the U.S.

5. Understand the extent of employed family members raising children/youth with disabilities.

- *How are disabilities affecting children/youth conceptualized by researchers and policy makers?*

- *What are some of the most common types of disabilities affecting children/youth?*

- *What is the difference between chronic and acute conditions?*

- *How many employed parents are raising children/youth with disabilities?*

What Makes a Disability a Disability?

Historically disabilities have been conceptualized through the **medical model of disability**.[1] From this perspective the disability is seen as a condition of the individual, which needs to be managed or cured so that the person can live more "normally". More recently, the **social model of disability** has been developed.[2] The disability from this viewpoint is the result of barriers and exclusion by society—the gap between an individual's capabilities and the demands of the environment. In other words, an individual may have a health condition, but it is not a disability unless the community fails to provide adequate services and supports for accommodation and inclusion.

Person First Language

Deciding what terminology to use when discussing disabilities is not easy. Reviewed here are different words, terms, or concepts frequently used in the literature and in policies. For the purposes of this manual, we have chosen to use the concept "children/youth with disabilities". The concept of disabilities is familiar to organizations through legal requirements for employers set forth by the **Americans with Disabilities Act of 1990 (ADA)**.[3] The ADA addresses both adults and children/youth, and has provisions for caregivers of persons with disabilities that are relevant to employed parents (See Module 3). We also use **person first language**. Thus, we refer to children/youth with disabilities (or a specific disability) and not "disabled children".

Frequently Used Terms Describing the Concept of Disabilities Associated with Children/Youth

There are several similar expressions used in describing children/youth with developmental, cognitive, health, or behavioral health disorders. For example, it is common for "**special needs**" or "**special health care needs**" to be used interchangeably with the term "disabilities". In part, terminology related to the concept of disability is developed from and associated with different U. S. federal policies.

Disability

The term disability is frequently associated with the Americans with Disabilities Act of 1990 (ADA). The legal definition in the ADA of an individual

with a disability covers adults and children/youth with "a physical or mental impairment that substantially limits one or more major life activities" or who have a "record of" or are "regarded as" having such an impairment.[3]

Children/Youth with Special Needs

The concept of children/youth with special needs was developed in relationship to special education services in public schools. The **Individuals with Disabilities Education Act (IDEA)** is a federal mandate that young children who have been diagnosed as having developmental delays, or any child/youth who has been evaluated as having one of a limited list of disabilities specified in IDEA are considered as having special needs that affect their learning and required to receive special education and related services.[4]

Children/Youth with Special Health Care Needs

Children/youth with special health care needs includes those who have chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children/youth generally. The concept or term is not related to any specific legislation, but is used as a definition in the **National Survey of Children with Special Health Care Needs (NS-CSHCN)** which has been conducted by the U. S. Department of Health and Human Services every 4 years.[5]

Acute vs. Chronic Conditions: An Important Distinction

Illnesses and disabilities are often described as either an **acute** or a **chronic condition**. This is an important distinction to keep in mind when working with parents of children/youth with disabilities. An acute condition develops and worsens rapidly. A chronic condition develops over an extended period of time and has persistent symptoms that may not improve and could deteriorate. The terms acute and chronic do not refer to the severity of the disability. Both acute and chronic conditions can be mild, severe, or even fatal. For example, a child/youth with a cold virus or a sprained ankle is considered to have an acute condition and the parent is likely to need a short-term flexible work arrangement to provide care. In contrast, a parent of a child/youth with a chronic condition, such as epilepsy is likely to require access to flexibili y on a more regular basis. A chronic condition also has acute episodes, that can be anticipated but the onset cannot be

predicted. For instance, a youth's anxiety disorder is a chronic condition, but an anxiety attack is an acute episode.

Categories of Disabilities Affecting Children/Youth

A child/youth may experience a disability in any number of ways. The disability can have varying degrees of visibility to others and the child/youth and family may require a variety of services to assist with functioning in the home and community. While there are different categories of disabilities, these are not necessary discrete. Children/youth may experience multiple disabilities that may or may not be related. The categories of disabilities generally refer to the area of functioning in which the individual is experiencing difficulties.

Disabilities are often categorized into general types. For example, diabetes, asthma, and muscular dystrophy are classified as **physical disabilities**. Depression, anxiety, and attention-deficit/ yperactivity disorders may be referred to as **behavioral health or emotional disabilities**. **Intellectual disabilities** is another category, that includes diagnoses such as autism spectrum disorder, Down syndrome, and learning disabilities.

Key Points

- The terms disabilities, special needs, and special health care needs are often used interchangeably by researchers, providers and policymakers.

- There are many different types of disabilities affecting children/ youth; most are considered chronic conditions that have acute episodes.

- Using person first language communicates respect for people with disabilities by indicating that the individual has a disability rather than characterizing the total person as disabled.

Prevalence in Families

Now that the many types of disabilities affecting children/youth have been introduced, we can begin estimating the number of families involved in **exceptional caregiving responsibilities.** Different sources of national data have estimated the number of children/youth with disabilities and the number of households with children/youth who have disabilities, but currently there has yet to be a national study to determine the number of employed parents caring for children/youth with disabilities.

Sources of Prevalence Data & National Estimates

The estimated number of children/youth with a disability or the number of families caring for a child/youth with a disability varies across the type of method used to collect the data and the definition of disabili y used.

- The **U.S. Census Bureau**, based on survey data collected in 2010, estimates that about 8.4% of children under 15, 6.2 million, had some form of disability. The survey used a strict definition for a sensory, physical, or behavioral disability.[6]

- Based on the 2011-12 survey, the **National Survey of Children with Special Health Care Needs** estimates that 19.8% of children/youth under 18 years of age, or approximately 14.6 million children/youth have special health care needs.[5] This represents 23.0% of households with children/youth.[5]

- Families of children/youth with disabilities are at increased likelihood of living below the poverty line.[7]

Estimates of Prevalence of Specific Chronic Conditions Affecting Children/Youth in the U. S.

- Asthma affects an estimated 10.3 million children/youth under the age 18, making this the most common chronic disorder in childhood.[8]

- Of children/youth between 4-17 years of age, 11.1% of children have been diagnosed with Attention Deficit Hype activity Disorder (ADHD).[9]

- Autism affects an estimated 2% of school-aged children/youth.[10]

- Behavioral health disorders affect a significant number of children/ youth. One in 8 children was found to have at least one behavioral health disorder in a national study, and 11.3% had serious impairments as a result.[11] Of those children who had been diagnosed, only about half had received behavioral health services within the past year. In 2005-2006, the parents of 15% of children/youth aged 4-17 in the U.S. expressed concerns about their child's emotional or behavioral difficu- ties to a health care provider or school personnel.[12]

Number of Employed Parents of Children/Youth with Disabilities

The types and severity of disabilities that children/youth experience are wide ranging. We know that parents must find the best strategies and re- sources to meet the exceptional caregiving needs of their children/youth and maintain employment.[13] To approximate the number of parents who are employed while caring for a child with a disability, researchers from the Center for Child and Adolescent Health Care Policy considered the national estimate of children/youth with disabilities and the employment rate of par- ents of children/youth age 18 and under.[14] Using both of these statistics, they estimated that almost 9% of employees are parents of children/youth with special health care needs/disabilities.

Key Points

- The U. S. Census Bureau and the National Survey of Children with Special Health Care Needs are two key sources of prevalence data, although the statistics vary by definitions used

- Some families are not receiving services needed by their children/ youth. For example, only 1 in 2 children with behavioral health needs receive behavioral health services.

- Approximately 9% of employees are caring for children/youth with a disability.

DEFINITIONS AND PREVALENCE

Notes and Reflections

Make notes and refle t on key ideas from this module, questions you may have and how this module relates to you personally.

Key Ideas:

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Personal Reflections

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2 Exceptional Caregiving Responsibilities

- Tasks and activities more complex & extensive than typical caregiving.

- Require coordination with many community-based resources.

- Can lead to caregiver strain affecting health & well-being of employed parents.

2

Exceptional Caregiving Responsibilities

Introduction

Every parent of a child/youth with a disability must learn about the condition and how to meet the associated caregiving needs. Employed parents' **work-life integration** experiences depend on finding the right set of resources and supports in the home, in the workplace, and in the community that assist them to effectively meet the needs of their family and perform job tasks. Care needs of children/youth with disabilities are different than those of children/youth with typical development. **Exceptional caregiving** differs from **typical caregiving** in both the amount of time necessary to provide and coordinate care and the scope of care needs.

- *How do the care needs of children/youth with disabilities differ from those of children/ youth with typical development?*

- *In what ways do exceptional caregiving responsibilities shape work-life integration for the employed parent?*

Objectives

By the end of Module 2, you will be able to:

1. Define and identify "exceptional caregiving responsibilities."

2. Explain the differences between exceptional caregiving responsibilities and typical caregiving responsibilities.

3. Describe caregiver strain and its effect on well-being.

What are Exceptional Caregiving Responsibilities?

Employers have long been aware of the child care challenges faced by employed parents and some organizations have created policies to address this work-family issue. The concept of *exceptional caregiving responsibilities* initially received attention because of the increasing number of employees caring for elderly parents. When companies began to better understand the dynamics of elder care, the dimensions of the needs and experiences of these employees closely resembled those of employed parents of children/youth with disabilities, as well as employees caring for partners and adult family members with chronic illnesses and disabilities. Exceptional caregiving responsibilities encompass the physical, psychological, emotional, familial, time, and financial demands on these groups of employed caregivers.

How Do Exceptional Caregiving Responsibilities and Typical Caregiving Responsibilities Differ?

Exceptional caregiving responsibilities are different from typical care responsibilities on several important dimensions, including:[15]

- Predictability of need
- Duration and intensity
- Level and frequency of crises
- Coordination of care resources
- Type of tasks performed
- Life-style adjustment of the caregiver and family

EXCEPTIONAL CAREGIVING RESPONSIBILITIES

EXCEPTIONAL CAREGIVING RESPONSIBILITIES[15] (ROUNDTREE & LYNCH, 2006)	
Caring for a child/youth with typical development	**Caring for a child/youth with special needs/disabilities**
Constant care that diminishes	Constant care that often escalates
Ordinary input of time and energy	Extraordinary input of time and energy
Easier as time goes by	Often harder as time goes by
Few interruptions are emergency-driven	Many interruptions are emergency-driven
Child/youth grows increasingly independent	Child/youth may grow increasingly dependent
Requires some lifestyle adjustments	Requires numerous lifestyle adjustments
Challenges and successes are easily shared	Challenges are rarely shared; successes are fewer

What are the Exceptional Caregiving Responsibilities of Employed Parents of Children/Youth with Disabilities?

Parents of children/youth with disabilities frequently:

- Arrange for and participate in their children's/youths' ongoing and frequent physical and behavioral health treatments.
- Provide consultation to school personnel about their children's/youths' special educational needs.
- Face significant obstacles in locating and sustaining adequate child care arrangements.
- Are the primary, if not the only, source of their children's/youths' transportation.
- Respond to frequent health or behavioral health crises, sometimes requiring hospitalization of their children/youth.[16]

Caregiver Strain

In addition to identifying the tasks that are involved in exceptional care-giving responsibilities, understanding the notion of **caregiver strain** is important. The term caregiver strain refers to the demands, responsibilities, and difficulties resulting from caring for a child/youth (or relative) with special needs, such as disabilities. It also includes the psychological impact of the caregiving demand, which may include: financial stress, disruptions in partner, family, and social relationships, fatigue, sadness, guilt, and other negative effects. Without sufficient support, caregiver strain impacts the health and well-being parents, and may lead them to withdraw from the workforce.[17-22]

Key Points

- In contrast to parents of children/youth with typical development, parents of children/youth with disabilities engage in care tasks that are more complex and extensive.

- Exceptional caregiving responsibilities require coordination with multiple community-based supports, such as health care providers, school personnel, and child care staff.

- Parents involved in exceptional caregiving may experience caregiver strain which can have negative health effects.

EXCEPTIONAL CAREGIVING RESPONSIBILITIES

Notes and Reflections

Make notes and refle t on key ideas from this module, questions you may have and how this module relates to you personally.

Key Ideas:

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Personal Reflections

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3 *Employed Parent Challenges*

- Employment is challenging to find difficult to sustain

- Top 5 Challenges:
    - Child care
    - Managing child/youth care appointments and crises
    - Building a career/upward job mobility
    - Experiencing courtesy stigmatization
    - Disclosure decisions about child/youth disability

Employed Parent Challenges

Introduction

Exceptional caregiving responsibilities shape the manner in which parents of children/youth with disabilities experience employment and the ease with which they can combine job, family, and community participation—their **work-life integration**.[23] The likelihood of work interruptions may be greater for these employed parents compared to those with typical caregiving responsibilities because children's/youth's disability-related needs can be unpredictable and relevant community resources, such as child care or transportation, are often lacking. There are also relational or interpersonal challenges within the workplace, specificall , **courtesy stigmatization**, also referred to as "stigma by association," that affect the employee with exceptional caregiving responsibilities.

Objectives

By the end of Module 3, you will be able to:

1. Explain how exceptional caregiving responsibilities often affect the job status or career development of employed parents of children/youth with disabilities.

2. Describe the top 5 work-life integration challenges for employed parents of children/youth with disabilities.

3. Define courtesy stigmatization and describe how it may manifest in the workplace.

- *What are the unique work-life integration challenges experienced by employed parents of children/youth with disabilities?*

- *How does the combination of exceptional caregiving responsibilities and scarcity of supportive community resources influence job and career decisions?*

What is Work-Life Integration?

The idea of work-life integration has been expressed in different forms since the influx of women into the workforce beginning in the 1960s and 1970s. Initially the idea was framed primarily as an issue for employed mothers who were seeking *work and family balance*. Work-life integration is a more inclusive and fluid concept. First, instead of focusing solely on *family* concerns of employees, work-life integration acknowledges that all employees have lives outside of the workplace; and that there are multiple domains in which we participate and have commitments. Second, balancing time and activities across domains is not always possible or desirable; rather, what is needed is the **flexibility** to participate in all domains as necessary to enhance the well-being of self, family, and the community.[22-25]

Employment: Challenging to Find, Difficult to Sustain for Parents of Children/Youth with Disabilities

The impact of exceptional caregiving responsibilities on a parent's ability to find suitable employment is remarkable. At first a child's disability may create minor disruptions in a parent's work day. However, eventually the child's health/behavioral challenges, care, and crises can interfere with the ability to maintain employment and sustain a career. This is particularly true for working mothers of children/youth with disabilities who frequently report quitting their jobs, reducing the number of hours worked or changing jobs to accommodate the exceptional caregiving demands, often resulting in lost income.[23]

In a survey of 349 parents of children/youth with behavioral health disabilities, researchers found that:

- 48% reported having quit a job at some time to care for their children/youth.
- 27% reported job termination due to work disruptions related to care responsibilities.
- 17% indicated that they were unemployed.
- 11% could not find work because of e ceptional care demands.[23]

Top 5 Work-Life Integration Challenges

Challenge #1: Child Care

- Locating high-quality child care that is flexible and affordable is a universal concern for employed parents, especially for single-parent households and dual-earner families.[24]

- For families with children/youth who have disabilities, finding and maintaining child care can be very difficult. Specially trained child care providers or inclusive child care centers are uncommon and frequently unaffordable; and often because of the child's special needs, relatives or neighbors are not an option.[25]

- Compared to parents of children/youth with typical development, parents of children/youth with behavioral health disabilities are 20 times more likely to be asked to remove their child/youth from care; and have higher expulsion rates from pre-kindergarten.[25]

- When care for children with disabilities is available and affordable, parents report lower quality, lower satisfaction.[22]

- **"Tag-team parenting"** is a common child care strategy often used by employed parents, i.e., scheduling work shifts that do not overlap, so that one parent is always at home with the child. Bottom line, without child care a parent cannot work.[25,]

> *"I would literally get calls from the day care, 'I quit. I can't handle him.' I was like, 'I have two more hours. Could you just hold on for two more hours?' I can relate completely and it is very stressful. By the grace I didn't get fired. The school helped. I put him in a contained classroom where there are ten kids and five adults, so he had the one-on-one that he needed and that really helped."*
>
> - Employee/Parent

Challenge #2: Managing Care Appointments and Crises

- Parents of children/youth with disabilities spend hours each week coordinating care appointments for their children/youth.[7, 26]

- Whereas most employed parents find it necessary to occasionally take time off from work to care for a sick child, the frequency is much higher for parents of children/youth with disabilities.[27]

- Children/youth with disabilities typically receive ongoing care and therapy from a large team of professionals who accept appointments only during daytime hours on weekdays. In addition to these appointments, parents may need to spend more time in meetings with school personnel including principals, counselors, teachers, aides and therapists to continually update and monitor their children's individualized education plans (IEPs).[27]

- Symptoms associated with disabilities, such as asthma and some behavioral health disorders, are often unpredictable even when treatment has been prescribed and is being followed. There are times when a parent must immediately respond to an urgent call from the care provider or school when the child/youth is in crisis.[26] The call may require that the parent leave work immediately and take the child/youth to a health care provider.[27]

> *"The other thing I was getting to is if I don't do that, then it will be complete mayhem, if I don't keep him on medication and keep the checkups regular and stuff, things will progressively get worse. That will be the point where it is complete necessity. I can't be at work for a week. Lately it has been a lot of parent-teacher conferences outside of the normal parent-teacher conference fall/spring time, flexing my schedule."*
>
> - Employee/Parent

Challenge #3: Building a Career/Upward Job Mobility

- Because of the time commitment required to care for their children, especially with suitable child care options lacking, parents report making a number of employment adjustments including: a reduction in total paid hours, finding a less challenging job, or declining assignments or promotions that involve long hours or travel.[28-29]

- These job modifications create barriers to enhancing skills, to promotion, and to the use of other strategies that allow an employee to continue career growth.[27]

- Parents of children/youth with disabilities may step out of their chosen career altogether in order to find a job that allows for more flexibili y to respond to care needs.[27,28]

> *"If I would have accepted the half-time position, it would have cut my benefits in half, so I would have had half as much vacation, half as much sick, qualify for less FMLA. It would have paid for half of my benefits. It wouldn't have been worth it to me at all, other than to stay home with my kids. I chose to leave in hopes of a better situation, more understanding supervisor."*
>
> – Employee/Parent

Challenge #4: Experiencing Courtesy Stigmatization

- **Stigmatization**, including prejudice, stereotyping and discrimination, is commonly experienced by persons with disabilities and their families.[29-32] Stigmatization is driven by cultural and societal myths, misperceptions, and social structures that devalue persons with disabilities. Because of fear of stigmatization, there has been significant under treatment of behavioral health problems, especially in children/youth.

- Employed parents of children/youth with disabilities often experience what is called **courtesy stigmatization**.[34,35] Courtesy stigmatization is a concept that refers to the stigmatization projected toward family members and friends associated with the person with the disability. Family members have often reported being subjected to discrimination and exclusion due to their association with the child/youth with a disability.[36]

- Courtesy stigmatization is particularly common for parents of children/youth with behavioral health disabilities. These parents, especially mothers, are often blamed by extended family members and professionals for causing their children's behavioral health disorders through poor parenting practices.[35,36]

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- Parents of children/youth with disabilities are subject to **double jeopardy courtesy stigmatization** in the workplace. When parents are blamed for their children's disability, they are judged as *faulty parents*.[35] Simultaneously, when exceptional caregiving responsibilities create distractions, disruptions, and absences from the job, they may be judged by co-workers and supervisors as *faulty employees*, as well.[36]

- Stigmatizing comments, actions, and responses may be internalized by the employed parent and create feelings of shame, self-blame, isolation, and being misunderstood by others within the workplace. Courtesy stigmatization, either experienced directly or witnessed when directed toward other employed parents of children/youth with disabilities, inhibits the employee's ability to disclose about his or her child's health status or request informal or formal support.[35,36]

> *"…That it is a biological disorder. It is not a result of poor parenting or character defects, or that you feed your kid too much of this food or you didn't feed them enough of that food, or you didn't give them enough hugs, or you gave them too many hugs. Just as if someone's child was diagnosed with leukemia and everyone in the office takes up a collection and everybody at church brings them food, that when you have a child who is diagnosed with a mental health disorder, you need support and encouragement. You don't need people's judgment upon you and your character. Suddenly there is something wrong with you because you have a child who has a diagnosis. I think that is just general in our society. There is still so much misunderstanding about that."*
>
> *- Employee/Parent*

Challenge #5: Disclosure Decisions about Child/Youth's Disability Status

- Deciding if, when, and how to **disclose** about a child/youth's disability within the work setting is personal and complicated. It is not a singular decision, nor a static one; it is multi-faceted and multi-layered.

- Decisions about revealing or concealing are considered in the context of prior experiences of stigmatization and courtesy stigmatization that have affected employees and their families. Employees may be

reluctant to disclose, fearing additional stigmatization, possibly including career penalties or workplace discrimination.

- Even without explicitly disclosing, family concerns can spill into the workplace through interruptions from the school or child care, unexpected departures in response to crises, and stress that affects performance and health. These negative "**spillover effects**" can shape perceptions of supervisors and coworkers. They come to believe that the parent is not adequately meeting job responsibilities.[35]

"The last crisis we went through, my son was out of the home. It was harder to explain to my employer of why I had to go out, I needed to go to these appointments, either for team meetings or meetings with his doctor or visitations. Then it became you have to go into a long story of why is he not in your home, and how the agencies, which agency are you involved with. It was kind of complicated, and always a dread to have to explain why I needed the time or anything."

- Employee/Parent

Key Points

- Exceptional caregiving responsibilities can signific ntly affect a parent's ability to find employment that fits with care demands, while also sustaining an upward career or job trajectory.
- Child care resources for children/youth with disabilities are limited and care demands are ongoing.
- Courtesy stigmatization, stigma by association, is a common experience for parents of children/youth with disabilities, especially those with behavioral health disorders, and may lead to the individual's negative self-appraisal and inhibit actions to seek necessary support within the workplace.
- Employees' decisions to disclose about their exceptional caregiving responsibilities are highly personal and influenced by many factors including prior experiences with disclosure, and risk/benefit assessm nts.

Balancing Work & Family Responsibilities: A Guidebook for Parent Support Providers

Notes and Reflections

Make notes and refle t on key ideas from this module, questions you may have and how this module relates to you personally.

Key Ideas:

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4

- Family and Medical Leave Act (FMLA).

- Americans with Disabilities Act (ADA), Association Provision.

- Individuals with Disabilities Education Act (IDEA).

- Family Responsibilities Discrimination (FRD).

Key Policies

Introduction

When supporting an employed parent, it is important to explore with them their company's work-life initiatives, policies, and practices. These policies necessarily relate to federal and state-level legislation that addresses employees' work-life challenges. Their company's supervisors and human resource professionals can be torn between supporting the employed parent and protecting the organization against legal difficulties. Understanding which policies are most relevant to employed parents of children/youth with disabilities can help Parent Support Providers better assist the employed parents they are serving.

Objectives

By the end of Module 4, you will be able to:

1. Identify major federal policies that address work-life concerns of employed parents of children/youth with disabilities.

2. Discuss the challenges of implementing work-family policies.

3. Describe family responsibilities discrimination (FRD) and understand the legal protections that are in place to assist employed parents.

- *What workplace policies can support work-life integration needs of potential employees and currently employed parents of children/youth with disabilities?*

- *What laws assist and protect employed parents of children/youth with disabilities?*

Policy Supports and Legal Rights of Employed Caregivers with Exceptional Caregiving Responsibilities

Employed caregivers in the U.S. have legal support within statutes and laws that provide for:

- Prohibitions against discrimination and retaliation
- Short term leaves
- Protection of medical and other employment benefit

These policies and laws help to support employees with exceptional caregiving responsibilities by increasing access to flexibili y during work hours to manage their care responsibilities. The Family and Medical Leave Act (FMLA) and the Americans with Disabilities Act (ADA) are the two major federal policies that employed parents of children/youth with disabilities may rely on for work-life integration support.

The Family and Medical Leave Act

The FMLA was established to assist families in balancing the demands of work with those of their family by providing an entitlement of up to 12 weeks of job-protected, unpaid leave during any 12-month period and applies to all public sector employers but only those private sector employers with 50 or more employees.[37]

Specifics

- An eligible employee is one who has been employed continuously for 12 months by the employer and who has worked for at least 1200 hours during the previous 12 month period.
- Family circumstances require that employee be absent from work due to (1) a newborn child, (2) a newly adopted child/youth or foster child/youth, (3) an employee having a serious health condition, (4) a spouse, child/youth or parent of employee who has a serious health condition.
- A serious condition is defined as an illness, injury, impairment, or physical or behavioral condition that involves inpatient care in a hospital, hospice, or residential medical care facility; or continuing treatment by a health care provider.
- Leave can be taken in full, in part or on an intermittent basis depending on medical necessity and what agreement is reached between the employer and the employee.

- FMLA allows employers to require that employees use paid leave (sick days, vacation) as part of the 12 week entitlement.

- If necessity for leave is foreseeable the employee is required to make reasonable efforts to schedule treatment so as not to disrupt the operations of the employer, and to notify the employer at least 30 days before the leave date is to begin.

- Under FMLA the employee is entitled to return to the same position after a leave period or be restored to an equivalent position with similar pay, benefits and other terms of empl yment.

- Employment benefits such as group life insurance, health insurance, disability insurance, sick leave, annual leave, or educational benefit may not be terminated and must be restored to the level of benefit received prior to taking the leave (also protected under the **Employee Retirement Income Security Act [ERISA]**).

It is important to also note that employed parents of children/youth with disabilities may be reluctant to use FMLA because they cannot afford the lost wages as the federal policy does not provide for pay during leave. California and Vermont now have paid leave based on state insurance programs, but parents may be too overwhelmed to access the pay associated with the leave.[38] Parent Support Providers working in these states may want to become familiar with this benefit

The Association Provision of the Americans with Disabilities Act

The ADA is a federal civil-rights statute protecting the rights of people with disabilities.[3] In 2005 the ADA was extended to include discrimination in the workplace aimed at caregivers who provided care for children/youth or adults with disabilities. The "**association provision**" of the ADA protects caregivers against discrimination at work based on their responsibilities for persons who have a disability.[3,39] Specifics

- Employers cannot decline to hire, refuse to promote, or fire employees because of their association with persons or relationships to persons with disabilities (ADA Restoration Act of 2007). The person must have a close association with the person with a disability; this clearly covers parents.

- If the employer provides time off or flexible work arrangements to other

employees for other reasons, the employer must provide these to their workers who care for a child/youth with a disability.[39]

- Although employers are obliged to provide reasonable accommodations for workers with disabilities, the ADA does not require employers to provide for the particular needs of a parent of a child/youth with a disability.[40,41]

The Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act (IDEA) is not a policy that directly addresses the needs of employed parents of children/youth with disabilities within the workplace, but it is a major federal policy that is critical to children/youth with special needs. Knowledge of IDEA provisions may assist you in further supporting employed parents.

The IDEA was established through the U.S. Department of Education to support children/youth with disabilities through the provision of early intervention, special education and related services.[4] Children under the age of 2 are served by Part C while children/youth 3–21 are served by Part B of the IDEA.[42]

Specifics:

- Schools are obligated to teach children/youth with disabilities in as inclusive a setting as possible. Children/youth with disabilities may only be removed from this setting if their disability inhibits their learning.

- Children/youth identified as having a disability under the conditions specified within the IDEA are entitled to specialized services within the school that support their education (includes in-school counseling, Individualized Education Plans).

- Parents have the right to be involved in the development and review of Individualized Education Plans.

- Some employers allow parents to attend IEP meetings during work hours.

Family Responsibilities Discrimination

An area of increasing concern for employers and employed caregivers alike is the area of **family responsibilities discrimination (FRD)**.[43,44] Also referred to as **caregiver bias**, this newly emerging area of employment law can be confusing with seemingly few clear guidelines for employers. During the past decade there has been an overwhelming increase, estimated at 400%, in the number of lawsuits brought against employers by employees who believe that they have been discriminated against because of their caregiving responsibilities in the home.[43] According to a report by the Center for WorkLife Law at the University of California, Hastings College of the Law, the majority of these lawsuits are being won by the plaintiffs and resulting in multimillion dollar settlements.[43]

What laws are being used by employees to make FRD claims?

- Family and Medical Leave Act
- Americans with Disabilities Act
- Pregnancy Discrimination Act
- Civil Rights Act of 1964

Some Examples of FRD Related to Exceptional Caregiving Responsibilities

- Demoting a female employee who returns to work after taking time off to care for a chronically ill youth based on the assumption that she will not be able to perform as well because of her commitment to her caregiver role.

- Denying a male employee who has a young child with a behavioral health disability leave for child care purposes while approving a female employee for the leave because of the gendered assumption that males are the "breadwinners" and females are the "caregivers".

- Passing over a well-qualified employee who has a child/youth with a disability that would require extra travel because of the assumption that she would probably not like to be away from her child/youth.

- Not hiring an employee who discloses he is a single parent raising a child/youth with a disability based on the assumption that the employee would in some way be less reliable because his child's disability might negatively affect his attendance and work performance.

Equal Opportunities Employment Commission (EEOC)

*Enforcement Guidance: Unlawful Treatment
of Workers with Caregiving Responsibilities*

The EEOC guidelines illustrate circumstances in which stereotyping or other forms of disparate treatment could violate Title VII of the Civil Rights Act of 1964 or the prohibition under the ADA against discrimination based on a worker's association with an individual with a disability.[40] The guidelines cite the fi e different types of discrimination covered under both Acts and provide examples of different types of potential caregiver discrimination scenarios.

- Sex-based treatment of female caregivers
- Pregnancy discrimination
- Discrimination against male caregivers
- Discrimination against women of color
- Unlawful caregiver stereotyping under the ADA
- Hostile work environment

Additional Policy Supports for Parents of Children/Youth with Disabilities

- Tax credits for child care through the **Child and Dependent Care Tax Credit (CDCT)**
- Cash assistance for low-income families through the **Earned Income Tax Credit (EITC)**
- Child care subsidies through the **Child Care Development Fund Subsidies (CCDFS)**
- Social Security subsidies through the Supplemental Security Income (SSI) for children/youth with disabilities (under 18 years) and the **Security Disability Insurance (SSDI)** (over 18 years)

Key Points

- Children/youth with disabilities and their families are supported by a number of laws that protect them from discrimination at school and at work.

- Supports found within the FMLA and the Association Provision of the ADA are intended to protect employment rights of parents who have children/youth with disabilities by allowing them to take time off work to meet the demands of their care responsibilities and return to work with impunity.

- Employers need to be familiar with the specific laws and policy supports that protect employees who have children/youth with disabilities in order to better meet their employees' needs as well as protect their organization from litigation.

Notes and Reflections

Make notes and refle t on key ideas from this module, questions you may have and how this module relates to you personally.

Key Ideas:

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5 Strategies and Supports

- Employment-based strategies enhance work-life integration.
- Top 5 Key Strategies
  - Find a family-friendly workplace
  - Learn about rights and relevant benefit
  - Structure work to maximize flexibili y
  - Make a disclosure plan
  - Negotiate reciprocity

Strategies and Supports

Introduction

Work-life integration for parents of children/youth with disabilities requires a wide ranging assortment of strategies and solutions that *maximize* flexibili y to successfully meet work and care demands and *minimize* stress and strain on self, family, and relationships, including those with supervisors and co-workers. Presented here are some suggestions of how to think about finding a good fit between employment and family responsibilities. Also described are supports that may be available within the workplace.

Objectives

By the end of Module 5, you will be able to:

1. Describe strategies identified by parents of children/youth with disabilities that help find and sustain employment that promotes their work-life integration experiences.

2. Recognize the steps in the parents' decision-making process when reflecting about disclosing information within the workplace related to the child/youth's disability and/or related exceptional caregiving responsibilities.

3. Identify formal and informal workplace supports that may assist in work-life integration for parents of children/youth with disabilities.

- *What strategies might employed parents of children/youth with disabilities utilize to enhance their experience of work-life integration?*

- *What are the formal and informal workplace supports that parents with exceptional caregiving responsibilities find helpful?*

5 Key Employment Strategies for Work-Life Integration

Employed parents of children/youth with disabilities are resourceful in their pursuit of work-life integration. Discovering strategies and sources of support that fit their situation and needs is a trial and error process. The work-family fit formula is not static, but one that needs constant recalibrating as the child/youth develops and symptoms ebb and flo . Key among the strategies developed and potential supportive resources are those in the workplace.

Strategy # 1: Find a Family-Friendly Workplace

- Parents of children/youth with disabilities report actively seeking job opportunities at workplaces considered to be "*family-friendly*". Simply defined, a **family-friendly workplace** is one that has a variety of policies and practices specifically designed to assist all employees with achieving a satisfactory level of work-life integration or improve work-family fit. Literature on family-friendly workplaces identifies four interrelated components:

  ▸ Benefits, policies, and programs

  ▸ Workplace culture and climate

  ▸ Workplace relationships

  ▸ Work processes, systems, and structures/practices[45]

- Historically family-friendly policies and practices were designed to meet the needs of working mothers of young children with typical development based on the assumption that the use of support will be for a relatively short period of time. More recently, some companies are expanding their work-life initiatives to be more inclusive of different family types and a diversity of caregiving responsibilities.

- It is also important to address the work-family needs of fathers. Some studies suggest that fathers experience more difficul y integrating work and family than mothers.[46] Fathers are increasingly interested in taking an active role when it comes to raising their children,[47] but they are struggling just like mothers to find a fit between the needs of family and work.

STRATEGIES AND SUPPORTS

> *"The strategy that I now have is to find an employer who is family friendly. I work for an airline and it provides me with great flexibility. I am able to trade shifts with other people to accommodate my needs. I also communicate more with my supervisor. Also, at the airline I don't feel stigmatized."*
>
> — Parent

A parent with exceptional caregiving responsibilities might research a company prior to applying for a job to determine the extent to which the company is family-friendly or may strategically ask questions during the interview process. Parents sometimes consider, or find it necessary, to move to communities where there are family responsive businesses and services.

Strategy # 2: Learn About Rights and Relevant Benefits

- Parent and parent support partners need to be knowledgeable about their rights and relevant benefits that support work-life integration through the workplace. By networking informally with other parents and accessing information through the internet, parents and parent support partners can educate themselves about laws that improve their access to services and enhance work-family fit

- Health insurance benefits are critical for parents of children/youth with disabilities. The majority of parents rely on benefits through the workplace to cover their children's medical costs. Indeed, 60% of children/youth with special needs are covered under their parent's workplace insurance.[7]

- Parents of children/youth with disabilities wanting to sustain job security and flexibili y are better informed about unnecessary barriers in the workplace. The upswing in Family Responsible Discrimination lawsuits is evidence of this.

> *"If I have a headache and I am sick, I just write it off as sick time, but if it is something to do with my child, then I write it down as FMLA. It is nice because fortunately I don't have to use the whole 12 weeks a year, but I probably do use at least half. It is nice. To me it is like a safeguard."*
>
> — Parent

Strategy # 3: Structure Work to Maximize Flexibility

- The most essential ingredient for work-life integration is **flexibility**. Recent reports indicate that prospective employees increasingly favor flexibili y over higher salary.[48] Flexibility in the workplace most often refers to **flexible work arrangements (FWA)**, also known as flexibl work options (FWO).

- Flexibility allows the employed parent to have a level of control over when and where work occurs, including arrangements such as variability in starting and stopping times and telecommuting. In other words, flexible work arrangements are alternative options that allow work to be accomplished outside of traditional workday schedules and/or outside of the centralized location.

- Flexibility may be gained through a **formal FWA**, involving a written request and approved via an administrative process, or through an **informal FWA**, an arrangement most likely left to the discretion of a supervisor, or negotiated directly with a co-worker.

- Formal or informal, a FWA may be a permanent restructuring, or the latitude to decide hours and location on a daily basis.

Workplace flexibility is essential for parents of children/youth with disabilities

- The ability to adjust the timing and/or the physical location of work tasks enables parents to maintain productivity and increase their response availability to care concerns and crises.[16,49]

- Unlike parents of children/youth with typical development, for parents of children/youth with disabilities, the need for flexibili y is often unpredictable and sporadic.[27] For example, a parent may need to leave work immediately when the child's symptoms are active; such episodes may continue for several days at a time.

- Parents with exceptional caregiving responsibilities may want to seek out information about FWAs, submit a request to their supervisor or HR for a formal arrangement, or negotiate informal arrangements with a co-worker. These requests and arrangements may or may not involve disclosure of the child/youth's disability status

> *"My current strategy has been to quit my job and go back to school for medical transcription so I will increase my odds of being able to have a much more flexible employment situation."*
>
> *- Parent*

Strategy # 4: Make a Disclosure

- Parents often develop a strategy of "if, when, and how" to disclose to others about their children's/youths' disability. Parents with exceptional caregiving responsibilities are likely to be more cautious than parents with typical care responsibilities, when sharing about their children/youth. This cautionary stance has been shaped by prior reactions from others and experiences of stigmatization.

- Parents developing a disclosure strategy, often consider the following factors:[35]

  ▶ Type of job/position held

  ▶ Workplace culture

  ▶ Availability and accessibility of formal support

  ▶ Perceptions of informal support

  ▶ Concerns about privacy and confidentiali y

> *"I do try to be up front with selective people about this. Some people I tell about my son's emotional disorder; to others I just say that my son has a chronic illness that sometimes requires hospitalization."*
>
> *- Parent*

Dimensions of the Disclosure Decision Process

Parents may want to reflect on the pros and cons across 3 major dimensions of disclosure: 1) timing of the disclosure, 2) primary recipient of the disclosure, and 3) type of information to disclose. Within each dimension there are different options to consider.[32]

Additionally, parents may want to consider issues of confidentiali y and privacy and not assume that the information will be held in confidence

Choice or Necessity? Cost or Benefit?

- The parent's decisions concerning disclosure are personal and individual, as these depend on a variety of circumstances. It is important that a parent not feel forced to disclose. However, it is important to note that a parent may sense the need to disclose to avoid losing one's job.

- Disclosure within the workplace is a strategy that a parent may use to access interpersonal and organizational support. Sharing about one's child may benefit the parent by increasing emotional support, reducing stigma, and educating others. Disclosure could also allow parents greater access to formal benefits that may improve work-life integration.

- Disclosure within the workplace is not without risks. Personal family information can be misperceived, leaving the parent vulnerable to discrimination in the hiring process, job evaluations, work assignments, or promotions, and can lead to job insecurity or job loss.[42]

- greater access to formal benefits that may improve work-life integration.

- Disclosure within the workplace is not without risks. Personal family information can be misperceived, leaving the parent vulnerable to discrimination in the hiring process, job evaluations, work assignments, or promotions, and can lead to job insecurity or job loss.[43]

STRATEGIES AND SUPPORTS

DIMENSIONS OF THE DISCLOSURE DECISION PROCESS

Timing Possibilities	Primary Recipient Possibilities	Type of Information Possibilities (General or Specific)
• Never • During the interview process • When the job is secured • When a positive performance pattern is established • When a response to a non-crisis family matter is needed • When a crisis occurs with the parent's child	• No one • Employer • Immediate supervisor • A higher level manager • One or more co-workers • HR personnel • Employee assistance program staff	• Disability • Chronic illness • Behavioral health disorder • Specific diagnosi • Description of specific beh viors • Type of treatment needed • Impact on self and family

POSSIBLE OUTCOMES OF THE DISCLOSURE DECISIONS[32,35]

	Positive	Negative
Disclosure	• Access formal supports • Access flexible wor arrangements • Increase informal supports • Educate others	• Possible courtesy stigmatization • Equity concerns • Increase performance scrutiny • Increase co-worker resentment • Job insecurity/loss
Concealment	• Minimize courtesy stigmatization • Minimize equity concerns • Minimize performance scrutiny • Minimize co-worker resentment • Maintain a "normal appearing" work life	• Diminished access to formal supports • Diminished flexibl work arrangements • Diminished informal support • Isolation

Strategy # 5: Negotiate Reciprocity

- **Reciprocity**, between the employed parent and the employing company is part of the flexibili y equation. In the workplace, reciprocity is a relational process—a mutual exchange between employee and immediate supervisor/ coworker resulting in benefits to all sta eholders.

- An example of this is when the employed parent agrees to performing a less important task or role in exchange for coming to work at a later time. The parent gains necessary autonomy over work scheduling to meet caregiving demands; and the employer benefits from the worker's increased engagement, productivity, and loyalty.

- Based in respect and trust, reciprocity (give and take) requires negotiation and subsequent accountability for the commitments made.

- **Reciprocity**, between the employed parent and the employing company is part of the flexibili y equation. In the workplace, reciprocity is a relational process—a mutual exchange between employee and immediate supervisor/ coworker resulting in benefits to all sta eholders.

- An example of this is when the employed parent agrees to performing a less important task or role in exchange for coming to work at a later time. The parent gains necessary autonomy over work scheduling to meet caregiving demands; and the employer benefits from the worker's increased engagement, productivity, and loyalty.

- Based in respect and trust, reciprocity (give and take) requires negotiation and subsequent accountability for the commitments made.

> *"It is a give and take relationship with flexibility and understanding during times of crisis and when things even out, I attempt to give back 150%."*
>
> - Parent

STRATEGIES AND SUPPORTS

Strategy specifics from a parent's point of view:

- Be Proactive

  ▸ Alert supervisor/coworker to exceptional caregiving responsibilities whenever possible

  ▸ Learn about availability of flex options, formal and informa

- Offer Win-Win Solutions

  ▸ Brainstorm and make specific suggestions about mutually beneficial exchanges

  ▸ Identify unique skill set developed through exceptional caregiving responsibilities experience

  ▸ Leverage skills in exchange negotiation

- Demonstrate Organizational Commitment

  ▸ Follow through on agreements

  ▸ Communicate appreciation to supervisors/co-workers

Key Points

- Many employed parents of children/youth with disabilities utilize specific employment strategies to enhance their work-life integration experience.
- Employed parents of children/youth with disabilities engage in complex processes of disclosure and negotiation to access workplace benefits and supports
- The type of flexibili y needed to meet exceptional caregiving responsibilities may differ from what is needed to meet typical caregiving responsibilities.

STRATEGIES AND SUPPORTS

Notes and Reflections

Make notes and refle t on key ideas from this module, questions you may have and how this module relates to you personally.

Key Ideas:

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6 Understanding HR Professionals' Support Dilemmas

- Dilemmas of meeting competing demands and needs:

  - Balancing the work-life needs of the employed parent of children/youth with business goals.

  - Having too much information vs. not having enough information to provide support.

  - Minimizing potential litigation with maximizing flexibili y and support.

HR Professionals' Support Dilemmas

Introduction

Human resource (HR) professionals are frequently responsible for developing and implementing a variety of work-life policies and practices, including flexible work arrangements (FWAs). Immediate supervisors and line managers are often brokers of informal flexibili y and negotiators of formal requests for FWAs. However, HR professionals are the key sources of dissemination and interpretation of organizational policies and practices. HR professionals can positively influence the work-life integration experiences and access to resources of employees of children/youth with disabilities through direct employee contact, policy development, program design, consultation with managers, and modeling family-friendly practices. This influence, in turn, can shape **workplace culture**, including the reduction of courtesy stigmatization. When parents and Parent Support Providers understand the influence of HR on policy, practice, and culture, accessing workplace supports can be enhanced.

Objectives

By the end of Module 6, you will be able to:

1. Understand crucial organizational considerations facing HR professionals (and supervisors/managers) when interacting with employed parents of children/youth requesting support, such as flexible work arrangements.

2. Share and discuss with parents about the organizational context of flexible work arrangements and other possible workplace supports.

- *What is the range of dilemmas faced by human resource professionals addressing the work-life integration needs of employed parents of children/youth with disabilities?*

- *How are these dilemmas similar to and different from work-life integration needs of employed parents of children/youth with typical development?*

Being Prepared

Mid-size and large companies typically have a Human Resources Department that may have one or several individuals in the role of an HR professional. Large organizations may have both generalist and specialist HR professionals with varying responsibilities. Overall, the primary responsibility is to interact with employees about a range of concerns, including recruiting, onboarding, and benefits. A critical function of an HR professional is to balance the needs of both the employees and the company.

An employed parent may have direct contact with an HR professional to discuss work-life integration struggles, gain an understanding of policies and rights, or make a request for flexibili y. Likewise, the parent's supervisor may connect with HR for similar reasons. It is important for an employed parent of a child/youth with disabilities, or prospective employee, to remember that HR professionals and supervisors may not be knowledgeable about exceptional caregiving responsibilities or work-life integration experiences related to caring for a child/youth with disabilities, especially how these differ from employed parents with children/youth developing typically. Parents who are aware of the dilemmas faced by HR professionals will be more prepared for interactions regarding requests for flexibili y, and other work-life supports.

Flexibility policies and practices may not give adequate guidance for the requests made by employed parents of children/youth with disabilities. Moreover, training for HR professionals, supervisors or line managers about how to handle work-life issues can be limited, and may not be inclusive of all family situations.

Common Dilemmas

Dilemma: Needs of the employed parent of child/youth with disability vs. Business goals

What the HR professional will consider: Balancing the needs of employed parents of children/youth with disabilities for flexibility against the flexibility requests made by other employees, needs of the workgroup, and business needs of the organization.

- HR professionals continually look to balance *employee needs* with *business goals* of the company. Despite a desire to be supportive and helpful to the employee needing more flexibili y, not all positions within a business lend themselves to FWAs.

- Equitable treatment of all employees is a core consideration when an employee requests flexibili y. Even when an employee makes a flexibi ity proposal that is possible to approve, implementation of the plan may raise questions of equity and favoritism among co-workers.

- Well functioning co-worker relationships are critical to overall productivity. Perceptions of preferential treatment can be detrimental to the workgroup.

- When a parent of a child/youth with disability needs flexibili y, the request may be made at the time of a presenting crisis or as a well thought-out proposal. The family's compelling story leads to a compassionate response and the HR professional wants to "do the right thing"—but there are business goals that must be met.

> *"You have to take a look at what position this person is in. Is there flexibility there with the work hours, with the work rules? Can they do some of the work at home, or will we allow that to happen? Can you flex their hours? Do they have to be there as part of a core team and interact certain core hours? I don't know how you could approach it without really looking at all these."*
>
> — HR Professional

Dilemma: Too much information vs. Not enough information

What the HR professional will consider: Balancing knowing too much personal information with not knowing enough about the family's situation to truly understand the needs of the employee with a child/youth experiencing a disability.

"If you allow one employee to do a certain flexibility on issues and then you say 'no' to another, then that brings up a whole other situation of equity that you might have to speak to, or you might be breaking your work rules and whatnot. There are just a ton of factors, like everything else in human resources."

- HR Professional

"If the other employees don't know and don't understand the circumstance, then the rumor mill gets cranked up, and then the peer pressure and the backbiting and the whining and moaning goes on. This person is put into a really tight position and the company is sitting there saying, well, I can't say how come she is not showing up for work…."

- HR Professional

- HR professionals often have concerns about knowing too much about employees' personal lives and confidentiali y issues when responding to disclosure.

- A recent national survey of HR professionals found:

  ▸ 9% of HR professionals who responded indicated that disclosure is discouraged within their organization due to potential privacy/legal reasons.

"You earn a lot of loyalty from your people, as an employer, when you do work through these difficult times with them. You have had their babies with them, and you have been through their cancer treatments, and that, I think, goes a long way in building loyalty in your employees."

- HR Professional

▸ Yet, 77% reported that employee disclosure of personal circumstances can help in obtaining flexibili y.[50]

- HR professionals must balance having the knowledge of why the fle - ibility request is needed and yet at the same time not wanting this information for fear of confidentiali y breaches and the consequences to the organization. In the words of an experienced HR professional:

"It seems that there are issues out there that you really don't, from a professional standpoint always acknowledge that exist. Part of that may be motivated by the fear that in a situation that is highly personal like this, you have conflicts with confidentiality issues and you have how much [as an employer] should I know, and how much do I dare ask?"

Dilemma: Minimizing potential litigation vs. Maximizing flexibility & support

What the HR professional will consider: Potential litigation, protecting the company while addressing the needs and flexibility request from the employed parent of a child/youth with a disability.

- HR professionals base their decisions to grant flexibili y on a number of issues relating to the nature of the employee's request; organizational needs as well as federal and state laws.

> *"It is such a litigious environment. I'm dealing with one situation right now, it is not related to this, but you really have to watch your P's and Q's, because just the slightest thing can set someone off. […] You have to be absolutely careful every step of the way. Otherwise you are opening yourself up to an enormous potential lawsuit."*
>
> - HR Professional

Key Points

- HR professionals face overlapping dilemmas such as ensuring that legal requirements are being followed and that responses to requests for flexibili y from employees with exceptional caregiving responsibilities are fair and appropriate.
- HR professionals must balance a need to know why the flexibili y is needed with the legal consequences of knowing, when making decisions about granting flexible work arrangements.

Discussion Example: Introducing Charlie and Cindy

Charlie has been employed for the past 10 years as a full-time Administrative Assistant in the Atlanta office. His job is demanding with incoming phone calls, reports that need publication, and professional staff making requests. He is the father of two daughters who are 8 and 5 years old. His wife Cindy works as a nurse and has long and demanding shifts at a local hospital. Recently, Charlie's supervisor expressed concerns about the frequency of family related calls he has been getting at work and about the times he has left the office to deal with his younger daughter's asthma. Charlie would like to take time off to stabilize his daughter's health and then drop back to part-time work, but he knows that this may be difficult to arrange. He has asked to see HR to explore his options.

Questions for Discussion:

1. What are some of the organizational dilemmas that may need to be considered by the HR Professional (or supervisor/manager) when reviewing Charlie's request?

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2. How would you share information about the HR support dilemmas discussed in this module with Charlie and Cindy ahead of Charlie's meeting with HR?

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Notes and Reflections

Make notes and refle t on key ideas from this module, questions you may have and how this module relates to you personally.

Key Ideas:

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Questions:

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Personal Reflections

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7 Accessing Workplace Support

- Identifying Resources for Support:
    - Inventory
    - Access Plan
- Disclosure Planning:
    - When? Who? What?
- Communication Strategies:
    - Speak to organizational concerns
    - Partner for solutions
    - Re-connect, re-evaluate, re-commit

Accessing Workplace Support

Introduction

You now have the knowledge foundation to better assist parents in their development of strategies and skills for accessing workplace support. Parents' access to all types of support involves communication, ranging from making written requests for flexibili y arrangements to informal sharing with a coworker about a recent flare up in a child's condition. Of course, speaking directly with a supervisor or co-worker about personal matters, such as their child's or youth's health status and care requirements is sensitive, and sometimes, quite emotional. Managing feelings and boundaries, balancing the personal with the professional, while being clear and concise is not easy. Enhancing your ability to help parents prepare for challenging conversations and to access workplace support is the focus of this final module.

Objectives

By the end of Module 7, you will be able to assist parents with:

1. Identifying and planning to access available formal and informal workplace resources that support employed parents of children/youth with disabilities.

2. Planning if, how, and when to disclose about their children's/youths' disability statuses and care needs within the work setting.

3. Expanding skills for dialogues about their work-life integration experiences, needs and solutions with supervisors, HR professionals, and co-workers.

- *What are the many creative and effective strategies that parents can implement to access supportive resources within the workplace?*

- *How can parents enhance their communication strategies in problem solving dialogues with supervisors and HR professionals?*

Workplace Support

Information from the previous modules has provided you with:

- Knowledge about the prevalence and multiplicity of disabilities experienced by children/youth.

- Increased understanding about exceptional caregiving responsibilities.

- Information about relevant federal and state employment-related policies.

- Familiarity with the work-life integration challenges and strategies of employed parents of children/youth with disabilities, including disclosure decision processes.

- Identification of dilemmas facing HR staff (and supervisors) in providing support that addresses work- life integration challenges for parents with exceptional caregiving responsibilities.

You are now ready to expand your support strategies for employees caring for children/youth with disabilities.

Accessing Workplace Support

Inventory of Supportive Resources

Disclosure Planning

Communication Strategies
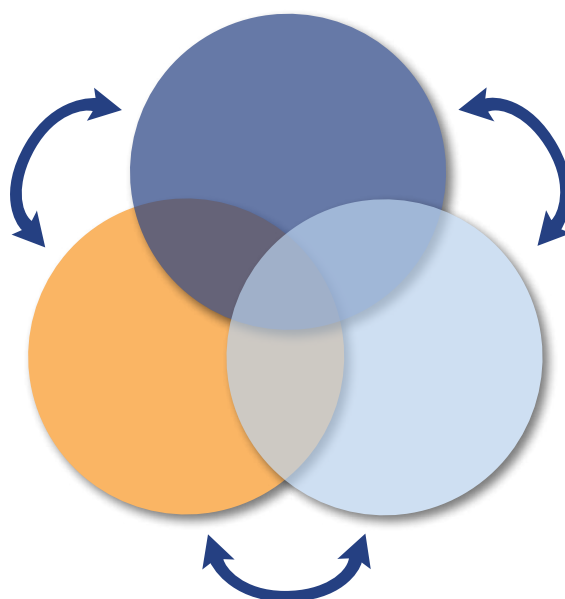
Workplace support comes in all different forms. Some resources are formal, such as a request for flexible scheduling; others are informal, such as swapping shifts with a coworker. There are many ways to access and receive support within the workplace. To fully understand what resources are available within the workplace and facilitate accessing these, it is useful to develop a thoughtful and actionable plan. Described here are 3 core dimensions that contribute to the overall plan: 1) Inventory of Supportive Resources; 2) Disclosure Planning; and 3) Interpersonal Communication Strategies. The dimensions are overlapping, interacting, and complementary. In other words, any one dimension is valuable on its own and together each is strengthened. A parent may choose to work with you on one dimension or all three.

Organizational Policies And Practices Layer

At the back of this guidebook, you will find a reproducible Workplace Support Resources Inventory form that can be completed with parents to help them identify supportive resources within their workplaces. The form is designed to identify possible supportive resources that when accessed are likely to enhance work-life integration experiences. The form and responses may need to be reviewed over time, as the availability of resources may change and the family's need for different supports may shift. Importantly, even if a resource is identified as available, a parent may choose not to access that resource.

On the following page is a sample portion of the inventory and response examples.

WORKPLACE SUPPORT RESOURCES INVENTORY FOR PARENTS OF CHILDREN/YOUTH WITH DISABILITIES			
Resource	**Available?**	**Accessed?**	**Strategy to Access or Gain More Info**
FLEXIBLE WORK ARRANGEMENTS			
change start/stop times	yes	yes	
work any hours to equal FT	no		
telecommute/work from home	no		
move FT to PT, reverse if needed	maybe	no	*talk w/supervisor about reducing hours*
swap schedule with coworkers	n/a	n/a	*not applicable (n/a) for my job*
temporary reduction in workload	not sure		
information in hand-book on how to request, negotiate	yes	no	*will read and check with HR if have questions*
LEAVE POLICIES			
paid provided	yes		
unpaid provided	yes		
sick provided	yes	yes	
can use above leave flexibl	somewhat	yes	*was granted intermittent leave*
family medical leave	no		*don't meet requirements for federal FMLA*
time off for seriously sick child	not sure		*ask HR*

Disclosure Planning

Disclosure decisions about a child's disability status is a constant for parents of children/youth with disabilities. For instance, parents are well aware of how comfortably parents of children with typical development share about their children's/youths' developmental milestones and daily accomplishments. Parents of children with disabilities are regularly gauging how to participate in such interactions, especially with individuals who do not know their children's health status. Parents of children with disabilities may also be hesitant to disclose to supervisors or HR staff, even when necessary to access resources such as flexible schedules [52]

Presented in Module 5, Strategies and Supports, is information about how parents often consider if and how they might disclose information concerning their children's disabilities status within the workplace. As discussed, if a parent's prior experiences of disclosure, in or outside of the employment domain, included receiving responses that were hurtful, blaming and stigmatizing, the idea of accessing workplace support to meet work-life needs can be overwhelming.

Not every parent with whom you work will want or need a workplace disclosure plan. For those who do, the following is a helpful discussion and planning guide.

Conversation Starters about Disclosure:

The following questions are designed as conversation starters with parents about disclosure. It is not necessary to use the exact words, or sequence of questions. The main intent is to open a discussion. Often, sharing thoughts, feelings, and experiences about a sensitive issue with another person brings increased clarity and understanding.

Starters:

- In general, could you tell me about your experiences when sharing information about your child's disability (you could choose to use the name of the condition here)?

- What are your thoughts and feelings about sharing information with others in the workplace about your child's disability?

- What do you identify as the positives and negatives of disclosing or not disclosing in the workplace to: A coworker? Your supervisor? An HR Professional? Promote an environment that values and encourages open communication.

- Who, if anyone at work, have you told that your child has (condition)?

    ▶ Tell me about how you made this decision?

    ▶ How would you describe the person's response?

Disclosure Plan

Some parents might choose to develop a more specific disclosure plan after having a discussion. This plan can be as simple as reviewing the choices included on the three questions below; or can be more fully developed on a separate sheet of paper. This plan may need to be updated over time due to employment or child health status changes.

MY WORKPLACE DISCLOSURE STRATEGY (identify/discuss all that applies)					
When might you decide to disclose?					
Never	Interview Process	Job Secured	Positive Performance Established	Response Needed to Non-Crisis Family Matter	Response Needed to Crisis Family Matter
Other: _____					

ACCESSING WORKPLACE SUPPORT

MY WORKPLACE DISCLOSURE STRATEGY   **(identify/discuss all that applies)**

With whom might you share?

No one	Employer	Immediate Supervisor	Higher-Level Manager	HR Staff	EAP	Co-worker

Other: _____

What type of information might you share? (ranging from general to specific language and details)

Disability	Chronic Illness	Behavioral Health Disorder	Specific Diagnosis	Description of Condition	Treatments Needed	Impact on Self and Family

Other: _____

Collaborative Communication Layer

Even the most skilled communicators in the workplace can get stuck when entering into a conversation about personal matters in the workplace. Parents seeking workplace support may have difficul y finding the balance between sharing enough information about their children's disability status to feel supported and access resources, and not over disclosing. This balance is made even more challenging in the face of potential stigmatization or job insecurity.

Communication about family matters in the workplace is:

- Personal

    ▸ Involves sharing of information that is private and sensitive—often parents are struggling to make sense of what is happening with their children/youth, dealing with the stresses and strains of keeping on top of everything, trying to make their life appear normal, and having difficul y finding the words to express the profound sadness of watching their children/youth suffer.

- Relational

    ▸ Involves both members of the communication dyad contributing to an atmosphere of warmth, trust, and understanding.

- Informational

    ▸ Involves exchanging information. Each person offers understanding and explanations, uses non-jargon language, and encourages questions for clarity and specifics

- Collaborative

    ▸ Involves successful and constructive communication strategies in which each member of the dyad acknowledges his/her own and the other's needs. Contributions by each member to the solution are explicitly identified

Effective communication between parents of children/youth with disabilities and their co-workers, supervisors, and HR professionals is vital to accessing and receiving support. As discussed earlier in this module, parents often struggle to speak of or share with others the experience of having a child/youth with a disability and face challenging decisions about whom to tell and what to say.[46] Enhancing a parent's interpersonal communication strategies contributes to creating a safe environment in which to have these challenging conversations.

A three-step circular process for collaborative communication:

Three key skill areas to enhance for interpersonal communication strategies within the workplace for accessing support include:

- Speak to Organizational Concerns,

- Partner for Solutions, and

- Re-connect, Re-evaluate, & Re-commit.

Each of these areas are described and talking tips for parents are included. You may want to suggest role-playing conversations with parents in each of the areas.

1. Speak to Organizational Concerns

Effective interpersonal communication includes the ability to see the other person's perspective. Module 6 reviewed primary concerns that HR or supervisors may have, for example, when reviewing a request for a flexible work schedule. These concerns may also surface directly or indirectly in face-to-face conversations about work-life needs. Parents can benefit from practicing responses that address organizational concerns in advance of any actual conversations.

For practice, the following questions identify common concerns from the organizational side about flexible work arrangements. Knowing how to respond will improve a parent's chances for a successful negotiation.

- How will having a flexible schedule benefit our employer?

- How will you maintain communication with your supervisor and coworkers with a flexible schedule

- What is your plan to review the effectiveness of the flexible work schedule with your supervisor or HR?

- What support will you need from your manager and co-workers to make the flexible ar angement successful?

- How will having a flexible schedule benefit our employer?

Talking tips for parents:

▶ "I appreciate you listening to the challenges I am facing and also the strengths I have as a problem solver and productive employee."

▶ "I understand that you have to balance the overall needs of the company and other employees."

2. Partner for solutions

Co-creating solutions or collaboration is essential to interpersonal communication. Parents of a children/youth with disabilities and HR or supervisors are typically talented problem-solvers. Each brings something valuable to the "solution table". Partnership in problem solving creates a stronger investment in the solution.

How do you partner for solutions?

• State your appreciation of and commitment to partnering for solutions.

• Identify what is currently working well for you in managing work-family responsibilities.

• Identify and prioritize needs and possible solutions for your current situation.

• Brainstorm with HR, supervisor, or co-worker about possible resources to meet your current work-life needs.

• Speak directly to organizational concerns.

• Identify the level of feasibility of possible solutions.

• Establish a timeline for implementation.

Talking tips for parents:

▶ "I know together we can find a way of working toward solutions that are beneficial for both of us "

▶ "Not all of my job responsibilities or work days are equally affected by my exceptional caregiving responsibilities. For example…"

▶ "Here are some ways I have successfully problem-solved my work-family challenges in the past."

3. Re-connect, re-evaluate, and re-commit

Ongoing communication, timely follow-through, and plan adjustments are essential ingredients to the continued success of the collaboration and interpersonal communication.

- Initiate contact in a timely manner to acknowledge and reiterate commitment to problem solving.
- Agree to re-evaluate in a specific timef ame.
- Request adjustments in the support plan as indicated and maintain connection.

Talking tips for parents:

▶ "Thank you for taking time and providing an opportunity to problem solve with me. I will keep you updated about how well the strategies are working. Please share with me any concerns that arise."

▶ "I look forward to meeting with you at your convenience to evaluate the plan."

Key Points

1. Accessing workplace supports is a multilayered process that includes an inventory of existing resources, disclosure planning, and interpersonal communication strategies.

2. The approaches used by parents are unique to their situation and may change over time.

3. Strategic planning and practicing communication skills and talking points can help parents preparing for challenging conversations and accessing workplace supports.

Notes and Reflections

Make notes and refle t on key ideas from this module, questions you may have and how this module relates to you personally.

Key Ideas:

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Questions:

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Personal Reflections

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Appendix

Glossary

Acute Condition: A condition of short duration that starts quickly and has severe symptoms.

Americans with Disabilities Act of 1990 (ADA): A wide-ranging civil rights law that prohibits, under certain circumstances, discrimination based on disability.

The Association Provision of the American with Disabilities Act: The provision of the Americans with Disabilities Act (ADA) that protects caregivers against discrimination at work based on their association with a person who has a disability

Behavioral/Emotional Disability: Social, emotional or behavioral functioning that so departs from generally accepted, age appropriate ethnic or cultural norms that it adversely affects a child's academic progress, social relationships, personal adjustment, classroom adjustment, self-care or vocational skills.

Caregiver Bias: See Family Responsibilities Discrimination (FRD).

Caregiver Strain: The demands, responsibilities, and difficulties resulting from caring for a child (or relative) with special needs, such as disabilities. It also includes the psychological impact of the caregiving demand, such as financial stress, disruptions in spousal, family, and social relationships, fatigue, sadness, guilt and other negative effects.

Center for Child and Adolescent Health Care Policy: A dedicated group of researchers interested in improving the lives of children - in particular those who are poor, minority, or chronically ill - and their families through identifying, developing and supporting effective health care policies and interventions.

Child and Dependent Care Tax Credit (CDCT): A federal tax credit up to $6,000 for child care and adult day care expenses.

Child Care Development Fund Subsidies (CCDFS): A contracted child care slot or a voucher that may be used to access child care available to low-income families so that they may work or prepare for employment.

Children with Special Health Care Needs: Children and adolescents who have chronic physical, developmental, behavioral, or emotional condition and who requires health and related services of a type or amount beyond that required by children generally.

Children with Special Needs: Young children who have been diagnosed as having developmental delays, or any child who has been evaluated as having one of a limited list of disabilities specified in IDEA are considered as having special needs that affect their learning and require special education and related services.

Children/Youth: The use of the term "children/youth", rather than just "children" is preferred by consumers that are in the adolescent/young adult age group.

Chronic Condition: Condition that develops over an extended period of time and has persistent symptoms that may not improve and could deteriorate.

Courtesy Stigmatization: The stigmatization projected toward family members and friends of persons with disabilities.

Developmental Disability: Life-long disabilities attributable to mental and/or physical or combination of mental and physical impairments, manifested prior to age twenty-two. Disability: A physical or mental impairment that substantially limits one or more major life activities.

Disclosure: An employed parent speaking up or telling co-workers, supervisors, or human resource professionals about a child's disability.

Double Jeopardy of Courtesy Stigmatization: Parents are held responsible for their children's disability and thus, labeled as bad parents. At the same time, disruptions and absences from work resulting from exceptional caregiving responsibilities, lead co-workers and supervisors to form a perception of the parents as bad employees, as well.

Earned Income Tax Credit (EITC): Cash assistance for low-income families in the form of a refundable tax credit.

Emotional/Behavioral Disability: Social, emotional or behavioral functioning that so departs from generally accepted, age appropriate ethnic or cultural norms that it adversely affects a child's academic progress, social relationships, personal adjustment, classroom adjustment, self-care or vocational skills.

Equal Opportunities Employment Commission (EEOC): A federal agency that investigates discrimination complaints based on an individual's race, color, national origin, religion, sex, age, disability and retaliation for reporting and/or opposing a discriminatory practice.

Exceptional Caregiving Responsibilities: Care responsibilities that differ from typical caregiving responsibilities on several dimensions: time spent arranging care (13.5% of parents caring for children with special health care needs spent 11 or more hours per week coordinating care for their children), ongoing parental responsibilities which can persist throughout childhood into young adulthood or beyond, and more frequent, intense, and crisis-driven care needs.

Family-Friendly Workplace: A workplace where the boundary between work and family life is permeable and support is available from the employee's immediate supervisor and co-workers.

The Family and Medical Leave Act (FMLA): Provides an entitlement of up to 12 weeks of job-protected, unpaid leave during any 12-month period and applies to all public sector employers but only those private sector employers with 50 or more employees.

Family Responsibilities Discrimination (FRD): A form of workplace discrimination that affects employees with family responsibilities (i.e., caregivers of children, elderly, and dependent adults).

Flexible Work Arrangements (FWA): A group of alternative work options that allow work to be accomplished outside of traditional workday schedule and/or outside of the traditional, centralized location.

Individuals with Disabilities Education Act (IDEA): A federal mandate that young children who have been diagnosed as having developmental delays, or any child who has been evaluated as having one of a limited list of disabilities specified in IDEA are considered as having special needs that affect their learning and require special education and related services.

Medical Model of Disability: A condition of the individual, which needs to be managed or cured so that the person can live more "normally".

Mental Health Disability: A mental impairment that substantially limits a major life activity.

National Survey of Children with Special Health Care Needs (NS-CSHCN): A survey conducted by the U. S. Department of Health and Human Services every 4 years.

Person First Language: A semantic technique used when discussing disabilities to avoid perceived and subconscious dehumanization of the people having the disabilities.

Physical Disability: A physical impairment which has a substantial and long term effect on a person's ability to carry out day-to-day activities.

Social Security Disability Insurance (SSDI): Social Security subsidies for children with disabilities over 18 years of age.

Social Model of Disability: Barriers, prejudice and exclusion by society (purposely or inadvertently) are the ultimate factors defining who has a disability and who does not in a particular society.

"Spillover" Effects: Interruptions from the child's school or child care provider, unexpected departures in response to a child crisis, and stress that affects performance and health of the employed parent shape perceptions and beliefs of supervisors and coworkers, often that the parent is not adequately meeting job responsibilities.

Stigmatization: The prejudice, stereotyping, and discrimination that adults and children with disabilities experience, affecting all areas of their lives.

Supplemental Security Income (SSI): Social Security subsidies for children with disabilities under 18 years of age.

Typical Caregiving: Attending to the needs of a child or dependent adult through various dimensions.

U.S. Census Bureau: The government agency that is responsible for the United States Census.

Work-life Integration: The degree to which a person is able to successfully combine paid work with other aspects of personal life.

Workplace Culture: Shared assumptions, beliefs and values regarding the extent to which an organization supports the integration of employees' work and family responsibilities.

Workplace Support: Incorporates flexibili y in work arrangements, supervisor support, supportive workplace culture, positive coworker relations, respect in the workplace, and equal opportunity for workers of all backgrounds.

Resources

Americans with Disabilities Act – Association Provision
This web resource discusses potential situations that workplaces may encounter regarding employee leave requests under the association provision.
http://eeoc.gov/facts/association_ada.html

Center for Child and Adolescent Health Policy, Employee Benefits Study
The Center for Child and Adolescent Health Policy at the MassGeneral Hospital for Children has undertaken a project to examine employer-sponsored benefit systems and workplace supports as they relate to employees who have children with special needs.
http://content.healthaffairs.org/content/26/4/1096.long

Center for Mental Health Services
Part of the Substance Abuse and Mental Health Services Administration, US Department of Health and Human Services. Comprehensive website containing resources and information designed to improve the lives of people at risk for mental and substance abuse disorders.
www. samhsa.gov

Center for Work Life Law
A national research and advocacy center at the University of California, Hastings College of Law with a mission to eliminate discrimination against employees due to their status as caregivers, and using the legal system to prevent discrimination.
http://www.uchastings.edu/?pid=3634

Child Care and Children with Special Needs: Challenges for Low-Income Families
A multi-method study, focusing predominantly on Maine, of the challenges and barriers facing low-income working families with special needs children in fin - ing and retaining child care services and in balancing work and family, based on parent interviews and focus groups, a field study, a child care provider survey, a parent survey, and an analysis of data from the 1997, 1999, and 2002 rounds of the National Survey of America's Families
http://www.child careresearch.org/location/12772

Employee Benefits Study for Children with Special Health Care Needs
http://www.familyvoices.org/admin/work_workplace/files/HelpfulEmployeeBenefits.PD

Employee Retirement Income Security Act (ERISA) – Compliance Assistance
This site provides technical assistance with compliance issues related to ERISA.
http://www.dol.gov/ebsa/compliance_assistance.html

Family and Medical Leave Act (FMLA) – Final Rule
Latest updates on FMLA.
http://www.dol.gov/esa/whd/fmla/

Family Network
Family Network, a Family Focus Center, is a not-for-profit, non-sectarian, family support agency open to all regardless of ability to pay or geographic location. Their mission is to promote the well being of children from birth by supporting and strengthening their families in and with their community.
http://www.familynetworkcenter.org/index.html

Family Voices
Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through their national network, they provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.
http://www.familyvoices.org/

Families & Work Institute
A nonprofit center for research that provides data to inform decision-making on the changing workforce, changing family, and changing community. Resources and publications addressing work-life, fatherhood, families and communities, development of young children, parenting, and education.
http://www.familiesandwork.org

RESOURCES

Fathers Network
Their mission is to celebrate and support fathers and families raising children with special health care needs and developmental disabilities.
http://www.fathersnetwork.org/

Federation of Families for Children's Mental Health
National family-run organization designed to help children with mental health needs and their families achieve a better quality of life. Local chapters in each state provide resources and support to families.
http://www.ffcmh.org

Individuals with Disabilities Education Act (IDEA)
A "one-stop shop" for resources related to IDEA and its implementing regulations that are updated regularly by the Department of Education.
http://idea.ed.gov/

Labor Project for Working Families
A national, non-profit advocacy and policy organization providing technical assistance, resources, and education to unions and union members on family issues in the workplace including: Child care, Elder care, Family leave, work hours, Quality of life.
http://www.working-families.org

National Alliance on Mental Illness
The "nation's voice on mental illness." A grassroots mental health organization dedicated to improving the lives of persons living with serious mental illness and their families. Chapters in every state provide resources and supports for families affected by mental illness.
http://www.nami.org

National Dissemination Center for Children with Disabilities (NICHCY)
Federal center that provides information on disabilities and disability-related issues for families and professionals.
http://www.parentcenterhub.org/resources/

National Mental Health Association Stigma Watch
The largest and oldest national non-profit association dedicated to all aspects of mental health and mental illness. The stigma watch program tracks

the portrayal of mental illness in the news and entertainment coverage for fairness and accuracy to prevent stigmatizing advertising, television, radio and print programming.
http://www.mentalhealthamerica.net/newsroom/chiming-in

Office of Special Education and Rehabilitative Services
Provides leadership and financial support to states and local districts to improve academic and social well-being for children and youth with disabilities.
http://www2.ed.gov/about/offices/list/osers/osep/index.htm

Our-Kids-Adults
A site that provides information and resources on assistive technology, events, disability links, finan ial and legal issues and information on the needs and supports for children with disabilities transitioning to adulthood
www.our-kids.org/OKAdults/

PACER Center
Center dedicated to providing parent training and information for families of children with disabilities.
http://www.pacer.org

Research & Training Center on Family Support & Children's Mental Health
Family focused children's mental health research, resources and publications relevant for parents, service-providers, researchers and policy-makers
http://www.rtc.pdx.edu

The Catalyst Center
The Catalyst Center is a national center dedicated to improving health care insurance and financi g for children and youth with special health care needs
http://www.hdwg.org/catalyst/

Work and Family Researchers Network
The network is designed to support research and teaching, promote best practices at the workplace, and inform state policy on issues that affect the lives of working families and the places where they work.
http://workfamily.sas.upenn.edu/content/welcome-1/

Workplace Flexibility 2010
Workplace Flexibility 2010 is a campaign to support the development of a comprehensive national policy on workplace flexibili y. By the year 2010, we hope to have helped develop consensus-based policy solutions that work for business and families.
http://www.workplaceflexibili y2010.org

Parent Support Provider Knowledge Check

We are interested in understanding your overall knowledge level about children or youth with disabilities and their parents' work-life balance experiences. Your knowledge on any or all topics may be based on personal or Parent Support Provider experiences. In this section, please read each statement and select the letter that corresponds to the answer you believe to be correct. There is only **one** correct answer for each question. Please make sure to select one answer for every question.

1. As a group, children with disabilities may also be referred to as:
    a. Children with special health care needs.
    b. Children with special needs.
    c. Children with physical, sensory, developmental, emotional, or behavioral impairments.
    d. All of the above.

2. In any given U.S. business, approximately how many employees are caring for a child under the age of 18 with special health care needs?
    a. 1 in 20 (5%)
    b. 1 in 10 (10%)
    c. 1 in 5 (20%)
    d. 1 in 6 (17%)

3. The demands, responsibilities, and difficulties resulting from caring fo a child or youth with disabilities can result in:
    a. Compassion fatigue.
    b. Caregiver strain.
    c. Tag team parenting.
    d. Work-life integration.

4. For parents of children with disabilities, finding and maintaining chil care is:

   a. No harder than for parents of children developing typically.

   b. Problematic since they have to select child care arrangements from many suitable options.

   c. Difficult since their children are often expelled from child care se - tings.

   d. None of the above.

5. When parents experience prejudice, stereotyping, and discrimination due to raising a child or youth with a disability, this is called:

   a. Blaming the victim.

   b. Courtesy stigmatization.

   c. Flexibility stigma.

   d. Negative attribution.

6. The Americans with Disabilities Act (ADA) mandates that parents of children with disabilities:

   a. Are not discriminated against because of their caregiving responsi-bilities.

   b. Receive accommodations in the workplace.

   c. Are not dismissed due to poor performance at their jobs.

   d. Are allowed to leave work for appointments involving their children.

   e. None of the above.

7. The most common reason that Family and Medical Leave Act (FMLA) leaves are not used by employed parents of children or youth with special health care needs is because these employees:

   a. Do not have suitable documentation for their child's health issue.

   b. Cannot afford to lose the income since FMLA is unpaid in their state.

   c. Believe supervisors will not let them take it.

   d. Take sick days.

   e. None of the above.

8. Which of the following is a positive outcome from an employee's decision to **not** disclose his or her child/youth's disability to employers?
   a. Avoid courtesy stigmatization.
   b. Maintain a "normal-appearing" working life.
   c. Avoid co-worker resentment.
   d. Avoid performance scrutiny.
   e. All of the above.

9. Which of the following is the term used to describe disability-care?
   a. Intensive dependent-care responsibilities.
   b. Home-based disability care.
   c. Specialized family care.
   d. Special needs caregiving.
   e. Exceptional care responsibilities.

10. Which of the following is an example of Family Responsibilities Discrimination:
    a. A mother of a child with a disability who refuses a promotion that requires travel.
    b. An employer not hiring a father of a child with autism and who doesn't meet minimum job requirements.
    c. The unwilling transfer of an employee to a less demanding position after giving birth to a child with a disability.
    d. Not providing additional time off after an employee with a sick child has exhausted all sick leave or family leave.
    e. All of the above.

11. The Individuals with Disabilities Education Act (IDEA) specifies tha parents of children receiving special education services have a right to:

    a. Take calls any time during the workday.

    b. Leave work in response to a crisis during the school day.

    c. Attend individualized education planning meetings.

    d. Administer medication during the school day.

    e. None of the above.

12. Human resource professionals

    a. Are not responsible for granting formal flexible work ar angements.

    b. Need to balance the needs of the employees against their responsibilities to the organization that employs them.

    c. Need to know all of the details about employees' family responsibilities.

    d. Are not concerned with possible legal issues.

13. Family friendly workplaces

    a. Are focused on the dependent care responsibilities of mothers.

    b. Always have onsite child care provided.

    c. Never require formal flexible work ar angements.

    d. Have benefits, policies and prog ams that make it easier for parents to meet both work and family responsibilities.

14. Flexible work arrangements:

    a. Refer to employers' right to change their workers' schedules to meet their business needs.

    b. Are only available through informal agreements.

    c. Can involve working from home or on a schedule requested by employees.

    d. Always require a written request.

15. Parent support providers can help employed parents of children with disabilities request workplace supports by:

   a. Working with them to find and access resources at their place of employment.

   b. Thinking through the ways in which they can address organizational concerns when talking to employers.

   c. Planning ways to partner with their supervisors to find win-win solutions.

   d. Encouraging them to keep communication lines open with supervisors.

   e. All of the above.

The answer key for the *Parent Support Provider Knowledge Check* is available in the materials for training facilitators, posted at the *website of Balancing Work and Family Responsibilities: A Toolkit for Parent Support Providers*:

WORKPLACE SUPPORT RESOURCES INVENTORY FOR PARENTS OF CHILDREN/YOUTH WITH DISABILITIES

Resource	Available?	Accessed?	Strategy to Access or Gain More Info
FLEXIBLE WORK ARRANGEMENTS			
Change start/stop times			
Work any hours to equal FT			
Telecommute/work from home			
Move FT to PT, reverse if needed			
Swap schedule with coworkers			
Temporary reduction in workload			
Information in handbook on how to request, negotiate			
LEAVE POLICIES			
Paid provided			
Unpaid provided			
Sick provided			
Can use above leave flexibly			
Family medical leave			
Time off for seriously sick child			

WORKPLACE SUPPORT RESOURCES INVENTORY FOR PARENTS OF CHILDREN/YOUTH WITH DISABILITIES

Resource	Available?	Accessed?	Strategy to Access or Gain More Info
TIME-OFF POLICIES			
For child's medical appts			
For child's teacher meeting			
For care coordination			
For child emergency/crisis			
Coworkers can donate their time			
CHILD CARE			
On-site child care with staff trained for child with disabilities			
Specialized resource & referral			
Child care subsidies, vouchers			
Flexible spending accounts			
Child come to work occasionally			
HEALTH BENEFITS			
Comprehensive coverage for child's needs			
Choice of plans			
Coverage available for PT			
Dental, vision, or mental health			

WORKPLACE SUPPORT RESOURCES INVENTORY FOR PARENTS OF CHILDREN/YOUTH WITH DISABILITIES

Resource	Available?	Accessed?	Strategy to Access or Gain More Info
PEOPLE			
Supportive supervisor			
Supportive coworker(s)			
Knowledgeable & supportive HR			
Notified quickly if emergency call about child			
Support groups or networks for employees with child-disabilities			
Employee Assistance Program			
OTHER			
Can take & make personal child related calls			
Workshops, seminars on children/youth with disabilities			
Disabilities information on company intranet			
Affinity groups in our organization of other families caring for children/youth with disabilities			

* Based on Employee Benefits Study for Children with Special Health Car Needs (See http://www.familyvoices.org/admin/work_workplace/files/Hel - fulEmployeeBenefits.PD , and Perrin, J.M., Fluet, C.F., Honberg, L., Anderson, B., Wells, N., Epstein, S., Allen, D., Tobias, C., & Kuhlthau, K.A. (2007). Ben-efits for employees with children with special needs: Findings from the collab-orative employees benefits stud . *Health Affairs, 26*(4), 1096-1103.