Children/Youth with Disabilities: Their Parents Are YOUR Employees
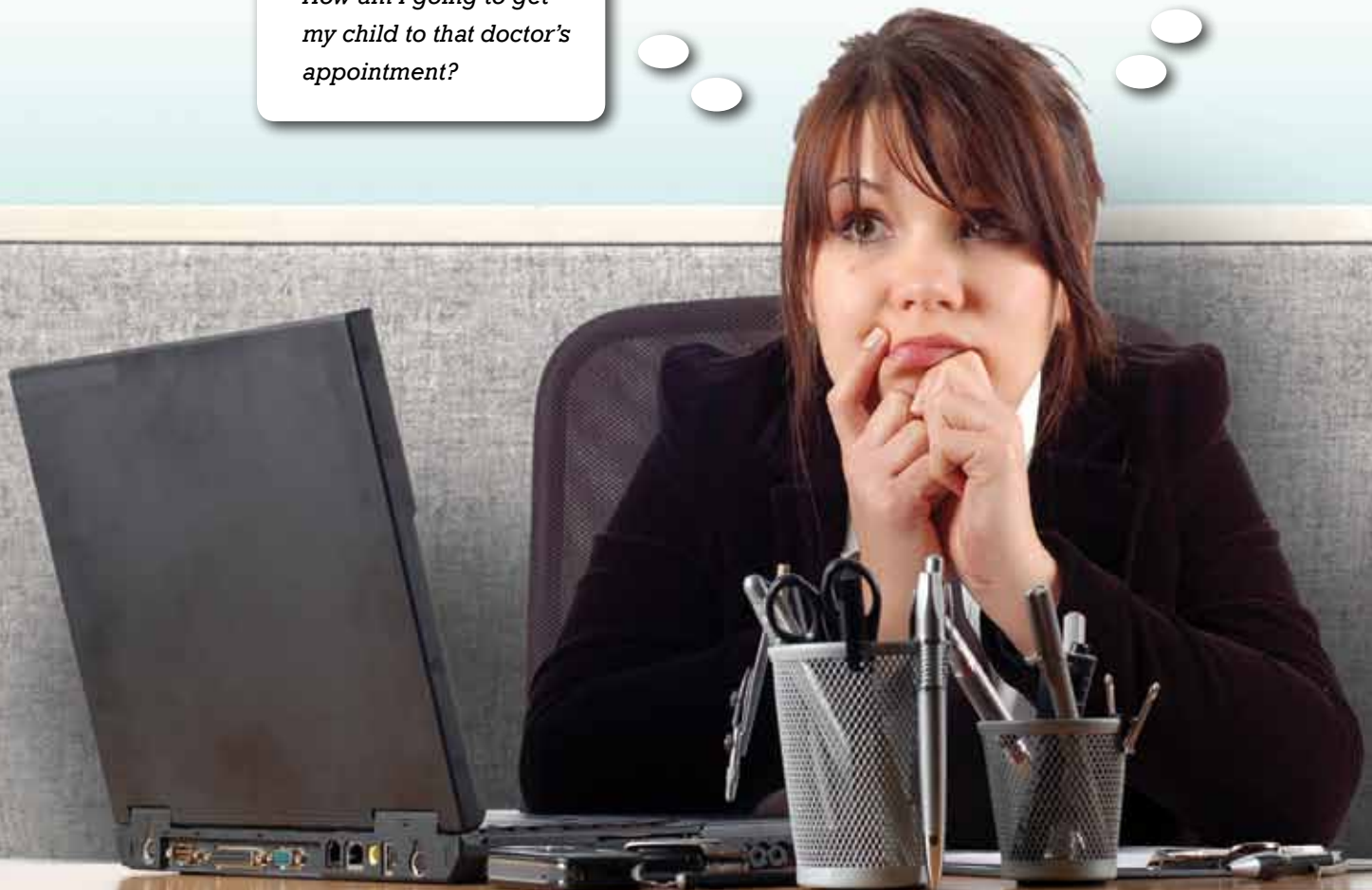
Training Manual and Workbook

It's so hard to find a child care provider who understands my child's special needs.

I hope I don't get another call from the school this week... How many times can I leave early before my supervisor and coworkers want to know what's really going on?

I would be SO grateful to have a flexible schedule...

How am I going to get my child to that doctor's appointment?

Julie M. Rosenzweig, Anna M. Malsch, Eileen M. Brennan, Kathryn L. Mills, & Lisa M. Stewart
Work-Life Integration Project, Portland State University

Organization and Suggested Use of the Manual and Workbook

*T*he training manual and workbook, including the survey, were originally designed as supplemental materials to a workshop delivered to human resource professionals by the Work-Life Integration Project. Once the materials were compiled and reviewed, we decided to make the document available as a printed resource for a more general audience. While the materials were initially developed for use with human resource professionals, they are readily adaptable for use with other groups of employees, such as supervisors, managers, or teams of co-workers. The manual is also suitable to be used by members of family support organizations and other individuals interested in knowing more about the topics included. Supplemental materials to the manual are available and include a slide presentation, case studies, and a more comprehensive pre-post assessment. Project staff is also available for consultation or on-site training.

The survey, modified somewhat from the one used in the training, may be used as a pre/post evaluation of knowledge and attitudes; or simply as an evaluation of one's learning after working through the modules. Each of the 8 modules includes a brief introduction, objectives, salient information, summary of key points, and an action plan page. Action plans for each module can be completed by individuals or by a group, depending on the reader and needs of the organization. Modules 7 and 8 are slightly different from the preceding modules. Module 7 introduces case study material and has questions for discussion. Module 8 is focused on skill building, also uses case material, and has more detailed action planning. We encourage you to make adjustments in the case studies to fit best with your company's needs.

You will notice that throughout the modules some concepts are in bold print. These concepts are listed in the Glossary which can be found in the Appendix. Also in the Appendix is a brief list of resources, accompanied by current website addresses.

If you have any questions or suggestions please contact us.

Children/Youth with Disabilities: Their Parents Are YOUR Employees

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research & training center portland
ON FAMILY SUPPORT AND CHILDREN'S MENTAL HEALTH

Table of Contents

Introduction and Acknowledgments

We are grateful for the opportunity to share our knowledge about the work-life integration experiences, needs, and strengths of employees who are parents of children and youth with disabilities. During the past fifteen 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 a training publication.

The material included in *Children/Youth with Disabilities: Their Parents are YOUR Employees* synthesizes much of what we have learned. It is our hope that the information presented bridges the gap between the workplace needs of employed parents of children and youth with disabilities and the business objectives of companies. Moreover, we believe that the manual will assist all stakeholders, including policy makers and human service professionals, 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 workbook would not have been possible without encouragement, support, and advice from many individuals. We wish to thank Debora Bubb and Linda Roundtree who patiently guided us in our learning about the human resource profession and relevant training formats. Their support and expertise was invaluable in the completion of this manual. We are also appreciative of the efforts of Catherine LaTourette and the Portland State University Human Resource staff who helped us pilot test the survey. We are indebted to KPMG, LLC, whose corporate leaders graciously accepted our invitation to offer the training to their human resource personnel. John Wyatt, Barbara Wankoff and their colleagues Joey Lynn Monaco, Mary Swaney, and Cynthia Carranza who were tireless in their efforts to help us format and deliver the training to their staff.

We hope that the training materials facilitate successful partnerships between employed parents of children/youth with disabilities and workplace professionals supporting them.

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1 Definitions and Terminology

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

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

- Chronic conditions with acute episodes.

- "Person first" language communicates respect, minimizes stigmatization.

Definitions and Terminology

1

Introduction

Disabilities affecting **children/youth** take many forms and significantly shape the way families live in their communities. It is likely that there are employees in your organization 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? To better address the needs of employed parents of children/youth with disabilities, it is necessary to understand what is meant by the concept of "disability" and related terms.

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.

- *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?*

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 employers (See Module 4). 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 mental health disorders. For example, it is not uncommon 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)** 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 flexibility on a more regular basis. A chronic condition also has acute episodes, that can be anticipated but the onset can not 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 different 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 be categorized into general types. For example, diabetes, asthma, and muscular dystrophy are classified as **physical disabilities**. Depression, anxiety, and attention-deficit/hyperactivity disorders may be referred to as **mental health, emotional, or behavioral disabilities**. **Developmental 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.

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2 *Prevalence*

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

- 22% of households have children/youth with special health care needs.

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

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

Prevalence

Introduction

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. There has yet to be a national study to determine the number of employed parents caring for children/youth with disabilities, but with the available data on prevalence, you can approximate how many employees in your company may be caring for children/youth with disabilities.

Objectives

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

1. Identify key sources of prevalence data on children/youth affected by disabilities and special health care needs, and the current national estimates.

2. Estimate the number of employees in your company caring for children/youth with disabilities.

- *How many families have children/youth with disabilities?*

- *How many school-aged children/youth meet the criteria to receive special education services?*

- *How many parents of children/youth with disabilities are estimated to be employed in a typical company?*

Children/Youth with Disabilities: Their Parents are YOUR Employees

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 disability used.

- The **U.S. Census Bureau**, based on survey data collected in 2000, estimates 9.2% of households are caring for at least one child/youth with a disability. The survey used a strict definition for a sensory, physical, or mental disability.[6]

- Based on the 2005-06 survey, the **National Survey of Children with Special Health Care Needs** estimates that 13.9 % of children/youth under 18 years of age, or approximately 10.2 million children/youth have special health care needs.[5] This represents 21.8% of households with children/youth.

- Prevalence of disabilities may vary by sex, age, ethnicity, and income level. For example, when considering the occurrence of mental health disorders, surveys suggest the following:

  ▸ Rates of occurrence are higher in male children/youth than in female children/youth.

  ▸ There is a higher incidence in school-aged children compared to younger children.

  ▸ Rates of occurrence are highest among children/youth with multi-racial identity.

  ▸ Families of children/youth with disabilities are at increased likelihood of living below the poverty line.[5]

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

- Asthma affects an estimated 6.2 million children/youth under the age 18, making this the most common chronic disorder in childhood.[7]

- Attention Deficit Hyperactivity Disorder (ADHD) affects an estimated 2 million children/youth.[8]

- Autism affects an estimated 1 million children/youth; approximately 1 in every 150 children/youth is diagnosed with the disorder.[9]

- Mental health disorders affect a significant number of children/youth: 20% experience symptoms with at least mild functional impairment,

and of this 20%, 11% suffer from disorders which cause significant impairment.[10] The Surgeon General in 2001 called the state of children's mental health care a "public health crisis" because only 1 in 5 children/youth with mental health needs were receiving services.[11] In 2005-06, the parents of 15% of children/youth aged 4-17 in the U.S. expressed concerns about their child's emotional or behavioral difficulties to a health care provider or school personnel.[5]

Children/Youth with Disabilities Receiving School Services

An estimated 7 million children/youth with disabilities meet the criteria to receive special education services in the schools under the federal mandate of the **Individuals with Disabilities Education Act (IDEA).**[4] The number receiving services has steadily increased. For example, in 2006-2007 approximately 8.6% of children/youth ages 3-21 (6.7 million children) received services compared with 7.8% in 1996-97.[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 resources to meet the exceptional caregiving needs of their children/youth and maintain employment. How many employees in your company are parents of children/youth with disabilities? To approximate this number, the **Center for Child and Adolescent Health Care Policy** considered the national estimate of children/youth with disabilities (20-21%) and the employment rate of among parents of children/youth age 18 and under (43%).[13] This formula suggests that in any given company there are almost 9% of employees who 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.

- The state of children's mental health care in the U. S. is considered a public health crisis.

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

Children/Youth with Disabilities: Their Parents are YOUR Employees

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Exceptional Caregiving Responsibilities

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

- Requires coordination with many community-based resources.

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

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 depends 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 3, 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 effect on well-being.

Children/Youth with Disabilities: Their Parents are YOUR Employees

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 spouses 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:[14]

- 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[14] (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 mental heath 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 mental health crises, sometimes requiring hospitalization of their children/youth.[15]

Children/Youth with Disabilities: Their Parents are YOUR Employees

Caregiver Strain

In addition to identifying the tasks that are involved in exceptional caregiving 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 of the parent.[16,17,18,19]

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

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Children/Youth with Disabilities: Their Parents are YOUR Employees

4 Employee 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

Employee 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—**work-life integration**. 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, specifically, **courtesy stigmatization**, that affect the employee with exceptional caregiving responsibilities.

Objectives

By the end of Module 4, 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?*

Children/Youth with Disabilities: Their Parents are YOUR Employees

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.[20]

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/mental concerns, 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.[21]

In a survey of 349 parents of children/youth with mental health disabilities, researchers found that:[21]

- 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 exceptional care demands.

EMPLOYEE CHALLENGES

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.

- 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.

- Compared to parents of children/youth with typical development, parents of children/youth with mental health disabilities are 20 times more likely to be asked to remove their child/youth from care; and have higher explusion rates from pre-kindergarten.[22]

- When care 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 can not work.[23]

> *"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 11 or more hours per week coordinating care appointments for their children/youth.[5]

- 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.[15]

- 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).[15]

- Symptoms associated with disabilities, such as asthma and some mental 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. The call may require that the parent leave work immediately and take the child/youth to a health care provider.[15]

> *"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.[24]

EMPLOYEE CHALLENGES

- 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.

- Parents of children/youth with disabilities may step out of their chosen career altogether in order to find a job that allows for more flexibility to respond to care needs.[24]

> *"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.[25,26] 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 mental health problems, especially in children/youth.

- Employed parents of children/youth with disabilities often experience what is called **courtesy stigmatization**.[27,28] 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.

- Courtesy stigmatization is particularly common for parents of children/youth with mental health disabilities. These parents, especially mothers, are often blamed by extended family members and professionals for causing their children's mental health disorders through poor parenting practices.[29,3]

- 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*.[30] 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.[31]

- 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.[31]

"…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

EMPLOYEE CHALLENGES

to disclose, fearing additional stigmatization, possibly including career penalties or family caregiver 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.[31]

> *"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 significantly affect a parent's ability to find employment that fits with care demands, moreover, sustain an upward career or job trajectory.

- Child care resources for children/youth with disabilities are limited and care demands are ongoing.

- Courtesy stigmatization is a common experience for parents of children/youth with disabilities, especially those with mental 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 assessments.

My Action Plan:

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5

Key Policies

- Family and Medical Leave Act (FMLA).

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

- Individuals with Disabilities Education Act (IDEA).

- Family Responsibilities Discrimination.

Key Policies

Introduction

A company's work-life initiatives, policies, and practices necessarily relate to federal and state-level legislation that addresses employees' work-life challenges. Achieving a balance between supporting the employed parent and protecting the organization is often accomplished by addressing these policies and their implementation. Understanding which policies are most relevant to employed parents of children/youth with disabilities helps achieve this goal.

Objectives

By the end of Module 5, 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 how to minimize potential litigation.

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

- *What legal issues are of concern to human resource professionals when communicating with employed parents of children/youth with disabilities?*

Children/Youth with Disabilities: Their Parents are YOUR Employees

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 benefits

These policies and laws help to support employees with exceptional caregiving responsibilities by increasing access to flexibility 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.[32]

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 mental 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 employment.

- Employment benefits such as group life insurance, health insurance, disability insurance, sick leave, annual leave, or educational benefits may not be terminated and must be restored to the level of benefits 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.

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.[33,3]

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.[34]

- 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.[35]

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.[12]

Specifics:

- Schools are obligated to teach children/youth with disabilities in an inclusive 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.

KEY POLICIES

Family Responsibilities Discrimination

An area of increasing concern for employers and employed caregivers alike is the area of **family responsibilities discrimination (FRD)**.[36] 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.[37] 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.[37]

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 mental 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.

Children/Youth with Disabilities: Their Parents are YOUR Employees

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.[34] The guidelines cite the five 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

How can Employers Prevent FRD Lawsuits?

- Increase awareness within your organization about how stereotypes relating to caregiving roles may result in FRD lawsuits.
- Increase awareness among HR and front line managers about the nature and scope of disability-related dependent care.
- Become knowledgeable about the various community supports in your area for families with exceptional caregiving responsibilities.
- Make resources and supports known to employees (i.e., backup child care supports).
- Assess how the employment practices, e.g., recruitment, retention and productivity expectations, might impact employees caring for a child/youth with a disability.
- Create an organizational policy aimed at preventing FRD (similar to other diversity-related policies, i.e., sexual harassment and discrimination).

- Use your organizational FRD policy when evaluating employee work performance or attendance complaints.

- Promote workplace culture that ensures personnel decisions are made based on legitimate business needs and individual employee performance not stereotypes and biases.

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.

Children/Youth with Disabilities: Their Parents are YOUR Employees

My Action Plan:

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6 *Strategies and Supports*

- Employment-based strategies enhance work-life integration.

- Top 5 Strategies
    - Find a family-friendly workplace
    - Learn about rights and relevant benefits
    - Structure work to maximize flexibility
    - Make a disclosure plan
    - Negotiate reciprocity

6

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* flexibility to successfully meet work and care demands and *minimize* stress and strain on self, family, and relationships, including those with supervisors and co-workers. While research on work-life integration specific to these parents is limited, the findings compiled suggest strategies that can enhance integration. Presented here are **employment-based strategies and supports**. Work-life includes several domains of activities, including the family and community; therefore, parents also develop and rely on other domain-specific strategies and supports to achieve a sense of integration and well-being.

Objectives

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

1. Describe key employment-based strategies developed and used by employed parents of children/youth with disabilities to enhance work-life integration.

2. Recognize the steps in the employee's decision-making process regarding disclosing information within the workplace about the child/youth's disability and related exceptional caregiving responsibilities.

3. Identify formal and informal workplace supports that may increase 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?*

Children/Youth with Disabilities: Their Parents are YOUR Employees

Top 5 Employer-Based Strategies/Supports 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 flow. 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[38]

- 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.

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."*
>
> *- Employee/Parent*

A prospective employee with exceptional caregiving responsibilities for a child/youth may 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 report willingness, albeit sometimes a necessity, to move to communities where there are family responsive businesses and services.

Strategy # 2: Learn About Rights and Relevant Benefits

- Employees are getting savvy about their rights and relevant benefits that support work-life integration. By informal networking with other parents and accessing information through the internet, parents of children/youth with disabilities are educating 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 these 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.[5]

- With the recent surge in Family Responsibilities Discrimination lawsuits, clearly parents understand their legal rights as caregivers of children/youth with disabilities. Parents of children/youth with disabilities wanting to sustain job security and flexibility are informed about unnecessary barriers in the workplace.

> *"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."*
>
> *- Employee/Parent*

Strategy # 3: Structure Work to Maximize Flexibility

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

- Flexibility allows the employee 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.[15]

- Unlike parents of children/youth with typical development, for parents of children/youth with disabilities, the need for flexibility is often unpredictable and sporadic.[15,39] For example, an employee may need to leave work immediately when the child's symptoms are active. An active period may continue for several days at a time.

- Parents with exceptional caregiving responsibilities for a child/youth with disabilities, whether a prospective employee or a current employee, may seek out information about FWAs, submit a request 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."*
>
> *- Employee/Parent*

Strategy # 4: Make a Disclosure Plan

- Parents of children/youth with disabilities 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.

- This general disclosure strategy is carried into the workplace and adapted to the organization. Workplace factors considered in determining disclosure include:[21]

  ▶ Type of job/position the employee holds

  ▶ Workplace culture

  ▶ Availability and accessibility of formal support

  ▶ Perceptions of informal support

  ▶ Concerns about privacy and confidentiality

Dimensions of the Disclosure Decision Process

The employee reflects on the pros and cons across 3 major dimensions of disclosure: timing of the disclosure, target audience of the disclosure, and type of information to disclose. Within each dimension there are different options to consider.[21]

DIMENSIONS OF THE DISCLOSURE DECISION PROCESS		
Timing Possibilities	**Target Audience 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 employee'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 • Mental health disorder • Specific diagnosis • Decription of specific behaviors • Type of treatment needed • Impact on self and family

Additionally, employees consider issues of confidentiality and privacy and do not assume that the information will be held in confidence.

STRATEGIES AND SUPPORTS

Choice or Necessity? Cost or Benefit?

- The decisions concerning disclosure are personal and individual. Ultimately decisions about disclosing are the employee's choice; however, it is important to note that disclosures may be made out of necessity to avoid losing one's job.

- Disclosure related to the employment domain is a strategy that may be used to gain interpersonal and organizational support. Personal and social benefits gained can include an opportunity to receive emotional support, reduce stigma, and educate others. Disclosure may also allow employees greater access to formal benefits that can enhance work-life integration.

POSSIBLE OUTCOMES OF THE DISCLOSURE DECISIONS[40]		
	Positive	**Negative**
Disclosure	• Access formal supports • Access flexible work 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 • Minimize worries from home • Maintain a "normal appearing" work life	• Diminished access to formal supports • Diminished flexible work arrangements • Diminished informal support • Isolation

Children/Youth with Disabilities: Their Parents are YOUR Employees

- Disclosure 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.[21]

> *"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."*
>
> - Employee/Parent

Strategy # 5: Negotiate Reciprocity

- **Reciprocity**, explicitly or implicitly, is part of the flexibility equation. In the workplace, reciprocity is a relational process—a mutual exchange between employee and immediate supervisor/coworker resulting in benefits to all stakeholders.

- For example, the employee agrees to a less prestigious task in exchange for a later start time. The employee gains necessary autonomy over work scheduling to meet caregiving demands; and the employer benefits from the worker's increased engagement, productivity, and loyalty.

> *"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%."*
>
> - Employee/Parent

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

STRATEGIES AND SUPPORTS

Strategy specifics from an employee's point of view:

- Be Proactive

    ▶ Alert supervisor/coworker to exceptional caregiving responsibilities whenever possible

    ▶ Learn about availability of flex options, formal and informal

- 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 the agreement

    ▶ 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 flexibility needed to meet exceptional caregiving responsibilities may differ from what is needed to meet typical caregiving responsibilities.

Children/Youth with Disabilities: Their Parents are YOUR Employees

My Action Plan:

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7 HR Professionals: Support Dilemmas

- Dilemmas of meeting competing demands and needs:

  - Balancing the needs of the employed parent of child/youth with business goals.

  - Having too much information vs. not having enough information.

  - Minimizing potential litigation with maximizing flexibility and support.

HR Professionals: Support Dilemmas

Introduction

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 flexibility 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 influence the work-life integration experiences of employees of children/youth with disabilities through direct employee contact, policy development, program design, consultation with managers, and modeling family-friendly practices, all of which can positively influence **workplace culture**, including the reduction of courtesy stigmatization. Addressing the needs of this particular group of employees is not without challenges and dilemmas, such as issues of organizational liability and equity.

Objectives

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

1. Recognize and discuss major organizational dilemmas facing HR (and supervisors/managers) when interfacing with employed parents of children/youth needing support who are requesting flexibility.

2. Identify your own dilemmas and questions about supporting employed parents of children/youth with disabilities in your company.

- *What is the range of dilemmas experienced 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?*

Children/Youth with Disabilities: Their Parents are YOUR Employees

A Range of Dilemmas

As an HR professional you may interact directly with employees having work-life integration struggles and needing flexibility to accomplish work tasks; and/or you may consult with supervisors and managers on these matters. Negative spillover from family situations into the workplace is not unusual and as previously discussed, is more likely and different in nature for employed parents of children/youth with disabilities compared to employees with children/youth developing typically.[21] Although you understand the scope of their situations and the significant need for flexibility, you are sensitive to issues of favoritism and must make decisions about FWA requests based on standard criteria.

- Decisions about FWAs are never easy. Some companies have a well-defined set of policies and procedures regarding work-life issues, whereas other businesses manage flexibility primarily on an informal basis.

- 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.

- With knowledge about children/youth with disabilities and the concomitant work-life integration experiences of their parents, we now consider various dilemmas that arise in the workplace when, formally or informally, providing support for employees with exceptional caregiving responsibilities. Dilemmas can surface in a number of different contexts— the development and implementation of policy, disparities in informal practices, or during interpersonal interactions. Furthermore, dilemmas are not discrete and often have a significant degree of overlap with multiple dilemmas occurring simultaneously.

HR PROFESSIONALS: SUPPORT DILEMMAS

Common Dilemmas

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

How do I balance 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 flexibility, not all positions within a business lend themselves to FWAs.

- Equitable treatment of employees is a core consideration when an employee requests flexibility. Even when an employee makes a flexibility 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 flexibility, 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. You want 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

Children/Youth with Disabilities: Their Parents are YOUR Employees

Dilemma: Too much information vs. Not enough information

How do I balance 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 confidentiality 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.

▸ Yet, 77% reported that employee disclosure of personal circumstances can help in obtaining flexibility.[41]

> *"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

HR PROFESSIONALS: SUPPORT DILEMMAS

- HR professionals must balance having the knowledge of why the flexibility request is needed and yet at the same time not wanting this information for fear of confidentiality 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

I am constantly concerned about litigation; how do I protect 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 flexibility 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 flexibility from employees with exceptional caregiving responsibilities are fair and appropriate.
- HR professionals must balance a need to know why the flexibility is needed with the legal consequences of knowing, when making decisions about granting flexible work arrangements.

Children/Youth with Disabilities: Their Parents are YOUR Employees

Case Study: Introducing Charlie

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 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 dilemmas you may face as a result of Charlie's request?

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HR PROFESSIONALS: SUPPORT DILEMMAS

2. What additional dilemmas have you experienced in the past when handling similar requests?

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3. What issues do you foresee occurring if you expand support for employees with exceptional caregiving responsibilities?

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Children/Youth with Disabilities: Their Parents are YOUR Employees

My Action Plan:

1.

2.

3.

8 Providing Layers of Organizational Support

- A multi-layered process:
  - Organizational policies & practices
  - Workplace culture
  - Collaborative communication
- Dialogues that make a difference:
  - Empathy without promise
  - Partner for solutions
  - Re-connect, re-evaluate, re-commit

Providing Layers of Organizational Support

8

Introduction

Support and communication—two words so ubiquitous that the richness of their meanings can often be lost. Yet, providing support and effectively communicating are key ingredients to all business strategies. You now have the foundation for developing multiple layers of organizational support for employed parents of children/youth with disabilities. All types of support involve communication in various forms, ranging from print materials to dyadic interactions. Communicating directly with employees about personal matters, such as their children/youth's disabilities and care requirements takes sensitivity and skill. Managing boundaries and expectations while being understanding is crucial but not always easy.

Objectives

By the end of Module 8, you will be able to:

1. Identify and describe layers of organizational support that target your employed parents of children/youth with disabilities.

2. Describe and use communication strategies for dialoguing with employed parents of children/youth with disabilities about their work-life integration needs and solutions.

3. Write your own strategic plan for supporting employees with exceptional caregiving responsibilities for their children/youth.

- *What are the many creative and effective strategies—"layers of organizational support"—that HR professionals can implement to reduce barriers and enhance work-life integration for employed parents with exceptional caregiving responsibilities?*

- *How can HR improve their collaborative communication in problem solving dialogues with employed parents of children/youth with disabilities?*

Children/Youth with Disabilities: Their Parents are YOUR Employees

Layers of Organizational Support

The foundation for building your Layers of Organizational Support Plan includes:

- Knowledge about the prevalence and multiplicity of disabilities experienced by children/youth.
- Understanding about exceptional caregiving responsibilities.
- Information about relevant federal and state policies.
- Familiarity with the work-life integration challenges and strategies of employed parents of children/youth with disabilities, including stigmatization issues.
- Identification of dilemmas facing HR in supporting and resolving work-life integration challenges in the workplace.
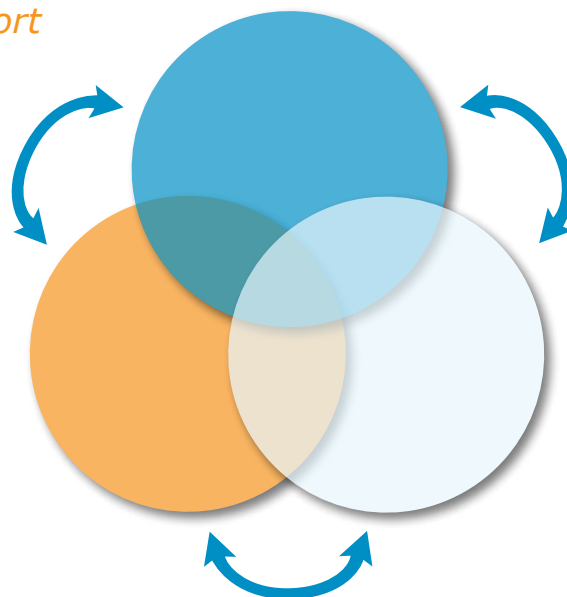
You are now ready to expand your support strategies for employees caring for children/youth with disabilities.

Core Layers of Organizational Support

● **Organizational Policies And Practices**

○ **Workplace Culture**

● **Collaborative Communication**

Support comes in all shapes and sizes. There are many ways to provide support to employees. The layers of support are both overlapping and interacting. In other words, while one layer can stand on its own, it is strengthened and made more effective by the other layers.

PROVIDING ORGANIZATIONAL SUPPORT

Organizational Policies And Practices Layer

Building on your foundation, review your company's current benefit plans, relevant work-life policies and practices (formal and informal) for items that specifically address the needs of employed parents of children/youth with disabilities. Highlight, add-on, and develop policies and practices for these employees. For this layer it is important to have both paper and people processes in place. This layer is crucial for signaling to your target group of employees that you are aware of their needs and are supportive.

Suggestions:

- Develop specific policies and formalized programs targeting employees with exceptional caregiving responsibilities, identifying parents of children/youth with disabilities.

- Provide financial health care support, e.g., ensure comprehensive health care that includes coverage for therapies and medications.

- Supply financial child care support.

- Train relevant staff, e.g., supervisors, managers, EAP.

- Develop and disseminate materials specifically relevant to employees with children/youth with disabilities.

- Develop support networks and affinity groups for employees of children/youth with disabilities; this can be both in person and online.

- Develop and disseminate materials that identify local, regional, and national resources for parents/families of children/youth with disabilities.

- Offer opportunities for parent networking groups to organize and meet at company locations. Provide workshops, brown bag lunch-time gatherings, and other forums for employees of children/youth with disabilities to talk about relevant policies and practices, disclosure concerns, and work-life issues.

- Publish an article in your employee newsletter about available support at your company—perhaps share an employee's personal story.

- Provide web-based tools to help employees compare health care plan options including employee contributions, co-pays, deductibles, and coverage limits.

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- Offer seminars in the workplace that provide information and resources for parents on topics such as accessing federal and state programs, setting up a special needs trust and preparing for the future, and understanding a child's rights in the public school system.

Workplace Culture Layer

Successful workforce participation of parents of children/youth with disabilities has been linked to the flexibility found in their workplaces. Although most employers have both formal policies and informal practices allowing flexible work arrangements, many workers do not make use of them due to organizational cultures that deter asking for, and receiving these benefits or options.

Suggestions:

- Promote awareness and education about disabilities affecting children/youth.
- Stamp out stigmatization by raising awareness, correcting misperceptions.
- Identify and develop champions in your organizations.
- Educate and train front line supervisors.
- Promote an environment that values and encourages open communication.
- Demonstrate respect for employees' personal responsibilities.
- Develop work systems and structures that emphasize supporting employees' personal lives and enhancing productivity.

Collaborative Communication Layer

Even the most skilled communicators in the workplace can get stuck when entering into a conversation with an employee about personal matters. It is often difficult to find the balance between getting enough information from the employee to be helpful, and not being too intrusive. This balance is

made even more challenging when there are potential issues of litigation looming. An additional balancing challenge is being supportive without misleading or implying that you can provide tangible support, such as a flexible work option when that is not available.

Communication about family matters is:

- Personal

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

- Relational

    ▸ Involves creating an atmosphere of warmth, trust, empathy, responsiveness, and support.

- Informational

    ▸ Involves an exchange of information in which both people offer understanding and explanations, use clear language, and encourage questions.

- Collaborative

    ▸ Involves successful and constructive communication strategies in which both people acknowledge their own and the other's needs as well as what each has to offer the other in return.

Effective communication between employees caring for a child/youth with a disability and their co-workers, supervisors, and HR professionals is vital to accessing and receiving support. Employees often struggle to speak of or share with others the experience of having a child/youth with a disability and have to make difficult decisions about whom to tell and what to say.[38] Collaborative communication between employers and employees creates a supportive and safe environment in which to have these difficult conversations.

A three-step circular process for collaborative communication:

1. Empathy without promise

Sometimes we are concerned that being compassionate and empathetic to the employee's situation is not appropriate in the workplace. Or we worry that our understanding will mislead the employee to think that we will overlook performance issues and provide maximum flexibility. However, empathy is the key to connecting with the employee and the platform for collaborative problem solving to emerge.

> *"I think I've found that one of the most important qualities for me, as an HR person, was the ability to just sit and listen. The employees would sometimes come in and talk to me and they just want to talk."*
>
> **- HR Professional**

What is empathy without promise?

- Giving support through listening to both the employee's challenges and solutions in and out of the workplace.
- Inviting strengths and capacities into the conversation.
- Taking the perspective of the other person; putting yourself in his or her shoes
- Reflecting back challenges, needs, and capacities.
- Connecting capacities and needs to workplace performance.

Talking tips:

- "I'm not sure what solutions I might be able to offer, but I can listen to the challenges you are facing."
- "Tell me about your strengths and the resources that you draw on to manage your situation."
- "I see your capacity for multi-tasking in the work you do; now I know where it comes from."

2. Partner for solutions

Co-creating solutions is at the core of collaborative communication. Both you and the employed parent of a child/youth with disabilities are talented problem-solvers. Each of you 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 commitment to the strategy partnership.
- Make a list of all needs and all concerns—big and small.
- Prioritize needs and concerns.
- Identify what is currently working well.
- Ask about where success is experienced.
- Brainstorm about resources for needs and solutions for concerns.
- Identify level of feasibility and responsibility for the top 5.
- Decide responsibilities for each action and establish a timeline.

Talking tips:

- "Together we can find some way of improving the situation."
- "Let's talk about which job responsibilities and what part of your work day is least affected by your (exceptional) caregiving responsibilities."
- "How have you successfully problem-solved your 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 collaborative strategy plan. You will need to adjust the timeframe and specifics of the follow-up reflecting the particulars of the employee's position, the family situation, and the agreed upon strategies.

PROVIDING ORGANIZATIONAL SUPPORT

- Initiate contact in a timely manner to acknowledge the employee and reiterate commitment to problem solving.
- Provide resources and support in a timely manner.
- Build-in follow-up to re-evaluate in a specific timeframe.
- Make adjustments in the support plan as indicated and maintain connection.

Talking tips:

- "I appreciated the opportunity to problem solve with you, please keep me informed about how well the strategies are working and any concerns."
- "Just wanted to let you know that we agreed to meet next week to evaluate the plan—looking forward to hearing about your experiences." "Let's discuss what worked and what did not."

Your strategic plan for improving your organizations' Layers of Support

- Identify the current strengths in each layer of organizational support.
- List your top three priorities for development in each layer.
- Describe the first three steps in each priority and timeframe.
- What will you do immediately to increase support to employed parents of children/youth with disabilities?

Key Points

1. Providing support to your employees who are taking care of a child or youth with a disability is a multi-layered process that includes organizational policies and practices, workplace culture, and collaborative communication.

2. Communicating with employees about their family matters is personal and requires unique approaches and strategies.

PROVIDING ORGANIZATIONAL SUPPORT

Case Study: Introducing Susan

Susan joined the corporation 18 years ago, and moved to the Midwest to take a position as an auditor. Susan was known for her dedication to client service, spent long hours at work, and was promoted to increasingly responsible positions over the next ten years; she is now a Senior Associate. She is a single parent of a twelve year old son, Justin, who is diagnosed with bipolar disorder and ADHD. Justin was frequently suspended due to difficult behavior and Susan spent many hours at his school meeting with his teachers. She knew that her work was suffering, but Susan was still reluctant to disclose what her actual family situation was, fearing possible consequences for her career. Clients started to complain to Susan's manager that her work was not getting done in the timeframe that they expected. She was not meeting deadlines, and frequently seemed distracted or was absent from the office for hours at a time. When Susan talked with her manager Joe, she assured Joe that everything was all right, although she was having trouble adjusting to Justin's behavioral difficulties. When Susan's performance didn't improve after two months, Joe turned to Human Resources for help.

Questions for Discussion:

1. What are your organizational policies or practices that may apply to Susan's situation?

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2. What are aspects of your company's culture that may support Susan?

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3. What are aspects of your company's culture that may restrict Susan?

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4. What is the first thing you would say to Joe?

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5. What information do you need from Joe?

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6. What information do you need from Susan?

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7. What resources would you provide to Joe?

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8. *What do you suggest is Joe's first step of action?*

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9. *What talking points would you offer to Joe?*

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10. *How would you problem-solve with Susan? (Or how would you coach Joe in problem-solving with Susan?)*

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PROVIDING ORGANIZATIONAL SUPPORT

My Action Plan:

Organizational Policies and Practices

1. Current strengths:

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2. Top three priorities for development:

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    2a. Action steps for Priority 1:

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    2b. Action steps for Priority 2:

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    2c. Action steps for Priority 3:

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Workplace culture

1. Current strengths:

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Children/Youth with Disabilities: Their Parents are YOUR Employees

2. Top three priorities for development:

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    2a. Action steps for Priority 1:

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    2b. Action steps for Priority 2:

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    2c. Action steps for Priority 3:

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Collaborative Communication

1. Current strengths:

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2. Top three priorities for development:

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    2a. Action steps for Priority 1:

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PROVIDING ORGANIZATIONAL SUPPORT

2b. Action steps for Priority 2

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2c. Action steps for Priority 3

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Immediate actions for increasing support:

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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.

Children/Youth with Disabilities: Their Parents are YOUR Employees

GLOSSARY

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 flexibility 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://www.massgeneral.org/children/professionals/ccahp/empl_benefit_study/default.aspx)

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.
(http://www.mentalhealth.samhsa.gov/cmhs/default.asp)

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 finding 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)

RESOURCES

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/about/index.html)

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/)

RESOURCES

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.laborproject.org6)

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.nichcy.org)

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/go/action/stigma-watch)

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://www.ed.gov/about/offices/list/osers/osep/index.html)

Our-Kids-Adults

A site that provides information and resources on assistive technology, events, disability links, financial 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)

Sloan Work and Family Research 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://www.bc.edu/bc_org/avp/wfnetwork/index.html)

The Catalyst Center

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

Workplace Flexibility 2010

Workplace Flexibility 2010 is a campaign to support the development of a comprehensive national policy on workplace flexibility. By the year 2010, we hope to have helped develop consensus-based policy solutions that work for business and families.
(http://www.law.georgetown.edu/workplaceflexibility2010/)

Survey

Children/Youth with Disabilities: Their Parents are YOUR Employees

ABOUT THIS SURVEY
This survey can be used as a pre/post evaluation of knowledge and attitudes; or simply as an evaluation of one's learning after working through the modules.

SECTION 1. The following is a list of items related to activities that human resource professionals might be asked to do, or choose to complete within their employing organization. You may or may not have ever completed any task on the list. We are interested in knowing how confident you would feel in performing the task. There is no one best response to any of the items.

Part A: Using the scale provided, please indicate your **confidence level** for successfully performing each task by typing a number from 0 to 100 in the space provided.

0	10	20	30	40	50	60	70	80	90	100
VERY LITTLE CONFIDENCE					SOME CONFIDENCE				QUITE A LOT OF CONFIDENCE	

TASK	CONFIDENCE (0 - 100)
Calculate approximately how many employees in your organization have children of any age with disabilities.	
Describe to others in your workplace what types of conditions are included in the definition of "children with special health care needs."	
Discuss with others in your workplace important differences between typical dependent care responsibilities and exceptional dependent care responsibilities.	
Assist employees struggling with meeting both job responsibilities and caring for their children with disabilities.	
Refer to community resources that could help employees caring for children with disabilities.	
Protect your company from family responsibilities discrimination accusations and lawsuits.	
Decrease workplace stigmatization experienced by parents of children with disabilities.	
Articulate to senior management the business case for flexible work arrangements on behalf of employees with exceptional care responsibilities.	
Identify two or more federal policies directly relevant to employees with exceptional care responsibilities.	
Manage communication with an employee who discloses about a child's disability during a request for flexible work arrangements.	
Coach supervisors about communicating with employees caring for a child with a disability.	
Facilitate communication between employees caring for children with disabilities and their supervisors.	
Appropriately safeguard confidentiality of an employee caring for children with a disability.	

Section 2. In this section, please read each statement and select the letter that corresponds to the answer you believe to be correct by clicking on the dial beside it. There is only one correct answer for each question. Please make sure to select **one** answer for every question.

1. Approximately how many U.S. households have at least one child with a sensory, physical, or mental disability:

   a. 1 out of every 20 (5%)

   b. 1 out of every 10 (10%)

   c. 1 out of every 7 (14%)

   d. 1 out of every 5 (20%)

2. How many children and adolescents in the U.S. with mental health disorders actually receive treatment?

   a. 1 out of every 50 (2%)

   b. 1 out of every 20 (5%)

   c. 1 out of every 5 (20%)

   d. 1 out of every 2 (50%)

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

   a. Receive accommodations in the workplace

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

   c. Are not discriminated against because of their caregiving responsibilities

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

   e. None of the above

4. The most common reason that Family and Medical Leave Act (FMLA) leaves are not used by employed parents of children 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

5. Which of the following is a positive outcome from an employee's decision to **not** disclose his or her child's disability to employers?

   a. Avoid courtesty stigmatization

   b. Maintain a "normal-appearing" working life

   c. Avoid co-worker resentment

   d. Avoid performance scrutiny

   e. All of the above

6. Nationally, how many children are estimated to be receiving special education services?

   a. 250, 000

   b. 500, 000

   c. 2 million

   d. 7 million

7. 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. Exceptional care responsibilities

8. Compared to children with typical emotional development, children with mental health disorders are how many times more likely to be dismissed from a child care setting?

   a. 2 times as likely

   b. 5 times as likely

   c. 10 times as likely

   d. 20 times as likely

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

   a. Blaming the victim

   b. Courtesy stigmatization

   c. Labeling

   d. Negative attribution

   e. None of the above

10. Which of the following is **not** an example of Family Responsibilities Discrimination:

   a. An employer assuming a mother of a child with a disability wouldn't want a promotion that requires travel

   b. An employer not hiring an applicant because he is the father of a child with Downs syndrome

   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. None of the above

11. When is a parent of a child with a disability most likely to disclose his or her family situation at work?

   a. During the initial job interview

   b. 6 months into employment

   c. At a time of child crisis

   d. When getting first work assignment

   e. None of the above

12. The Individuals with Disabilities Education Act (IDEA) specifies that 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 crises during the school day

   c. Attend individualized education planning meetings

   d. Administer medication during the school day

   e. None of the above

13. In a recent national survey, how many parents of children with special health care needs reported quitting or reducing work hours because of exceptional dependent care responsibilities?

    a.   1 out of 20 (5%)

    b.   1 out of 10 (10%)

    c.   1 out of 4 (25%)

    d.   1 out of 3 (33%)

14. 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

15. 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 6 (17%)

    d.   1 in 5 (20%)

16. What does collaborative communication imply for HR managers?

    a.   Empathy without promise and partnering for solutions

    b.   Getting the employee's supervisor and coworkers involved in putting a plan together

    c.   Having the employee learn new communication strategies through the Employee Assistance Program (EAP)

    d.   Getting the employee to reveal every pertinent detail of her or his family situation

This training manual and workbook will teach you how to:

- *Calculate the number of parents of children/youth with disabilities working for your organization*

- *Increase the public perception of your organization as an "employer of choice"*

- *Employ effective communication strategies that will help you partner with employees to find win-win solutions*

- *Create a family-friendly workplace culture and reduce disability-related stigmatization within your organization*

- *Establish organizational policies that support employed parents of children/youth with disabilities and encourage employee loyalty to your company*

- *Balance the needs of employed parents of children/youth with disabilities against the business needs of your organization*

- *Negotiate reciprocity in exchange for flexible work arrangements (FWA)*

- *...And more*