

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

TRAINING SCRIPT

February 2015



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Note: An instructor's copy (with answer key) of The Parent Support Provider Knowledge Check from the accompanying guidebook is included at the end of this document.

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Slide 1: Balancing Work and Family Responsibilities: Parent Support Provider Training

Welcome to Balancing Work and Family Responsibilities: A training for parent support providers. These slides and this training have been prepared by Julie Rosenzweig, Lisa Stewart, Eileen Brennan and Claudia Sellmaier from Portland State University in Portland Oregon.

Slide 2: Acknowledgements

This training has been developed with funds and support from The Technical Assistance Network for Children’s Behavioral Health, and Pathways to Positive Futures Research and Training Center, National Federation of Families, SAMHSA, and NIDRR.

Slide 3: Balancing Work and Family Responsibilities

Slide 4: Agenda [Welcome participants provide time for introductions]

This training is accompanied by a training manual, which covers the content of these seven training modules. We recommend that you work through this training manual in addition to the training itself. Each module in the training manual includes the most salient information with key points at the end and has a notes and reflection page. We invite you to use this page to write down what has been most important for you, any additional questions, and your personal reflections. The training manual also includes a glossary with important terminology used in the training and references and resources for further information. This training will take two hours and the focus will be on knowledge and skill building. At the end of the training you should walk away with tools to support parents in dealing with their employment issues. Please feel free to raise questions as they come up during this training session.

Slide 5: Balancing Work and Family Responsibilities

As parent support providers you have walked in the shoes of employed parents of children with disabilities and have first-hand insights on how to best support

them. In addition, this training might be useful for you personally when trying to balance work and family responsibilities.

Slide 6: Learning objectives

In order to build knowledge and skills the training will cover the following learning objectives. Please take your time to read through these four objectives.

Module 1: Definitions and Prevalence

Slide 7: Definitions and Prevalence [Survey Q 1]

First we want to cover some terms and categories relevant for this training.

- People use different terms such as children with disabilities, children with special needs, or children with special health care needs.
- In part, terminology is developed from and associated with different U. S. federal policies.
- For example, the **Americans with Disabilities Act of 1990 (ADA)** uses the term “disability” when referring to a child, youth or adult with “a physical or mental impairment that substantially limits one or more major life activities” or who has a “record of” or is “regarded as” having such an impairment.
- In contrast, the concept of children/youth with special needs was developed in relationship to **special education services** in public schools and stems from a particular piece of legislation that governs education rights for children and youth with disabilities within the education system. A child/youth is considered to have a “special need” if they have been evaluated and found to have one or more of a limited list of disabilities specified in the **Individuals with Disabilities Education Act (IDEA)**. **[Knowledge check 1]**
- Children/youth with special health care needs include children/youth 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. This definition doesn’t come out of any specific legislation per se – rather it is used as a definition in one of the major health surveys called the **National Survey of Children with Special Health Care Needs (NS-CSHCN)** conducted by the U. S. Department of Health and Human Services.

- No matter what terminology you use it is important to use person first language. An example of person first language: “Children/youth with disabilities (or a specific (or a specific disability) and not “disabled children”.
[Knowledge check 2]
- We can also distinguish between various categories of disabilities, which refer to the different areas of functioning affected by the disability such as:
 - **Physical disabilities.** Diabetes, asthma, and muscular dystrophy.
 - **Mental health, emotional, or behavioral disabilities.** Depression, anxiety, and attention-deficit/hyperactivity disorders
 - **Developmental disabilities:** autism spectrum disorder, Down syndrome, and learning disabilities.
- Another thing that we also need to be aware of is that while there are a number of categories of disabilities with different levels of visibility, children can also experience multiple disabilities that may or may not be related to the primary disability.
- A last distinction that needs to be discussed is that between what constitutes a chronic vs. acute health condition when talking about 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.
 - A chronic condition can also have acute episodes, that can be anticipated but the onset cannot be predicted.

So, now that we have a little bit of a better picture of what we mean by “disabilities” let’s talk a bit about the rate of disabilities and its impact on families, and workplaces. When we do this we have to keep in mind that these numbers are affected by the definition used for data collections. For example, the rate of children with disability can differ from the rate of children with special health care needs.

Slide 8: Prevalence of Children with Special Needs

When we look at the 2009-10 **National Survey of Children with Special Health Care Needs** we find that about 15 % of children/youth under 18 years of age, or approximately 11 million children/youth have special health care needs.

This represents 23% of households with one or more children/youth with special health care needs. Compare this to the number of households caring for at least one child with disability a narrower definition that special health care needs which has been estimated to be 9.2% in 2000 by the U.S. Census Bureau.

Slide 9: Public Health Crisis

As if these numbers weren't alarming -- research has shown that many of these children with mental health challenges do not receive any help. In fact, "a public health crisis" was exactly what the Surgeon General called the state of children's mental health care in 2001 when it was found that only about 1 in 5 children/youth with mental health needs receive services.

And in the years that have followed not a lot has changed.

Slide 10: Employees with Children with Disabilities [Survey Q 2]

But the numbers of children with disabilities or special health care needs can't really tell us how many employees in any given company may have a child with a disability.

In order to estimate this we need to look at the estimates suggested by the **Center for Child and Adolescent Health Care Policy**.

They used both the estimated national rate of children/youth with disabilities (20-21%) and the employment rate of among parents of children/youth age 18 and under (43%) and from these estimate that ...

Almost 9% of employees who are parents of children/youth with special health care needs/disabilities. [Survey Q 2]

As we will see in the following slides, this number is significant given the particular set of challenges faced by parents of children with disabilities when they try to meet both their job responsibilities and their child or youth's care needs.

But before we do this – let's take a moment to think about what we've learned so far and what we can do with this learning.

Slide 11: [Read] Checkpoint. What can I do?

Slide 12-15: Knowledge check and knowledge debrief

Please select the correct answer

Module 2: Exceptional Caregiving Responsibilities

Slide 16: Exceptional Caregiving Responsibilities

A growing body of research has found that employed parents' **work-life integration** experience depends on finding the right set of resources and supports in the home, in the workplace, and in the community that assist them in effectively meeting both the needs of their family and their work.

In the following section I'm going to try and describe to you how the care needs of children and youth with disabilities are very different from those of children with typical development.

So what do we mean by ECR? The concept initially received attention because of the increasing number of employees caring for elderly parents but similarities

were found between some of the dimensions found within eldercare and the care of spouses, children and youth with disabilities – particularly in terms of how the care needs interacted with the workplace.

The term exceptional caregiving responsibility encompasses the physical, psychological, emotional, familial, time, and financial demands of the care of the relative with the disability on these groups of employed caregivers. [Survey Q 9]

Therefore, the tasks and activities related to exceptional care responsibilities are more complex and intensive than typical caregiving.

They also require the coordination with many different services and resources. For example, parents need to organize children's/youth's physical or mental health treatments, participate in school meeting for IEP planning, arrange transportation to and from services, and respond to health crises.

These tasks are physically, emotionally, and financially draining, they require a lot of time and can disrupt family and social relations. This emotional, physical, financial, and social toll of caring for a person with special health care needs is called caregiver strain [Survey Q 3]. Without sufficient support, caregiver strain impacts the health and well-being of the parent.

Slide 17-18: How are exceptional care responsibilities different?

This slide shows you a list of responsibilities that are different for parents with exceptional care and typical care. As you can see there are differences in:

- Predictability of need
- Duration and intensity
- Level and frequency of crises
- Coordination of care resources
- Type of tasks performed and
- Life-style adjustment asked from parents and family members [Knowledge check 3]

Knowing that these differences exist between TCR and ECR – you may want to know exactly what are the Exceptional Caregiving Responsibilities of the parents you work with.

Module 3: Employee Challenges

Slide 19: Employee work-life integration challenges

First, we need to understand that because of the complex and unpredictable nature of disability-related care the likelihood of work interruptions can be greater for these employed parents compared to those with typical caregiving responsibilities.

It is also a result of an absence of supports within the community to assist parents in managing their child or youth's care needs.

When we talk about challenges what we are really talking about is the parent of the child with the disability's ability to achieve work-life integration.

A term you may or may not be familiar with...

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.

Instead of focusing solely on *family* concerns of parents, work-life integration acknowledges that we all have lives outside of the workplace; and that there are multiple domains in which we participate and have commitments.

Further, the concept acknowledges that balancing time and activities across different life domains is not always possible or desirable; instead, the concept acknowledges that what is needed is the flexibility to participate in all domains as necessary to enhance the well-being of self, family, and the community.

Challenge #1: Child care

Work-life integration can be especially difficult for parents of children with disability because of child care issues. While finding child care that is reliable,

flexible, and affordable is a universal concern for any employed parent, it is even more so for families of children and youth with disabilities.

They need specially trained child care providers or inclusive child care centers but these are uncommon and frequently unaffordable. While relatives or neighbors are an option for parents of children with typical development – they are not an option for employed parents of a child with a disability because of the complexity and intensity of the care needs.

Parents of children/youth with mental health disabilities are also more likely to be asked to remove their child/youth from care; and have higher expulsion rates from pre-kindergarten. [Survey Q 4]

Other research finds that when parents do find care and it's affordable, they often report that it is of lower quality, and they express lower satisfaction with it.

Because the care is not there or it's not a viable option due to its expense or quality the work-life strategy used by parents of a child with a disability usually involves "**Tag-team parenting**" i.e., scheduling work shifts that do not overlap, so that one parent is always at home with the child. Bottom line, without child care a parent cannot work. Knowledge check 4

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.

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.

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).

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 a crisis. The call may require that the parent leave work immediately and take the child/youth to a health care provider.

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/promotions that involve long hours or travel.

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.

Challenge #4: Experiencing Courtesy Stigmatization

Stigmatization, including prejudice, stereotyping and discrimination, is commonly experienced by persons with disabilities and their families. 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.**

Courtesy stigmatization is especially 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. [Survey Q 5]

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*.

At the same time, 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.

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.

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 multi-faceted and multi-layered.

Decisions about revealing or concealing are weighted within the context of prior experiences of stigmatization and courtesy stigmatization that have affected employees and their families.

Parents may be reluctant to disclose, fearing additional stigmatization, possibly including career penalties or family caregiver discrimination. [Survey Q 8]

Even without explicitly disclosing, family concerns can spill into the workplace through interruptions from the school or child care, unexpected departures in response to a crisis, 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.

Slide 20: Work-family challenges

Just to put these challenges into perspective: Almost 24% of families caring for a child with special health care needs report that at least one member had to quit employment altogether or at least reduce work hours because of exceptional care responsibilities.

Slide 21: Child care challenges

And children with mental health problems are 20 times more likely to be dismissed from child care.

Slide 22: Employed parents' focus group

Please take some time to read the statements of parents trying to integrate work and family and the challenges they experience on their paths. Based on what we've learned so far, are there any questions?

Slides 23-27: Knowledge check 3 & 4, and Checkpoint--What Can I Do?

[Have participants indicate their answers, show correct answers. Talk through actions points]

Module 4: Key Policies

Slide 28: Key policies and legal issues

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 their work day to manage their care responsibilities.

The **Family and Medical Leave Act** and the **Americans with Disabilities Act** 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 Family and Medical Leave Act (FMLA) was established to assist families in balancing the demands of work with those of their family.

The 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.

To be considered as eligible an employee must:

Be employed continuously for 12 months by the employer and who has worked for at least 1200 hours during the previous 12 month period.

Have family circumstances that require that the employee be absent from work due to a family related medical reason.

Can include:

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.

Under the FMLA, 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. [Knowledge check 5]

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**. [Survey Q 7]

The Association Provision of the Americans with Disabilities Act

The Americans with Disabilities Act (ADA) is a federal civil-rights statute protecting the rights of people with disabilities.

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 Americans with Disabilities Act (ADA) protects caregivers against discrimination at work based on their association with persons who have a disability. [Survey Q 6]

How the ADA may support persons with disabilities in the workplace:
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.

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.

The Individuals with Disabilities Education Act

The Individuals with Disabilities Education Act **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.

The Individuals with Disabilities Education Act (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. Children under the age of 2 are served by Part C while children/youth 3–21 are served by Part B of the IDEA.

How the IDEA may support employed parents of children/youth with disabilities:

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

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

Parents have the right to be involved in the development and review of Individualized Education Plans. [Survey Q 11]

Family Responsibilities Discrimination

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

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.

According to a report by the Center for Work Life 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.

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”. [Survey Q 10]

Slides 29, 30: Knowledge check

Slide 31: Parent story: Charlie

Read Charlie's story aloud, or have group member read it. Break out in smaller groups and work through Charlie's story. What major work-life integration challenges does Charlie face? What are some of the federal policies that might apply when talking with Charlie about his request? Briefly share your ideas or any question with the group after 10 minutes.

Parent Story: Charlie

Thanks so much for seeing me on such short notice. I've been working in the Atlanta office of my company as an Administrative Assistant since I graduated from business college ten years ago. In all that time the job has been a great fit. My boss Janine and I are in a really good rhythm. But things haven't been going so well in the past year. I wanted to talk with you today to see if I can figure out how to talk to my employer about adjusting my work schedule, so that I can take care of some family issues.

This is hard for me to talk about. My wife and I have two daughters: Anna, who's 8 years old and Maria, who just turned 5. Anna is doing great. She's healthy, loves school, and is a real athlete. But our little Maria has always been sickly, and she's been having some serious asthma attacks lately. We haven't been able to find a preschool that's willing to enroll Maria, because of her health problems. We've been paying one of our neighbors to take care of her during the day. Well, our neighbor keeps calling me at work, and sometimes I have to leave early to take Maria to the doctor. My wife's an operating room nurse, and she spends most of the day in surgery, so I'm really the only one who can respond.

My wife and I have talked this over. It hasn't been an easy decision, but what seems to make the most sense is for me to take some time off to get Maria's health more stable, and then come back to work part-time until she goes to public school. I know it'll be hard for my boss to manage without me, but we're really at the end of our rope.

Can you help me to figure out how I should approach this at work?

Module 6: EMPLOYMENT BASED STRATEGIES AND SUPPORTS

Slide 32: Employment based Strategies and Supports

This section will cover strategies that can be used by employed parents with ECR in their workplace to access and create more flexibility. We will introduce five different strategies:

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

Strategy 1: A family-friendly workplace is a workplace that has policies and practices that are specifically designed to increase employees' work-life integration.

Survey Question 13. This means that:

- Organization has:
 - Generous menu of benefits, policies and programs
 - Positive workplace culture and climate
 - Positive workplace relationships
 - Work processes, systems and structures and practices
- Parents, for example, can research a company prior to applying for a job to determine the extent to which the company is family-friendly or they can strategically ask questions during the interview to determine the extent of policies, culture, climate and relationships.

Strategy #2: Learn about Rights and Relevant Benefits

- The previous module has introduced certain policies relevant for employed parents with ECR. Additionally, health insurance benefits are especially critical
 - 60% of children/youth with special needs are covered under their parents employer sponsored health benefits
- Parents also use networking with other parents or the internet to learn more about their rights and benefits.
- IDEA – plays a huge part in the lives of parents – they will be advocating in the schools – need time away from work to attend to this
- Surge of FRD cases demonstrates that parents are beginning to understand their legal rights and want to sustain job security and flexibility

Strategy #3: Structure work to maximize flexibility Survey Question 14

- Flexibility or flexible work arrangements allow the employee to have a level of control over when and where work occurs
- Essentially FWA = alternative options for completing work outside of the traditional workday schedules.
- Two ways to arrange flexibility:
 - Formal FWA – written request and administrative approval
 - Informal FWA – arrangement with supervisor or negotiated with a co-worker

In the next few slides we'll explore how employees use these strategies, and then go on to strategies 4 & 5

Slide 33: Focus group findings

Please take the time to read the following focus group statements in which parents talk about these strategies and how they use them to increase their workplace flexibility.

Slide 34: Strategy #4: Make a Disclosure Plan

- Parents will often develop a strategy of “if, when, how” to disclose to others about their child’s disability status
 - Strategy is shaped by past reactions and experiences

General disclosure strategy is brought into the workplace and adapted to the organization

- Parents consider a number of workplace factors when deciding when, what and how to disclose
 - Type of job/position they hold
 - Workplace culture
 - Availability and accessibility of formal support
 - Concerns about privacy and confidentiality

Let’s talk a bit more about the dimensions of the **Disclosure Decision Process**.

Employee reflects on the pros/cons of the disclosure, the target audience and the type of information they will need to disclose

The **timing for disclosure**. There are different options for example never, during the interview, when the job is secured, when a positive work pattern is established, response to a non-crisis family matter, when a crisis occurs with child. And we learned from parents that **it is when they are in crisis!**

Target audience (who to disclose to):

Again a variety of options: No one, employer, immediate supervisor, higher level manager, one or more coworkers, HR personnel, EAP staff

The same is true for **the type of information** (what to disclose)

Disability, chronic illness, mental health disorder, specific diagnosis, type of treatment needed, impact on self and family

Above all – employees consider issues of confidentiality and privacy and do not assume that the information will be held in confidence.

Utmost question in an employee’s mind...

As you can see from this table, both disclosure and concealment can come with different costs and benefits. Therefore,

- Decision to disclose is personal and individual—ultimately it’s up to the individual to decide whether to tell or not
- Just as important to understand that the disclosure is most often being made out of necessity to avoid losing one’s job
- Disclosure of one’s child’s disability status is a strategy that may be used by the employed parent to gain:
 - **Interpersonal support**
 - **Organizational support**
- Personal and social benefits can also result
 - **Receive emotional support**
 - **Reduce stigma**
 - **Educate others**
 - **Allow for greater access to benefits**

- Important to understand that there is no disclosure without risk
 - **Personal information can be misperceived**
 - **Stigmatization**
 - **Discrimination**

These can lead to poor performance reports, job insecurity and job loss.

Strategy # 5: Negotiate Reciprocity

It is important to keep in mind that these strategies are based on **Reciprocity** – part of the flexibility equation regardless of whether it's implicitly or explicitly stated. And it is a **Relational process** – mutual exchange between employee/supervisor/coworkers that results in win-win for all. For example,

our HR research participants have told us that when they give people flexibility and help them work out their children's problems, at work they have loyal workers who give 150% while they are at work.

Module 6: Understanding HR Professionals' support dilemma

Slide 35: Understanding HR Professionals' Support Dilemmas

There are three common dilemmas

Dilemma 1: Needs of the employed parent of child/youth with disabilities vs. Business goals

- Despite a desire to be supportive and helpful to the employed parent needing more flexibility, not all positions within a business lend themselves to FWAs.
- Equitable treatment of employees is a core issue considered when an employee requests flexibility.
 - Questions of equity and favoritism
- Well-functioning co-worker relationships are critical to overall productivity. Perceptions of preferential treatment can be detrimental to the workgroup.

Dilemma 2: Knowing too much versus not knowing enough

HR professionals have real concerns about knowing too much personal information and confidentiality issues when responding to disclosure.

Recent national survey of HR professionals found that:

- 77% indicated that disclosure of personal information helps in obtaining flexibility
- 9% of HR professionals who responded indicated that disclosure was discouraged within their organization due to privacy/legal reasons
- Need to balance having the knowledge of why flexibility request is needed
- With not wanting this information for fear of confidentiality breaches and consequences to the organization

Dilemma 3: Minimizing Potential Litigation with maximizing flexibility

HR professionals base their decisions on the number of issues relating to the nature of the parents' requests; organizational needs as well as federal and state laws.

Slide 36: HR professionals' focus group

The quotes on this slide illustrate the support dilemmas faced by HR professionals. Please take your time to read them.

Slide 37: Checkpoint

From what we have learned in the previous two modules you as a parent support provider can work with parents who are seeking employment on identifying a family-friendly employer. If they are already employed you can discuss ways to

obtain flexibility using either formal or informal options. This discussion should also include a consideration of disclosure and reciprocity.

It is also useful to review with parents the roles and responsibilities of HR professional and what support dilemmas they may face. This will help to develop specific strategies to address these dilemmas. The last module will talk about these tools and strategies in more detail.

Module 7: Accessing Workplace Support

Slide 38-41: Accessing Workplace Support

Now that we have talked about the nature of exceptional care responsibilities, the workplace needs of employed parents of children with special health care needs and the support dilemmas faced by HR professionals we want to turn to three key strategies for accessing workplace support. You can work on these strategies with parents so that they can effectively negotiate their workplace and family needs.

Survey Question 15 Advance slides 39-40 to indicate the layers of work support.

- Identifying resources for support
- Disclosure planning
- Communication strategies

Slide 42-43: Inventory of supportive resources

The next two slides give you some ideas of supportive resources that you can explore with employed parents. Do they already have flexible work arrangements or do they know of other employees who use flexible work arrangements? What are the leave and time-off policies of the company? How can they find out about those policies? Is there on-site child care or do they have access to child care subsidies? What are their health benefits? Can parents identify any people in their company that might be supportive and helpful? Are there affinity groups? Other important questions can cover the option to make and take personal phone calls, or to access disability information on company internet.

Do you have any additional ideas?

Slide 44: Disclosure planning

We already talked a little bit about disclosure planning and it will be important to discuss the when, with whom, and what type of information with parents. They need to consider the potential benefits and costs and weigh their options. Some conversation starters for you might be:

- Could you tell me your experiences when sharing information about your child’s disability?
- What are your thoughts, feelings about sharing information with others at your workplace?
- Who, if anyone, have you told that your child has (condition)?

Can you think of other questions to introduce the issue of disclosure planning?

Slide 45: Collaborative communication

Communication about family matters is:

Personal

Involves sharing of information that is personal and sensitive. 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.

Collaborative communication between parents caring for a child/youth with a disability and their co-workers, supervisors, and HR professionals is vital to accessing and receiving support.

Three skills can enhance this often difficult communication:

- Speak to organizational concerns. Think with parents about what potential concerns might be raised by HR professionals or supervisors. Module 6 about support dilemmas might be useful in thinking through possible concerns. Keep in mind that successful access to workplace support is based on reciprocity.
- Partner for solutions. Collaboration is key because it will strengthen the commitment to the solution for all parties involved. The goal is to co-create solutions because both parents and employers bring valuable ideas to the solution table. Can parents think of previous situations where they found a solution together? Parents should provide ideas for solutions and show that they are interested in partnering for solutions. Discuss how parents could envision this partnership maybe through brainstorming with supervisor and coworkers? Can you think with parents about examples of successful work-family integration in their work history that they can use to illustrate the feasibility of workplace supports?
- And finally, re-connect, re-evaluate, and re-commit. It is crucial that parents think about a timeline for implementation and evaluation. They can offer to meet in two weeks to review the strategies and see if it actually works for all parties. Keep communication open and adjust the solution if indicated.

Slide 46: Parent Story Susan--Read or distribute the scenario

We would like to finish this training by working through another parent story. Susan has been with her employer for 8 years and she is a FT accountant. Her supervisor, Joe, has referred her to HR because she has missed deadlines and Joe had received negative phone calls from clients. Susan has been divorced recently and is now a single parent of a son with mental health and substance abuse difficulties. How can you help Susan to prepare for a conversation with Joe with the goal of making her work-life situation more manageable? Please break out in small groups and work on the three questions provided on this slide:

- *What would you suggest Susan discuss with Joe?*
- *How will you help her prepare before she meets with HR?*
- *How can developing the three skill areas discussed in Module 7 help Susan get the workplace supports she needs?*

We will get back together after 15 minutes to share our ideas.

Parent Story: Susan

You know, this is the first time I've actually talked to someone about my problems at work. This is all very embarrassing for me, especially since my supervisor Joe has referred me to HR. I take a lot of pride in the work I do and in the fact that I've recently been promoted after working at my company for 8 years. I know – my work hasn't been quite as solid as it used to be. I know Joe's worried that I've missed some deadlines and that he's had some calls from the client.

What we say here is going to be confidential, right? Okay, two years ago, my life started to fall apart. My son Justin started hanging out with a rough crowd when he went into middle school. He started skipping school and smoking marijuana every day. Recently he's been diagnosed with bipolar disorder and ADHD and he needs to take medication. My husband Steve found it all overwhelming – the fights over homework, medication, drug use, and Scott's friends. Steve re-connected with his old girlfriend over the internet. Last year he divorced me to start a new life with her. Steve agreed to take care of Scott during the summers, but at this point I don't think I really trust him.

I've told Joe that I'm a single parent now and that I'm having problems with Justin, but I haven't told anybody on my team the details. I don't want them to think that I'm a bad parent or that I can't do my job. I'm trying to live a "normal life" at work, but the school keeps calling, and it's a lot to deal with by myself. I've been doing my best to meet my professional obligations, but I admit I'm overwhelmed. Since I seem to be out of ideas, I'd love to hear any suggestions you might have.

Slide 47: Questions

Wrap up, ask participants if there are any questions about the material provided in this session.

Slide 48: Thank you

[Thanks for your time and attention we hope that this training has provided you with the information and tools so that you are better able to support the needs of employed parents of children with disabilities]

Parent Support Provider Knowledge Check

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

(Correct answers highlighted below.)

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

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

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

4. For parents of children with disabilities, finding and maintaining child care is:
 - a) No harder than for parents of children developing typically.
 - b) Problematic since they have to select child care arrangements from many suitable options.
 - c) Difficult since their children are often expelled from child care settings.
 - d) None of the above.

5. When parents experience prejudice, stereotyping, and discrimination due to raising a child or youth with a disability, this is called:
 - a) Blaming the victim.
 - b) Courtesy stigmatization.
 - c) Flexibility stigma.
 - d) Negative attribution.

6. The Americans with Disabilities Act (ADA) mandates that parents of children with disabilities:
 - a) Are not discriminated against because of their caregiving responsibilities.
 - b) Receive accommodations in the workplace.
 - c) Are not dismissed due to poor performance at their jobs.
 - d) Are allowed to leave work for appointments involving their children.
 - e) None of the above.

7. The most common reason that Family and Medical Leave Act (FMLA) leaves are not used by employed parents of children or youth with special health care needs is because these employees:
 - a) Do not have suitable documentation for their child's health issue.
 - b) Cannot afford to lose the income since FMLA is unpaid in their state.
 - c) Believe supervisors will not let them take it.
 - d) Take sick days.
 - e) None of the above.

8. Which of the following is a positive outcome from an employee's decision to **not** disclose his or her child/youth's disability to employers?
- a) Avoid courtesy stigmatization.
 - b) Maintain a "normal-appearing" working life.
 - c) Avoid co-worker resentment.
 - d) Avoid performance scrutiny.
 - e) All of the above.
9. Which of the following is the term used to describe disability-care?
- a) Intensive dependent-care responsibilities.
 - b) Home-based disability care.
 - c) Specialized family care.
 - d) Special needs caregiving.
 - e) Exceptional care responsibilities.
10. Which of the following is an example of Family Responsibilities Discrimination:
- a) A mother of a child with a disability who refuses a promotion that requires travel.
 - b) An employer not hiring a father of a child with autism and who doesn't meet minimum job requirements.
 - c) The unwilling transfer of an employee to a less demanding position after giving birth to a child with a disability.
 - d) Not providing additional time off after an employee with a sick child has exhausted all sick leave or family leave.
 - e) All of the above.
11. The Individuals with Disabilities Education Act (IDEA) specifies 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 crisis during the school day.
 - c) Attend individualized education planning meetings.
 - d) Administer medication during the school day.
 - e) None of the above.

12. Human resource professionals

- a) Are not responsible for granting formal flexible work arrangements.
- b) Need to balance the needs of the employees against their responsibilities to the organization that employs them.
- c) Need to know all of the details about employees' family responsibilities.
- d) Are not concerned with possible legal issues.

13. Family friendly workplaces

- a) Are focused on the dependent care responsibilities of mothers.
- b) Always have onsite child care provided.
- c) Never require formal flexible work arrangements.
- d) Have benefits, policies and programs that make it easier for parents to meet both work and family responsibilities.

14. Flexible work arrangements:

- a) Refer to employers' right to change their workers' schedules to meet their business needs.
- b) Are only available through informal agreements.
- c) Can involve working from home or on a schedule requested by employees.
- d) Always require a written request.

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

- a) Working with them to find and access resources at their place of employment.
- b) Thinking through the ways in which they can address organizational concerns when talking to employers.
- c) Planning ways to partner with their supervisors to find win-win solutions.
- d) Encouraging them to keep communication lines open with supervisors.
- e) All of the above.