

The Impact of Children with Special Needs on Employment

Upon completion of this course, you will be able to:

- Define special needs in relation to obtaining and maintaining employment.
 - Identify issues related to W-2 participation when there is a special needs child in the family.
 - Identify resources to address employment needs.
 - Identify and assign appropriate W-2 activities to develop employment skills.
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For civil rights questions call (608) 422-6889 or the Wisconsin Relay Service (WRS) – 711.

W-2 Contact Information

Questions regarding this training material should be directed via your local agency process to the Partner Training Team,

Email: PTTTrainingSupp@wisconsin.gov

A contact person is available to answer e-mailed questions related to this training material, assist you in completing any activity that you are having difficulty with, and/or provide explanation of anything else about this training material.

Questions regarding W-2 production cases and systems should be directed via your local agency process to the W-2 Help Desk at:

Email: DCFW2CARESHD@wisconsin.gov

Telephone: (608) 422-7900.

W-2 Policy questions should be directed to your Regional Office staff.

Introduction

Defining Special Needs

The W-2 Policy Manual does not specifically define children with special needs. Form DCF-F-DWSP10786 (available in the Forms section of the DCF website: <http://dwd.wisconsin.gov/dcf/forms/viewsort/default.asp?ID=NEW>) documents disability related special needs of a family member. There is a definition of Severely Disabled Child in chapter 14.1 of the W-2 Manual, but it is a definition that is used specifically to determine Two Parent Participation Requirements. Special Needs are much broader than how we may define Severely Disabled Child.

Children with special needs may have physical disabilities, developmental delays, chronic health conditions, behavioral problems, or sensory disabilities.

W-2 Policy Manual: <http://dcf.wisconsin.gov/w2/manual/default.htm>

Think about the families that you work with. Do any of the families have children with special needs? If so what are those special needs?

What unique challenges does a parent of a child with special needs face?

Your Thoughts - Record your thoughts on the following questions.

Think about:

- your typical responses related to W-2 in situations in which there is a child with special needs in the family,
- the types of W-2 placement determinations for parents, and
- the types of W-2 activities you assign.

What are your initial reactions related to W-2 placement and participation requirements for parents who have children with special needs?

How do you approach the initial assessment process?

What is your current philosophy for participation requirements for parents with children with special needs?

The issue of sufficient resources to support not only the needs of the child, but also those of the family are of paramount importance in determining whether a family stays stable enough to engage in employment activities.

Video Note Taking

Employment Issues:

Resources Issues:

What resources might LuAnn have used to meet her child care needs and the needs of her family, along with her need to be employed?

Assessment

What methods do you use to obtain information related to the child's special needs and its impact on the family and on the parent's employability?

Assessment of the parent's employability in light of the family situation as well as the needs of the child is necessary. The FEP may utilize many types of informal assessment, but may need additional assistance with more formalized methods.

Barrier Screening Tool

Family Needs Screen (W-2 Manual 5.4.1.2)

The Family Needs Screen is a part of the Barrier Screening Tool (BST) that allows workers to collect information related to family members with special needs. There are two parts to this section: Section I Family Needs and Section II (Child or Adult). Section I is a mandatory part of the BST. The worker must either complete the five questions or indicate that the individual has declined to respond.

Section II is an optional set of questions that may be used to gather more comprehensive information about a family member with special needs. There is no requirement to complete any of the questions. Section II is broken down into one set of questions for children and another set of questions for adults with special needs. Section II was designed to allow the worker to bypass any questions that are not relevant to the special need(s) being discussed. After a question in Section II has been answered, a checkmark appears next to it. This allows the worker to more efficiently review information that was entered on a previous date.

The screenshot displays the 'Barriers Screening Application' interface. On the left is a navigation menu with categories like 'Functional Screen', 'Domestic Abuse', 'Screen 2', 'Family Needs', and 'Summary'. The main content area is titled 'Department of Children & Families' and 'Section I - Family Needs' for user 'Jones, Linda (PIN #201672260)'. It features an 'Interviewer Narrative' field, a 'Decline Section I' button, and three numbered questions with radio button options for 'Yes', 'No', and 'Declined To Respond'. Each question includes a 'Summary' section and a 'Current Size: 0' indicator.

Record Keeping Book

Completing a daily journal that tracks and organizes the child's medical, nutritional and daily needs may assist in the approval of child health care programs. In addition, it can assist the FEP in identifying exactly what kinds of demands are on the parent each day in caring for his or her child. The information gathered in a daily journal can aid the FEP in evaluating employability, determining W-2 placement and assigning appropriate W-2 activities. The Wisconsin Council on Developmental Disabilities has created a tool, called the "*Record-Keeping Book*" (see Appendix I), that parents may use to track issues surrounding their child's health care needs. The completed tool then can be used to assist in determination of W-2 placement and related activities.

Additional Screening Tool

In Appendix II of this document, you will find the “Screening Tool to Determine Family Needs of Children With Disabilities, Developmental Delays and/or Chronic Health Care Conditions.” This document was created for W-2 workers to assist in identifying the needs of families with children who have special health care issues. It was part of the “W-2 Case Management Resource Guide” released by DWD shortly after implementation of the W-2 program.

Part A: General Background

To determine if a family has a child with disabilities, developmental delays, and/or chronic health care conditions that require special consideration for job placement, ask the questions in Part A of all parents screened. The questionnaire is structured so that responses may be gathered orally, or in writing.

Part B: Special Health Needs

Part B questions involve the type and frequency of special services and medical interventions. Questions here also explore the level of parental involvement in medical care.

Part C: Daily Living Needs

At this point in the screening, if a parent has expressed significant health care and daily living needs, you should obtain additional information from contacts identified in Part A. This may require a signed release from the parent. The contact person may be able to provide more information about the care needed and the schedule requirements so that an ideal work schedule and child care can be arranged.

Part D: Child Care Needs

These questions are designed to determine if there are barriers to obtaining child care. Barriers may take the form of special health needs, like required nursing care, or a vulnerable immune system; or they may be supervision needs beyond that normally provided in a child care facility.

How could these screening and assessment tools be useful to you in determining the extent of the special need(s) impacting the family and employment?

Key Actions

Document Special Health Care Needs

W-2 workers must verify the incapacitation or special health care needs of a child through third party sources. The worker may consider statements from medical professionals such as general practitioners, the Family Support Program, the Birth to Three Program, school professionals and other experts for children with special health care needs.

The W-2 worker must determine whether appropriate and adequate child care is available to allow the participant to engage in activities outside of the home. The Americans with Disabilities Act (ADA) requires that all day treatment or care facilities accommodate a child or elderly person. However, where reasonable accommodation cannot be made or care is not available, lack of adequate child care is a good cause reason for not assigning activities outside the home (see W-2 Policy Manual 11.2.2.1).

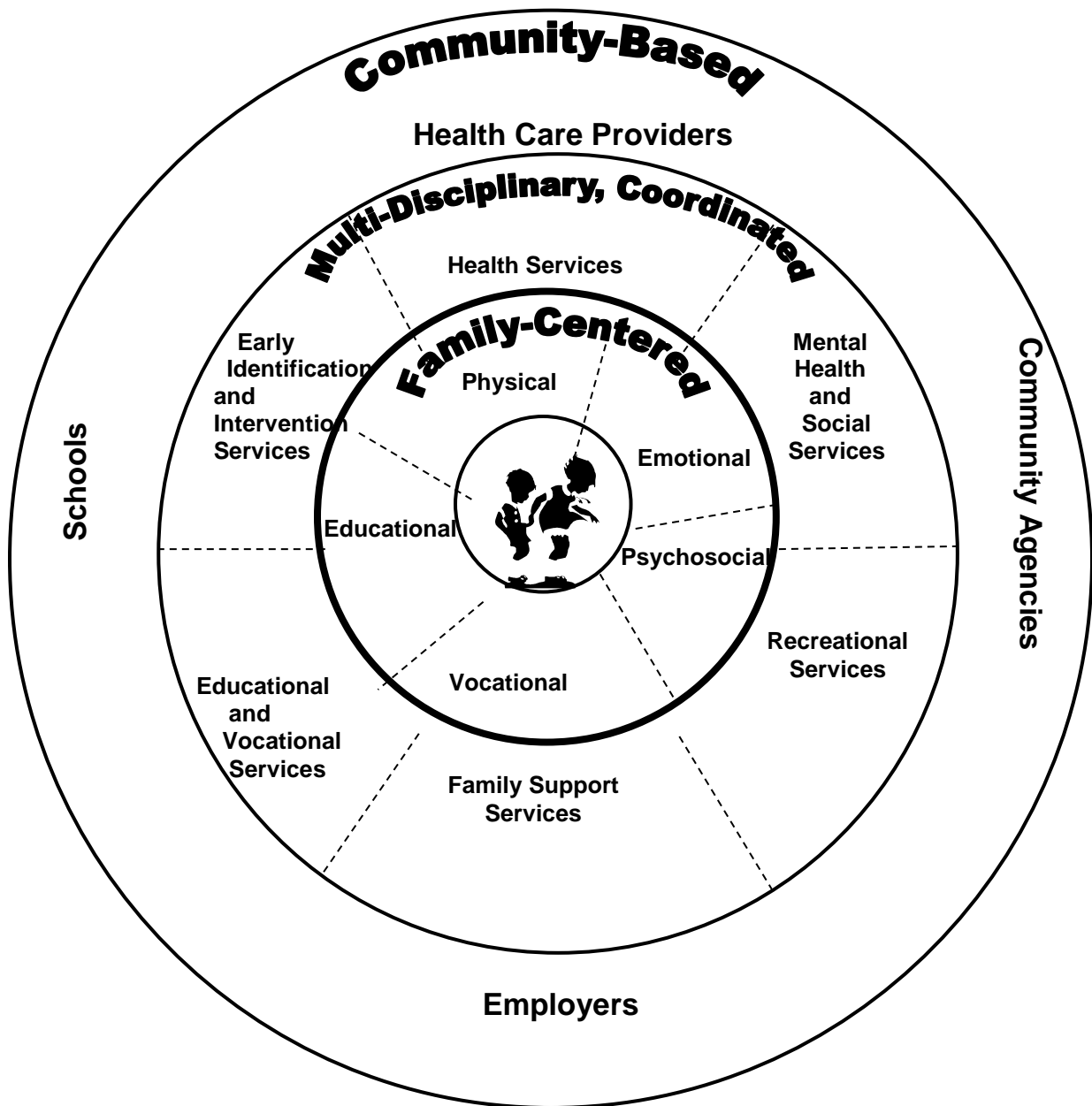
Form DCF-F-DWSP10786 (located in the Forms section of the DCF website: <http://dwd.wisconsin.gov/dcf/forms/viewsort/default.asp?ID=NEW>) is used for documentation of the Need to Care for a Disabled Family Member.

Schedule Regular Reassessment Appointments

It is imperative for appropriate case management of these families that evaluation and reassessment occur at intervals dictated by the child's condition and the parent's ability to maintain work activity. Some families may need weekly assessment due to the severity or volatility of their child's condition, and others may need monthly, quarterly or bi-annual reviews. Successful determination of an appropriate schedule of reassessment will rely heavily on thorough documentation of the child's condition. The parents and service providers involved with the child will be valuable assets in this determination.

Comprehensive Care Model

The Comprehensive Care Model provides an example of how to serve families with children with special needs. The intent is for the various agencies serving the family to collaborate with each other and the family in meeting both the child's needs and the parent's need to provide financial support through vocational activities and employment. A parent's ability to function is enhanced greatly with a sufficient support system. Workers can help these families by engaging in a philosophy of building bridges to the services a family needs.



The following information is excerpted directly from *Mothers and Children: The Bridge to Comprehensive Care for Children with Special Health Care Needs*, a Wisconsin Maternal and Child Health Coalition publication.

Family-Centered

Comprehensive care responds to the needs of children and their families. The family is not required to adapt to the system. Instead, the system adapts to the family. The W-2 Program/FEP can accommodate the family by looking at the work and activities an individual can participate in and at assigning appropriate activities. This type of care recognizes the importance of the family's natural role as the child's primary caregiver. Furthermore, the family is treated as an equal partner in developing and implementing the child's care plan. ***Comprehensive care also acknowledges that the family has needs of its own, which are directly related to the child's well being.***

Multi-Disciplinary and Coordinated

Because children with special health care needs often have conditions that require many specialized services, case management is essential. Comprehensive care begins by assisting the family in identifying problems and service needs. Then, with the family, a detailed care plan is developed. The care plan is monitored, evaluated, and revised as the child's needs and the family's situation changes. The EP should reflect this plan, not conflict with it. ***The goal of coordinated care is to support and help families, not control or limit them.***

Children with special health care needs and their families often require the help of a variety of professionals and programs. These include, but are not limited to:

Health Services
Early Identification and Intervention Services
Educational and Vocational Services

Mental Health and Social Services
Recreational Services
Family-Support Services

Community-Based

Families are able to provide care at home by assuring that needed health care, educational, and social services are available in or near the family's community. To make this a reality, many services must be decentralized while maintaining a high level of quality.

Health Services

Depending on the type and severity of the condition affecting a child, the family must have access to a wide range of professionals. Primary, secondary and tertiary care needs must be met.

Mental Health and Social Services

Children with special health care needs and their families ***often have unique psychosocial adjustment issues***. Family dynamics are altered by the added care required by the child. This not only affects the parents' relationship with the child, but also has an impact on brothers and sisters. Often the child and family must face the constant presence of pain from the condition or its treatment. For some children, there is a lingering shadow of death.

Recreational Services

Participation in recreational programs and activities enhances development, enriches children's lives, and directly affects how children mature and function in society. Recreational services for children with special health care needs may mean "bending the rules a bit" without giving the child an extra special advantage.

Family-Support Services

The child is not the only family member in need of services. Training about how to care for their child, respite care, homemaker assistance, parent support groups, individual or group counseling, medical financial counseling, assistance with housing, housing modification, special transportation, and other services are necessary to keep families intact. The Individual Family Support Plan (IFSP) is developed as a method for meeting the needs of families and ensuring they set and work toward goals. The IFSP needs to be reviewed and taken into account during the development of the Employability Plan (EP). Any appropriate activities outlined on the IFSP should be used as W-2 participation hours. At a minimum, be sure that the EP does not conflict with the IFSP.

Early Identification Intervention Services

Early identification and intervention can reduce or even eliminate some of the effects of many conditions. By incorporating these services, the child's potential to lead a productive and independent lifestyle is preserved.

Educational and Vocational Services

Children with special health care needs may require special placements, which address learning, social and emotional development problems. Also, they may need help with problems due to time lost from school because of treatment or illness. As these children become adolescents, vocational training may be required to make their transition into the work world a reality. The goal is to successfully integrate the child into the community. This begins with a positive integration into school. Individual Education Plans (IEPs) are a part of the planning and goal setting process for children with special needs. The IEP and any goals/activities related to parental responsibility must be reviewed by the FEP and taken into account when planning W-2 activities. In addition, these plans can be used to assist in serving Learnfare children within W-2.

In Summary

Forming relationships with the other agencies opens communications and reduces the confusion that often accompanies multiple helping systems.

Benefits of Collaboration

- Cost efficiency
- Improved client advocacy and outcomes
- Enhanced access and tracking of services
- Expansion of resources
- Increased ability to address complex issues
- Mutual understanding of agencies' constraints
- Reduction of duplication of services

Benefits for Families

- **The Right Service at the Right Time** – By working together, programs and workers can do a better job of getting families the support they need, when they need it, thereby enhancing economic self-sufficiency.
- **Fewer Conflicting Demands** – Multiple system families often are overwhelmed by the multiple requirements. It is necessary for FEPs to be aware of various issues related to participation. W-2 is flexible and can accommodate activities related to various programs and support systems.
- **Better Experiences with the W-2 Agency** – When agencies work together, families gain a better understanding of their expectations and interactions are less confusing.

Remember...Confidentiality Issues

The following W-2 policies (taken directly from the W-2 Manual) related to confidentiality apply not only to the W-2 participant, but also to information gained on behalf of the participant related to the child.

4.2.2.1 Protecting Confidential Information about W-2 Participants

Due to the nature of the barriers W-2 participants have, it often is necessary to obtain highly sensitive, confidential information regarding these barriers.

Information related to the following barriers is considered confidential for purposes of the W-2 program:

1. AODA treatment
2. Mental health treatment
3. Domestic violence counseling
4. HIV/AIDS
5. Medical conditions

Information related to these barriers may include, but is not limited to:

1. Details of Assessments
2. Medical Test Results
3. Treatment Notes
4. Medical Diagnosis

The laws governing protection of confidential information are stricter than general information about the W-2 participant. In general, the laws narrowly restrict the disclosure and use of this information to a “bona fide need to know.” An individual or program in possession of such information (for example, a federally-assisted substance abuse program) may not release it except as authorized by the individual. Anyone who receives such information from a substance abuse program (for example, a W-2 agency) may not again disclose it without the individual’s consent and cannot retain this information unless confidentiality can be maintained.

W-2 agencies may disclose this information in the following circumstances without a release of information:

1. To other staff within the W-2 agency who have a bona fide need to know;
2. To another W-2 agency if the individual changes agencies; and
3. To staff from the DCF, which has direct administrative control over the W-2 program.

4.2.1.1 Requesting Confidential Information about Participants

When requesting confidential information, the FEP must use the Authorization for Disclosure of Confidential Information form (DES-10779). This form meets federal and state requirements for the confidential release of information from treatment providers, including alcohol and other drug abuse (AODA) treatment, mental health treatment, domestic violence counseling, HIV/AIDS and medical conditions.

Example: How a Similar Model Is Being Used



the management group, inc.
Wisconsin Based - Nationally Focused

The Single Coordinated Care Plan

The Single Coordinated Care Plan (SCCP) is a team-based, family-centered care planning process to help consumers achieve improved outcomes. Initiated in 2000 as a key part of Milwaukee County's NEXUS: Connecting Families to Recovery program, the SCCP initially served TANF-eligible persons receiving substance abuse treatment who also were involved with one or more other service systems, such as Child Welfare, Corrections, or Wisconsin Works (W-2). It now is being used as the care planning process in the expanded Milwaukee Wiser Choice Program.

The SCCP Process involves teams consisting of the consumer, a facilitator (called a Recovery Support Coordinator in Wiser Choice) who is trained in the SCCP and the Wraparound process, representatives of the systems with which the consumer is involved, and friends, family members, or other support people for the consumer.

Access more information about this model at:

http://www.tmg-wis.com/sccp_overview.asp

Bridge or Road Block?

The FEP and the W-2 program can be either a bridge or a road block for families participating in the Comprehensive Care Model, in accessing and utilizing all services and supports for themselves and for their employability skills development.

List some ways that the FEP/W-2 Program can be either a Bridge or a Road Block.



W-2 Allowable Activities

In addition to work related activities, those activities that support the goal of strengthening a family's ability to handle challenges are allowable. Employment-planning decisions should focus on developing work-related skills that accomplish this goal.

W-2 Participation Requirements

W-2 agencies should be creative in developing flexible activities appropriate for families with special needs. This includes creating or expanding appropriate child and/or respite care resources.

The FEP should consider ways to develop activities that provide support and assistance to the family while moving them closer to employment and self-sufficiency.

1. Assignment of work and work-related activities (career exploration, independent skill-building, etc.)
2. Activities that support work and the development of work related skills such as motivational activities, personal and family management skills (financial planning, budgeting, time management), and parenting activities.
3. Activities that support the family and promote self-sufficiency and the ability to obtain employment such as mental health counseling, activities addressing issues related to the special needs of the child, and participation with partner agencies.

Although it is expected that for most families, additional activities outside the home may be assigned, it is recognized that for a small portion of these cases, outside activities cannot be assigned due to the need for full-time supervision of a child. When suitable child care or respite care is not available or medically advisable, it may be appropriate that the parent's only assigned activity be full-time care of his or her child.

The CD Activity Code

If it is appropriate, be sure that the "CD" component (Caring for a Disabled Child) is posted for the case. The posting of this component removes a family from the calculations that determine Wisconsin's Federal TANF Work Participation rate. To determine if the "CD" code is an appropriate activity, review the definition of it in the Activity Codes appendix of the W-2 Manual.

Appropriate Activities

List some activities that are appropriate for W-2 and for parents who have a very limited ability to work in unsubsidized employment, but that may lead to employment or the development of employment skills.

W-2 Community Steering Committee

Providing resources for families with children with special needs is neither just the responsibility of the W-2 agency, nor just a W-2 issue. The community also must meet this obligation. Schools, child care providers, churches and volunteer agencies must be involved in partnerships to meet community needs. W-2 agencies can do their part by working with their Community Steering Committees (CSCs). The Community Steering Committee can work with employers and encourage them to provide flexible schedules for employees with children with special needs. By raising these concerns through the CSCs, W-2 agencies and workers need not work alone to address these issues.



Here's A Thought...

Have you considered contacting your local W-2 Community Steering Committee regarding the current issues you face in meeting the needs of families with children with special needs? Meeting the needs of the W-2 customer population within the employment community is a function of the W-2 Community Steering Committee as defined in the Glossary of the W-2 Manual.

Children's Services Network

A Children's Services Network (CSN) provides a link to community services for children and families who often do not have personal networks in the community and assist them in developing these networks (Glossary, W-2 Policy Manual). The Children's Services Network may also be used to increase the number of child care providers with the expertise to care for children with special needs. Finding ways to provide child care on a year-round basis is critical to the needs and successes of all families with children with disabilities. Individuals and agencies that collaborate with a common goal in mind are able to find success and use resources more efficiently than any single person or agency can.

Challenges

No family possesses all the resources it needs to meet every challenge. Families with children with special needs may have some or all of the following challenges listed below.

Some things to keep in mind as we look at challenges:

- Students are likely to be in school all day.
- Students may spend all or part of their day in a special education curriculum.
- Older children may spend portions of their day in the community or involved in vocational programs.
- Some children in severe situations may receive homebound services on a time-limited basis.

One adult in the home

Lack of broad informal and formal support systems to help, especially in times of overwhelming demand

Little understanding of available systems and how to access them

Lack of appropriate basic work skills

Inadequate transportation

Inadequate child care

Few internal resources such as cognitive ability and emotional strength

Addressing the Challenges

Read each challenge on the following pages. Note resources in your area that you can use to address each challenge.

I. Access to Child Care

- **Appropriateness of child care centers.** Many child care centers are not equipped to handle the needs of children with emotional or behavioral challenges, or who have high medical needs.
- **Expense of child care.** Child care centers that have the professional staff and resources needed to meet the needs of children with disabilities can be very expensive.
- **Scarcity of child care.** Child care is hard to find for children who have a disability, especially for infants and toddlers. The demand for child care slots far exceeds availability.
- **Child Care for older children with disabilities.** Children age 13 and older may continue to need supervision and assistance, and can't be left alone after school, on holidays, or during summer breaks. Child care for children age 13 and older is difficult to find.

II. Access to Transportation

- **Lack of transportation.** Some parents must rely on public transportation or the help of friends and family to get to work, or transport their child to medical or therapy appointments. Early Intervention and Family Support providers have reported that lack of transportation is a barrier to parent employment in rural areas, as parents often have to travel outside of their communities to find jobs.

III. Maintaining Health Insurance Coverage

- Children with disabilities often have significant and ongoing health care needs that require therapies, medications, equipment and other medically necessary services. Parents with disabled children are concerned about accessing affordable, comprehensive medical coverage.

IV. Access to Flexible Work Options

Parents must tend to their child's health and educational needs, so jobs must be flexible enough to allow parents to take their children to medical and therapeutic appointments or to attend school meetings for truancy/behavioral related issues.

- **Early intervention participation.** Parents need to be available to participate in early intervention programming. A primary component of early intervention programs is parent involvement and collaboration with therapists and other early intervention staff.
- **School participation.** Parents must be available to their school-age child during school hours. Many parents report that they often are needed during school hours to fill in for their child's aide, or accompany their child on a school field trip.
- **School holidays and absences.** Parents may have to stay home when school is not in session, when their child is sick, or when their child cannot attend school for other reasons. Teacher in-service days, holidays, and summer breaks are times when parents may need to take care of their children. Lack of child care or school programming during these periods means that parents may have to stay home with their children.
- **Medical appointments and illness.** Children who have special health care needs or severe disabilities have medical and therapy appointments that must be attended, and tend to get sick more frequently. Parents report spending a large proportion of their time making sure their child receives necessary medical and therapeutic services.

W-2 Placement and Employability Plan Development

The primary goal of W-2 is to assist families in obtaining and maintaining employment. W-2 is a work program, so it is necessary that all participants be willing and able to work and participate in activities that move them toward work.

Throughout the day you have looked at

- defining special needs,
- assessment,
- comprehensive care planning,
- opening our minds to various W-2 activities, and
- challenges.

Placement Activity

Now it's time to pull all this together and look at families with specific needs and apply what you've learned to your assigned scenario.

Ideas

At the end of the activity, list any new ideas you gained from the other groups.

Brief Descriptions of Families

Family A

- Single parent, 3 children (9½, 8 (Cerebral Palsy), 7)
- Applying for W-2, receives SSI, minimal child support
- Little support from family members
- Two children with behavior issues in addition to CP child
- Public transportation
- Mother may have depression and AODA issues

Family B

- Single parent, 2 children (17 and 15 (ADHD, special education)), live in boyfriend
- ADHD child takes medication, but sporadically
- ADHD child does not get along with boyfriend; mother needs support of boyfriend
- Mother recently lost job
- Applying for W-2
- 17 year old sister attempting to provide care for ADHD child and take on parental role

Family C

- Single parent, 2 children (5 (Down's Syndrome) and 3)
- Receives SSI and has applied to various support programs, but on waiting lists
- Mother has worked, but is frequently called away from work for medical reasons
- Living with Aunt and Uncle who provide support
- Mother overwhelmed with responsibility and is pregnant again
- Children are demanding and mother has few parenting skills

Family D

- Two parents, father is out of the home and recently released from jail, 2 children (16 (truancy/juvenile probation) and 8 (special education))
- Involved with child welfare due to domestic violence and substance abuse
- 16 year old daughter misses a lot of school and spends a lot of time with her boyfriend
- Mother works part time, grandmother provides child care
- Mother receives prorated W-2 payment because she is unable to increase her hours in her current job due to barriers
- With the father wanting to move back into the home, it makes it difficult for mother to cope and manage the family

W-2 Case Management Truths

- The clock will not stop ticking
 - W-2 time limits are always ticking, and eligibility will end after time limits have expired unless there are extensions.

- Life skills mean life self-sufficiency
 - The goal is self-sufficiency, so every activity should be considered for its effectiveness in meeting this goal for each customer.

 - In other words, activities should not be simply “busy work”; they should lead toward employment skills and self-sufficiency.

- Networking is a powerful tool
 - The customer will be part of the community long after W-2 eligibility runs out. Connecting a customer with a network is essential to a family’s success in accessing agencies and organizations that can help with needs the family cannot handle alone.

- Documentation backs up case management decisions
 - Documentation is essential to verifying employment activity and justifying its inclusion in an employment plan. It is very important in assessing a customer’s progress or regression and in identifying new areas of need.

Closing

All W-2 applicants and recipients are expected to participate in activities related to obtaining and maintaining employment. W-2 is a work program, and as such it emphasizes work activity and activities to assist individuals in finding and maintaining employment. Families with children with special needs may face additional barriers to employment, but W-2 is a flexible program that offers many options for meeting participation requirements and participating in activities that will lead to work or to gaining work skills.

There are always ways to take steps forward...

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NOTE: The Resource Section beginning on the next page has additional references included with each topic.

Appendix I

Record-Keeping Book

This record-keeping book is for families who have a child with a disability or chronic health condition to help organize information to share with W-2 workers, with health providers, with teachers, and with other professionals.

I. Family Information

Names of Parent(s) _____ Phone: _____

Address: _____
(street) (city) (zip code)

Name(s) of Children	Date of Birth

Name of child with a disability or chronic health condition: _____

Disability or diagnosis: _____

Does your child currently receive SSI?

Yes

No

Have you applied for SSI, but have not yet been told if your child is eligible?

Yes

No

When did you apply?

II. People Who Know Your Child Best

A. Doctors and Medical Specialists

List here doctors and medical specialists who know your child best.

<i>NAME of person</i>	<i>WHAT does the person do? (Example: pediatrician, neurologist.)</i>	<i>WHERE does the person work? (name of hospital or clinic)</i>	<i>PHONE NUMBER</i>

III. Medical, Therapy, and Educational Needs and Services

A. Medical Appointments

Record here the type, frequency and length of you child's regular medical appointments.

<i>TYPE of medical appointment (appointment to get braces adjusted, dental appointment, etc.)</i>	<i>HOW OFTEN are these appointments scheduled? (number of times a year, or month)</i>	<i>HOW MUCH TIME does an average appointment take, including travel time?</i>

B. Specialized Transportation:

List here any needs your child has for specialized transportation, including cost and equipment:

C. Therapies

Record any therapy services (occupational therapy, physical therapy, speech therapy, etc.) your child may be receiving.

TYPE OF THERAPY	FREQUENCY (# sessions/week)	LENGTH OF SESSIONS	WHERE (clinic, home, school)

Are you with your child during the time she/he is getting therapy? Is so, describe what you do during that time.

Use this space for any additional information about your child's therapy needs:

D. Parents' Participation at Child's School or Day Care

How much time do you spend at your child's school or day care center?

<i>WHY do you need to be there? (example: helping with child's medical needs, controlling child's behavior)</i>	<i>HOW OFTEN does this happen? (How many times a week or month?)</i>	<i>HOW LONG does it usually take? (number of hours spent at school or day care center)</i>

Expected parent participation at child's school or day care in the next year.

<i>I will need to spend time at my child's school or day care because...(example: to provide training to my child's teachers, to help when the classroom aide is not available)</i>	<i>I expect that I will need to spend...(write expected number of days or frequency of visits)</i>

VI. Work

List below what you need to enter the workforce or increase your work hours.

WHAT IS NEEDED	DESCRIBE YOUR NEEDS (example: I need to work 3 rd shift, find day care, leave work when child is sick, etc.)
SCHEDULING (1 ST , 2 ND , 3 RD)	
# OF HOURS PER WEEK	
JOB FLEXIBILITY (employer's ability to understand that parent may have to leave work to care for child)	
TRANSPORTATION	
LOCATION OF WORK	
DAY CARE	
MY OWN HEALTH ISSUES/PROBLEMS	
OTHER THINGS THAT ARE NEEDED:	

VII. Tips for Meeting and Working with the W-2 Agency and Others

- **Get organized.** Before going to a meeting, have all of the information that you need on hand. Filling in the sections in this workbook is a good place to start. You also may need information from other sources, such as doctors' letters, medical records, a copy of your child's IFSP, etc.
- **Save everything.** Save every letter you receive and make a copy of any letter that you send out. Put all letters relating to your child in a central place so that you can find them easily.
- **Write everything down.** Every time you call or receive a call from any professional involved with your family, write down the date of the call and what was said. Write down the times you tried to call but couldn't get through, as well as the times you reached an answering machine.
- **Think about your questions** for the meeting, and write them down. Writing down your questions can help keep you on track during the meeting. You can use the blank pages at the end of this workbook to write your questions down.
- **Bring someone with you.** It may help to have someone come with you when you meet with professionals who will be making decisions that affect your family. This person can help you remember to ask specific questions, to share information or to help you remember what was said.
- **Bring solutions or ideas for change.** Think about what may need to change, and share your ideas on how to fix problems with the W-2 agency (for example, say, "If I could work at my child's school, that would solve a lot of problems" instead of, "There's no way I can work. I have to be at my child's school all the time.>"). When you offer solutions, you have some influence over how problems are addressed—otherwise, you may be faced with solutions that do not fit in with your family's needs.

Appendix II

SCREENING TOOL TO DETERMINE FAMILY NEEDS OF CHILDREN WITH DISABILITIES, DEVELOPMENTAL DELAYS AND/OR CHRONIC HEALTH CARE CONDITIONS

Instructions and Referral Interpretation

Part A: General Background

To determine if a family has a child with disabilities, developmental delays, and/or chronic health care conditions that require special consideration for job placement, ask the questions in Part A of all parents screened. The questionnaire is structured so that responses may be gathered orally, or in writing.

If the answer is YES to question 1, but NO to question 2, you also may need to make a referral to one of the programs listed. Call your local school district or 1-800-642-STEP for referral information about these programs in your community. Continue on with the rest of the screening questions if the parent's response to questions 1 and 2 justify the need for more information. Because question 1 may elicit positive responses that are not significant (e.g., mild learning disabilities or mild forms of juvenile diabetes or asthma), not all positive responses may require completion of the full screen.

Part B: Special Health Needs

Part B questions involve the type and frequency of special services and medical interventions. Questions are also included that explore the level of parental involvement in the medical care.

Part C: Daily Living Needs

At this point in the screen, if a parent has expressed significant health care and daily living needs, you should obtain additional information from contacts identified in Part A. This may require a signed release from the parent. The person may be able to provide more information about the care needed and the schedule requirements, so that an ideal work schedule and child care arrangements can be arranged.

Part D: Child Care Needs

These questions are designed to determine if there are barriers to obtaining child care. Barriers may take the form of special health needs, like required nursing care, or a vulnerable immune system, or they may be supervision needs beyond that normally provided in a child care facility.

Does Your Child Have Special Health Care Needs?

Part A: Background

1. Do you have any concerns about your child's health or development?

- NO
 YES

If yes, what are these concerns?

2. Does your child receive services from any of the programs listed below?

- NO
 YES

If yes, provide the contact name and phone number for each program. If the information is not available now, place an X on the line so that we can collect it later.

<u>Program</u>	<u>Contact and Phone Number</u>
Birth-to-Three	_____
Family Support	_____
Exceptional Education Needs	(Special Education-Public Schools) _____
Children with Special Health Care Needs	_____ _____
Other	_____

(Place an asterisk (*) next to the name of the person who knows the most about your child's situation and needs)

Also, if yes, tell us why your child is seen by the program or agency.

If the answer is YES to either question 1 or 2, please continue to **Part B**.

If the answer is YES to question 1, but NO to question 2, you should consider calling your local school district or 1-800-642-STEP for referral information about these programs in your community.

Part B: Health And Developmental Needs

1. How often does your child receive program services and/or medical treatment?

Program Services

- Daily
- 3 to 4 times per week
- 1 or 2 times per week
- 3 or 4 times per month
- 1 or 2 times per month
- less than 1 time per month

Medical Treatment

- Daily
- 3 to 4 times per week
- 1 or 2 times per week
- 3 or 4 times per month
- 1 or 2 times per month
- less than 1 time per month

2. How often does your child see a physician?

- every week
- every month
- more than once a year
- less than once a year

Name: Dr. _____

Type of physician or specialty:

When was your child last seen? Why?

3. Does your child receive therapeutic or educational services (Birth-to-Three program, public school or other) for health care needs, such as:

- | | |
|---|---|
| <input type="checkbox"/> Physical Therapy | <input type="checkbox"/> Mental health issues |
| <input type="checkbox"/> Educational services | <input type="checkbox"/> Occupational Therapy |
| <input type="checkbox"/> Vision | <input type="checkbox"/> Speech Therapy |
| <input type="checkbox"/> Deaf and Hard of Hearing | <input type="checkbox"/> Other _____ |

What is your role in these services and follow up? How often are you involved in this role?

Part C: Daily Living Needs

1. Does your child have needs (other than what is expected for his/her age) for daily supervision/assistance, such as:

- | | |
|------------------------------------|--|
| <input type="checkbox"/> Dressing | <input type="checkbox"/> Communicating |
| <input type="checkbox"/> Eating | <input type="checkbox"/> Behavior |
| <input type="checkbox"/> Mobility | <input type="checkbox"/> Forming Relationships/Friendships |
| <input type="checkbox"/> Breathing | <input type="checkbox"/> Toileting |
| <input type="checkbox"/> Sleeping | <input type="checkbox"/> Other _____ |

Comments:

2. Does your child have need for medical/health treatments, such as:

- G-tubes
- Suctioning
- Tracheotomy
- Medicines
- Other _____

Who administers to these needs above, and how often?

What is your role in caring for your child with these treatments, and how often is this done?

3. Does your child require assistive devices for communication, such as:

- Computer
- Picture Cards
- Sign Language
- Hearing aids or other assistive listening devices
- Other talking devices

What is your role in using these devices, and how often is this done?

4. Does your child require supervision/assistance with mobility, such as:

- Crutches
- Braces
- Wheelchair
- Special Transportation Monitor
- Other _____

What is your role in meeting your child's needs with these assistive devices, and how often?

Appendix III

Wisconsin's Community Options

What Is the Community Options Program (COP)?

- COP is for people who need long term care stay in their own homes and communities.
- It provides cost-effective alternatives to expensive care in institutions and nursing homes.
- A care manager assists in arranging the services and supports needed

Who Can Get Help through Community Options?

- Community Options serves people who need long term support, *regardless of age or type of disability*, who need the same levels of physical or mental health care as nursing home residents.
- There are no income limits on eligibility for a COP assessment and care plan.
- Income guidelines are used to determine whether Community Options will pay for part or all of the costs of services that the assessment determines are necessary.
- People who can afford to pay may receive help finding the services they need after an assessment is completed.
- All other sources of funding will be considered before Community Options funds are used to pay for services. For example, Community Options will use federal Medicaid funding for services arranged by the same care managers.
- Getting services also will depend on the availability of program funds. Counties may have waiting lists for Community Options funding.

How Can Community Options Help?

Community Options provides services, equipment or aids that allow you to live safely, with dignity and respect in the community. Examples include:

- Home Modifications
- Adaptive Equipment
- Care Management
- Home Health Care
- Personal Care
- Respite Care
- Financial Counseling
- Communication Aids
- Residential Services
- Housekeeping

More Information:

Wisconsin DHS

http://dhs.wisconsin.gov/LTC_COP/cop.htm

Family Support Program

What Is the Family Support Program?

- Offers in-home support for families who have children with severe disabilities.
- Provides individual services and supports to families that include a child with several disabilities.

The Program offers:

- Information and help in finding services and maximizing community resources;
- Limited funding to buy needed services and goods that can't be bought through other sources;
- Help in linking families with other families to strengthen natural supports.

Program Guidelines

- The foundation of the Family Support Program is the belief that parents of children who have severe disabilities know best what they need.
- Family Support Coordinators and parents work together to develop an individualized service plan (IFSP) for each family.
- Home modifications, transportation, specialized equipment, nursing care and respite are examples of items and services the Family Support Program can help the family purchase.

Who Is Eligible?

- Families are eligible for services if they have a child with a severe disability, under the age of 21, and living at home.
- Although family income is not a basis for eligibility, cost-sharing may be required on a sliding fee scale.

Will the Program Meet the Needs of all Eligible Families?

Family Support is a state-funded program. Because each county has limited funding for this program, eligibility does not guarantee a family will receive services. Agencies may have waiting lists for services and assessments. Administering agencies make the final decision on who is served and approve each family's service plan.

Priority for services may be given to families in a crisis situation or families who are bringing a child home from an out-of-home placement.

More Information:

DHS Family Support Program website

<http://dhs.wisconsin.gov/children/fsp>

Katie Beckett Program

Purpose of the Program

The Katie Beckett Program is a special eligibility process that allows certain children with long term disabilities or complex medical needs, living at home with their families, to obtain a Wisconsin Medicaid card.

Children who are not eligible for other Medicaid programs because the income or assets of their parents are too high, may be eligible for Medicaid through the Katie Beckett Program, if they meet all the following eligibility criteria:

- Under 19 years of age and determined to be disabled by standards in the Social Security Act;
- Requires a level of care at home that typically is provided in a hospital or nursing facility;
- Can be provided safe and appropriate care in the family home;
- As an individual, does not have income or assets in his or her name in excess of the current standards for a child living in an institution; and
- Does not incur a cost at home to the Medicaid Program that exceeds the cost Medicaid would pay if the child were in an institution.

Katie Beckett Program Benefits

If the Katie Beckett Program application is approved, the child will receive a Medicaid card that can be used to pay for services and equipment allowed under the Wisconsin Medicaid Program. Information about how to use the card and covered services will be sent to parents with the approval letter.

All rules and benefits for card-covered services for the Wisconsin Medicaid Program apply to children who receive their Medicaid card under the Katie Beckett Program. The Division of Health Financing administers the Medicaid Program and is responsible for ongoing assistance to families regarding coverage and benefit questions.

More Information:

DHS Katie Beckett Program website

<http://dhs.wisconsin.gov/children/kbp>

The Birth to 3 Program

Birth to 3 is Wisconsin's early intervention program for infants and toddlers with developmental delays and disabilities and their families.

More Information:

DHS Birth to 3 Program Website

<http://dhs.wisconsin.gov/children/birthto3>

Home Health Care Services

What Is Home Health Care?

- It is a variety of services that can be provided in order to enable an individual with medical and related needs to continue living at home.
- Services can include "skilled care" provided by licensed professionals such as registered nurses and therapists and "supportive services" such as assistance with personal care and chore services.

More Information:

Wisconsin Consumer Guide to Health Care

<http://dhs.wisconsin.gov/guide>

Respite Care

What Is Respite Care?

- It supports families who have a child with disabilities living at home by giving parents an occasional "break" from the responsibility of providing continuous care and support to their child.
- This temporary relief could be on a regular, as needed, or an emergency basis.

How Do You Get Respite Care?

Getting the kind of respite care needed depends on the resources available in your community and the other types of services and supports the child is receiving. For example, CIP, Community Options, and Family Support Program funds can be used for respite care. However, if the family is receiving services through any of those programs, there are rules regarding the number of hours of respite care and the kind of respite care paid for by program funds.

There may be agencies in the community, such as United Cerebral Palsy, Association for Retarded Citizens, or day care centers that provide respite services. For those programs, you might have to pay all or part of the cost of respite care.

Co-payment methods will differ among agencies and/or counties providing respite care. In some communities, parents of children who have disabilities have organized respite co-ops to share child caring responsibilities.

For children who have Medicaid (MA), more restrictive kinds of respite care provided in nursing homes or other institutions might be covered. Those types of respite care might be needed if the child has serious medical needs that require special attention during the respite period.

More Information:

Respite Care Association of Wisconsin

<http://www.respitecarewi.org/>

Appendix IV

Disability-Related Organizations

What Are Disability-Related Organizations?

There are several different support groups and organizations in Wisconsin, each organized through a shared concern for individuals with a specific disability. Although each group or organization may have a specific mission or purpose, most disability-related organizations provide some type of information and referral assistance, educational materials, and support for individuals with a disability and their families.

How Could a Disability-Related Organization Help?

A support group or organization could help locate needed services. Often these groups can provide "tips" on how to deal with the service system and how to advocate for a child. Some organizations can advocate on behalf of the family. Disability-related organizations also can advocate on a system's level for increased services.

Examples of Disability Related Organizations

The ARC – Wisconsin: The ARC (formerly the Association for Retarded Citizens) is a statewide membership organization serving people with developmental disabilities and their families. The ARC provides advocacy, guardianship services, training and information and referral services. For more information: <http://www.arc-wisconsin.org>

Autism Society of Wisconsin: This is a statewide organization providing advocacy for the education and welfare of children and adults who have autism. For more information: <http://www.asw4autism.org/>.

Citizen Advocacy: Citizen Advocacy initiates and supports freely given one-on-one advocacy relationships between members of the community and people with developmental disabilities. Citizen Advocacy focuses on long-term relationships that bring people together.

Down Syndrome Association of Wisconsin (DSAW): DSAW is an organization created by families. DSAW offers many programs including a newsletter, new parent information packet, parent match services, community education and special events. For more information: <http://www.dsaw.org>

Epilepsy Foundation – Heart of Wisconsin: Offers services for families, schools, employers and public health workers that engage and educate individuals in order to raise awareness and reduce the stigmas and myths associated with seizures and epilepsy. <http://epilepsywisconsin.org/>

MUMS: Mothers United for Moral Support, based in Green Bay, is a statewide self-help group for parents of a child with any disability. MUMS has a wide range of different disabilities among its membership and will match parents whose children have the same or similar diagnoses. For more information: <http://www.netnet.net/mums/>.

Muscular Dystrophy Association: MDA has county and regional offices throughout the state that offer assistance to persons with muscular dystrophy by providing orthopedic aids, respiratory equipment, physical and occupational therapy, transportation and recreational programs. For more information: <http://www.mda.org/>.

United Cerebral Palsy: In addition to a statewide office, UCP also has three regional offices, which offer information, referral and direct advocacy for people with cerebral palsy and their families. For more information:

UCP of Greater Dane County : <http://www.ucpdane.org/>

UCP of Southeastern Wisconsin: <http://www.ucpsew.org/>

UCP of West-Central Wisconsin: <http://www.ucpwcw.org>

Wisconsin Family Ties: This is a statewide organization for families that include children and adolescents with serious emotional and behavioral disorders. WFT provides a variety of parent-to-parent support, education and advocacy services. For more information: <http://www.wifamilyties.org/>.

Wisconsin Spina Bifida Association: There are five regional spina bifida support groups in Wisconsin. They provide educational materials, resources assistance, and support for families with children who have this disability. For more information: <http://sbawi.org>.

Whom Do You Contact for More Information?

One way to find out about the support groups and organizations in your community is to look in your yellow pages under "Human Service Organizations" or "Social Service Organizations." Your county United Way office also will have a list of most local organizations.