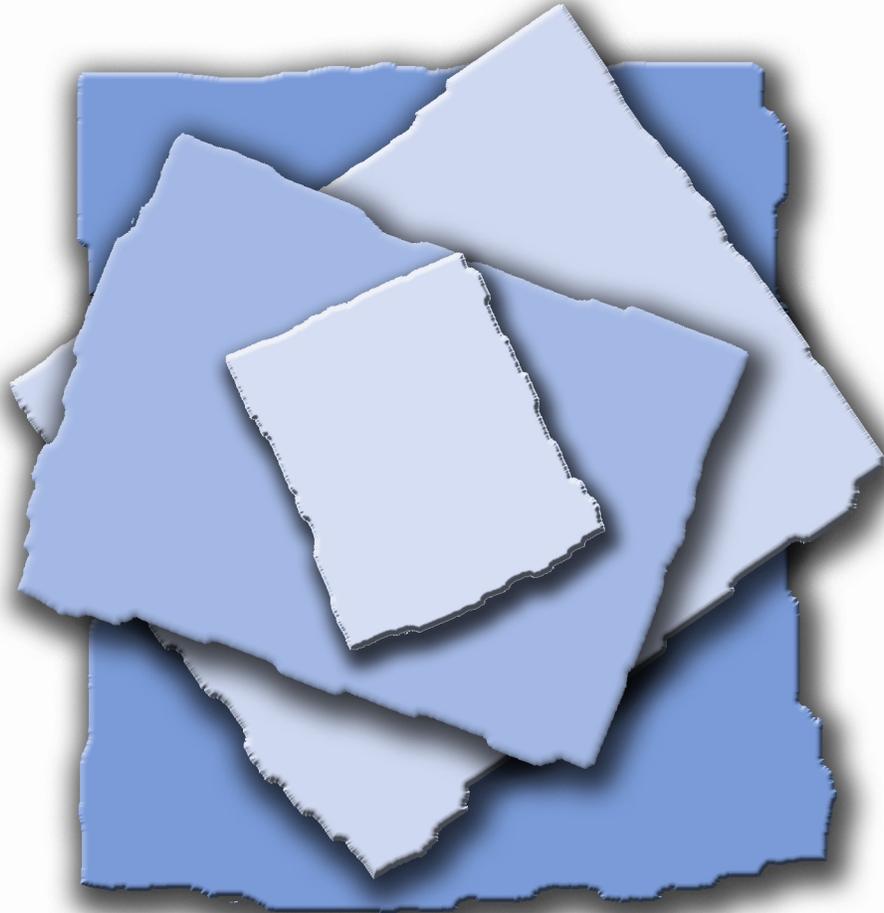


Oklahoma

Individual and Family Support



Principles to Practice

Indicators

*Oklahoma Family Support Partnership Project
Center for Learning and Leadership/UCEDD
College of Medicine, University of Oklahoma Health Sciences Center*

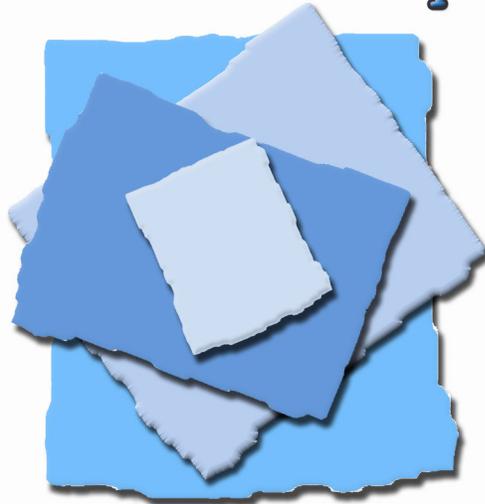
Recommended citation for this publication:

Oklahoma Family Support Partnership Council (2004). Oklahoma Individual and Family Support Principles to Practice Indicators. Oklahoma City: Center for Learning and Leadership (Oklahoma's Federally designated University Center for Excellence in Developmental Disabilities), College of Medicine, University of Oklahoma Health Sciences Center.

This publication was developed by members of the Oklahoma Family Support Partnership Council as part of the Oklahoma Family Support Partnership (OFSP) project. The OFSP is a Project of National Significance in Family Support funded by the U.S. Administration on Developmental Disabilities (Grant #90DF00074) with matching funds from the University of Oklahoma Health Sciences Center College of Medicine and the Oklahoma Department of Human Services, Developmental Disabilities Services Division. 1000 copies of this publication have been printed and distributed at no cost to the taxpayers of the State of Oklahoma.

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Oklahoma Individual and Family Support



Principles to Practice Indicators





Oklahoma Individual and Family Support Principles

- ...are guiding truths that shape the way individuals, families and service providers interact
- ...establish common ground upon which individuals, families, advocates and service providers operate
- ...form the basis for program policy and practice.

WHEN WE ENGAGE WITH INDIVIDUALS AND FAMILIES WE WILL...

HONOR THEIR EXPERTISE and right to make choices that they know to be in their own best interest.

RESPECT AND ACCEPT THEIR VALUES that are based in personal preferences, cultural beliefs and life-ways.

SUPPORT INDIVIDUAL AND FAMILY RELATIONSHIPS that are safe, stable and long lasting.

FOCUS ON THE ENTIRE FAMILY as it is defined by the family.

PROMOTE FLEXIBLE SERVICE AND FUNDING supporting individual and family control over who, what, when, where and how supports are provided.

AFFIRM LIFESPAN PLANNING AND SELF-DETERMINATION that encourages decision-making and planning for independence beginning within the family when children are young, following the individual throughout their life and including aging issues.

ASSURE PARTNERSHIPS THAT ACTIVELY INCLUDE INDIVIDUALS AND FAMILIES in planning, development, implementation and evaluation of policies, practices and personal programs.

PRACTICE OPEN COMMUNICATION promoting a clear understanding of all aspects of systems policy, procedure, practice and all other information regarding them.

RECOGNIZE THE IMPORTANCE OF THE COMMUNITY, where individuals and their families belong and realize their full potential.

All people need enduring, stable family and community relationships. All families need support at times in their lives to maintain these lasting relationships. Individual and family support must assist across the life-span, supporting the child within the family and the individual reaching independence. This assistance builds on natural sources of support including extended families, friends, neighbors and community associations. The way support is provided is a reflection of what we believe about individuals and families, a way of thinking about individuals and families and a way of engaging with individuals and families.





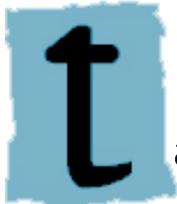


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acknowledgements

The Oklahoma Individual and Family Support Principles to Practice Indicators is the collaborative effort of many people. Thanks to all who contributed time and talent, including the members of the Oklahoma Family Support Partnership Council:

Lisa Bradley
Linda Broerse
Traci Castles
Amy Corley
Olga Deloera
Jacqueline Devereaux
Tera Dome
Jerry Durbin
Alice Echo Hawk
LeAnna Hart
Tonda Ivory
Mike Kiser
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Karen Landolfi
Brigita Leader-Harley
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Tara Lozano
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Wes McFarland
Kathy Moore
Jan Moss
Rose Ann Percival
Heather Pike
Lu Potts
Laurene Powers

Cyd Roberts
Sally Selvidge
Donna Shanor
Lathonya Shivers
Peggy Stucky
Lyn Thoreson
Jamie Van Dycke
Sherilyn Walton
Steve Wells
Linda Wilson
Louis Worley

and the Oklahoma Department of Human Services, Developmental Disabilities Service Division for providing staff members, Rose Ann Percival and Linda Broerse, and former staff member, Kathleen Kovach, as liaisons to the project.

Susan Yuan, our friend and colleague from the University of Vermont, she cheered us on and took the Oklahoma Individual and Family Support Principles around the country.

Ronda Madole Weaver, for designing this book.



Introduction

The *Oklahoma Individual and Family Support Principles to Practice Indicators* is a document that identifies ways of interacting, providing services and developing policy that reflect the principles of family support. *The document is a guide; it is not intended to be used as a measurement tool or behavioral scale.*

The *Oklahoma Individual and Family Support Principles to Practice Indicators* were developed by families of individuals with disabilities, service providers, advocates, higher education faculty, and students. The document identifies indicators (actions and attitudes) for three groups. The indicators describe behaviors to expect if the members of each group practice the principles. The three groups are described below:

1. Individual and Family – persons with developmental and other disabilities and the family members of persons with developmental and other disabilities.
2. Provider – direct service providers, state and local agency administrators, higher education faculty, students, advocates, and others who directly or indirectly provide services to individuals with disabilities and their families.
3. System – the state and local entities that have authority to develop and implement policies and programs, responsibility for the preparation of personnel, and responsibility for the governance of funds for programs and services for individuals and their families.

Let us know what you think! We want to hear from those who use the *Oklahoma Individual and Family Support Principles to Practice Indicators*. Please take time to give us your comments and suggestions for changes to include in future revised editions. Use the form at the back of the book or send your comments by e-mail to:

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honor their expertise

Indicators:

Individual and Family:

- Communicate preferences about best meeting times and places, best ways to communicate, and other important considerations.
- Communicate what works and what does not work.
- Ask for information that will help us make decisions.
- Write questions and send to providers ahead of time so they are prepared to answer them.
- Ask providers to explain words or concepts that we do not understand.
- Take time to gain an understanding of the information and time to consider the information before making decisions.
- Communicate changes in our needs that require adjustments in the supports and services.

Provider:

- Ask the individual and the family to “tell their story.”
- Give the individual and family’s information the same respect as the provider’s information.
- Listen for and identify the strengths of the individual and family.
- Ask what they have learned from years of experience.
- Ask what questions they want answered.
- Answer questions in understandable terms.
- Acknowledge that individuals and families have different expertise that evolves over time.
- Match the services to the preferences and needs expressed by the individual and family.

System:

- Provide staff training in self-determination and family support practices.
- Support creativity of direct service providers.
- Develop policies and procedures that support differences in needs and preferences of the individual and family.
- Provide flexible work schedules for staff to accommodate best times to meet with the individual and family.

Questions:

Individual and Family:

- Did we describe our situation clearly?
- Did we say what would help?
- Did we list everyone we consider to be part of our family?
- Did we describe the strengths of our family?

Provider:

- Did I listen first?
- Did I ask what works and what does not work?
- Did I ask if the support services they receive are helpful?
- Did I recognize the family as the “constant” in the life of the individual?
- Did I identify the individual and family’s natural supports?
- Did I acknowledge that individuals and families change over time?

System:

- Are program requirements and services explained clearly?
- Do the policies convey respect for individuals and families?
- Are all team members trained in how the expertise of individuals and families should be valued, respected and considered?
- Are all team members trained in how to include individuals and families in planning based on the evaluation of information?

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espect and accept their values

Indicators:

Individual and Family:

- Share information about the cultural and ethnic values that are important to us.
- Ask for interpreters if needed.
- Ask that information be translated into language that we understand.
- Bring family or friends to the meeting who can support us.
- Understand the value of compromise.

Provider:

- Acknowledge, respect and honor the cultural and ethnic values of the individual and family.
- Arrange for interpreters if the individual and family do not speak English.
- Provide written information that is translated into the language of the individual and family.
- Address the individual or the family member as Mr., Mrs., Ms., or Miss unless they asked to be called by first names.
- Attend to and respect family preferences and culture.
- Take the time to learn about and respond to diverse cultures.

System:

- Provide staff training in culturally sensitive practices.
- Require that individuals and families of the cultural and ethnic communities of the state be represented on boards, commissions and task forces that make policy recommendations.
- Hire staff from diverse cultural and ethnic communities.

Questions:

Individual and Family:

- Did we describe our family values to the providers?
- Did we decline service that is inconsistent with our values?
- Did we talk about how our culture views services and service systems?
- Did we ask for an interpreter or written information in language we understand?

Provider:

- Did I listen for the preferences, beliefs and “lifeways” of individuals and families?
- Did I show respect for the values and cultural beliefs of the individual and family?
- Do I know how to accommodate culturally specific approaches to services?

System:

- Do policies allow services to incorporate the values of the individual, family and community?
- Is there flexibility in the way services are delivered?
- Is agency staff representative of the cultural and ethnic groups in the community?

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Support individual and family relationships

Indicators:

Individual and Family:

- Identify the people we rely on for support on a daily basis.
- Bring people who are part of our support system to meetings.
- Ask for help if concerned about abuse or neglect of self or others.
- Communicate how family members and friends are involved in planning for and helping with services.
- Understand that the roles of family members and friends change over time.

Provider:

- Acknowledge the importance of family and friend relationships.
- Understand that different cultures may describe relationships differently.
- Assist individuals and families in maintaining long-lasting relationships with friends and family members, including living arrangements that allow physical access to family and friends.
- Support individual and family access to all aspects of the community.
- Know what resources are available to assist families with concerns about physical or emotional abuse.
- Provide professional help for individuals and families involved in abusive relationships.

System:

- Establish policy to fund services to keep children with disabilities living in the family home.
- Require staff training in identifying and reporting abuse and neglect and resources to assist individuals and families who are experiencing abuse and neglect.
- Require staff training in the philosophies and practices of self-determination and family support.
- Provide services that support long-lasting relationships.
- Ensure that the role of the whole family is recognized as service is provided to the individual.

Questions:

Individual and Family:

- Did we communicate our long-term plans and dreams?
- Do we know when a relationship is harmful?
- Do we know whom to contact if a family member or friend is harming us?
- Do I want to live near family? Did I tell the service provider?

Provider:

- Did I honor, respect and listen to the person who is receiving the services?
- Did I leave my definition of family at the door and accept the individual and family's definition?
- Do I recognize when "safe" becomes "unsafe" and do I know what to do?

System:

- Do policies and funding support keeping families together?
- Does the system recognize and respond to the impact of the person with disabilities on the whole family?



ocus on the entire family

Indicators:

Individual and Family:

- Identify the people who live in the home and others who are important to us.
- Describe the way we work together to meet the needs of the individual as well as the needs of the other family members.
- Explain why a service does or does not make sense or fit our lifestyle.
- Work together to increase the independence of the individual throughout his/her life.

Provider:

- Accept how the family is defined by the individual and family.
- Support the individual and family in bringing whomever they choose to meetings.
- Recognize and respect the role that each member plays within the family.
- Provide resources and services that fit into the individual and family lifestyle as much as possible.
- Support the individual and family to increase the independence of the individual.

System:

- Establish policies and procedures that allow a flexible definition of the family.
- Support staff training to improve communication skills and knowledge of family support practices.
- Allow flexibility in funding so services are responsive to the individual and family lifestyle as much as possible.
- Allow the individual and family to bring whomever they choose to meetings and appointments.

Questions:

Individual and Family:

- Did we tell who lives in the house and what each one does to help care for/support our family member with disabilities?
- Did we tell who else is important to our family -- who helps with daily care, who helps with emergencies, who we talk with when we have difficult decisions to make?
- Did we tell who to call to set up meetings, to discuss health care information, and to discuss services and planning?
- Did we describe the kinds of services, times of day, and days of the week that work best for our family?

Provider:

- Did I understand the impact that the disability has on the individual and family?
- Did I ask the individual and family how best to work with each family member or friend to support the member with disabilities?
- Did I ask the individual and family what resources and services would help and how to fit those services into their routines and lifestyle?
- Did I ask who are included in the friend and family network that provide support for the member with disabilities and the other family members?
- Did I ask whom the individual and family want to include in meetings, appointments and planning sessions?
- Did I ask the individual and family what they have considered in planning for increased independence of the member with disabilities?

System:

- Do policies require staff training in family support practices and communication skills?
- Does staff training include a practicum experience designed to increase awareness of individual and family perspectives, needs and daily living issues?
- Do individuals and family members help develop and review policies and procedures to ensure flexibility in the design and delivery of services?

promote flexible service and funding

Indicators:

Individual and Family:

- Communicate what we really want the services to do.
- Learn about the funding options and restrictions.
- Learn about resources and services of all systems.
- Ask questions and problem-solve with others to get needed services.
- Identify natural (non-system) resources that work for us.
- Clearly express how much control we want over services and funding.

Provider:

- Trust the individual and family to make good decisions about the use of services and funds.
- Proactively offer information and assistance as services and funding are planned and delivered.
- Ask the individual and family what works in designing service plans.
- Provide the individual and family with information about how funds can be spent.
- Provide information about resources and services of all systems.
- Collaborate with other professionals who are involved with the individual/family to maximize all sources of services and benefits.

System:

- Support innovation of the direct service providers.
- Provide an ongoing mechanism for using input from individuals, families and providers to improve service delivery.
- Develop funding structures to allow the individual and family to decide how much, when and what services are provided.
- Provide training about the resources and eligibility requirements of all systems.
- Provide training on how to work in a team with individuals/families and other professionals.

Questions:

Individual and Family:

- Do we understand what the agency can and cannot do to address our concerns and needs?
- Did we describe our current situation including what resources and services we have, what is working well and what we need?
- Did we describe how our family could contribute to solving the problems?
- Do we know how much control we want over funding and various aspects of the services?
- Do we have enough information to make decisions?

Provider:

- Did I give the individual and family an opportunity to tell their preferences and needs, and how they want services delivered?
- Did I ask the individual and family what resources or services they are currently using and whether they are helpful?
- Do I know what resources and services are available within and outside the agency I represent?
- Did I acknowledge the individual and family's concerns and history of managing important issues?
- Did I talk with others providing services to the individual and family?

System:

- Did we make the rules (policy and funding parameters) clear to the individual and family members and then engage them as partners in designing cost-effective ways to meet their needs?
- Do policies and funding support the individual and family in understanding how to contribute to the system-change process?
- Is staff supported to get training that increases effectiveness in working in collaboration with individuals, with families, and with other service providers and advocates?
- Are policies flexible enough to support the needs of the whole family?



affirm lifespan planning and self-determination

Indicators:

Individual and Family:

- Tell about our dreams, hopes and goals.
- Understand the role of the family in planning for the future.
- Understand the role of the individual in planning for the future.
- Identify what support we need to live independently.
- Identify choices about where, how, and with whom we want to live and work.
- Seek help from other individuals and families with experience in planning for the future.

Provider:

- Understand the importance of connecting current services with future life-plans.
- Support the individual and family as they develop a vision for the future.
- Work collaboratively with the individual and family to achieve their goals.
- Work with the community to identify supports and promote community inclusion for individuals and families.

System:

- Establish policies that are flexible enough to respond to current needs and supportive of future opportunities.
- Provide staff training in lifespan planning and service delivery.

Questions:

Individual and Family:

- Do we plan for greater independence for our family member with disabilities?
- Do we know what our family member with disabilities wants?
- Do we value integration into the community?
- Do we know what it will take to live independently?
- Have we asked other individuals and families for advice and help?

Provider:

- Do I understand the impact of disabilities on the life of the individual and the family over time?
- Did I find out what kind of support is available in the community and how to access it?
- Do I build relationships with community members in order to promote community living for individuals and families?
- Did I consider the lifespan issues as I helped the individual and family plan for the services they need?

System:

- Do we use individual and family input to make improvements in the service delivery?
- Does funding provide options for all aspects of community living for the individual and family?
- Are staff trained in lifespan planning, self-determination and family support practices?

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Assure partnerships that actively include individuals and families

Indicators:

Individual and Family:

- Find out what the agency policies (rules) say about services.
- Give feedback about services and policies to agency administrators and staff.
- Serve on advisory committees that meet with agency administrators and staff.
- Find out what it takes to get changes made in policies and services.
- Identify and communicate what improvements are needed in services and policies.
- Contribute ideas to solve problems and deal with budget shortfalls.
- Get to know the service providers and what they do.

Provider:

- Ask the individual and family what support they need to participate in planning, development and evaluation activities.
- Ask the individual and family what improvements are needed in policies and services.
- Ask the individual and family to participate in planning new programs.
- Ask the individual and family to evaluate the effectiveness of services.
- Ask the individual and family to contribute ideas to solve problems and deal with budget shortfalls.
- Provide individual and family's input to system administration.

System:

- Use information from the individual and family to make systems' improvements.
- Make sure that information collected from the individual and family includes diverse community groups.
- Provide training for families and professionals to give them skills in collaboration, communication and team building.
- Provide funds to hire individuals and family members to work in the system.

Questions:

Individual and Family:

- Did we understand the information provided?
- Did we ask questions until we understood?
- Did we seek out and attend training that was offered?
- Did we clearly identify what improvements were needed?
- Did we feel that our opinions were heard and valued?
- Did we offer any possible solutions?

Provider:

- Did I make sure the individual and family were included in all planning and evaluation activities?
- Did I make sure the individual and family were present when policies and procedures were developed and reviewed?
- Did I give the individual and family opportunities to comment on policies and procedures through surveys, forums, advisory committees, etc.?
- Did I ask the individual and family to help develop new programs and services?
- Did I request constructive criticism from the individual and family and use it to improve my practices?

System:

- Was the information from the individual and family used to make positive changes or just included in reports that sit on a shelf?
- Did staff receive training about policies, resources and ways to improve service delivery?
- Was training offered at convenient times for the individual and family?
- Did the individual and family understand the information about our agency/organization?
- Did budgets provide funds for hiring or involving individuals and families in the activities of the agency/organization?



Practice open communication

Indicators:

Individual and Family:

- Request, understand and use system policies to support our plans.
- Ask questions to clarify information.
- Identify the kinds of information that are most useful to us in making decisions.
- Consult another individual or family to help me understand information, systems processes, etc.

Provider:

- Listen and communicate in a respectful manner.
- Understand and use policies to support the plans of the individual and family.
- Provide copies of policies and assistance in understanding how the policies impact the individual and family.
- Provide practical and useful information.
- Offer mentors to help the individual and family understand information, systems processes, etc.

System:

- Write policies in language that is clear and easy to understand.
- Accommodate different reading levels, visual abilities and languages.
- Provide copies of the agency policies and practices that govern the services and how they are delivered.
- Give the individual and family time to read the policies and assistance in understanding how the policies impact them.
- Provide funds for training mentors to help the individual and family understand information, systems processes, etc.

Questions:

Individual and Family:

- Did we ask for copies of the agency policies and procedures?
- Did we ask questions until we understood the policies and other information about services?
- Did we describe how, when and what services we want?
- Did we explain why we want the services delivered in the way we described?

Provider:

- Did I really listen to what the individual and family want?
- Did I accept their values and expertise?
- Did I provide information that was easily understood and answer questions to clarify?
- Did I provide mentors who can assist the individual and family throughout the process?
- Did I provide options instead of expecting the individual and family to fit in the agency “mold”?
- Did I give the individual and family time to read and understand policies and procedures before making decisions?

System:

- Are policies and procedures written in language that is easily understood?
- Are policies and procedures available in other languages and formats, including Braille and large print?
- Do policies and funding support the development of mentors?

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ecognize the importance of the community

Indicators:

Individual and Family:

- Tell where we choose to live and what support we will need.
- Identify the community's natural supports that are available to us.
- Try to get services in natural settings within the community, such as churches, daycares and recreation centers.

Provider:

- Provide services in natural settings within the community.
- Support the individual and family to use community resources, such as recreation centers and daycares, rather than specialized settings.
- Support the individual and family to access their communities of choice.

System:

- Establish policies and funding for community-based services that are provided in the least restrictive environment.
- Establish policies and funding for staff training in development of community-based resources and services.
- Provide support to increase the community's understanding of the assets of the individual and family.
- Establish policies and funding to support full community integration.

Questions:

Individual and Family:

- Do we have a preference about where we live?
- Are we willing to seek out and use natural supports within our family and community?
- Have we taken time to learn what supports are available in our community?

Provider:

- Did I assist the individual and family in learning about and accessing supports in their community?
- Did I help create services where needed?

System:

- Is funding flexible enough to purchase services in the community, based on the choices of the individual and family?
- Do policies support the community-based choices of the individual and family?
- Is staff trained in development of community-based supports?

OKLAHOMA INDIVIDUAL AND FAMILY SUPPORT INDICATORS

Comments and Feedback

Please tell us what you think about the *Oklahoma Individual and Family Support Principles to Practice Indicators*.

TYPE OF REVIEWER (CHECK ONE)

- | | |
|---|--|
| <input type="checkbox"/> Person with disabilities | <input type="checkbox"/> Family member of person with disabilities |
| <input type="checkbox"/> Direct Service Provider | <input type="checkbox"/> State Agency Personnel |
| <input type="checkbox"/> Advocate | <input type="checkbox"/> Student |
| <input type="checkbox"/> Faculty | <input type="checkbox"/> Other |

INSTRUCTIONS

Members of the Oklahoma Family Support Partnership Council developed this document through activities of the Oklahoma Family Support Partnership project funded in part by the U.S. Administration on Developmental Disabilities (Grant # 90DF00074). The purpose of this document is to list actions and attitudes that are indicators of the practices associated with the Oklahoma Individual and Family Support Principles and key questions that serve as a self-check for the indicators.

We want your perspective about the document. Please complete the sections below and send back to: Vyonda G. Martin, Center for Learning and Leadership, PO Box 26901, ROB 342, Oklahoma City, OK 73190 or fax to (405)271-1459. You may e-mail comments to vyonda-martin@ouhsc.edu.

General Reactions to the Document:

Suggested Changes to the Indicators:

Suggested Changes to the Questions:

Other Comments/Feedback

Endorsement

I/we endorse the Oklahoma Individual and Family Support Principles. I/we agree with the principles and want to share information about the principles with others. Please count on me/us to:

(Check all that apply):

- Distribute copies of the principles to others
- Use the principles in training/education of others
- Use the principles to describe how I/we want services delivered

Signature

Date

Name

Agency/Organization/University (If applicable)

Mailing Address

City

State and ZIP Code

E-mail Address

Telephone:

I am: Individual with a Disability Family Member

To order copies of
**Oklahoma Individual and Family Support
Principles to Practice Indicators**
or the
Oklahoma Individual and Family Support Principles
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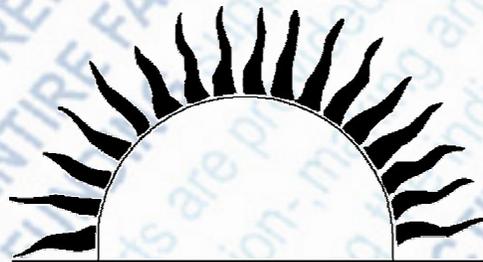
Web site: <http://w3.ouhsc.edu/thecenter/>

Endorse the Oklahoma Individual and Family Support Principles

The Center for Learning and Leadership invites you to endorse the Oklahoma Individual and Family Support Principles. If you agree with the principles and want to join others in distributing or sharing them, complete and sign the form on the opposite page. If you are signing on behalf of an agency or organization, please provide a letter of endorsement on letterhead. Send or fax the form and/or letter to the attention of Vyonda G. Martin at the above address. We will add yours to the list of endorsements and send you copies of the principles to share with other individuals, families, faculty and representatives of agencies and organizations.



Oklahoma
Family
Support
Partnership



Center for Learning and Leadership

A University Center for Excellence
in Developmental Disabilities

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