

We've got principles. Now what?

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The Oklahoma Individual and Family Support Principles to Practice Indicators is a booklet that represents a next step in the evolution of how we promote supportive practices that are centered on individuals with disabilities and their families. The booklet provides indicators to answer the question, "Now what?"

The Oklahoma Individual and Family Support Principles to Practice Indicators identifies ways of interacting, providing services, and developing policy that reflect the principles of individual and family support. The indicators are an attempt to put into words the expectations that individuals and families have when interacting with the representatives of the agencies and organizations that serve them and the expectations that those representatives have of the individuals and families. The indicators guide families, providers, and policy makers by offering suggested behaviors and action steps to achieve individual and family-centered services. The principles describe the standard for service and the practice indicators describe how we achieve the standard. It is possible to practice what we preach!

The Oklahoma Individual and Family Support Principles to Practice Indicators was developed in collaboration with families of individuals with disabilities, providers, advocates, higher education faculty, and students to help the whole service community understand how to take the principles into practice. We believe the principles that guide us toward this goal are universal. Principles for individuals are connected to principles for families, just as individuals are always connected to their families. These connections look different over time, but they guide our decisions across the lifespan. With these principles we hope to influence individuals, their families, providers, and the policies that govern the service delivery systems.

To understand the Oklahoma Individual and Family Support Principles to Practice Indicators you must first know the *Oklahoma Individual and Family Support Principles*. The principles a) are guiding truths that shape the way individuals, families, and service providers interact, b) establish common ground upon which individuals, families, advocates, and service providers operate, and c) form the basis for program policy and practice.

OKLAHOMA INDIVIDUAL AND FAMILY SUPPORT PRINCIPLES

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 WHICH 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 lifespan, 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.

The Oklahoma Individual and Family Support Principles to Practice Indicators describes actions and attitudes that illustrate the *Oklahoma Individual and Family Support Principles*. Sets of indicators were identified for each of three groups: 1) the individual and family, 2) the providers, and 3) the system. All players have responsibility to act on principles. Follow-along questions accompany each of the indicators. These questions provide opportunities for self-reflection about each of the principles. An individual and family indicator for the principle, *Focus on the Entire Family*, asks families to “Describe the way we work together to meet the needs of the individual as well as the needs of the other family members.” It has a follow-along question: “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?” One of the provider indicators for the

principle, *Promote Flexible Service Funding*, is “Trust the individual and family to make good decisions about the use of services and funds.” Its follow-along question asks providers to answer: “Did I give the individual and family an opportunity to tell their preferences and needs, and how they want services delivered?” Indicators for the system also were developed. For the principle, *Affirm Lifespan Planning and Self-Determination*, a system indicator is “Establish policies that are flexible enough to respond to current needs and supportive of future opportunities.” The question for the system is “Do we use individual family input to make improvements in the service delivery?”

The box below is a sample page from the Oklahoma Individual and Family Support Principles to Practice Indicators that illustrates the gentle teaching through follow-along for the principle, *Honor their Expertise*.

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.

Individual and Family Indicators:

- 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.

Questions for Individuals and Families:

- 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 Indicators:

- 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.

Provider Questions:

- 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 Indicators:

- 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.

System Questions:

- 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?

The Oklahoma Individual and Family Support Principles have been endorsed by organizations across the state and are featured prominently in clinic waiting rooms and centers that serve families. More important than being seen, however, we hope that families and providers experience the benefits of the principles as they interact with each other. The Oklahoma principles have been adopted or endorsed by groups from other states including the University of Vermont, Special Education Department of the College of Education and Social Services and the Vermont Human Services agency. In June of 2006 Community Living Services, a provider agency in Michigan, utilized the Oklahoma Individual and Family Support Principles to Practice Indicators as the basis to develop their agency principles and the strategies they will use to put the principles into practice.

An additional publication was developed to illustrate the practical application of the Oklahoma principles. Supported Families, a book of personal stories from Oklahoma families illustrates each of the principles at work. The stories talk about times when these principles were practiced by professionals. Sometimes the practice was intentional while other times the principle was experienced in action because it was a matter of doing the right thing. To request copies of these documents contact: Jan Moss, Director of Community Leadership and Advocacy or Vyonda Martin, Associate Director, Center for Learning and Leadership, Oklahoma's University Center for Excellence in Developmental Disabilities at the University of Oklahoma Health Sciences Center. Telephone: 405-271-4500 or 1-800-627-5827, extension 41004 or extension 41005. Email: jan-moss@ouhsc.edu or vyonda-martin@ouhsc.edu.

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