

Risk Management and Quality in HCBS: Individual Risk Planning and Prevention, System-Wide Quality Improvement

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Prepared by:

**Sara Galantowicz
Becky Selig
The MEDSTAT Group, Inc.**



**Elizabeth Pell
June Rowe
Human Services Research Institute**



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Introduction

We all face risks every day in the communities where we live and work. As individuals we manage risk in our homes, when we drive, in our personal investing, and in managing our health. Communities and governments manage risk as well, through a variety of strategies, including environmental safety and disaster preparedness.

Risk is the potential for realization of unwanted, adverse consequences to human life, health, property or the environment. (Oxford English Dictionary)

Risk management embraces all the decisions we make and activities we undertake with the intent of improving our health and safety and the environment. Each risk concerns the possibility of detrimental consequences and their likelihoods. The management part of risk management concerns decisions about these risks. Thousands of such decisions are made in the legislation and regulations in states and the federal government; millions are made by families and individuals. (National Quality Inventory Project)¹

Risks, and the need to manage them, are part of providing community-based services and supports to people with disabilities and the elderly. Depending on their individual circumstances, people who receive services under Medicaid home and community-based services (HCBS) waivers can be at risk of adverse outcomes. These potential risks fall into three general categories, as articulated in the National Quality Inventory Project.¹

- **Health Risks:** In addition to the omnipresent risks of disease and trauma faced by the general population, people who are elderly or who have severe disabilities face additional health risks due to their disabling conditions (e.g., malnutrition, seizures, respiratory and/or cardiac illnesses, etc.). Generally, persons who are over 70 years of age and persons with disabilities are more likely to be in poor health than non-elders and non-disabled individuals. In addition, a number of national and international studies have identified a risk for premature death among individuals with mental retardation and/or developmental disabilities.²
- **Behavioral Risks:** Some people with disabilities may place themselves and others at greater risk through their behavior. Behavioral risks include: poor decision-making about safety and health issues as a result of a brain injury or cognitive limitation; violent or criminal behavior; substance abuse; and suicide.
- **Risks to Personal Safety:** Many people who are elderly or who have severe disabilities are vulnerable to abuse and exploitation. They are often dependent on others for assistance with everyday activities such as eating or bathing, as well as with participation

¹ National Inventory of Quality Assurance and Improvement Systems: Medicaid HCBS Waiver Programs for Developmentally Disabled Individuals, NQIP MR/DD Tabular Survey Results, 2004. Glossary, p. 121.

² Sutherland, G., Couch, M.A., and Iacono, T. (2002). Health Issues for Adults with Developmental Disability. *Research in Developmental Disabilities* 23(6):422-445.

in the community. As a result, they face the additional risks of neglect, abuse, and financial exploitation. In addition, personal safety, including safe evacuation, can be compromised by mobility and cognitive impairments.

The responsibility for addressing these risks is not new to state waiver programs. States already address risk proactively through individual assessment and service planning processes, and in their efforts to assure the health and welfare of waiver participants through appropriate services and supports. Effective risk management builds upon the service planning and monitoring processes that states have already developed. Successful risk management for individuals on HCBS waivers requires three interrelated steps to build a comprehensive risk management system:

1. Identifying and documenting risks and developing written, individualized plans for addressing them;
2. Ongoing monitoring of risk levels and risk management strategies, along with training of key staff; and
3. Analysis of individual risk and risk management strategies to provide states with the evidence to develop a system-wide risk management strategy, and to continuously improve the quality of their programs.

Purpose and Methodology

Recognizing that states are engaging in risk planning for HCBS waiver participants, the Centers for Medicare and Medicaid Services (CMS) requested that the National Contractor for Quality in Home and Community Based Waiver Services³ explore the topic of effective individual risk management in community-based services. Specifically, we (the National Contractor staff) were asked to: determine how some states were currently addressing risk for waiver participants on an individual level; identify risk management themes and emerging issues; and identify any state tools or policies that can be useful to other states.

To fulfill this task, we selected 11 states that represented a range of waiver types and geographic areas. We then developed an interview guide and interviewed administrators from the state operating agencies. These agencies served at least one of four waiver populations (the elderly, people with physical disabilities, mental retardation and/or developmental disabilities or brain injuries). The selected states and the waiver populations served are shown in Table 1. Contact information for the participating states is in *Appendix A*.

³ The Centers for Medicare and Medicaid Services has contracted with The MEDSTAT Group, Inc. to assist states to design and implement quality assurance and improvement efforts in state Medicaid home and community-based waiver programs. This technical assistance initiative, called the “National Contract for Quality in Home and Community Based Waiver Services,” helps states to develop effective and reliable quality assurance and improvement systems and strategies for assuring the health and welfare of HCBS waiver participants.

Table 1. Selected States and Waiver Populations

| State | Waiver population(s) |
|----------------|--|
| Arizona | People with developmental disabilities |
| Florida | Elders |
| Kansas | People with physical disabilities |
| Kentucky | People with brain injuries |
| Massachusetts | People with mental retardation and/or developmental disabilities |
| New York | People with brain injuries |
| Oregon | Elders and people with developmental disabilities |
| Ohio | People with developmental disabilities |
| South Carolina | Elders |
| Vermont | Elders |
| Washington | Elders and people with developmental disabilities |

Key themes were distilled from these interviews, as well as from a limited review of the literature on risk and risk management, especially as it pertains to HCBS waiver populations. Selected articles, references, and resources from the literature review are in *Appendix B*. In addition, tools used by these states for individual risk identification, assessment, planning, and monitoring were reviewed. Many of these are available for use by other states. State tools are presented in *Appendix C*.

This monograph is designed to serve as a guide for states in examining their own risk management strategies for individual waiver participants. It is divided into five broad topic areas, each followed by conclusions and state examples where relevant. The five topics are:

- The Relationship Between Risk Management and Quality Management
- Identifying and Planning to Mitigate Risk at the Individual Level
- Monitoring and Remediating Risk at the Individual Level
- Training and Resources for Staff to Support Individuals
- Addressing Risk System-wide

Interspersed throughout the document are examples of how selected states have put into practice the concepts presented here. Whenever possible, we have included links to referenced documents or policies in *Appendix C*. Since this review is limited, readers are encouraged to contact the state agency staff listed in *Appendix A* to obtain more comprehensive information, documents and materials.

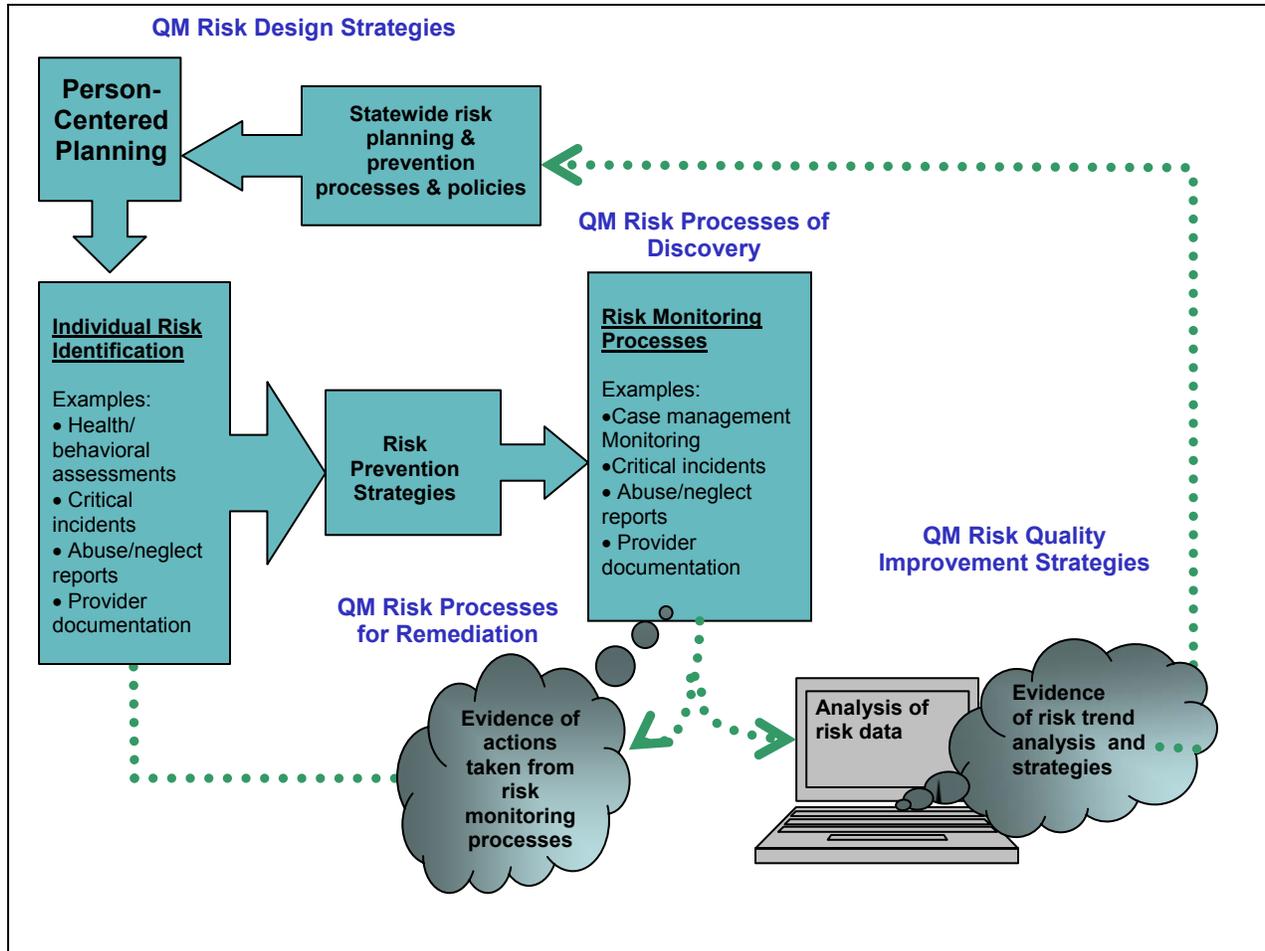
The Relationship Between Risk Management and Quality Management

Theme: Risk management is an essential component of quality management. Both are processes – a series of stages with feedback loops.

Managing risk is one key dimension of managing quality overall. Both risk and quality management processes start with the individual, and then progress to systemic management based on aggregated individual experience. The risk management process begins with

identifying or assessing known and potential risks; planning for them; intervening and/or treating risks; monitoring risk; and communicating about the process and results. Figure 1 illustrates this cycle of risk management and its relationship to quality management.

Figure I – Risk Management Cycle



As state waiver populations grow in both size and complexity, the ability to track and trend risk and risk management data becomes a key aspect of quality management. States can more effectively manage both individual and population-based risks when they have longitudinal information about those risks. It is also becoming increasingly important for states, as public entities, to not only document the results of waiver processes and policies they have implemented but also to produce evidence of the benefits of their programs. The documented actions taken by states to address risks for individual participants are the starting point for evidentiary-based reports on risk management that reflect the collection, aggregation, and analysis of individual level data from participants, providers, or case managers. This

documentation and analysis of specific state planning efforts lays the foundation for future, systemic quality improvement efforts.⁴

Identifying and Planning to Mitigate Risk at the Individual Level

Theme: Effective risk management begins with assessment and service planning centered around the individual waiver participant's needs and preferences. Potential risks are identified and documented, and individualized mitigation strategies are mapped out. Ongoing documentation of services targeted to address risk and negotiations around risk provide evidence of risk management.

Effective risk management starts with assessment and individualized service planning – something that states have been practicing for decades. Indeed, the goal of service planning – to create a system of services and supports to appropriately address individual needs and assure health and welfare – is essentially the same as the goal of managing risk. What may seem new to states is the terminology of risk management applied to a traditional focus on safeguarding health and welfare, along with an increased emphasis on documenting practices and decisions in order to create evidence.

Risk Management Begins with the Individual Assessment Process

Just as service planning begins with a needs assessment, risk management should begin with an effort to identify potential and perceived risks to the individual. In many cases, these risks are directly linked to the disability-specific needs identified during the assessment process. However, the presence and projected consequences of such risks may not always be documented in a participant's case records. Risk identification is more than a conversation between waiver participants, their families, case managers and others. It also involves a comprehensive documentation of that conversation. Such documentation provides the context and rationale for elements in the service plan and provides evidence that a risk management process is in place.

Not surprisingly, all the states we interviewed that have formal processes for risk identification and assessment have directly linked these processes to service planning. Most reported that some degree of risk identification was an essential part of the service planning process. In addition, the 2002 National Quality Inventory Project (NQIP) survey of waivers nationwide showed that both aging/disabled and developmental disabilities waiver administrators use standard assessments for identifying risk factors in a participant's life during the service planning process.⁵ Table 2 illustrates findings from the NQIP surveys regarding how state operating agencies identify the personal risk and safety factors of program participants.

⁴ The quality management process for HCBS waivers is outlined in the Quality Framework, released by CMS in 2003. Quality management functions identified in the Quality Framework include design, discovery, remediation, and improvement. Access the Quality Framework at: <http://www.cms.hhs.gov/medicaid/waivers/82902ltr.pdf>.

⁵ NQIP A/D Tabular Survey Results, p. 65 and NQIP MR/DD Tabular Survey Results, Appendix B, p.62.

Table 2. Results from the NQIP on Risk Identification Activities (2002)

| State Methods of Risk Identification | Waiver Program Respondents Who Report Using | |
|---|---|----------------------|
| | Aging/Disabled | MR/DD |
| Standard assessment incorporating health, behavior, safety, clinical and activities of daily living | 91.4% (n = 64/70) | 48.7% (n = 37/76) |
| Clinical assessment including psychological, medical, behavioral | 17.1% (n = 12/70) | 79.2% (n = 57/76) |
| Personal safety assessment tool | 12.9% (n = 9/70) | 22.4 (n = 17/76) |
| Health risk assessment tool | 11.4% (n=8/70) | 30.3% (n=23/76) |
| Behavior risk assessment tool | No data | 19.4% (n=14/76) |
| One or more strategies employed | No data | 94.7% (n=72/76) |

Consistent with the NQIP national findings, some of the 11 states we interviewed are using formal assessments to identify people who are potentially or currently at risk. In states that have developed comprehensive risk screening and/or assessment tools, we found these tools cut across disability populations because many of the risks people face are similar from one population to the next. Table 3 illustrates our review of tools used by six selected states, used either as a stand-alone instrument to assess risk or as part of a broader assessment process. Three of the tools are used in state waiver programs supporting persons with mental retardation/developmental disabilities (California, Massachusetts, and Pennsylvania), one is used in a state waiver program for persons with physical disabilities (Kansas), one is used with an aged/disabled waiver (Oregon) and one is used in a program that cross waiver populations (Washington). The categories listed were used in at least two or more of the tools we reviewed. We found that risks are often more broadly assessed when states incorporate risk assessment directly into service planning, because these assessments are fundamental to the individual's comprehensive service plan. In contrast, where separate risk assessment tools are used, these tools tend to more narrowly focus on risks that could lead to significant harm for the individual or others.

Table 3. Common Indicators of Potential Risk

| Assessment Categories | Assessed Potential Indicators of Risk |
|----------------------------|---|
| Mental Health | • Capacity/cognition |
| | • Depression screening |
| | • Dementia screening |
| | • Psychiatric hospital admission/suicide gestures or attempts |
| | • Psychosocial stressors (losses, frequent moves, etc.) |
| Health and Wellness | • Communication |
| | • Seizures |
| | • Skin integrity |
| | • Sleep disturbances |
| | • Preventative screenings (e.g., PAP) and dental care |
| | • Vision |
| | • Hearing |
| | • Bladder/bowel |
| Medication | • Medication reviewed periodically/medication consistent with diagnosis |
| | • Interactions and adverse reactions |
| | • Emergency medication use |
| Nutrition | • Choking/swallowing |
| | • Diet compliance |
| | • Caregiver trained/compliant with diet |
| Behavior Related | • Aggressive behavior |
| | • Self-injurious |
| | • Substance use/abuse |
| | • Unsafe/criminal sexual behavior |
| | • Law breaking behavior/fire fascination or fire setting |
| Personal Safety | • Risk of falls/mobility level |
| | • Emotional or physical abuse or financial exploitation vulnerability |
| | • Caregiver stress/neglect |
| | • Participant/caregiver service refusal/interfering |
| | • Social isolation |
| Environment | • Unsanitary/unsafe housing |
| | • Unsafe neighborhood |
| | • Multi-client household |
| Resources | • Lack of adequate supports |
| Other | • Prior residence in institution |

- California’s Risk Assessment, Evaluation and Planning (DD waiver)
- Kansas’ Uniform Assessment Instrument (PD waiver policies and procedures)
- Massachusetts’ Risk Management System (MR/DD waiver)
- Oregon’s Client Assessment and Planning System
- Pennsylvania Health Risk Profile (MR waiver)
- Washington State’s Comprehensive Assessment Reporting Evaluation (across waiver populations)
- Washington State’s Challenging Cases Protocol

State Examples of Risk Identification Tools

Arizona has developed a prevention, risk assessment, and health-planning tool that is an integral part of the participant’s service plan and specifically assesses and documents risks for that individual. The assessment tool defines risk contextually. Dimensions include medical risk (such as diabetes or the risk for aspiration), behavioral risks (including concerns that a participant may run away), and community risks (such as vulnerability to abuse and forensic

risk). These tools are for individuals in residential settings funded by the Division of Developmental Disabilities, as well as for any other individuals for whom the support team feels they are necessary and would be beneficial.

In **Pennsylvania**, the Office of Mental Retardation developed the Health Risk Profile to screen for physical and behavioral health risk factors for the population of people with mental retardation. Initially it was used for a population of people who have resided in or were being transferred from state institutional residences. Currently it is used with people who live in the community. Using this statewide data set of health information for this special population, state agency staff have learned that the most prevalent behavioral diagnosis in the ‘high risk’ group was bipolar disorder and the most prevalent physical diagnoses in the ‘high risk’ group were dysphagia, constipation, and seizures.

Washington recently implemented an automated, comprehensive assessment and planning tool for Medicaid funded personal care. Known as the Comprehensive Assessment, Reporting, and Evaluation (CARE) tool, the tool contains over 60 personal care screens and is used for all individuals receiving in-home and residential services. Some of the personal care screens assess a variety of risk factors, including: environmental issues; cognition, behaviors, depression, suicidal tendencies; medical diagnoses and treatments, medication, skin care indicators, pain, falls; psychological/social assessment; personal elements (smoking, alcohol, substance abuse); and legal issues (including the potential for abuse and neglect).

The Role of the Consumer in Managing Risk

Consumer involvement and choice, in service planning and all aspects of waiver programs, is an important dimension of the risk management conversation. Like the individual needs and preferences that must be addressed in service planning, risk is also highly individualized. What constitutes risk for one person can pose little or no risk for another. Risk is a combination of individual circumstances, events, and perceptions. A cognitively-intact frail elder needs services that are different from those needed by a strong young adult with a severe brain injury, and the risks they face in community settings differ as well. Different, also, are their expectations and preferences, which in turn influence their perceptions of, and tolerance for, risk.

All people, disabled or not, take risks. However, people with disabilities and the elderly may be more vulnerable to negative outcomes, as well as more vulnerable from the effect of negative outcomes. This is due not only to poor health status, but also to the inability of some to make informed decisions about risky behaviors and their consequences. Health experts also recognize that low literacy negatively impacts an individual’s ability to make informed decisions, as do factors such as adequate vision, concentration, working memory, and the ability to process information – all competencies that deteriorate with age.⁶ Balancing a waiver participant’s right to make choices, including potentially unhealthy or unsafe ones, with the State’s need to assure the health and welfare of waiver participants is an over-riding concern for states. There is consensus that consumers must be involved in all aspects of HCBS waiver services, including the way in which risks are managed.

⁶ Dubow, J. (2004). *Adequate Literacy and Health Literacy: Prerequisites for Informed Health Care Decision Making*. AARP Public Policy Institute (http://research.aarp.org/health/ib70_literacy.html).

As author Michael Smull notes, “Choice is the most powerful word and the most abused word in the current lexicon of the disabilities services system.”⁷ He defines choice in service planning as including three related and embedded concepts: preference, opportunities, and control. In short, control is the authority to make use of an opportunity to satisfy a preference. Smull says that one of the traps of planning is that we determine how people can be safe before we examine what they require to be happy. We should start the planning with an understanding of what people need for their happiness and then examine the risks entailed, as risk is both relative and contextual.

Consumer involvement in service planning exists in its most evolved form in consumer-directed services and supports. In consumer-direction, waiver participants may hire, train, and direct their own service providers, some of whom are independent providers who do not work for agencies. This presents waiver participants with both new opportunities and new risks. Addressing these risks is discussed in the CMS sponsored monograph “Quality Assurance and Improvement Systems: Components When Using Independent Providers,”⁸ and will not be discussed here.

Developing Risk Mitigation Strategies and Plans

It is not enough to just identify and list the risks faced by a particular waiver participant. Such an enumeration must also be used to develop the strategies, supports, and services to mitigate these risks. Because risk is individual, so too must be the plans for managing it. Waiver participants, along with their circles of support, must play a key role in developing these strategies. Furthermore, while clearly linked to the development of the service plan, the identification and planned mitigation of risk may, in some cases, be best presented as a companion to the plan of care. This complementary risk management plan can help staff to focus specifically on the concept of managing risk, and subsequent collective analysis of individual strategies will enable states to develop systemic improvement efforts.

For a risk management strategy to address risk as fully as possible, it must identify those risks as fully as possible. The states we interviewed that use standardized risk assessment tools use this information to develop strategies to meet the unique needs of program participants. However, other states told us that standardized assessment tools are not always appropriate, given the diversity of their waiver populations. Standardization could limit the scope of the assessment to only those items covered by the assessment tool and, because the waiver must safeguard the health *and* welfare of its participants, the scope of potential risks can be appreciable.

State Examples of Planning for Risk Mitigation

Arizona developed a Community Protection and Treatment program to work with high-risk individuals. The State’s Division of Developmental Disabilities designed the program to allow for cross-agency identification of high-risk participants and subsequent development of community protection plans on an individual and a system level. The program lists training competencies that qualify provider staff to support participating individuals. Currently the state

⁷ Smull, M.W. (1995). *Revisiting Choice*. in *A Little Book about Person Centered Planning*. J. O’Brien and C.L. O’Brien, eds. Inclusion Press, p. 37. Also available at: <http://www.elpNet.net/choice.html>.

⁸ Forthcoming.

has identified approximately 50 individuals for the program, some of whom are court-ordered to participate.

In **Kentucky's** acquired brain injury waiver, when an individual becomes eligible for services, the waiver-administering agency authorizes a service plan for just 30 days. This allows the individual and his or her service planning team to start working together to customize a service plan with individualized goals and objectives and a separate Crisis Prevention and Response plan. This latter document articulates potential risks, and the planned supports to mitigate these risks. The state recognizes that this is a difficult population to serve due to the high prevalence of substance abuse, criminal justice involvement, and mental illness, as well as the cognitive deficits caused by brain injuries. Therefore, both the service and crisis plans need to be flexible enough to address the individual's specific needs and situations. As a result, Kentucky does not have standardized templates for either the service or crisis prevention plan, and discourages the use of generic plans by case managers.

In **New York**, service plans developed for brain injury waiver participants include a separate document known as the "Plan for Protective Oversight." This document identifies risk factors and the services needed to mitigate them, and designates specific persons to be responsible for providing the necessary services and oversight. Each person must sign the plan, indicating acceptance of his or her responsibility. Previously, this type of information was buried in the service plan. However, the State determined that it was necessary to explicitly document risks and their mitigation strategies. Some of the areas that may be addressed in the plans include money management, medication management, kitchen safety, and backup staffing for unscheduled staff absences. These plans are revised at least every 6 months, and more often if circumstances warrant.

Also in **New York**, the statewide NeuroBehavioral Project evaluates risks among current and potential brain injury waiver participants. Instead of using a standardized assessment tool, the review team looks for a combination of factors that indicate whether or not the individual's health and welfare can be assured in the community. Some of the risk factors considered include:

- Long-standing history of substance abuse (without a commitment to quitting);
- Criminal justice history;
- History of violence;
- Refusal to accept 24 hour supervision (when deemed appropriate); and
- Concerns about safe behavior towards self and others in a community setting.

Data for these assessments are drawn from providers, service coordinators, and incident reports. If the review team determines that an individual cannot be served safely in the community, he or she will either be removed from the waiver, or not accepted onto the waiver. Regardless of the team's decision, they extensively document their findings and decision process.

Oregon recently redesigned its individual support plan to create a standardized service plan format, so that risk factors and strategies to ameliorate risk are carried across providers and services. With only one plan to encompass the person's life, all providers and involved parties

are at the table together to develop the unified document. A new risk identification tool is part of the support planning process. It covers medical, behavioral, and financial risk, but is particularly focused on medical risks. Oregon found a correlation between medical risks and severe risks when it reviewed the deaths of persons with developmental disabilities over the past 8 years, and learned that the four most common causes of death were aspiration, constipation, seizures, and dehydration.

Negotiating and Documenting Conflicts in Risk Management Strategies

When individuals begin receiving waiver services, many new players, such as providers, case managers, and state QA staff, will impact decisions about risk. This can make exercising individual choice a negotiated process. Although the goal is still to honor choice and individual preferences in the service planning process, waiver participants and their families may not always agree with the strategies and supports for mitigating risk recommended by a provider or others. This may be especially true for brain injury survivors and people with cognitive limitations, whose disabilities can distort their perception of the risks they face. But, just as people vary in their perception of acceptable levels of risk and their degree of risk tolerance, so too will waiver participants have differing ideas about the amount of risk they are willing to take.

States and providers are still exploring ways to formalize this negotiation process. While states are required to assure health and welfare, CMS has not published thresholds for acceptable levels of risk, because risk is highly individualized. In negotiating trade-offs between choice and safety, states will best be served by documenting: the concerns of participants, waiver staff, providers, and any other stakeholders; the negotiation process; and the analysis and rationale for decisions made and actions taken. When states document these aspects of their monitoring activities, they will have solid evidence to support their policies and individual plans.

One tool that offers the participant some negotiated authority is the individual risk contract – an agreement that outlines the risks and benefits of a particular course of action, the conditions under which the participant is assuming responsibility, and the accountability trail.⁹ Negotiated risk contracting has been used in some settings, primarily assistive living, as a tool to support consumer-directed care. It allows individuals to assume responsibility for their choices personally, through surrogate decision makers, or through support team consensus. The NQIP results showed that about 18.6% of waiver programs for the elderly and disabled and 15.8% of waiver programs for mental retardation/developmental disabilities nationwide were using some form of risk assumption agreements in 2002.¹⁰

A debate of the pros and cons of negotiated risk agreements as a tool for consumer empowerment has been ongoing since the mid 1990s. Some feel that risk agreements allow consumers to make an informed decision to accept both risk and responsibility.¹¹ Others think that negotiated risk contracting also complements consumer-directed initiatives because it allows

⁹ Moseley, C. (June 2001). *Balancing Safety and Freedom in Consumer-Directed Systems of Support*. A technical assistance paper of the national project, Self-Determination for People with Disabilities. Institute on Disability), University of New Hampshire, p. 7.

¹⁰ NQIP A/D Tabular Survey Results, p.73 and NQIP MR/DD Tabular Survey Results, p 62.

¹¹ Kapp, M. and Wilson, K.B. (1995). *Assisted Living and Negotiated Risk: Reconciling Protection and Advocacy*. *Journal of Ethics, Law and Aging*, 1(1):27.

consumers to take responsibility for their choices by informed consent, following discussion with a circle of support.¹² However, there is an implied reduction of provider liability when the consumer assumes risk. Others have written that the use of negotiated risk agreements is bad public policy because existing law already affords individuals the right to make choices. They argue that negotiated risk agreements are harmful to consumers because, instead of creating rights, they waive a facility's liability for injuries to the consumer. Therefore, they violate public policy and are unenforceable.¹³

Negotiated risk agreements have not been widely adopted in HCBS waivers. They are a relatively new phenomenon in long-term care and no court has yet ruled on the enforceability of liability waivers in this kind of contract. States may be concerned because courts traditionally will void agreements when a person's choice was influenced by unequal bargaining power.¹⁴ Instead, some states have reconciled the individual's right to assume risk with efforts to assure his or her health, safety, and welfare by developing protocols for negotiation or resolution at the individual and team planning levels. These are discussed below.

State Examples of Risk Negotiation

Kansas provides case management in its waiver supporting individuals with physical disabilities through Independent Living Centers (ILCs), non-medical peer support programs with a core philosophy of person-centered services and self-direction. If a participant is identified as being at risk, the roles of the State are to provide the participant with advice about the perceived risks and their potential consequences and to document the decision-making process. In many cases, the role of the ILC is to bring peers and surrogate decision makers into the risk assessment and planning process *without* taking away the participant's rights to make decisions. In extreme cases, a waiver participant may be moved from self-directed to agency-directed services, with transfer of the case management from the ILC to a home health agency. However, this is rare.

In **New York**, when brain injury waiver participants elect to choose less assistance than staff believe is appropriate, service coordinators are directed to conduct an evaluation to test the participant's proposed level of services. During a specified evaluation period, participants agree to accept services and regional oversight staff closely monitor both the service provider and the participant to evaluate appropriateness.

Vermont has developed a negotiated risk management agreement for elders and people with disabilities called "The Informed Consent and Negotiated Risk Policy." It commits the participant and/or legal representative and service providers to a process of negotiation that results in a formal written agreement. This process respects the participant's preferences,

¹² Duvall, N.M. and Moseley, C. (June 2001) *Negotiated Risk Agreements in Long-Term Support Services*. Institute on Disability (supported by National Program Office on Self-Determination, a project funded by The Robert Wood Johnson Foundation), p.5.

¹³ Carlson, E. (Spring 2003). *In the Sheep's Clothing of Resident Rights: Behind the Rhetoric of "Negotiated Risk" in Assisted Living*. National Academy of Elder Law Attorneys. *NAELA Quarterly*, (http://www.nslc.org/articles/neg_risk_naela.pdf).

¹⁴ Duval, N.M. and Moseley, C. (June 2001). *Negotiated Risk Agreements in Long-term Support Services* at: http://consumerdirection.org/docs/Negot_Risk.doc.

choices, and capabilities, and is designed to decrease the possibility that participants' decisions or choices will place them or others at risk of significant harm. Participants are advised of this option by their case managers and through written materials about their rights under the waiver program. The case manager and waiver team determine when a risk management agreement is warranted, which is not often. Waiver administrators estimate that less than 5% of elderly participants have ever had such an agreement.

Washington implemented a Challenging Cases Protocol to promote statewide consistency in responding to situations in which the service recipient or applicant refuses or sabotages services and supports crucial to maintaining his/her health and safety. The protocol also addresses behaviors of recipients/applicants that endanger the safety of both the recipient/applicant and care providers. The protocol emphasizes that an individual's safety is a shared responsibility between the recipient/applicant, the Department of Social and Health Services, and other relevant community agencies. To this end, the protocol involves community-based interdisciplinary, inter-agency teams that consider all available assessments, services, costs, and obstacles to implementation before denying or terminating services.

Interagency Coordination can be Very Effective in Managing Risk

The risks faced by HCBS waiver participants are highly individual, but some of them also cut across providers and settings. For those individuals at greatest risk (due to serious health conditions, precarious living situations, or behavioral issues), coordinating risk mitigation strategies across agencies can be very effective in assuring that all of their individual needs are met appropriately. Through our interviews with the 11 states, we identified states that have initiated inter-agency or inter-department collaborations to coordinate interventions and share information regarding citizens considered at high-risk in the community. State examples are given below.

During these interviews, some states identified the need for more seamless communication between waiver-administering agencies and state Adult Protective Services (APS). In some states, waiver staff can identify the number of APS cases for people with disabilities, but not how investigated cases are resolved. Managing the risks that may lead to APS involvement in advance is an important part of assuring health and welfare. In addition, system-level analysis of data on cases referred to APS can be a powerful diagnostic tool for quality improvement efforts.

State Examples of Interagency Coordination

Arizona has selected specialty interagency coordination strategies, including a statewide training with police departments in the state to decrease the risk when law enforcement becomes involved with people with developmental disabilities. Through this effort, the agency serving people with developmental disabilities works with law enforcement officials to identify people at risk, both case-by-case and system-wide. This agency also maintains close linkages with the behavioral health system to promote coordination.

In **Ohio**, the state agency administering HCBS waivers for people with developmental disabilities has established Memoranda of Understanding to coordinate support for program participants with two other state agencies, the Ohio Department of Mental Health and the Ohio

Department of Corrections. Realizing that no single department can fulfill one individual's needs, these agencies are cooperating at the state level to provide training and technical assistance to each system's comparable agency at the local level. These three agencies collaborate, negotiate, and learn what does and doesn't work to support individuals. In addition, through a Department of Mental Health initiative, the State has established a web site for coordinating centers of excellence and promoting and sharing best practices and resources.

Monitoring and Remediating Risk at the Individual Level

Theme: Effective planning is the foundation of an effective risk management system, but planning alone is not enough. Waiver programs must monitor implementation of these plans, and ongoing levels of risk. Case managers and good monitoring systems are the link between the risk management plan and its outcome. Monitoring allows real-time changes in services and supports when needed, and remediation of individual problems. Monitoring can also create evidence that systems and strategies are working.

Even the best risk mitigation strategies will be ineffective if appropriate services and supports are not provided. States must develop systems to ensure that risk management plans are being implemented and adjusted when necessary. Information about the required services and supports flows down through case managers and monitoring systems, and data about the provision and impact of these services flows up into the service planning process. Monitoring creates the feedback loop shown in Figure 1 (p.4). Changes in circumstances, conditions, and preferences affect risk and must be addressed on a timely basis.

States mobilize the case managers who plan services to play a key role in identifying and monitoring waiver participant risk. One common case management activity is monitoring the delivery of the supports identified in a person's service plan. Do paid staff show up on time, on the right days, and provide the proscribed services? In addition to this general tracking function, we found in our interviews some correlation between heightened risks to a waiver participant and increased monitoring by case managers. This includes both increased monitoring to evaluate the need for additional supports and increased contact between case managers and participants.

Waiver staff use a variety of information sources to monitor risk and participant outcomes. States learn about people who are involved in risky situations through case manager monitoring, health status monitoring, medication management and follow-up, reports to a supervisor or Adult Protective Services, and incident management and reporting systems. Sometimes states learn that waiver participants are considered dangerous to their communities through the criminal justice system (e.g., when a sexual assault occurs). When individuals present as dangerous to their communities, then the number of parties interested in that person's life increases. As a result, agencies may want to bring in another agency and coordinate monitoring and service delivery.

State Examples of Risk Monitoring and Remediation

Case managers with **Kentucky's** brain injury waiver are required to meet face-to-face with their clients every 2 weeks due to the population's overall high level of risk. At each visit, they are

required to monitor the delivery and outcome of services as well as document the waiver participant's health and welfare.

Ohio tracks all major and unusual incidents among participants in its developmental disabilities waiver, and a prevention plan may be developed in response to a significant incident. When three or more incidents occur, a prevention plan is required. Cooperation between agencies through Memoranda of Understanding enhances the State's ability to address individual needs and remediate individual problems.

In **Oregon's** developmental disabilities waiver, case managers are required to visit an individual face-to-face once a month and monitor plan outcomes. The visit protocol, which includes risk assessment, guides the case manager's evaluation of the provider's delivery of services and supports. The protocol contains a feedback loop as well, so that something observed in one visit must be checked again on a subsequent visit.

South Carolina has implemented a Care Call system to monitor and track the actual time that providers are in an individual's home. In-home providers call into the system by phone both when they arrive and when they leave. This allows the State to track the actual time of service provision for billing purposes. It also collects information about when providers don't show, or show up on the wrong day or at the wrong time. Data from the system can prompt a case manager to reevaluate whether services are provided and adequate, and whether unmet needs are placing waiver participants at risk. Care Call matches telephone numbers to locations so that providers cannot call on a cell phone from one location and report being elsewhere. (The State has used this function to prosecute fraudulent claims.) Monthly activity reports for each in-home worker are reviewed by case managers against service authorizations.

Washington is developing protocols in selected high-risk categories to be part of its quality assurance monitoring process. For example, the skin observation protocol is triggered automatically when certain clinical characteristics are identified in the assessment, such as a pressure sore or history of pressure sores, incontinence with cognitive impairment, and confinement of the individual to a bed or chair for most of the time. Once the protocol has been triggered, policy requires that it be followed. The tool also identifies critical indicators related to multiple medications, unstable diagnosis, immobility, etc. The assessor must analyze these indicators and the client characteristics which triggered them and decide whether to make a nursing consultant referral. A nurse may then review the file, make follow-up phone calls, or even make a home visit to evaluate a specific need or needs.

Training and Resources for Staff to Support Individuals

Theme: For risk management to be truly effective, staff must have the competencies and resources to support individuals in managing their own risk. A responsive system that maximizes people's health and welfare requires training case managers to: know when and how to adjust monitoring in response to risk; adjust expectations around ongoing identification of risk factors; and provide the necessary resources to address situations of risk.

Once states have developed or adopted risk management tools and strategies, it is essential that staff be trained to use them. Training not only imparts the skills and knowledge necessary for

the risk management process, but also underscores the importance attached to these activities. States that do have well-developed risk and/or service planning often require specialized training for their case managers. National Quality Inventory results for 2002 showed that 71.1% of state mental retardation/developmentally disabled waiver programs required case manager training in participant safety.¹⁵ In addition, in our interviews we found a number of states have developed clinical resources for case managers and/or others, such as providers, to help them address the needs of people who are at risk. Some have also developed formal training programs that include specific topics on risk-related subjects.

Adequate staffing and resources are essential components of a risk management system, in addition to training on the tools to do the job. Increased monitoring in response to increased risk requires case managers to have caseloads that allow them to spend the necessary time with clients. Requiring case managers to negotiate risk decisions with individuals implies that they should have access to sufficient resources, both written and personnel, during the negotiation process.

Insurance and risk adjustment agencies have developed consultation services and tools for HCBS services. One such agency offers states risk management tools, such as an assessment tool to help identify individual desires, risk preparedness, and risks associated with daily life activities in the community. Other resources include training materials on the steps in the risk management process, as well as technical assistance to provider agencies.

State Examples of Staff Training and Support

Arizona's case managers receive detailed training to use the prevention risk assessment, health and planning tool for individual service plans. This training curriculum provides seven scenarios used to practice balancing rights versus risks.

In **Kansas**, training for case managers has been incorporated into state law and appears on the Social and Rehabilitation Services web site for on-line access. Specific areas of training relate to assessment, making Adult Protective Services reports, and transferring a participant from self-directed to agency-directed services.

Massachusetts places risk managers in each regional office to provide technical assistance to staff at the local area offices, which employ and oversee the waiver case managers.

In **New York**, regional contracted staff, Regional Resource Development Specialists (RRDSs), oversee the state's TBI waiver. RRDSs receive intensive training regarding brain injury and the waiver program. This training includes a focus on Quality Management activities, balancing waiver participants' right to accept risk, and assuring participants' health and welfare. Training materials are disseminated through regular RRSD meetings. Additionally, the statewide Neurobehavioral Project is used to assess the waiver's ability to assure an individual's health and welfare when there is significant concern.

¹⁵ NQIP MR/DD Tabular Survey Results, Appendix B, p. 26.

In **Ohio**, the 12 developmental disabilities centers have expanded their focus to also serve as a resource to geographic portions of the state. Staff at the centers provide professional consultations for community-based staff on the topics of behavior supports and medical care. In addition, Ohio significantly increased the number of case managers in its waiver program over the last 5 years to handle the additional planning involved in working with each individual.

Oregon's developmental disabilities waiver maintains a team of nurses available through the five regional coordinators for on-site and off-site consultation and staff support. The regional coordinators are available to case managers for information and technical assistance and to coordinate responses to serious risks. In addition, Oregon's Individual Support Plan System manual has a chapter devoted to significant risks, including: the importance of identifying and tracking risk; instructions on procedures and review tools; specific assessments of health/medical, safety/financial, and behavior; and guidance for reviewing and updating the participant's risk tracking record and monitoring interventions.

In **Washington**, 40 hours of training per year on the State's Long Term Care Manual (LTCM) is provided to case managers at the state headquarters. It includes risk-related topics such as working with Adult Protective Services. Case managers receive additional core trainings via a contract with the University of Washington's Departments of Psychology, Nursing and Social Work for topic-specific, 3-day trainings annually for the first four years of employment.

Addressing Risk System-wide

Theme: Once states have developed comprehensive systems for managing individual risk, these systems form the basis for addressing risk system-wide. The long-term goal is to expand from monitoring quality on an individual basis to a systemic quality improvement effort. Analyzing collective data from managing risk for individual participants points the way toward improving risk management systems overall.

Risk management on an individual level, while critical, is only the first step toward continually improving systems to assure the health and welfare of all waiver participants. States gain knowledge to initiate systemic quality improvement activities by identifying and addressing the collective risk factors of individuals. Systemic identification activities could include reviews of aggregated service and risk planning efforts, incident reports and investigations, and documentation of case managers' communications with participants. Analysis of this data helps states to learn more about their waiver populations and the collective risks they face. The key is for states to review aggregate information to become knowledgeable about the risks involved in serving their entire waiver population, not just selected individuals.

Data on risk trends can come from a variety of sources, not just individual risk management plans. Claims data, participant surveys, and incident reporting systems can all indicate areas of unmet need, poor health status, suspected abuse, and other factors that place waiver participants at risk of adverse outcomes. In general, states are most likely to have and use data from incident reporting systems. Identifying and using other data has been a greater challenge. There are, however, many examples of national and state indicators for waiver populations, including a

web-based database of quality indicators for HCBS waivers.¹⁶ Further, to assist states to understand, design, implement and monitor the components of quality improvement for HCBS programs, CMS recently released an interactive guide called the “Work Book: Improving the Quality of Home and Community Based Services and Supports,” to walk users through the steps for developing and implementing quality improvement projects and to provide information on available sources of data.¹⁷

NQIP survey results showed that states currently examine available data and identify systemic trends with varying levels of sophistication. Some states, mostly in their MR/DD waivers, are collecting and using risk information at the individual level, as well as systemically for risk prevention and system-wide change. For states examining risk data at the systemic level, when negative trends in outcomes are identified, issues are prioritized and then action plans developed to intervene both on the individual and systemic level. Some states have developed comprehensive risk management systems that include data analysis at the system level, while others have developed data-review processes to address quality assurance domains such as mortality review, root cause analysis, and risk review committees.¹⁸ According to NQIP survey responses, 23.4% of state MR/DD waiver programs and 5.7% of aging/disabled programs reported having such a committee in 2002.¹⁹

The quality improvement activities that result from this type of analysis might include developing or furthering interagency collaboration, coordinating efforts to better meet the identified needs of at-risk waiver populations, or developing training initiatives for particular health or behavioral issues. State quality management systems will improve as states grow accustomed to using the documented results or evidence from aggregated reviews to identify and address potential areas of risk system-wide. Analysis of aggregated data, such as incident management data, can also lead states to develop and/or revise state regulations to better address individuals’ health and welfare.

State Examples of System-wide Analysis and Improvement

Arizona analyzes trends in data from the State’s incident management system. One early finding was that when incidents occur, direct care worker reporters were calling their supervisors before 911. As a result, the state conducted trainings to correct the reporting response.

Massachusetts developed a risk management system which includes four components integral to the quality improvement process: Risk Identification and Prevention; Risk Assessment and Planning; Risk Training, Consultation, and Support; and Risk Management System Oversight activities. Quality assurance oversight is standardized to incorporate a sample of individual reviews (proposed at 10% per area office). These reviews are conducted by regional risk management coordinators on individuals identified to be at risk. Reviewers also examine a few individuals not considered to be at risk to verify that these program participants do not pose a serious risk to themselves or others. Additional oversight activities include periodic individual

¹⁶ <http://qualitychoices.muskie.usm.maine.edu/qualityindicators/index.htm>

¹⁷ The Work Book is available on-line at: http://www.cms.hhs.gov/medicaid/waivers/7_workbook.pdf.

¹⁸ A more detailed discussion of root cause analysis can be found at:
http://www.hcbs.org/files/34/1669/Root_Cause_Analysis.pdf.

¹⁹ NQIP MR/DD Tabular Survey Results, Appendix B, p.61 and NQIP A/D Tabular Survey Results, p.65.

reviews by the central office Risk Management Manager, trainings in each region, and an annual statewide report on risk management in both community- and facility-based services. The risk management system is an ongoing, as opposed to annual, process that is operational at the participant level, the provider level, and the state monitoring level. It also provides outreach to community stakeholders such as police, health care providers, and other public entities.

In 2003, **New York** conducted a participant survey with approximately 200 participants in the state's traumatic brain injury waiver. Items on the survey included access to care and unmet need for personal assistance, case manager access, community integration, and theft and abuse, among others. A random sample of waiver participants state-wide allowed waiver staff to generalize their findings across the program. From the analysis of the data, the waiver program became aware that participants felt that staff did not understand what it was like to live with a brain injury. It was also clear that some participants were not aware of their right to choose staff, or services. As a result, written materials and a video on participant rights and on brain injury were developed, which will be sent to all providers of TBI waiver services. These materials were presented to providers in a train-the-trainer model. Once these materials are distributed, the waiver program will be requiring all staff working with waiver participants to review participant rights with individual participants on an annual basis. Signed forms, indicating that this process has been completed, will be sent to the service coordinators to assure full compliance.

Oregon has implemented a Serious Event Response Team (SERT) for people supported through their developmental disabilities program. For this population, the state has implemented web-based reporting of all critical incidents, protective services, and licensing reviews. Each county has an advisory committee that reviews the data for trends and concerns in their area and sends a monthly report to the Central Office Quality Assurance staff. The QA staff review standardized data by provider, by county, by non-respondents, by individual, and collectively statewide. The state has established a statewide advisory committee that reviews the data for trends and concerns in their area and makes recommendations for action and change. For seniors and people with disabilities, each area has a local senior advisory committee and disability advisory committee. The chairs from each of these local groups meet as a statewide senior or disability policy advisory committee. The state is also initiating a statewide quality assurance advisory committee.

Washington uses information from a variety of sources to make systemic improvements to their Comprehensive Assessment, Reporting, and Evaluation (CARE) tool for service planning (described above). The CARE tool includes a nursing referral "trigger" for critical issues. When the Skin Observation Protocol is triggered, a standardized set of caregiver instructions prints out automatically in the client's plan of care on how to prevent skin breakdown for clients at risk. Other Critical Indicators that may be triggered if the client has frequent falls, problems taking medications correctly, frequent hospitalizations, unstable medical condition, and so forth. The case manager is then required to determine if a nursing referral is required. Monitor these referral patterns provides state staff with data to develop new protocols, such as those designed to prevent problems related to falls and medication issues, similar to the Skin Observation Protocol. To ensure that field staff are coding the assessment correctly, state QA staff conduct routine site visits to review files and perform inter-rater reliability assessments on the CARE tool. QA staff also track compliance with follow-up on issues identified in the CARE.

Also in **Washington**, field staff can request an “exception” to the funding level established through the CARE assessment. By tracking and analyzing approximately 200 exception requests monthly, adjustments are made in the hour/rate payment algorithm in order to reduce the number of exceptions. State agency administrators also analyze patterns of questions from field staff about CARE to make systemic improvements. Trends identified through these QA processes are used to make ongoing improvements in the CARE tool and the payment method. This analysis also enables State administrators to target training and assistance to field staff in increase proficiency in the using CARE to identify participant service needs.

Conclusions

A comprehensive risk management system for individuals on HCBS waivers is composed of a series of necessary building blocks. These are:

- Identifying and planning to mitigate risk for individuals;
- Monitoring and remediating individual risk;
- Providing training and resources for staff to support individuals; and
- Addressing risk system-wide.

While states are already using some or all of these steps, they can improve their current service planning efforts by talking about and carefully documenting risk management activities, especially the negotiations around risk and individual choice. Further, states can use this documentation to move toward the ultimate goal of system-level improvements based on the information drawn from risk management at the individual level.

Appendix A. State Contacts

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| Arizona | <p>Barbara Brent, Deputy Assistant Director Department of Economic Security, Division of Developmental Disabilities Phone (602) 364-1140 E-mail: BBrent@mail.de.state.az.us</p> |
| Florida | <p>Ron Taylor, Director Division of Statewide Community-Based Services Phone (850) 414-2067 E-mail Taylorrrs@elderaffairs.org</p> |
| | <p>Horatio Soberon-Serrer, Director of Research and Quality Assurance Division of Statewide Community-Based Services Phone: (850) 414-2089 E-mail: Ferrerh@elderaffairs.org</p> |
| Kansas | <p>Margaret Zillinger, Director Social and Rehabilitative Services: Community Supports and Services Phone: (785) 296-3561 Email: MMZ@srskansas.org</p> |
| Kentucky | <p>Colleen Ryall, Division of Mental Health, Brain Injury Services Unit Phone: (502) 564-3615 E-mail: Colleen.Ryall@ky.gov</p> |
| Massachusetts | <p>Janice O’Keefe, Risk Management Director Department of Mental Retardation Phone: (617) 727-5608 E-mail: Janice.okeefe@dmr.state.ma.us</p> |
| New york | <p>Bruce Rosen, New York Department of Health Phone: (518) 474-6580 E-mail: bhr01@health.state.ny.us</p> |
| Ohio | <p>Dana Charlton, Deputy Director, Community Services Department of Mental Retardation and Developmental Disabilities Phone: (614) 644-5964 E-mail: Dana.Charlton@dmr.state.oh.us</p> |
| Oregon | <p>Marylee Fay, Director, Office of Home and Community Supports Department of Human Services, Seniors and People with Disabilities Phone: (503) 945-9787 E-mail: marylee.fay@state.or.us</p> |
| South Carolina | <p>Roy Smith, Director of Community Long-Term Care Program Department of Health and Human Services Phone: (803) 898-2590 E-mail: SmithRoy@dhhs.state.sc.us</p> |
| Vermont | <p>Bard Hill, Division Director Department of Aging and Independent Living Agency of Human Services Phone: (802) 241-2335 (direct) E-mail: Bard@dad.state.vt.us</p> |
| Washington | <p>Terry Rupp, Program Manager for Case Management Aging & Disabilities Service Administration Phone: (360) 725-2353 (direct) E-mail: rupptl@dshs.wa.gov</p> |

Appendix B. Selected References and Resources

Web Resources:

- AARP Web site for research results and reference information on a variety of subjects related to aging, including health and long-term care at: <http://research.aarp.org>.
- BRFSS, the Behavioral Risk Factor Surveillance System at: <http://apps.nccd.cdc.gov/brfssdatasystems/intro.asp>.

In the early 1980s, the Centers for Disease Control and Prevention (CDC) worked with several states to create the BRFSS to address behavioral health risks. This unique, state-based surveillance system is the largest continuously conducted telephone health survey in the world. Adults are randomly selected from each state and questioned, primarily about behavioral risk factors. The information received from these individuals is summarized and presented in a series of prevalence reports. Data in these reports are often a good first resource for summary information about selected risk factors and health conditions.

- CDC, the Centers for Disease Control and Prevention, National Center for Health Statistics, Healthy People 2000, National Health Promotion and Disease Prevention Objectives at: <http://www.cdc.gov/nchs/data/hp2000/hp2k01.pdf>
- Council on Quality and Leadership – contains information to improve the quality of services and supports for people with disabilities and mental illness. It offers a quality enhancement process for service provider agencies that may include accreditation, organization assessment, consultation, technical assistance, third-party evaluation and research studies. These methods are all based on The Council's Personal Outcome Measures at: <http://www.thecouncil.org>.
- GAO, the Government Accountability Office – for reports, testimony and correspondence, and to report allegations of fraud, waste, abuse, or mismanagement of federal funds (FraudNET). The GAO posts a daily list of newly released reports, testimony, and correspondence under “Today’s Reports” at: <http://www.gao.gov>
- Inclusion Press – for information about person-centered planning, books, workshops, resource materials for people with disabilities, and MAPS – Making Action Plans – a planning process for people and organizations at: <http://www.inclusion.com>.
- ISA, the Irwin Siegel Agency, Inc. – offers insurance and risk management services and materials for provider agencies within the developmental disabilities, medical/physical rehabilitation, mental health care, addiction treatment, and community/social service fields at: <http://www.siegelagency.com>.

Policyholders have access to online training programs such as the Incident Management Training Program. ISA’s Pinnacle Program, an interactive online quality assessment tool, serves as a compass to best practices and accountability in three areas: Administration, Loss Control, and Operations. ISA also offers a scoring

system to benchmark performance and areas for improvement, and helps leaders pilot their organizations through change. States may be particularly interested in these ISA products:

- Individual Risk Preparedness Assessment - An assessment tool designed to help identify individuals' desires, risk preparedness, and risks associated with daily life activities in the community.
 - Dollars & Sense of Risk Management - A general primer on insurance and risk management concepts that covers the risk management processes of risk identification, risk evaluation, risk treatment, decision and implementation, and monitoring.
- NPSF, the Department of Veterans Affairs National Patient Safety Foundation – a clearinghouse for patient safety literature including materials from medical, legal, news, and libraries at: <http://www.patientsafety.gov/resource.html>.
 - NRMC, the Nonprofit Risk Management Center – established in 1990 to provide assistance and resources for community-serving nonprofit organizations. Their mission is to help nonprofits cope with uncertainty. NRMC offers a wide range of services (technical assistance, software, training and consultations) on a vast array of risk management topics (employment practices, purchasing insurance, internal controls, and preventing child abuse) at: <http://nonprofitrisk.org>.

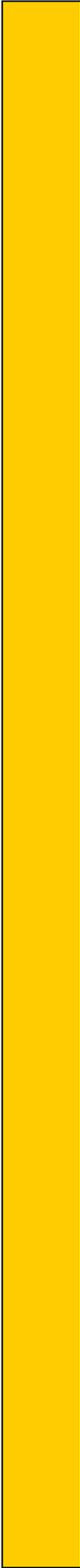
NRMC does not sell insurance or endorse organizations that do. It provides: free technical assistance by phone or email to nonprofit staff and volunteers; publications (some are free); an interactive risk assessment software program on the Web called Nonprofit CARES (Computer Assisted Risk Evaluation System); a Community Risk Management & Insurance newsletter, which is distributed to thousands of nonprofits three times each year; and workshops on risk management.
 - Quality Mall – for information about person-centered supports for people with developmental disabilities. The Health and Safety department provides information on: Monitoring Health and Safety; Safety Planning; Emergency Response and Disaster Recovery; Behavioral Support/Crisis Response; Physical Health; Mental/Emotional Health; Health and Wellness Promotion; and Health Care Provider Training at: <http://www.qualitymall.org>.
 - Research in Developmental Disabilities, a journal available online that is aimed at publishing original research of an interdisciplinary nature that has direct bearing on the remediation of problems associated with developmental disabilities at: http://www.elsevier.com/wps/find/journaldescription.cws_home/826/description#description.

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- Nursing Homes: Additional Steps Needed to Strengthen Enforcement of Federal Quality Standards. Report to the US Senate Special Committee on Aging, March 1999. GAO/HEHS-99-46. Access report: <http://world.std.com/~goldberg/gaoqual.pdf>.

National Quality Inventory Reports:

Results of national surveys, completed in 2002, on state quality assurance and improvement for aging and disabled waiver population and developmental disabilities.

- National Inventory of Quality Assurance and Improvement Systems: Medicaid HCBS Waiver Programs for Developmentally Disabled Individuals, NQIP MR/DD Tabular Survey Results, 2004.
- National Inventory of Quality Assurance and Improvement Systems: Medicaid HCBS Waiver Programs for Aging and/Disabled Individuals, NQIP A/D Tabular Survey Results, 2004.

Appendix C. State Risk Assessment and Planning Tools and Products

| Name of Tool/Product | Description of Tool/Product | State | How to Locate Tool/Product |
|---|---|-------|---|
| Prevention/ Risk Assessment | Assessment tool for identifying risk in a variety of dimensions, including home, work, and the community. Tool identifies risk prevention and mitigation strategies, as well as needed supports and the individuals who can/will provide these supports. | AZ | http://www.hcbs.org/moreInfo.php/nb/doc/1126 |
| Public Awareness and Staff Training: The Safety Net | Web site designed for consumers with developmental disabilities and their families, providers and staff. Disseminates information on the prevention and mitigation of risk factors for persons with developmental disabilities and includes information from across the nation on current research and best practices and practical information towards improving people's health and safety. Links to other sites with risk management and prevention. | CA | http://www.ddssafety.net |
| Training: Risk Assessment, Evaluation and Planning | Extensive training covering risk assessment inventories, special incident reporting, example profiles of participants with various risks, case studies, resource list, an incident response checklist and a preventative action checklist. | CA | http://www.ddssafety.net/risk/Training/Section1B.pdf |
| Risk Management Regulations | California Code of Regulations pertaining to risk management. Includes establishment and responsibilities of regional risk management committees. | CA | http://www.dds.ca.gov/Title17/SectionPrintText.cfm?Section=54327.2 |

| Name of Tool/Product | Description of Tool/Product | State | How to Locate Tool/Product |
|---|---|-------|---|
| Case Manager Training | On-line training for case managers working with participants with developmental disabilities. | KS | http://www.srskansas.org/hcp/css/DDCMWBT/ |
| | Policy and procedure manual with state law citations includes risk assessment. Instruction on when risk assessments are called for, whom to include in a risk assessment, and what elements the risk assessment should cover. | KS | http://www.srskansas.org/hcp/css/pdf/CManual.pdf |
| Risk Management Manual | Manual developed by the Department of Mental Retardation. The Risk Management System focuses on addressing the challenge of balancing the responsibility as a public agency to keep individuals with mental retardation safe, with the goal of promoting independence and self determination. | MA | http://www.mass.gov/dmr The “Health Promotion and Coordination Initiative” can be accessed from the home page. |
| Health Initiative Manual | Massachusetts developed a manual to guide support staff and families on health from prevention, to identification of symptoms for particular illnesses, to protocols for clinical consultations. Contains practical guides such as the preventative health standards checklist and instruction on how to speak with a health care practitioner. | MA | http://www.mass.gov/Eeohhs2/docs/dmr/hcpi_training_manual.pdf |
| Health Screening Recommendations | Required review tool summarizing screenings to conduct at the participant’s annual physical. Includes cancer screening, hypertension, infectious disease, sensory, mental and behavioral health, etc. | MA | http://www.mass.gov/Eeohhs2/docs/dmr/hcpi_training_manual.pdf [Go to Form HC-1 within document.] |

| Name of Tool/Product | Description of Tool/Product | State | How to Locate Tool/Product |
|--|---|-------|---|
| Plan of Protective Oversight | Used with participants with traumatic brain injury, this tool identifies risk factors and the services needed to mitigate them, and assigns specific persons who will be responsible for providing the necessary service and oversight. Each person must sign the plan, indicating they accept responsibility for their area of oversight. Some of the areas addressed in the plans include money management, medication management, kitchen safety, and back-up staffing for unscheduled staff absences. Plans are revised at least every six months; more often if circumstances warrant. | NY | http://www.hcbs.org/moreInfo.php/nb/doc/1127 |
| Policy: Clinical Risk Management/ Incident Management Plans | New York State's Office of Mental Health policy directive to set forth conditions and procedures for the development of a clinical risk management program to govern all programs under the auspices of State-operated psychiatric facilities. | NY | Contact state for Office of Mental Health Policy Directive QA-510 |
| Individual Support Plan System | Manual available in hard copy and disk. Includes consideration of 43 areas of risk and illustrates the state's risk tracking documentation in question and answer format. Provides instruction to staff with loops back to participant preference and guidance to protocols to address identified risks (e.g., Aspiration Protocol). | OR | http://www.hcbs.org/moreInfo.php/nb/doc/1128 |

| Name of Tool/Product | Description of Tool/Product | State | How to Locate Tool/Product |
|--|---|-------|--|
| Health Risk Assessment Process & Health Risk Profile (PA-HRP) | Pennsylvania’s Office of Mental Retardation designed a tool to collect health care information on people living in the community in a licensed home, including privately run ICFs/MR. The instrument is designed to identify physical and behavioral health risk factors, staff training related to individual health issues, and utilization of and access to health services. Information is collected and used in multiple ways including direct feedback about risks to the individual and their team, identification of knowledge deficits and topics for training, and for QI by establishing a statewide data set of health information for identifying systemic health patterns and trends. | PA | Contact state directly for a copy. |
| Care Call system | System which tracks the actual time providers are in a participant’s home. Providers call in when they arrive and leave, thus actual time of service provision is tracked. Monthly activity reports for each recipient are monitored by case managers against service authorizations. System matches numbers to detect fraud. | SC | Roy Smith or Maria Patton, Directors of SC’s Community Long Term Care Program at (803) 898-2590. SC’s long term care programs website is http://www.dhhs.state.sc.us/InsideDHHS/BureauofLongTermCareServices/service10181932003.htm |
| Service plan tool for service plans to address needs identified in assessment | A CMS Promising Practice. SC addressed inconsistency between assessed needs and inclusion in service plans via enhanced automation of the case management system implementing ‘triggers’ using the Microsoft Access application. When a CM enters assessment information the trigger automatically displays problems in the service plan. CMs approve suggested goals & interventions to address each problem. | SC | See above |
| Policy: Informed Consent and Negotiated Risk | Vermont’s DAD Home-Based Medicaid Waiver Manual policy Section XI states that providers shall support participants to make informed choices and participants have a right to receive services under conditions of acceptable risk. | VT | http://www.dad.state.vt.us/dail/Manuals.htm |

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|--|---|-------|---|
| CARE | <p>Washington automated, comprehensive, person centered assessment and planning tool to: a) measure the personal care needs of <i>anyone</i> receiving services at home or in a residential setting and b) develop a care plan. Contains 60 different screens some of which relate to risk. Included are the Mini Mental Status Exam, a caregiver burden interview guide, the CAGE questionnaire that indicates if a participant is at risk of substance abuse. After the participant selects a service setting (typically home) the program computes eligibility and need for services and a service plan that crosses service settings. Product package contains 1) CARES Training Manual, 2) CARES Assessment Tool (49 pgs.), and 3) Eligibility & Rates for LTC Services.</p> | WA | http://www.hcbs.org/moreInfo.php/nb/doc/1129 |
| Care plan protocols for addressing risk | <p>Washington has developed protocols in some high risk areas, such as skin breakdown. Protocols are automatically triggered when certain characteristics are identified in the assessment (a pressure sore or history of pressure sore, incontinence with cognitive impairment, etc.). The protocols dictates referral and recommendations for caregiver follow up.</p> | WA | http://www.hcbs.org/moreInfo.php/nb/doc/1130 |
| Challenging Client Protocol | <p>Protocol for use when the recommended plan of care can not assure the health and welfare of recipients due to participant issues, environment, or resources. Addresses shared responsibility for participant safety. Addresses service denial and service termination.</p> | WA | http://www.hcbs.org/moreInfo.php/nb/doc/1131 |