

Money Follows the Person: Population, Functional, and Quality Indicators for People with Developmental Disabilities

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Executive Summary

The U.S. Department of Health and Human Services Centers for Medicaid and Medicare Services (CMS) launched the Money Follows the Person Demonstration (MFP) to assist states in rebalancing long-term care by changing the locus of service delivery from institutional to community programs. Individuals with mental retardation and/or developmental disabilities (MR/DD) are a target population in twenty-eight (28) of the thirty-one (31) states/jurisdictions involved in the MFP demonstration program and comprise the second largest group of people expected to be transitioned into community-based services under the initiative.

This study was conducted in collaboration with Mathematica Policy Research, Inc. (MPR), which is performing a national evaluation of the MFP Demonstration. Information was gathered on data elements that are consistent with MPR's national evaluation strategy and specifically targets services and supports furnished to individuals with MR/DD under the Medicaid program. Key data elements examined in this study include:

- Total MR/DD service recipients;
- Total Intermediate Care Facilities for People with Mental Retardation (ICF/MR) residents stratified by public and private;
- ICF/MR residents as a percent of total MR/DD service recipients;
- MR/DD nursing home residents;
- Total Home- and community-based Services (HCBS) spending on Waiver services (2000 & 2005) and percent change;
- Annual HCBS Waiver spending per state resident;
- Total Medicaid expenditures;
- Total Medicaid expenditures as a percent of total Medicaid Long Term Care (LTC) spending.

Methodology. Information was gathered through a single page questionnaire sent to all state developmental disabilities agencies involved in the MFP Demonstrations. State officials were asked to identify: key population data elements currently kept by the states on individuals receiving developmental disabilities services, the screening and assessment tools used to evaluate functional skills, and the instruments employed to evaluate quality of life outcomes for persons with MR/DD in each state's service delivery system. Additional data was collected regarding a state's satisfaction with the different assessment instruments and several other factors.

Findings. All Developmental Disabilities agencies reported keeping information on people who receive waiver services. Of the twenty-seven surveys received, eighteen states (67%) indicated that they gather data on people receiving Medicaid State Plan services, and twenty-four (89%) collect information on people who receive services supported by state general funds. One state (New York) did not identify any people with developmental disabilities to move from ICFs/MR to community services and was therefore not included in this survey.

Eighteen of the twenty-seven states (67%) responding to the survey indicated that they use some type of nationally known tool to measure functional status. Twenty-one states (78%) report using a consistently valid and reliable tool statewide. Of the tools mentioned, the Supports Intensity

Scale (SIS) and the Inventory for Client and Agency Planning (ICAP) were most frequently identified. Two states (7%) use the Developmental Disabilities Profile (DDP) and two other states (7%) use the Support Needs Assessment Profile (SNAP). The remaining states reported using either a unique instrument developed for individuals receiving services in that state or different standardized tools in different parts of the state. The SIS is clearly gaining acceptance nationally. It not only is one of the most prevalently used tools, but also is the instrument mentioned most often by states that are considering making changes in their current functional assessment process.

Information gathered from states on the instruments used to assess service quality and performance showed an even stronger pattern of preference for a particular national tool than was found in the use of instruments evaluating functionality. In this case, fourteen of the twenty-seven states (52%) reported that they currently participate in the National Core Indicators Project (NCI). Five additional states indicated that they had participated in the past.¹ A handful of states use other nationally recognized tools, such as Ask Me!, The Council on Quality and Leadership (CQL) Personal Outcomes Measures, the Medstat Participant Experience Survey (PES) and the Quality of Life (QOL) Questionnaire. Fifteen states (56%) reported using some other type of quality assessment tool, either in addition to a national instrument or as a state specific stand-alone tool. Two states (7%) use no formal quality tool or protocol statewide. Seventeen states (63%) reported using a consistently valid and reliable tool statewide.

Discussion. The MFP state demonstration projects address all population groups receiving Medicaid funded institutional and home- and community-based services. Individuals who are frail and elderly, have intellectual and developmental disabilities, head injuries, mental illnesses, physical disabilities, or other needs have distinctive disability characteristics and different long-term support requirements. As a result, the issues, risk factors, and indicators of successful outcomes differ for each of the various groups that participate in the MFP effort. While it is an understandable desire to have common measures across populations, this approach masks many essential between-group differences that should be assessed.

Using existing tools that have been tested for validity and reliability, in terms of both content and the administration methodology makes sense. Responding state officials expressed a clear preference for the use of nationally recognized, valid, and reliable instruments that have been normed from people with developmental disabilities to assess individual functionality and quality of life and services. Several well-known instruments currently are in use in the MFP states that have targeted people with MR/DD for transition. For this population, it is appropriate to pursue an approach that tailors the assessment to the particular individual and treatment characteristics of each covered group, rather than attempting to develop a new set of composite measures to address all populations. Given the number of valid and reliable functional assessment and quality of life tools that MFP states are currently using, it is recommended that a range of options be offered to states rather than imposing a single assessment tool for use by all states with all MFP populations. This approach would likely increase cooperation from the states

¹*National Core Indicators: A Growing Commitment Five Years of Performance Measurement.* (2003). Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services, May 2003. Internet address: <http://www.hsri.org/nci>, 2-3.

with the pre- post assessment process for the MFP Demonstration project while ensuring that acceptable, psychometrically sound tools are used.

Regarding functional assessment instruments, the SIS and ICAP combined are used in more than half of the MFP states. Each instrument has been demonstrated to be valid and reliable for use with people with MR/DD. Given the interest in SIS expressed by a number of states, the MFP project may provide a good opportunity for states interested in making a change to “test the waters” with SIS before embarking on a full statewide changeover.

With respect to quality assessment tools, the NCI currently is being used in over half of the MFP states and provides an excellent option as a quality assurance tool. Additionally, NCI is used in parts of several other states. Five other MFP states have used NCI in the past. Other non-state specific tools with demonstrated reliability and validity include the QOL Questionnaire, Ask Me!, CQL Personal Outcomes Measures and the PES MR/DD version. The only state using the PES version for people who are frail elderly adults or non-elderly adults with physical disabilities (E/D) is also participating in NCI, making NCI the preferred tool as it is designed as a quality assessment tool specifically for people with MR/DD.

Recommendations.

- CMS should utilize valid and reliable population-specific measures to assess functionality and quality life of persons with developmental disabilities transitioning to community programs under the MFP demonstration.
- States involved in the MFP demonstrations should be offered the option of selecting either the SIS or ICAP as the tool to be used for MFP pre-post functional outcome measures.
- The MFP Demonstration should utilize valid and reliable population-specific instruments for assessing individual quality of life before and after community placement. CMS should work with states to assist them in selecting and using the instrument that best meets the state’s needs. The NCI currently is used by over half of the MFP states to measure service key system performance outcomes and track progress over time. Additional national tools with demonstrated reliability and validity being used by states include the Quality of Life Questionnaire, Ask Me!, CQL Personal Outcomes and the PES MR/DD version.
- If CMS is interested in using a single assessment instrument to evaluate quality of life for persons with developmental disabilities across all MFP states it is recommended that the NCI be used. The NCI is a nationally standardized instrument with over ten years of operational experience and state developmental disabilities agencies are familiar with its quality measures and use.

Background and Purpose

The U.S. Department of Health and Human Services Centers for Medicaid and Medicare Services (CMS) launched the Money Follows the Person Demonstration (MFP) to assist states in rebalancing long-term care by changing the locus of service delivery from institutional to community programs. The demonstration project covers all individuals currently receiving Medicaid-financed institutional services including persons residing in Intermediate Care Facilities for Persons with Mental Retardation (ICF/MR).

This study was conducted to provide CMS with information on assessment instruments currently being used by state developmental disabilities agencies to evaluate individual functioning and quality of life, and to make recommendations regarding the selection of appropriate assessment tools that may be used to collect and analyze data for the Money Follows the Person (MFP) Demonstration. The focus of the study is on the identification of assessment instruments that can be used to determine the functional/needs status and quality of life of individuals living in institutions before and after they transition to home- and community-based services. Additional information is provided regarding data elements that could be collected as a part of a national evaluation plan for state developmental disabilities agencies involved in the MFP Demonstration. Such elements would likely include the number of Intermediate Care Facilities for People with Mental Retardation (ICF/MR) beds, percentage of Medicaid recipients with MR/DD as a primary diagnosis in ICFs/MR by state, percent increase or decrease in spending on ICF/MR services over the past five years and any other measures that would be deemed appropriate and necessary for the MFP project.

Methodology

Collaboration. CMS' contractor for national data collection for the MFP state demonstration projects is Mathematica Policy Research, Inc. (MPR). MPR has analytical expertise in data collection and analysis and has performed an extensive review of claims records for nursing homes as well as a fairly robust assessment of appropriate tools for evaluating the impact of community placement on former nursing home residents. Individuals with MR/DD make up the second largest group of people expected to be transitioned into community-based residences under the MFP Demonstration.

This report was prepared in response to CMS' request for information regarding assessment tools for people with mental retardation/developmental disabilities (MR/DD) from an entity with content expertise in this area. NASDDDS provided assistance to CMS and MPR in the identification of population data that are relevant to people with MR/DD that should be collected throughout the MFP project and made recommendations regarding the data elements that should be collected as part of a national evaluation strategy.

Survey Development and Implementation. A single page questionnaire was developed and sent via email to the twenty-seven MFP states plus the District of Columbia (see Appendix 1) that

identified people with MR/DD as a target population.² The survey asked states to: (a) describe the type of population data that is kept on persons receiving services, (b) identify the screening and assessment tools used to evaluate community placements in developmental disabilities services, and (c) provide information about tools that may be successful with individuals with MR/DD in evaluating quality of life outcomes (see Appendix 2). The survey tool was reviewed by both MPR and CMS prior to being sent out. Three informal interviews were conducted with state DD agency directors or designated staff prior to distributing the survey to ensure that the instrument was designed to capture the type of information that states would be able to provide.

Rather than contacting the MFP state representatives, who have responsibilities across multiple MFP populations, an introductory email was sent to the DD Directors in all twenty-eight of the MFP states targeting MR/DD populations describing the project and scope of work, and requesting the state director to identify a person with knowledge about DD services to either respond or assist in responding to the survey. In the following weeks, the survey was distributed requesting information on the type of population data being kept, and the instruments being used to gather functional needs and quality of life information. Additional questions requested information on specific aspects of each of the various tools including:

- Reliability and validity
- Length of time tool has been in use
- Satisfaction with the tools
- Interest in changing the functional assessment tool
- User friendliness of tool/s
 - level of skill/education required of evaluator
 - average time required to administer tool
 - availability of automated version of tool for scoring
- Self advocate role in quality of life reporting/assessment
- State perception on strengths and weaknesses of tool/s

Findings

Population Data. Surveys were sent to twenty-eight states. Information presented in this section of the report on population data sent by each state is included in a chart labeled Data Collection for MFP States in Appendix 3.

One state (New York) did not identify any people with developmental disabilities to move from ICFs/MR to community services. Persons with MR/DD were included only as a subset of people who would be moving from nursing homes. Based on this information, NASDDDS and New York's Office of Mental Retardation and Developmental Disabilities decided that New York should not be included in this survey.

Of the twenty-seven surveys received, all twenty-seven state developmental disabilities (DD) agencies (100%) keep data on people who are receiving waiver services. Eighteen of the twenty-

² For ease of reference, Washington, D.C. is included in the data as the 27th state that completed a survey throughout the document.

seven (67%) have data on people who receive Medicaid State Plan services. Two states (North Dakota and Connecticut) report that they have only limited information. One state DD agency (Wisconsin) indicated that it can access Medicaid State Plan information from another branch of State Government. Twenty-four of the twenty-seven DD agencies (89%) keep data on people who receive non-Medicaid state general fund services, although one of the states (Wisconsin) has only limited information. The three states that do not have non-Medicaid state general fund services information are Iowa, Missouri and Texas, but Missouri reported that the information is available at the county level. Only six of the twenty-seven DD agencies (22%) (Iowa, Kansas, Louisiana, Ohio, Virginia and Wisconsin) have information on local non-state funding, with one of the states (Iowa) reporting they have only limited information. Three states (District of Columbia, Hawaii and Indiana) reported that the question was not applicable. Only two of the twenty-seven (7%) (District of Columbia and Kansas) have information about private pay services for people with developmental disabilities.

Individual/Functional Assessment Tool Data. Information presented in this section of the report on individual/ functional assessment data sent by each state is included in a hyperlinked chart labeled Individual/ Functional Assessment Tool Data Chart (Appendix 4). Information on the nationally recognized functional assessment tools is included in a document labeled Analysis of Functional Tools for 27 MFP States Chart in Appendix 5.

Use of a National Instrument. The survey responses revealed that eighteen of the twenty-seven states (67%) use some type of nationally known tool to measure functional status. Of those tools, the Supports Intensity Scale (SIS) is the most frequently used with seven states (26%) and several regions in California, followed closely by the Inventory for Client and Agency Planning (ICAP) at seven states (26%). One additional State (Virginia) uses ICAP in some counties. Louisiana just switched from ICAP to SIS and is included as a SIS rather than an ICAP State. . Two states (7%) use the Developmental Disabilities Profile (DDP) and two other states (7%) use the Support Needs Assessment Profile (SNAP). Indiana is in process of switching from the DDP to ICAP. The remaining states either use some type of tool that is specific to the state or they use different tools in different parts of the state. This occurs in some of the states with strong county-based systems, e.g. Virginia, Wisconsin, and Pennsylvania. Pennsylvania decided that the past practice of using different functional assessment tools in different counties was no longer acceptable and they switched to SIS in September of 2007. Nineteen of the states (70%) use only one tool with the others supplementing the use of one tool with one or more additional tools.

Use of Valid and Reliable Measures. Twenty-one states (78%) reported using a valid and reliable tool statewide. Eighteen of the twenty-one states reported that they used one of the nationally known instruments, SIS, DDP, ICAP, or SNAP. Missouri indicated that it recently switched from using the Vineland Adaptive Behavior Scale (ABS) to the SIS. Eighteen of the states (67%) use at least one tool that is automated. Nine states (33%) reported having only manual scoring options.

Instrument Structure: Assessment Domains. Domains that appear to be common across many tools, whether nationally recognized or state specific, include health and safety, home or daily living skills, social/ relationship skills, behavior support needs and communication. Listed in the chart below are the domains for the five nationally recognized tools used in the MFP states (See

Figure 1). Although the Vineland ABS is being phased out in Missouri, the only state that reported recently using it, it is still included in this chart based on its national significance and extensive use since the mid-1980s.

Supports Intensity Scale (SIS)	Vineland II Adaptive Behavior Scale (ABS)	Developmental Disabilities Support Needs Assessment Profile (SNAP)	The Inventory for Client and Agency Planning (ICAP)	Developmental Disability Profile (DDP)
Home living Community living Lifelong learning Employment Health/ safety Social Protection and advocacy Exceptional Medical Exceptional Behavioral	Communication Daily living Socialization Motor development	Daily living supports Health care supports Behavior supports	Motor Skills Social and communication Personal living Community living Also has general maladaptive behavior index	Health Adaptive Mal-Adaptive

Figure 1
Assessment Instrument Domains

Administration. Responsibility for administering the tools varies from direct support staff and family members to state case managers, psychologists and support brokers depending on the state. Almost all of the assessment tools are designed to be administered by an individual with no more than a bachelor’s degree and some experience working with people with MR/DD. In the vast majority of states assessments are completed by state, county, local, or private case managers or Qualified Developmental Disabilities Professionals (QDDP). In a few states (Arkansas, Texas, Louisiana only in its ICFs, and Nebraska only for its state specific tool) assessments are completed by provider agency staff. Four states (15%) (Maryland, Delaware, Indiana, and Pennsylvania) have chosen to contract out the service to an independent entity. The amount of training to be an assessor also reflects a wide variation - from just an hour orientation with a supervisor in some states to extensive multi-day training with a formal certification process in other states (Kentucky, North Carolina, and Ohio only for its state specific tool). The national tools appeared to have more consistent, although not necessarily more rigorous, training protocols.

Time in Use. The length of time that the functional tools have been used in the states ranges from less than one year to over twenty-years. Some states have used the same functional assessment instruments since the early 1980’s when waiver services first started. Other states, by contrast, have implemented new tools as recently as the fall of 2007. Most of the states beginning to use a new assessment instrument have chosen the SIS, with only one (Indiana) having opted to switch from the DDP to the ICAP. Although the question was not asked specifically, twelve states (44%) reported either current use or the desire to use their functional tools to assist in rate setting or funding of services. Four states (Connecticut, Maryland, Illinois, and Kentucky) reported encountering difficulties in their efforts to use their assessment instrument to project funding or reimbursement rates; three (Maryland, Illinois and Kentucky) of those four states cited provider

agency concerns with fairness of rates as the primary problem. Interestingly, all four states use different tools. Illinois also reported that their tool, the ICAP, was originally used solely for functional assessment purposes and had a rate setting function added several years later. Indiana just started a pilot project to switch from the DDP to the ICAP and plans to use ICAP for funding, as well as level of care determination.

Strengths and Weaknesses. Most states have aspects that they viewed as strengths and aspects that they viewed as weaknesses in their tools. Not surprisingly, the states that were not contemplating a change viewed their current tools as having more positive attributes than negative ones. Only five states (19%) reported no weaknesses in their tool. Two of those states (Louisiana and Washington) recently started using SIS and have been very pleased thus far. North Carolina reported no weaknesses with the SNAP, but they are looking to switch to the SIS, viewing it as a more comprehensive tool. The other states that reported no weaknesses are Wisconsin, which has its own tool, and Texas that is using the ICAP. Neither of those two states is contemplating a change of functional assessment tools.

Four states (15%) reported no strengths in their functional assessment tool. Three of the four states (Virginia, Pennsylvania, and Missouri) that reported no strengths with their tool/s are in process or getting ready to switch to the SIS. North Dakota, which reported no strengths with its tool, uses a state developed assessment and did not note any interest in making a change.

There are general categories of strengths that states reported for the tools such as: providing consistency, person centeredness, looking at all aspects of the person, focusing on strengths, ease of use, cost effectiveness, ability to make comparisons with other states or areas, ability to tie to funding, screening for service eligibility, reliability and validity. On the other hand, the perceived lack of these strengths comprised some of the most common weaknesses that states noted. States reported that weaknesses with their tools included: a lack of comprehensiveness enough, insufficient information about specific support needs, lack of reliability and interviewer subjectivity, too time intensive, too costly and only focused on deficits.

User Satisfaction. In terms of whether states were satisfied with their current assessment instrument, twenty-one states, more than 75% of the sample, indicated either a full or a qualified “yes.” The numbers were split closely with ten (37%) providing an unqualified yes and eleven (41%) providing a partial yes with exception/s noted. Some of these exceptions included the need to pair the tool with some other type of assessment of user satisfaction, and concerns over the comprehensiveness and reliability of the information provided.

Fifteen states (56%) reported that they are considering changing, or have recently made a decision about changing, their functional assessment tools. Seven states (Arkansas, Iowa, Illinois, Kansas, Maryland, Ohio, and Wisconsin) are reviewing various functional assessment options for the future. Three states (Missouri, Pennsylvania, and Virginia) indicated that they plan to use the SIS. Three other states (North Carolina, Oklahoma, and Texas) are considering, or have already chosen, the SIS when they switch at some point in the future. Only Nebraska said that they tried SIS and preferred the ICAP, which they are currently using. Indiana is in process of switching from the DDP to the ICAP.

Quality Assessment Data. Information presented in this section of the report on quality assessment data is included in a hyperlinked chart labeled Quality Assessment Tool Data Chart (see Appendix 6). Information on the nationally recognized quality assessment tools included in the state surveys is included in a document labeled Analysis of Quality Tools for 27 MFP States Chart (see Appendix 7).

Use of a National Instrument. Quality information from the twenty-seven states responding to the survey showed an even stronger pattern of preference for a particular national tool than with functional tools, with fourteen states (52%) and two regions in another state (California) participating in the National Core Indicators Project (NCI). Five other MFP states (Illinois, Indiana, Iowa, Nebraska, and Virginia) have participated in NCI in the past.³ Other states using nationally and/or internationally recognized tools include Ask Me! in Maryland, The CQL Personal Outcomes Measures in the District of Columbia and parts of Louisiana, the Medstat PES in Iowa and the Quality of Life Questionnaire in Nebraska. Fifteen states (56%) use some other type of quality assessment tool that was developed to meet the particular needs of that state. Eight (30%) of these states reported using one or more tools developed specifically for the state as a stand alone tool and seven (26%) using some type of state developed tool in addition to a national tool. Texas uses both NCI and the PES E/D version. Illinois and Indiana reported that they do not currently use any standardized quality assurance tool. Indiana is working with stakeholders in the state, CQL and the Commission on Accreditation of Rehabilitation Facilities, a national accreditation organization, to establish some common quality indicators. Overall, twenty of the twenty-seven states (74%) reported the use of a nationally or internationally recognized tool for assessing service quality and outcomes.

Validity and Reliability. Seventeen states (63%) reported using a consistently valid and reliable tool statewide. Of those states, only two states (Kansas and Wisconsin) had a survey that was used and developed exclusively for its state. While NCI, PES, and CQL Personal Outcomes Measures all offer automated versions, many states that use those tools are still using manual scoring. Fourteen states (52%) reported using a manual scoring system and seven (26%) reported using an automated system. Five states (19%) use some combination of manual and automated systems or are in transition from a manual to an automated system, as in the District of Columbia.

Instrument Structure: Assessment Domains. Domains that appear to be common across many tools, whether nationally recognized or state specific are rights, respect and dignity, health and well being, social or community inclusion, self determination, empowerment, consumer outcomes or choice and control. Listed in the chart below (Figure 2 on following page) are the domains for the five nationally and /or internationally recognized quality assessment tools that are used in the MFP states.

³ Ibid., 2-3.

TOOL NAME	Medstat Participant Experience Survey (PES)	Quality Of Life Questionnaire (QOL)	National Core Indicators (NCI)	Council On Quality And Leadership Personal Outcomes (CQL)	Ask Me!
Domains	Choice and control Respect and dignity Access to care Community integration	Satisfaction Competency Empowerment Social belonging Rights Relationships Economic security Growth and development Perception of well-being	Consumer Outcomes; System Performance; Health, Welfare & Rights; Staff Stability and Competence; Family Indicators; Case Management	Rights and protection Dignity and respect Protection from abuse, neglect, mistreatment, and exploitation Best possible health Safe environments Staff resources and supports Positive services and supports	Physical wellbeing Emotional wellbeing Interpersonal relations Material wellbeing Social inclusion Personal development Self-determination Rights

**Figure 2
Assessment Instrument Domains**

Administration. Half of the states listed a state or regional/local level staff as completing the quality survey. Five states (19%) (California, Kentucky, Maryland, Oklahoma, and Texas) used outside contractor agencies to administer their quality assessment tools. Volunteers/quality teams/ private case managers or QDDP staff comprised the rest of the group that administer surveys. Training runs the gamut from informal orientation from a colleague or supervisor to formal multi- day training with an outside training entity. Louisiana and Ohio provided a shadowing program for new surveyors. Pennsylvania, Georgia, and Kansas offered refresher training at various intervals to be sure that staff are kept up to date and still following appropriate survey protocols.

Time in Use. With the exception of Wisconsin, no state began using their current quality assurance tool or system any earlier than 1994, with the majority having started in the late 1990's to early 2000's. Wisconsin reported that they began using their current system with the advent of their waiver programs in the early 1980's.

Strengths and Weaknesses. As with the functional assessment tools, most states have some aspects that they viewed as strengths and some aspects they viewed as weaknesses in their quality assessment tool/s. Only one state, Virginia, listed no strengths for its quality assessment tool. Many of the types of strengths that were repeatedly cited across multiple tools and would be considered most important to states included: high self response rate, ability to track quality and satisfaction, adhering to the CMS Quality Framework, ease of use, comprehensiveness, person centeredness, use of multiple data sources, providing of reliable data and ability to compare data

over time. The data comparison with other states was a significantly positive feature noted in many of the NCI states, but not a feature that was available with any of the other quality tools. Whether the tool was viewed more positively or negatively by the state did not appear to correlate to whether it was a state specific or a nationally known tool, with the exception of the high number of NCI states (50%) that reported no weaknesses in their tool.

Some weaknesses were noted in seventeen of the twenty-five states using a quality tool statewide. The absence of any statewide quality tool or protocol was reported as a weakness by both Indiana and Illinois. Thus, 63% of states surveyed have some weaknesses in their quality tool. Ten states (37%) (California, Connecticut, Hawaii, Kentucky, North Dakota, Nebraska, New Jersey, Oklahoma, Pennsylvania, and Washington) listed no weaknesses in their tool, with seven of those states (26%) (Connecticut, Hawaii, Kentucky, New Jersey, Oklahoma, Pennsylvania, and Washington) participating in NCI. California cited no weaknesses for any of its quality assessment instruments. Four of California's twenty-one Regional Centers participate in the NCI Program. Many of the types of weaknesses cited in the surveys included: high cost, length of time needed to complete interview, lack of objectivity and reliability, difficulty getting information from people who are not verbal, institutional bias and not being translated into enough languages. The issue of not having enough translated language versions available was cited for both NCI and PES E/D, but only in one state, Texas.

User Satisfaction. In terms of satisfaction with the state quality system, Illinois and Indiana did not report on this as they do not currently have a statewide quality assurance tool or system. Of the remaining states, sixteen (60%) reported an unqualified yes in terms of satisfaction. Eight (30%) reported a qualified yes response or too early to tell if they recently switched tools, such as in New Jersey, Louisiana, and Connecticut. Iowa is currently designing a new quality system. Nebraska reported that they are considering using the PES, although they gave an unqualified satisfaction rating to the QOL Questionnaire, which they have been using for more than 10 years.

Self-Advocate Involvement. The involvement and role of self-advocates in the quality assessment process covered an extremely wide range. Arkansas reported that self-advocates are not typically asked questions directly as part of their quality survey process; rather families/guardians were primary responders. In Maryland self-advocates not only responded to the survey, but were a vital part of the design and field testing process for the tool, as well as serving as the exclusive group of interviewers. Most of the states fall somewhere between these two points on a continuum. In addition to having self-advocates as primary responders to the surveys, six states (22%) (Connecticut, Kentucky, Maryland, Missouri, Pennsylvania, and Washington) also have some role, either volunteer, paid, or as part of a survey team where self-advocates are the survey interviewers. As well as responding to survey questions, seven states (26%) have self-advocates involved in either the development process of the survey or providing some type of feedback on the implementation process. An additional eleven states (41%) asked the person questions directly, although three states may have the family answering as well. It is noteworthy that the role of the self-advocate did not seem to be governed by the tool used. For example, Arkansas, an NCI state, did not have consumers as the primary survey responders and Pennsylvania, another NCI state, used self-advocate surveyors as part of their quality review teams.

Family Involvement. The role of families in the quality survey process also represented a wide range in types of involvement. Nine states (33%) have defined a role for families by asking them for input in the design or requesting ongoing feedback on the quality process. Eight states (30%) (Connecticut, Delaware, New Jersey, Ohio, Oklahoma, Pennsylvania, Virginia, and Wisconsin) have a specific family survey tool or family interview component. Five states (19%) use families for additional information, back up information or as proxies. Only Kentucky and Washington (7%) have family members involved as interviewers. Arkansas uses the family, not the individual receiving services as the primary survey responder.

Discussion and Recommendations

Discussion. This study documented the nature and application of the assessment instruments currently used by states to evaluate the functional status and quality of life of individuals with developmental disabilities receiving publicly financed Home- and Community-Based Services under the state's Medicaid program. The study was performed to provide information to CMS and its contractor, MPR, to inform the development of a national assessment instrument and protocol to be used in evaluating the outcomes and impact of the MFP national demonstration project. Through this project a survey was sent to the state developmental disabilities agency directors in the twenty-seven states and the District of Columbia which are involved in the MFP demonstration. The questionnaire asked state officials to: (a) describe the type of population data that is kept on persons receiving services, (b) identify the screening and assessment tools used to evaluate community placements in developmental disabilities services, and (c) provide information about tools that may be successful with individuals with MR/DD in evaluating quality of life outcomes. Follow-up interviews were conducted to gather additional information on key population data elements currently kept by the states on individuals receiving developmental disabilities services. State officials also were asked to provide their perspectives on the strengths and weaknesses of screening and assessment tools used to evaluate functional skills and quality of life outcomes.

Implications for Assessing the Money Follows the Person State Demonstration Projects. The results of the survey of state developmental disabilities officials on the instruments their states use to assess individual functional status and service quality provide a number of implications for federal officials interested in assessing the impact of the MFP state demonstrations. The data underscore the importance of using appropriate functional assessment and quality of life measures to assess the impact of MFP for the target group of people with MR/DD moving from ICFs/MR to home- and community-based services.

Population Data. As noted above, all twenty-seven state developmental disabilities (DD) agencies keep data on people who are receiving waiver services and eighteen of the twenty-seven (67%) have data on people who receive Medicaid State Plan services. Some of the states reported having limited information on individuals receiving Medicaid state plan services and another state reported that although it does not gather the data itself, it is available from another branch of state government.

Use of Nationally Recognized Valid and Reliable Assessment Instruments. The data reveal strong preferences on the part of state officials in favor of using nationally recognized, standardized

assessment tools for evaluating both the functional and quality of life status of persons with developmental disabilities receiving state funded services and supports. Fully 67% of the states responding to this survey reported that they currently use a nationally recognized assessment instrument to evaluate the functional strengths and needs of individuals receiving developmental disabilities services. The trend was even stronger with respect to the tools used by states to assess service quality and performance with 74% reporting the use of a nationally or internationally recognized tool for assessing service quality and outcomes. . The vast majority of states report using valid and reliable measures to evaluate functional status (78%) and service quality (63%) statewide.

State developmental disability agency officials' preference for using nationally established instruments that have been specifically normed on persons with developmental disabilities is not surprising. The choice of evidence-based measures provides states with assurances that the assessment instruments evaluate the items, behaviors, and practices in a valid and reliable manner and increase the state's credibility with individuals and families as well as legislators, providers and advocates. The decision reflects Medicaid rules requiring that individual plans of care are developed through the use of assessment tools that are appropriate to each beneficiary's needs and recognizes that the long term support needs of individuals with developmental disabilities differ, sometimes significantly, from those of individuals who are aging, persons with traumatic brain injuries, individuals with mental illnesses and other Medicaid home- and community-based service recipients in significant ways. Individuals who are frail and elderly, have intellectual and developmental disabilities, head injuries, mental illnesses, physical disabilities, or other needs have distinctive disability characteristics and differing long-term support requirements. These individuals require an array of specialized services and supports that are tailored to the unique characteristics and needs of each population. The issues, risk factors, and indicators of successful outcomes differ for each of the various groups that will participate in the MFP effort. The assessment tools that are selected to document the changes these individuals undergo when they move from institutional to home- and community-based services must be carefully evaluated and documented by empirically sound evaluation measures that do not mask the important between-group differences that are essential to determining the impact of the initiative on the persons being served. Finally, it is important to note that the one-size-fits-all approach to assessing the needs of multiple population groups has not been found to be effective. The PES, for example, was originally developed as a cross disability assessment tool. But, following application, was determined to be unable to adequately assess the needs of people with developmental disabilities and a separate tool subsequently was developed.⁴

State developmental disabilities officials are utilizing proven population-specific assessment instruments that have been determined to produce valid and reliable data over time. Although some states indicated that they augment the standardized tool with state-specific queries, none reported constructing their own assessments from other published evaluation forms. Extracting measures from existing quality of life instruments to form a composite indicator presents a number of statistical problems. The determination of an instrument's validity and reliability typically is based on an evaluation of the entire assessment tool, rather than on the individual questions being asked. As a result, selecting particular measures for inclusion in a second tool is

⁴ Galantowicz, S., Jackson, B. (2005, March 14) *Development of the Participant Experience Survey (PES)* (Final Report). Cambridge: Research and Policy Division, The MEDSTAT Group., 8.

no guarantee that the new instrument will be either valid or reliable. The practice can be further complicated if any of the assessment instruments, from which questions are being taken, are copyrighted.

Method of Administration. As important as the content of the survey tool is its administration methodology. Whether the instrument would be completed during a face-to-face interview, by telephone, or on paper has a tremendous impact on the survey results, particularly for people with cognitive disabilities.⁵ Interview results can be influenced significantly by the skills and demeanor of the interviewer, the content of the questions and the interview format. Interviews conducted of persons with intellectual disabilities, for example, must allow for and support a wide variety of alternative answering methods with flexibility given with respect to language, written communication, and the use of gestures and facial expressions. Surveyor/interviewer training is critical. The more complex the structure of questions in a survey, e.g., varying between yes or no, multiple choice, open-ended and multi-part questions the more difficult it is for people with cognitive disabilities to answer for themselves.⁶ This use of proxy respondents who answer questions on behalf of other individuals raises additional issues and administration barriers.⁷ These and other administrative issues are familiar to state developmental disabilities officials and are believed to be effectively addressed by the standardized assessment instruments mentioned above.

Satisfaction. As noted above, the majority of survey respondents stated that they are satisfied with the assessments that the state currently uses for assessing functional status and service quality. Interestingly, however, more than half of the states reporting that they are satisfied with their current tools indicated that they are considering changing to another assessment instrument in the future. The SIS is clearly gaining acceptance nationally, not only as one of the most prevalently used two tools currently, but also as the tool states that are looking to make a change in functional assessment tools are most often considering.

Conclusion. The state survey responses reveal the existence of a variety of valid and reliable tools normed for people with MR/DD that currently are in use in many of the MFP states. States have considerable experience in the application of these instruments, interpreting the results, and communicating the findings and implications to individuals receiving support and their families. The widespread use of standardized instruments for assessing and documenting functional status and service quality offers a unique opportunity in the selection and development of effective tools for assessing the personal and support outcomes of individuals moving to home- and community-based services under the MFP state demonstrations.

Recommendations. CMS should utilize valid and reliable population-specific measures to assess functionality and quality life of persons with developmental disabilities transitioning to community programs under the MFP demonstration.

⁵ Ibid., 5.

⁶ Ibid., 9-13.

⁷ Bonham, G., Basehart, S. and Marchand, C. (2006, December) *Ask Me! FY 2006: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Support*. Annapolis: Bonham Research and The Arc of Maryland., iii-iv.

States involved in the MFP demonstrations should be offered the option of selecting either the SIS or ICAP as the tool to be used for MFP pre-post functional outcome measures.

The SIS, ICAP, DDP, and SNAP are all used in more than one state and have been proven to be valid and reliable instruments for use with people with MR/DD. The majority of states use SIS or ICAP and, as described above, many states are considering using the SIS in the future. States should be offered the option of selecting either the SIS or ICAP as the tool to be used for MFP pre-post outcome measures. Given the interest in SIS expressed by a number of states, the MFP project may provide a good opportunity for states interested in making a change to “test the waters” with SIS before embarking on a full statewide changeover.

The MFP Demonstration should utilize valid and reliable population-specific instruments for assessing individual quality of life before and after community placement. CMS should work with states to assist them in selecting and using the instrument that best meets the state’s needs. The NCI currently is used by over half of the MFP states to measure service key system performance outcomes and track progress over time. Additional national tools with demonstrated reliability and validity being used by states include the Quality of Life Questionnaire, Ask Me!, CQL Personal Outcomes and the PES MR/DD version.

If CMS is interested in using a single assessment instrument to evaluate quality of life for persons with developmental disabilities across all MFP states it is recommended that the NCI be used. The NCI is a nationally standardized instrument with over ten years of operational experience and state developmental disabilities agencies are familiar with its quality measures and use.

References

- Ashbaugh, J.W. & Smith, G. (1997, January) *National Core Indicators*. Cambridge and Alexandria: Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services.
- Bonham, G., Basehart, S., and Marchand, C. (2006 December) *Ask Me! FY 2006: The Quality of Life of Marylanders with Developmental Disabilities Receiving DDA-Funded Support*. Annapolis: Bonham Research and The Arc of Maryland.
- Braddock, D., Hemp, R., Rizzolo, M., Coulter, D., Haffer, L. and Thompson, M. (2005) *The State of the States in Developmental Disabilities*. (Preliminary Report) Denver: Department of Psychiatry and Coleman Institute for Cognitive Disabilities, The University of Colorado.
- Bruininks, R. H., Hill, B.K., Weatherman, R. F. and Woodcock, R. W. (1986). *Inventory for Client and Agency Planning: Response Booklet*. Chicago: Riverside Publishing Company.
- Eiken, S., Burwell, B. & Walker, E. (2005, May 9). *Medicaid HCBS Waiver Expenditures, FY 1999 through FY 2004*. Cambridge: Thomson-Medstat.
- Galantowicz, S., Jackson, B. (2005, March 14) *Development of the Participant Experience Survey (PES)* (Final Report). Cambridge: Research and Policy Division, The MEDSTAT Group.
- Gardner, J. (2000) *Personal Outcomes Measures*. Baltimore: The Council on Quality and Leadership.
- Hennike, J.M., Myers, A., Thompson T. and Realon, R. (1997) *Developmental Disabilities Support Needs Assessment Profile*. Butner: Murdoch Center Foundation.
- Lakin, K.C., Doljanac, R., Byun, S.Y., Stancliffe, R., Taub, S. and Chiri, G. (2006 September) *Medicaid Home and Community-Based Services for Persons with Intellectual and Developmental Disabilities: Background and Findings from Consumer Interviews and the Medicaid Statistical Information Systems Final Report*. Minneapolis and Boston: The University of Minnesota Research and Training Center on Community Living and Human Services Research Institute.
- New York State. Office of Mental Retardation and Developmental Disabilities. *Developmental Disabilities Profile*. Albany: 1990. Internet address: omr.state.ny.us/wt/manuals/wt_ddp2toc.jsp.
- Prouty, R.W., Smith, G. & Lakin, K.C. (Eds.), *Residential Services for Persons with Developmental Disabilities: Status and Trends through 2005*. Minneapolis: University of Minnesota, Research and Training Center on Community living, Institute on Community Integration.
- Schalock, R. L., & Keith, K.D. (1993) *Quality of Life Questionnaire Manual*. Hastings and Lincoln: Hastings College and University of Nebraska at Lincoln.

National Core Indicators: A Growing Commitment Five Years of Performance Measurement. (2003). Human Services Research Institute and National Association of State Directors of Developmental Disabilities Services, May 2003. Internet address: <http://www.hsri.org/nci>.

Smith, G., & Ashbaugh, J. (2001) *National Core Indicators Project: Phase II Consumer Survey Technical Report.* Human Services Research Institute, May 2001. Internet address: <http://www.hsri.org/nci>.

Sparrow, S. S., Balla, D. A., and Cicchetti, D. V. (1984) *Vineland Adaptive Behavior Scale.* New Haven: Yale University Child Study Center.

Thompson, J. R., Bryant B.R., Campbell, E. M., Craig, E.M., Hughes, C., Rotholz, D. A., Schalock, R. L., Silverman, W. P., Tassé, M. J., and Wehmeyer, M.L. (2004, January 6) *Supports Intensity Scale.* Washington, DC: The American Association on Intellectual and Developmental Disabilities.

Appendix 1

Participating States and Survey Respondents

STATE	SURVEY RESPONDER/S
AR	Herb Sanderson, Krista Hughes
CA	Kathleen Ozeroff
CT	Beth McArthur
DC	Cynthia Kauffman
DE	Scott D. Phillips, Valerie J. Smith
GA	Rie Kennedy-Lizotte
HI	Michael Tamanaha
IL	Reta Hoskin
IN	Andrew Ranck
IA	Deborah Johnson
KS	Frank Stahl
KY	Claudia Johnson
LA	Amy Bamburg
MD	Catriona Johnson, Gwen Winston
MO	Julie Ousley
NC	Vivian Leon
ND	Karen E. Tescher, Robbin Hendrickson
NEB	Ginger Goomis , Sue Clark, Pam Hovis
NJ	Joe Bongiovanni, Catherine Logan, Bill Holloway
NY*	Gary Lind
OH	Christina Miller
OK	Jean Lemonier
OR	Julia Brown
PA	Pam Kuhno
TX	Steven Ashman
VA	Cheri Stierer
WA	Janet Adams
WI	Marcie Brost

* NY identified people with MR/DD in their MFP application, but this only pertains to people with MR/DD in Nursing Homes. NY did not, therefore, participate in the survey.

Appendix 2

NASDDDS MFP Survey for the States

Name of State:

Name of person completing the survey:

Population Data

1. Do you keep, or are you able to report, data on the **number of people** with MR/DD who receive supports and/or services funded through the following sources:
 - a. Medicaid 1915(c), 1915(b/c), or 1115 waiver.
 - b. Medicaid State Plan Option.
 - c. Non-Medicaid state general funds or subsidies, etc.,
 - d. Local non-state funding for persons with MR/DD provided by municipal, county, or regional governmental or administrative units.
 - e. Private pay

Functional and Quality Assessment Tools

1. What individual assessment tool/s does your state currently use, e.g. ICAP, SIS, etc., to determine level of need? Please provide the full name, whether this tool was developed and/ or adapted for your state and a copy of the tool.
 - a. How long has the tool/s been in use in your state?
 - b. What do you view as the strengths and weaknesses of using this tool, e.g. provides very accurate data, takes too long to administer, etc.?
 - c. Does the instrument meet your needs?
 - d. Is your state considering the use of an alternative assessment instrument? If yes, what is it?
 - e. Who administers the tool and what training is required?
 - f. Is the tool reliable and valid?
 - g. Does the tool use manual or automated scoring?
 - h. What are the domains covered in this tool?
2. What quality tool/s does your state use, e.g. NCI, Council Personal Outcomes, etc.?
Please provide the full name, whether this tool was developed and/ or adapted for your state and a copy of the tool.
 - a. How long has the tool been in use in your state?
 - b. What do you view as the strengths and weaknesses of using this tool, e.g. promotes a high self-response rate, staff training is costly, etc.?
 - c. Does the instrument meet your needs?
 - d. Who administers the tool and what training is required?
 - e. Is the tool considered reliable and valid?
 - f. Does the tool use manual or automated scoring?
 - g. What are the domains covered in this tool?
 - h. Please describe the role of self-advocates in the process?
 - i. What is the family/guardian role in use of the quality tool?

Appendix 3

Data Collection for MFP States					
State	Medicaid Waivers	Medicaid State Plan	Non Medicaid-State General Funds	Local Non State	Private Pay
AR	yes	yes	yes	no	no
CA	yes	yes	yes	no*	no
CT	yes	yes**	yes	no	no
DC	yes	yes	yes	N/A	yes
DE	yes	yes	yes	no	no
GA	yes	yes	yes	no	no
HI	yes	no	yes	N/A	no
IA	yes	no	no	yes**	no
IL	yes	no	yes	no	no
IN	yes	yes	yes	N/A	no
KS	yes	no	yes	yes	yes
KY	yes	no	yes	no	no
LA	yes	no	yes	yes	no
MD	yes	no	yes	no	no
MO	yes	yes	no*	no	no
NC	yes	yes	yes	no	no
ND	yes	yes**	yes	no	no
NE	yes	yes	yes	no	no
NJ	yes	yes	yes	no	no
NY***					
OH	yes	yes	yes	yes	no
OK	yes	no	yes	no	no
OR	yes	yes	yes	no	no
PA	yes	yes	yes	no	no
TX	yes	no	no	no	no
VA	yes	yes	yes	yes	no
WA	yes	yes	yes	no	no
WI	yes	yes****	yes**	yes	no

* Counties have this info

** Limited information available

*** NY not included in survey since no people moving from ICFs/MR

**** Data kept by another department of state government

Appendix 4

INDIVIDUAL/FUNCTIONAL ASSESSMENT TOOL DATA

STATE	INDIVIDUAL ASSESSMENT TOOL/S CURRENTLY USED	LENGTH IN USE	STATE REPORTED STRENGTHS OF THIS TOOL	STATE REPORTED WEAKNESSES OF TOOL	DOES THE TOOL MEET NEEDS	ALTERNATIVE ASSESSMENT INSTRUMENT? IF YES, WHAT IS IT?	WHO ADMINISTERS THE TOOL AND TRAINING REQUIRED	IS THE TOOL RELIABLE AND VALID	DOES TOOL USE MANUAL OR AUTOMATED SCORING	DOMAINS COVERED IN THIS TOOL
AR	The Inventory for Client and Agency Planning (ICAP) only used for pervasive level of care	Since 1999	Provides service and level of care score Nationally normed	Does not discriminate well at the upper end of the skill range	Not as a stand alone tool, only with other info about the person	Yes, but has not decided yet	Staff at community provider agencies, occasionally by psych. Training done according to manual, must know administration procedures and person.	Yes	Automated	Motor Skills Social and communication Personal Living Community Living Also has general maladaptive behavior index
CA	Client Development and Evaluation Record (CDER)	Since 1986	Was developed specifically for CA	Being revised based on feedback from regional centers	Yes	No	Service Coordinators administer on an annual basis. They receive training at local level.	Yes, planning teams have found it to be valid and reliable	Manually scored	Motor skills Independent living Social Emotional Cognitive Communication
CT	CT Level of Need Assessment and Screening Tool	Since April 2006	CT developed tool in conjunction with CMS Independence Plus Grant; comprehensive, appears to be sensitive to individual levels of need, data application makes it easy to	Initial completion is somewhat time consuming, tying to resource allocation has been a challenge due to variability of historical cost data.	Yes	No	Case Managers and people who know the consumer well; family, friends and providers. All have received training in how to administer. Supervisors are expected to orient new	Formal reliability tests have been conducted Validity may not be strong, but CT views questions as key to knowing consumer need for support.	Tool is supported by Access data base that calculates level of need. This Fall, CT expects to launch web based application that will calculate level of need	Health and medical Personal care Daily living Behavior Safety Awake support Overnight support Comprehension and understanding Communication

STATE	INDIVIDUAL ASSESSMENT TOOL/S CURRENTLY USED	LENGTH IN USE	STATE REPORTED STRENGTHS OF THIS TOOL	STATE REPORTED WEAKNESSES OF TOOL	DOES THE TOOL MEET NEEDS	ALTERNATIVE ASSESSMENT INSTRUMENT? IF YES, WHAT IS IT?	WHO ADMINISTERS THE TOOL AND TRAINING REQUIRED	IS THE TOOL RELIABLE AND VALID	DOES TOOL USE MANUAL OR AUTOMATED SCORING	DOMAINS COVERED IN THIS TOOL
			update when needs change				staff. The tool also has comprehensive instruction manual.		and risk profile for each individual assessed.	Transportation Social life Recreation Community activities Unpaid caregiver support
DC	SIS	Since June 2007	Nationally normed Strong training and reliability components Direct talk with people who get services Focuses on what person would need rather than general menu Respondents have chance to think about what needs to be done rather than what is Comprehensive Potential for use as level of need, planning, and cost/rate setting	Need to supplement questions a bit No easy way to transfer the level of need to “risk” and cost Time intensive Need to build-in an ongoing reliability process	Yes	No	8 trained and reliable staff half District staff (DDA) and half from Georgetown Health Resources Partnership administer tool AAIDD provided fairly intensive training and conducted a thorough reliability process before staff were approved to conduct interviews	Yes	Manual Scoring	Home living Community living Lifelong learning Employment Health/ safety Social Protection and advocacy Exceptional medical Exceptional behavioral

STATE	INDIVIDUAL ASSESSMENT TOOL/S CURRENTLY USED	LENGTH IN USE	STATE REPORTED STRENGTHS OF THIS TOOL	STATE REPORTED WEAKNESSES OF TOOL	DOES THE TOOL MEET NEEDS	ALTERNATIVE ASSESSMENT INSTRUMENT? IF YES, WHAT IS IT?	WHO ADMINISTERS THE TOOL AND TRAINING REQUIRED	IS THE TOOL RELIABLE AND VALID	DOES TOOL USE MANUAL OR AUTOMATED SCORING	DOMAINS COVERED IN THIS TOOL
DE	ICAP	Since 2003	Provides accurate data as an adaptive behavioral assessment	Does not identify, via quantifiable score, medical and support service needs.	Yes, with exceptions noted under weaknesses	No	Arbitre Consulting as sole source contractual provider	Yes	Automated	See ICAP domains listed above for AR
GA	SIS	Since July 2006	Generally good	Tool does not take into account parenting skills and impact on needs of young children living at home	Yes, for how it is used	Not at this time	Support Coordination and Intake and Evaluation Staff administer tool Support coordinator must complete the inter-rater reliability assessment every 6 months	Yes	Automated	See DC above for SIS domains
HI	ICAP	Since 2002	Provides a tool to look at changes over time Problem Behavior section has been helpful in identifying behaviors and the relative degree of concern (severity) to family members.	Tool can be subjective and responses “slanted” by person being interviewed to make individual seem more dependent or have more severe challenging behaviors. Can be lengthy to administer dependent on individual being interviewed	Partially in having a systematic way of obtaining information.	SIS has been discussed but there is no decision to use that tool at this time.	Case Managers administer the ICAP. Training has been done for the Case Managers on administration and scoring.	Yes	Both manual and automated scoring	See ICAP domains listed above for AR

STATE	INDIVIDUAL ASSESSMENT TOOL/S CURRENTLY USED	LENGTH IN USE	STATE REPORTED STRENGTHS OF THIS TOOL	STATE REPORTED WEAKNESSES OF TOOL	DOES THE TOOL MEET NEEDS	ALTERNATIVE ASSESSMENT INSTRUMENT? IF YES, WHAT IS IT?	WHO ADMINISTERS THE TOOL AND TRAINING REQUIRED	IS THE TOOL RELIABLE AND VALID	DOES TOOL USE MANUAL OR AUTOMATED SCORING	DOMAINS COVERED IN THIS TOOL
IA	Iowa has standard assessment tools that are for determining level of care. The assessment is utilized for service planning but each case management entity has developed their own assessment tool for use in service planning	1992, implementation of HCBS MR waiver	Easy to use	Doesn't provide overall strengths or needs of individual but rather focuses on deficits to determine level of care	For level of care, yes	Iowa is implementing a new functional process- Goal of Functional Assessment project is to develop uniform screening and assessment process to ensure consumer needs and preferences inform plan of services and supports. Each assessment will be based upon functional abilities and limitations, not disability or diagnosis. Assessments will be used to assist in determination of eligibility for community-based services and to help plan for community capacity needed Tools are being identified.	Currently the case manager fills out the assessment tool. Trainings are conducted on as needed basis or by case management entity. State provides regional and statewide assessment trainings.	Yes, through testing with Iowa State University	Manual	Ambulation/ mobility Musculo-skeletal disabilities Self-help skills Domestic skills Elimination Eating Vision Hearing Communication Fine and gross motor Sensory Intellectual Prevocational/ vocational Community/ social skills Maladaptive behavior Health care

STATE	INDIVIDUAL ASSESSMENT TOOL/S CURRENTLY USED	LENGTH IN USE	STATE REPORTED STRENGTHS OF THIS TOOL	STATE REPORTED WEAKNESSES OF TOOL	DOES THE TOOL MEET NEEDS	ALTERNATIVE ASSESSMENT INSTRUMENT? IF YES, WHAT IS IT?	WHO ADMINISTERS THE TOOL AND TRAINING REQUIRED	IS THE TOOL RELIABLE AND VALID	DOES TOOL USE MANUAL OR AUTOMATED SCORING	DOMAINS COVERED IN THIS TOOL
IL	ICAP	Illinois began using ICAP as part of its pre-screening processes around 1990. It has been used for rate-setting purposes since 1994.	Provides single vehicle, to entire service system, that allows comparison of similarities and differences among persons in diverse service population. Not difficult to administer. Requires approximately an hour to administer and to score. Requires only a brief period of training (one day or less). Provides fairly comprehensive amount of service data for relatively short investment of time.	Providers say it does not adequately factor out emotional/psychiatric and/or physical disabilities from cognitive disabilities (no independent data to support or deny this claim). Allows degree of subjectivity in administering tool, so scores may vary according to rater.	Essentially, yes; however, amount of data is not adequate for determining whether person has adaptive functional limitations within range of mental retardation. For that Illinois requires more extensive assessment tools, such as Vineland, AAMR, etc.	Illinois has been watching other State's activities and practices in this area to identify possible alternatives, but at present time, does not have any specific plans regarding use of alternative assessment instrument.	Tool is generally administered by Qualified Mental Retardation Professional, in consultation with others who know individual well.	Publishers report studies that support tool's reliability and validity. Illinois's experience with ICAP suggests the claims are true, allowing for some subjectivity that may be part of any functional assessment tool.	Automated scoring, however State only collects Service Level and Behavior Score at central office level.	See ICAP domains listed above for AR
IN	Currently use Developmental Disability Profile (DDP) for LOC and eligibility, along with collateral	DDP since 2001 ICAP since 2007 IN is only 1/10th thru ICAP pilot process	ICAP rollout requires 3 interviews to insure capturing info about whole person.	Both tools still have some subjectivity to them	DDP meets current needs	Yes, IN believes ICAP will become standard for LOC, Eligibility, and funding as they move toward	DDP is administered by State employees for eligibility and annually thereafter for LOC by waiver	DDP is losing ground as valid at least on the surface. With DDP, Case Managers may skew evaluation to	Automated on both systems	DDP Health Adaptive Mal-Adaptive

STATE	INDIVIDUAL ASSESSMENT TOOL/S CURRENTLY USED	LENGTH IN USE	STATE REPORTED STRENGTHS OF THIS TOOL	STATE REPORTED WEAKNESSES OF TOOL	DOES THE TOOL MEET NEEDS	ALTERNATIVE ASSESSMENT INSTRUMENT? IF YES, WHAT IS IT?	WHO ADMINISTERS THE TOOL AND TRAINING REQUIRED	IS THE TOOL RELIABLE AND VALID	DOES TOOL USE MANUAL OR AUTOMATED SCORING	DOMAINS COVERED IN THIS TOOL
	documentation. IN is testing ICAP across Waiver population to assist in resource allocation and individual planning needs					more objective system They will use ICAP with collateral info, demographic info, and PCP process to fully evaluate service needs of person	case managers Training is done for state staff by state and training for case manager is provided by the entity, IPMG. ICAP is administered by Arbitre, private firm, and they provide intensive and ongoing training	deem individual more disabled than they actually are. ICAP has more “science” behind it and since it requires multiple interviews conducted by objective group, it should prove to be more reliable		See ICAP domains listed above for AR
KS	DDP adapted for Kansas use	Since 1990	Kansas uses Tiered Rate funding structure which fits nicely with this tool	Tool is quite medical in nature and scores higher for medical over behavioral issues. Therefore identification of staffing/ support needs may not be adequately identified	Kansas is working through Real Choice: Systems Transformation grant to review their assessment processes across all waivers. They will do needs based study to guide KS in decision making process	Don’t know at this time	Designated Case Managers State provides initial and on-going (quarterly) training. No specific degree or experience required.	Yes	Automated	See DDP domains listed above for IN

STATE	INDIVIDUAL ASSESSMENT TOOL/S CURRENTLY USED	LENGTH IN USE	STATE REPORTED STRENGTHS OF THIS TOOL	STATE REPORTED WEAKNESSES OF TOOL	DOES THE TOOL MEET NEEDS	ALTERNATIVE ASSESSMENT INSTRUMENT? IF YES, WHAT IS IT?	WHO ADMINISTERS THE TOOL AND TRAINING REQUIRED	IS THE TOOL RELIABLE AND VALID	DOES TOOL USE MANUAL OR AUTOMATED SCORING	DOMAINS COVERED IN THIS TOOL
KY	North Carolina Support Needs Assessment Profile (NC - SNAP)	Since 2000	Assessment covers 3 broad domains and can be completed within reasonable timeframe.	Some provider complaints that tool is not adequate for reimbursement rates	Yes	No	2 trained assessors complete assessments for state. Initial training was conducted by Murdoch Center and one KY assessor is certified NC-SNAP trainer	Yes	Manual	Daily living supports Health care supports Behavior supports
LA	ICAP used as single point of entry for all DD services. Also used for funding for private ICFs	Since May 2004 for single point of entry and October 2005 for rate setting in private ICFs First used starting in late 2005 to assess support needs of individuals receiving waiver services, state-funded vocational services, on the waiver registry, and living in private and public ICFs/DD	Simple, quick to administer, does not require staff with advanced degrees to complete	Does not provide detailed info re all areas of functioning	Yes, as an initial screening	Yes, SIS (see below)	Community support specialists in regional offices Training is provided by psychology staff	Yes	Automated	See Arkansas above for ICAP domains
	SIS/LA PLUS		Focus on support needs and not deficits Assesses activities requiring support that are important to person Follows person centered philosophy	None listed	Yes, the instruments are currently meeting the need of being comprehensive needs based assessments for adults. A children's version of the SIS is needed and is forthcoming	No	Support Coordinators for people in waiver ICFs/DD staff for people in those settings SIS/LA PLUS staff provide one day training with 2 more hours for electronic versions of instruments.	Yes	Both	See DC above for SIS domains

STATE	INDIVIDUAL ASSESSMENT TOOL/S CURRENTLY USED	LENGTH IN USE	STATE REPORTED STRENGTHS OF THIS TOOL	STATE REPORTED WEAKNESSES OF TOOL	DOES THE TOOL MEET NEEDS	ALTERNATIVE ASSESSMENT INSTRUMENT? IF YES, WHAT IS IT?	WHO ADMINISTERS THE TOOL AND TRAINING REQUIRED	IS THE TOOL RELIABLE AND VALID	DOES TOOL USE MANUAL OR AUTOMATED SCORING	DOMAINS COVERED IN THIS TOOL
MD	Individual Indicator Rating Scale (IIRS) developed by MD DDA	Tool was last revised in 2006; however original tool was developed over 20 years ago and has been revised periodically	Strengths: IIRS is used by a third party statewide, it easily aligns with rate system. Short to complete Rating based primarily on documentation so rater does not need to know person well	Weaknesses: IIRS does not translate into specific services or number of hours Process may be too "hands off" Documentation is not always readily available when individuals are newly entering service system	The IIRS meets most of our current needs; however we would like to move towards using tools that better translate into individual's specific support needs	MD has looked at a number of different tools, including the SIS, however no decisions are planned for near future	The IIRS is administered by contractor, APS Healthcare. Initial training on the tool was done by DDA staff, all ongoing training done internally by contractor	The tool has not been rigorously tested for reliability and validity, however in use has provided consistent documentation regarding level of need	Manual	Two overall elements are rated using the IIRS; health/medical and supervision/ supports. The resulting ratings compute to an individual assessment level
MO	Vineland Adaptive Behavior Scale Missouri Critical Adaptive Behavior Inventory modified version, (MOCABI)	Since 1991 for both tools	None listed	Indirectly measure support needs of the person	No	Yes, SIS Missouri is in process of implementing SIS. Waiver participants age 16 and over will have the SIS interview conducted between 10/07 and 10/08.	Current tools are administered by Regional Center staff.	Yes, both current tools are reliable and valid	Vineland and MOCABI are manual	Vineland Communication Daily living Socialization Motor development MOCABI Self Care Receptive and expressive lang. Learning Mobility Self-Direction Independent.

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	SIS- see section on alternative assessment tools						SIS train the trainer program is underway with goal of 100 statewide trainers	SIS is valid also	SIS is automated	living Economic self sufficiency SIS See above
NC	NC Support Needs Assessment Profile (SNAP)	Since 1998	Good comprehensive look at intensity of person's support needs, short form which can be done quickly if the case manager knows person	None listed	Yes, but NC is looking at more comprehensive assessment tools	Yes, SIS	Case managers must be trained and certified to administer the SNAP	Yes	Automated	Daily living Medical/health Behavioral health
ND	Progress Assessment Report (PAR) ND developed from Colorado tool (COPAR) but substantially revised. Another version for children under age 3 was developed from	PAR since 1997 Child PAR since 2006	None listed	It is not nationally standardized as are ICAP and SIS	Yes	The Child PAR was recently adopted since the PAR did not work well for assessing young children.	Administered by Case Managers that are employees of Single State Medicaid Agency. They are trained in protocol by experienced users	Statistical reliability studies not completed. Validity studies were done correlating results to level of intellectual functioning, other standardized developmental assessments,	Automated	Intellectual functioning Medical Residential Day Psychiatric Behavioral Communication Mobility support needs

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	Oregon assessment (Child PAR).							and results of LOC assessments conducted via professional judgment		
NE	ICAP used for community services and funding	Since 1997	Accurate data, consistent application, objective	It does not capture medical supports	Yes	NO, NE tried SIS and preferred ICAP	Service coordinators who require 6 training hours	Yes	Automated	See Arkansas above for ICAP domains
	For HCBS NE uses Developmental Index	Since 1988	Easy to use	Subjective, may not capture work abilities and skills	Yes, but may be revised to better address work skills	No	DD provider agency staff with no formal training provided	No	No scoring	Eating Meal prep Communication Hygiene Med administration Clothing care Mobility Reading and writing Telephone use Time orientation Money skills Adaptive behavior Vocational skills
	No standard tool for ICFs									
NJ	NJ Developmental Disabilities Resource Tool (DDRT)	Since 1994	Provides standard set of info for individual residing in many settings	None listed	Yes	No	Staff who know the person and are trained to administer the survey. Case managers are trained during orientation.	Yes	Manual	For DDRT Disciplines that complete the assessment are: Medical, Behavioral, Habilitation, Speech, OT,

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	Real Life Choices Assessment Tool	Since 2003	Determines an individual level of need for appropriate budget	None listed	Yes		Not listed	Yes	Manual	PT, Social Work, Nutrition Daily Living, Domestic Skills, & Personal Resources
	Self Care Assessment	Since 2005	Assesses for waiver eligibility only	Not comprehensive	Yes		Not listed	No	Automated	None listed
NY*	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
OH	Ohio Developmental Disabilities Profile (ODDP)	Since 2004	ODDP does provide funding range;	Manner in which the questions are weighted to achieve score/funding range	Not completely	Possibly. Further study on this matter needs to occur before that determination can be made	Service and Support Administrators at County Boards of MRDD administer tool; training by ODMRDD Attendees must pass certification test	Yes for both	Automated	ODDP: Residence Information Disability description Medical Sensory/ motor Cognitive/ communication Behavior Self-care/ daily living skills Routine voluntary care Clinical Services
	Ohio Eligibility Determination Instrument (OEDI) and the Children's Ohio Eligibility	Since 1991	OEDI/COEDI is clear-cut and provides data as it's supposed to, and filters out those who	Not all encompassing	Yes	No	Service and Support Administrators at County Boards of		Manual	COEDI Mobility, Language Self-Care Self-Direction

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	Determination Instrument (COEDI).		do not qualify for MRDD services.				MRDD administer tool; training provided by ODMRDD and attendees must pass test			Independent Living Learning OEDI – same domains, but adds Economic self-sufficiency
OK	Needs Assessment and Individual Support Plan	July, 1999	Concise, easy to use	Has not been validated and thus is not considered "reliable"	Yes, to a large extent	Yes , SIS	Case Managers. Training provided by Program Manager or Supervisor to complete assessment	No	Manual	General health Communication Daily living Mobility and community access Work, school and day activities Protection and advocacy Interaction styles
OR	SIS	Just starting, completed pilot test phase with 400 people in waiver	Accurate data, consistent application, objective	None listed	Oregon believes it will meet needs	NA, just starting to use SIS	For pilot used AAIDD trained interviewers	Yes	Automated	See DC above for SIS domains
PA	Currently, variety of recognizable and readily available tools are used for assessing the current needs of individuals. These include, but are not limited to the	These tools are currently used by County Mental Health/Mental Retardation Programs/Administrative Entities, and the Office of Developmental Programs does	None listed	Weakness within Developmental Programs system regarding needs assessment is inconsistency that results from using multiple tools across PA	Although the current assessments may meet local needs, using multiple assessments results in the inconsistent assessment of need across the Commonwealth	Yes. After much research and review of possible assessments, the Office has decided to utilize the SIS as the statewide, standardized needs	Independent entity will be selected through vending process. All assessors must be conflict free, have Bachelor's degree, and several years of	Yes. The AAIDD developed and tested this tool for both reliability and validity. They also certify the assessors through a standard training	Manual	See DC above for SIS domains

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	Supports Intensity Scale (SIS), ICAP, Functional Behavioral Assessment and Applied Behavioral Assessment	not have data on their utilization			. The Office recognizes policies and processes for a single standardized assessment are necessary	assessment, with assessments tentatively beginning in September 2007.	experience working with individuals with DD. Assessors must be certified to conduct SIS by completing AAIDD training course. Also assessors must complete PA specific training	developed to ensure the reliability and validity of the assessments conducted, and the information collected aggregately		
TX	ICAP	Since 1995	Easy to administer, Minimal training needed, very familiar since in use for long time, manual or computer scoring	None listed	Yes to determine relative service/ funding levels	Yes, SIS, but this would be a long term process	Family members, direct care staff, case managers , program directors and psychologists	Yes	Manual or automated	See Arkansas above for ICAP domains
VA	Level of functioning (LOF) tool and ICAP; Community Services Boards may use other tools if approved by Department	LOF Since the early 1980's	None listed	Outdated and uses old terminology	VA would like to change tool	Yes, SIS	Case managers employed by County Community Services Boards	Multiple tools are being used and some of them may not be valid	Depends on the tool	Variety of tools used See Arkansas above for ICAP domains

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WA	DDD assessment incorporates SIS	Since June 2007	Automated, standardized assessment process; can determine if service is needed and level; identify if people with similar needs receive similar service; and clarify policies and standardize practices.	None listed	Too soon to evaluate, but designed to meet WA's needs	No	State Case Resource Managers who must have one week of training	Based on SIS, which is nationally normed, valid and reliable	Mostly automated with all to be automated in future	See DC above for SIS domains
WI	Functional Screen developed by WI is used for eligibility and levels of care. WI Waiver Manual contains all content areas of assessment required for anyone with DD going onto Waiver whether MFP or not. Assessment is administered at county level addressing all content areas, but using different tools	The Functional Screen, which is an eligibility tool, has been automated since 2005. The individualized assessment process has been established as part of the waivers since early 1980's but is not automated and has been used by the counties since the beginning of the community based waivers.	Both the functional screen and the individualized assessment process have similar strengths. Both capture social /medical data in one place for care planning and provide consistency statewide.	No weaknesses noted	Yes	No, not for community based waivers. However, with expansion into managed care there will be different tools in future	Case managers at local level administer tool. Training was offered statewide when tool was automated and instructions are part of screens for tool Individualized assessment training occurs in large and small groups on frequent basis and is part of basic waiver training	Yes, reliability checked annually	The Functional Screen is automated but assessment is not automated.	Background and social history Physical and medical health history. Individual outcomes important to person, Ability to perform physical ADLs Ability to perform instrumental ADLs Emotional and cognitive function Behaviors that affect lifestyle or relationships

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	and methods shaped by county									Social participation, friendships, formal and informal social supports Cultural, ethnic and spiritual influences Community participation and involvement Preferences re how and where to live, daily activities/ routines and environment

Appendix 5

ANALYSIS OF FUNCTIONAL TOOLS FOR 27 MFP STATES

TOOL NAME	Supports Intensity Scale (SIS)	Vineland II Adaptive Behavior Scale (ABS)	Developmental Disabilities Support Needs Assessment Profile (SNAP)	The Inventory for Client and Agency Planning (ICAP)	Developmental Disability Profile (DDP)
Description	Measures support requirements in 57 life activities and 28 behavioral and medical areas. The assessment is done through an interview with the consumer and those who know the person well	Three domain structure: Communication, Daily Living, and Socialization. offers a Motor Skills Domain and an optional Maladaptive Behavior Index to provide more in-depth information	Developed in NC as an easy-to-use, reliable, and valid measure of individual need for people with DD that could then be tied to funding levels.	77 adaptive behavior items divided into four areas: assesses adaptive and maladaptive behavior and gathers additional information to determine the type and amount of special assistance needed	Four page tool developed by New York's Office of MR and finalized in 1990 to provide description of characteristics of people with DD related to service needs. It is used to describe, plan and manage a system of DD services. The DDP provides "snapshot" of individual's capabilities. DDP is an informant-based tool. It can be administered with individual, reliable informant or both.
State Reported Strengths	Engages consumer directly in interview process Nationally normed Strong training and reliability components Focuses on what person would need rather than general menu Respondents have chance to think about what	Survey interview form (open ended) and or parent/caregiver rating form which is shorter good norms and psychometric measures adaptive behavior of a broader age range from birth to age 90.	Very short Good comprehensive look at intensity of person's support needs, short form which can be done quickly if case manager knows person Assessment covers 3 broad domains and can be completed	Provides a service and level of care score Nationally normed Provides accurate data as an adaptive behavioral assessment Simple, quick to administer, does not require staff with advanced degrees Objective	Brief and easy to administer. It also contains sufficient functional information concerning adaptive functioning, maladaptive and health needs to provide a complete picture of individual's disabilities. Kansas selected

TOOL NAME	Supports Intensity Scale (SIS)	Vineland II Adaptive Behavior Scale (ABS)	Developmental Disabilities Support Needs Assessment Profile (SNAP)	The Inventory for Client and Agency Planning (ICAP)	Developmental Disability Profile (DDP)
	<p>needs to be done not just what is Comprehensive Potential for use as level of need, planning, and cost/rate setting Focus on support needs and not deficits Assesses activities requiring support that are important to person Follows person centered philosophy Accurate data, consistent application, objective Automated, standardized assessment process; can determine if service is needed and level; identify if people with similar needs receive similar service; and clarify policies and standardize practices.</p>		<p>within reasonable timeframe.</p>	<p>Minimal training needed, manual or computer scoring Provides one tool that allows comparison among persons in diverse service populations. Not difficult to administer. Provides fairly complete service data for relatively short investment of time looks at changes over time. Systematic way of obtaining information. Problem Behavior section helpful in identifying behaviors and relative degree of concern (severity) to families. More “science” behind it and since it requires multiple interviews conducted by objective group, it should prove to be more reliable</p>	<p>the DDP because it had low acquisition costs and is somewhat more compact than the ICAP. DDP does provide funding range Tiered Rate funding structure fits nicely with this tool</p>

TOOL NAME	Supports Intensity Scale (SIS)	Vineland II Adaptive Behavior Scale (ABS)	Developmental Disabilities Support Needs Assessment Profile (SNAP)	The Inventory for Client and Agency Planning (ICAP)	Developmental Disability Profile (DDP)
State Reported Weaknesses	Need to supplement questions a bit No easy way to transfer the level of need to “risk” and cost Time intensive Need to build-in an ongoing reliability process Tool does not take into account parenting skills and impact on needs of young children living at home	Interview process is somewhat complex and time-consuming Indirectly measure support needs of the person	Not very fine level of distinctions in needs Some provider complaints that tool is not adequate for reimbursement rates	Does not discriminate well at the upper end of the skill range Does not identify, via quantifiable score, medical and support service needs. Does not provide detailed info re all areas of functioning It does not capture medical supports well Providers say it does not adequately factor out emotional/ psychiatric and/ or physical disabilities from cognitive disabilities (no independent data to support or deny this claim). Allows degree of subjectivity in administering tool, so scores may vary according to rater. Can be lengthy to administer	All questions must have a response in order to score The DDP is a “deficits-based” assessment tool Tool is quite medical in nature and scores higher for medical over behavioral issues. Therefore identification of staffing/ support needs may not be adequately identified Manner in which the questions are weighted to achieve score/ funding range DDP is losing ground as valid at least on surface. With DDP, Case Managers may skew evaluation to deem individual more disabled than they actually are.
MFP states using tool	GA, WA, LA, DC, OR and sections of CA. MO and PA starting to use in Fall 2007.	Missouri has been using but is in process of switching to SIS	North Carolina, KY	Arkansas, DE, IL, HI Nebraska, Texas and parts of Virginia IN switching to ICAP as part of pilot started in 2007 has been used in Louisiana in the past	KS and OH use for level of care and funding of rates. In use since 1990 in KS and 2005 in Ohio IN has used for eligibility and LOC since 2001, but is switching to ICAP as of 2007

TOOL NAME	Supports Intensity Scale (SIS)	Vineland II Adaptive Behavior Scale (ABS)	Developmental Disabilities Support Needs Assessment Profile (SNAP)	The Inventory for Client and Agency Planning (ICAP)	Developmental Disability Profile (DDP)
Reliability and Validity	Extensively tested for reliability and validity	Extensively tested for reliability and validity	Extensively tested for reliability and validity	Extensively tested for reliability and validity	Demonstrably valid and reliable
Who administers	Case managers/social workers/psychologists	Must be administered by a trained social worker or psychologist other professional with a graduate degree and training in interview techniques	Case managers can be trained There is no strict educational requirement to become SNAP examiner, but typically, para-professionals should not be assigned as assessors.	Parent, teacher social worker, Qualified Mental Retardation Professional (QMRP) or other care person	Case manager, QMRP or service coordinator
Training and time required to administer	One hour or more to administer instrument. Evaluator needs to be trained with 4 year degree in field Under exceptional circumstances others with experience conducting individual assessments and possess extensive knowledge of behavior rating or psychological testing principles may be acceptable Assessors must be certified to conduct SIS by completing up to one week AAIDD training course	See above	Must be certified as a SNAP examiner 15- 30 minutes to administer if person knows the individual well	Requires only brief period of training (one day or less). Requires approximately an hour to administer and score	Training is done by the states MR/DD agencies and certified in Ohio. Reported to be both easy and quick to administer by Indiana.

TOOL NAME	Supports Intensity Scale (SIS)	Vineland II Adaptive Behavior Scale (ABS)	Developmental Disabilities Support Needs Assessment Profile (SNAP)	The Inventory for Client and Agency Planning (ICAP)	Developmental Disability Profile (DDP)
Manual or automated scoring	Automated scoring available through SIS Online and CD ROM version web system allows access to variety of reports and statistics, and maintains a database of historical information	has computer scoring	has computer scoring	has computer scoring	On line scoring is available
Domains	Home living Community living Lifelong learning Employment Health/ safety Social Protection and advocacy Exceptional medical Exceptional behavioral	Communication Daily living Socialization Motor development	Daily living supports Health care supports Behavior supports	Motor Skills Social and communication Personal living Community living Also has general maladaptive behavior index	Health Adaptive Mal-Adaptive

Appendix 6

QUALITY OF LIFE DATA

STATE	QUALITY ASSESSMENT TOOL/S CURRENTLY USED	LENGTH IN USE	STATE REPORTED STRENGTHS OF TOOL	STATE REPORTED WEAKNESSES OF TOOL	DOES INSTRUMENT MEET NEEDS	WHO ADMINISTERS AND TRAINING REQUIRED	TOOL RELIABLE AND VALID	DOES THE TOOL USE MANUAL OR AUTOMATED SCORING	DOMAINS COVERED IN THIS TOOL	SELF ADVOCATE ROLE	FAMILY/GUARDIAN ROLE
AR	National Core Indicators (NCI)	Since 2005	Tool has high response rate from providers and consumers, covers most of domains in Quality Framework, is easily administered	length of time to administer face-to-face interviews	Yes, is used with other information gathered about a person	State Staff	Yes	Manual	Consumer outcomes System performance Health, welfare & rights Staff stability and competence Family Indicators Case management	None at this time	Guardians are generally responders for survey AR does not administer family survey, but plans to do so in future.
CA	Mover Study annual evaluation of people moving from State developmental centers into community	Since 1994	Tracks quality of community programs and placements, and measures consumer and family satisfaction	None listed for any tools	Yes, the study population includes all persons moved as result of Coffelt court settlement agreement (1993) and people that moved from developmental centers	Contractor employs staff who receive extensive training before conducting interviews throughout state	Not stated	Interviews are manually scored	Staff characteristics Living situation Relationships Individual plan & case mgmt Daily life Challenging behaviors Physical and social envir. Health & safety Mental health & crisis intervention Legal concerns	DDS conducts an annual meeting of stakeholders including self advocates, that review the findings and make recommendations	DDS conducts an annual meeting of stakeholders, that review the findings and make recommendations

STATE	QUALITY ASSESSMENT TOOL/S CURRENTLY USED	LENGTH IN USE	STATE REPORTED STRENGTHS OF TOOL	STATE REPORTED WEAKNESSES OF TOOL	DOES INSTRUMENT MEET NEEDS	WHO ADMINISTERS AND TRAINING REQUIRED	TOOL RELIABLE AND VALID	DOES THE TOOL USE MANUAL OR AUTOMATED SCORING	DOMAINS COVERED IN THIS TOOL	SELF ADVOCATE ROLE	FAMILY/GUARDIAN ROLE
	Life Quality Assessment (LQA)	Since 1996	Assesses individual life quality		Yes, it was designed in response to the Coffelt Court settlement agreement, LQA is a tri-annual survey of consumers living away from home	Administered by local DD Area Board of State Council on DD staff employed to administer tool receive extensive training before conducting interviews		Interviews are manually scored and returned to regional center to develop Individual Program Plan (IPP)	Physical quality Choice Relationships Lifestyle Health and well being Assurance of rights Satisfaction		
	NCI is used in parts of CA – Bay Area Orange County	Use in the two areas Since 2002 Since 2004				Contractor staff receive extensive training before conducting interviews			See domains listed for NCI above	CA establishes Quality Review Commission made up of stakeholders	CA establishes Quality Review Commission made up of stakeholders
CT	NCI Quality System Review (QSR)	Since 1997 QSR begun region level in 2006, and will deploy at state level when web-	None listed Master list of indicators, data from variety of people across time,	None listed Technical start up problems, learning curve with new system, review process is	CT believes it will, although has not had experience with complete tool and system due	Quality reviews are conducted by regional and state quality monitors and	Yes Testing has been done, but validity and reliability have not	Both manual and automated Currently not automated but QSR web based application will provide	See domains listed for NCI above Planning and personal achievement; relationships and community	Several self advocates conduct NCI consumer interviews Consumer interviews are key method of gathering info in QSR and NCI.	NCI protocol mails surveys to families and guardians There is surrogate interview component to QSR review process with

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		based data starts	built in electronic follow up and notification feature, outcome based	extensive	to delays in application deployment.	case managers. Training is required in how to use data application and conduct reviews	yet been established.	automated scoring	inclusion; rights, respect and dignity; safety; health and wellness; satisfaction; administration	Consumers were involved in development of indicators and review processes	family member or friends of consumer. Questions are same as those for consumer interview.
DC	Basic Assurance Standards Authorization tool and review process was developed by District staff Basis for tool is The Council on Quality and Leadership's (CQL) person centered Basic Assurances.	Since April 2007	Person centered Based on world recognized, valid tool Review uses both policy/ document review Staff dialogue, observation and interviews with people who receive services Good provider buy-in Reliable data at individual and aggregate level which can help when people are looking for services	Time intensive	Thus far, the tool started with person-centered assurances on the basic foundations of health, safety, and well-being. In the next year, DDA will be developing or using tools that promote person-centered quality of life	District, Basic Assurance Unit staff conduct reviews. Training has been intensive for staff as this is a new tool and process. Training for providers has been offered in group and onsite forums	Validity: Not tested, but tool is based on internationally reliable and valid tool. Reliability process should be completed by end of first year Like Personal Outcomes, tool requires multiple sources to confirm measure is met or not	Moving from manual to automated currently	Rights and protection Dignity and respect Protection from abuse, neglect, mistreatment, and exploitation Best possible health Safe environments Staff resources and supports Positive services and supports	Self-advocates have had some involvement in the development process as have family members.	Family members have been actively involved in a stakeholder group that reviews and advises staff on the tool and process development and implementation

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DE	NCI	Since 2000	Provides comparison to other states' results. Data analysis done by HSRI Correlated with CMS assurances.	state-to-state comparisons take a number of months	Yes, for the most part	Contractor; HSRI did training with DE on use of NCI Consumer Survey	Yes	Manual in DE, some states have data-entry scanning systems developed and in place	See domains listed for NCI above	They are interviewed in Consumer Survey	Families provide feedback in mail-in surveys
GA	NCI Health Risk Screening Tool (HRST)	Since 2006 Web based since 2007	NCI –family surveys are helpful HRST -hope is that web based system will be more effective	Cannot guarantee interviewer objectivity Have not been able to trend provider workforce info Paper tool was not used well for health surveillance	Yes Most likely, need to see with web based format	NCI – Support Coordinator administers requiring six hour annual training. HRST – community providers with one day training use for people in service Intake and Eval. Staff administer tool when person first accesses services	Yes for both	NCI – manual HRST - automated	See domains listed for NCI above	Self advocates have not administered either tool used They provided input prior to decision to use tools.	Same as self advocate response for both

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HI	NCI	Since 2000	Face to face interview process Standardized means of comparing outcomes over time and against other states	None listed	Yes	DDD staff conduct interviews Training was done by HSRI via teleconference	Yes	Manual	See domains listed for NCI above	None at this time	A Quality Assurance committee of family members reviews results, recommends if other info should be obtained and recommends referral for follow up to address specific outcomes
IA	Iowa is in process of developing QA system that will incorporate HCBS waivers and MFP recipients. Tools are being developed and piloted HCBS "Inclusion through Quality" IQ Plan includes development of interview process utilizing Participant Experience	Presently designing new system	Intent of interviews is not only to review consumer satisfaction but also to address provider issues and improve service delivery	PES/MR focuses mainly on ADLs; but did not directly address support that included skill training, Although tool may identify deficit area for these activities, it did not always identify why deficit existed. Main focus on services in home with few questions related to service provision outside home. PES based on experience of	New system will be designed to meet Iowa's needs	Data shall come from a variety of sources including HCBS provider databases, site reviews, follow-up compliance reviews, complaint investigations, evaluation reports, consumer satisfaction surveys, consumer interviews, and consumer records. This	County / State service coord. through DHS field offices and Medicaid Case Managers	Combination of automated (ISIS) and manual	Health and safety issues of consumers receiving services, Abuse/neglect and exploitation of consumers, Consumer access to services Plan of care discrepancies Availability of services, Complaints of service delivery Training of providers, case managers, and	Not stated	Not stated

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	Survey (PES) and an associated case file review process. Implementing by HCBS field specialists has begun with waiver participants. PES has been utilized with various consumer waiver populations including the MR, BI, PD, I&H, and E.			family member, not agency delivering ADL supports. Tool did not work for children. MR PES appears more institutionally based Many consumers on MR waiver receive hourly supports and tool did not provide accurate or relevant data for that purpose		information will be compiled and analyzed to ascertain any needed systemic improvements			other stakeholders Emergency procedures Provider qualifications Consumer choice Supported employment, Consumer rights		
IL	Illinois participated in NCI several years ago; however, they stopped due to budgetary issues. For 3 years IL used IMAP, consumer satisfaction tool created for IL by CQL IL had issues with inter-rater	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

STATE	QUALITY ASSESSMENT TOOL/S CURRENTLY USED	LENGTH IN USE	STATE REPORTED STRENGTHS OF TOOL	STATE REPORTED WEAKNESSES OF TOOL	DOES INSTRUMENT MEET NEEDS	WHO ADMINISTERS AND TRAINING REQUIRED	TOOL RELIABLE AND VALID	DOES THE TOOL USE MANUAL OR AUTOMATED SCORING	DOMAINS COVERED IN THIS TOOL	SELF ADVOCATE ROLE	FAMILY/GUARDIAN ROLE
	reliability and IL did not believe benefits of survey were worth outlay of resources. IL does not currently use standardized quality tool										
IN	IN does not have statewide tool for measuring quality- requires each agency to maintain quality improvement systems including customer satisfaction piece.					IN working with CARF and CQL to determine future tool for survey/quality assurance. Working in collaboration all of stakeholders (providers, Medicaid, consumers, families) they are trying to define quality outcome measures which can be standardized					
	IN used to participate in NCI										

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KS	KLO-II (Kansas LifeStyle Outcomes 2nd Version) Kansas developed quality assurance / performance improvement tool to be used on random sample of service recipients	Since 1997	Comprehensive person centered individual outcome focused, data based	Not usable across disabilities, lengthy process requires staff highly trained re person centered services	Yes, for MR/DD but KS want to work all systems cross-disability. Real Choice Systems Transformation Grant will be utilized to develop concepts, tools and data base	State staff, employed at regional level. Staff are trained by Central Office before administering tool and kept up to date on regular basis. No specific degree or experience required.	Yes	Automated	Person-centered planning Individual choice and control Health and safety Rights Psychotropic medications/ behavioral issues	The survey tool is completed one on one with persons served where they live or work Provided input into its development and critical component in on-going data review and trending	Provided input into its development, and critical component in on-going data review and trending
KY	NCI	Since 2000	Self-response rate has consistently been 60-70%. independent interviewers high number of interviewers w/ disabilities or family members Survey enables KY to include items of state specific interest. For example,	None listed	Yes. Continued use of instrument has enabled KY to track progress over time as well as to assess regional and residential differences.	KY contracts with University of KY to administer NCI. Interviewer training is one day overview with role play followed by shadowing experience.	Yes	Interviewers may complete the survey with pencil and paper or may enter responses directly into a spreadsheet. Both are considered manual entry.	See domains listed for NCI above	As part of Kentucky's Real Choices grant (2001-2005) interviewer teams were developed with at least one self advocate or family member. About half of current interviewers are self-advocates	As part of Kentucky's Real Choices grant (2001-2005) interviewer teams were developed with at least one self advocate or family member. In addition, family is often present at interview.

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			body mass index, in an effort to address wellness issues.								
LA	Personal Outcomes Measures developed by The Council on Quality and Leadership (CQL). Used in public ICF/DDs Some private agencies use tool but no info on which agencies or how data is used	Prior to 1997	Consistent way to gather info to make comparisons Easy and person centered	Hard to do w/o good tracking systems Initial CQL training costly but having internal staff certified is less costly	From public ICF/DD perspective, it works From community perspective does not match new plan	Team Leaders or QMRPs at ICFs/DD	Yes	Manual	My world My dreams My self - living and work Relationships Community Health Safety and wellbeing Rights	Interview is done with consumer	Families are involved in interview when more info is needed
	The Partnership for Quality Tracking System was developed as pilot If successful this system will be used statewide when people move from public ICF to	Fall 2006	Individual and Uses person who knows best as primary responder Takes 1-2 hours Provides info on both health and safety and satisfaction Does not	Responder biases No reliability & validity yet Only assesses presence or absence of individualized supports , not quality	Too new to assess	Private support coordinators One day training with shadowing for 3 sessions	Reliability and validity have not yet been established	It is not scored Data is used for both individual and aggregate reports	Critical incidents Individualized support needs Satisfaction	Individual is primary responder to survey, with assistance as needed/ to indicate satisfaction Other info is derived from data or person's plan.	Family/ guardian is invited to participate unless an individual requests that they not participate

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	community		require highly trained staff								
MD	Ask Me!© Survey, a consumer survey.	Since July 1998	Implemented by self-advocates and information on agency results is made public.	The Ask Me! Survey does not capture important QA data, such as number of incidents and licensing issues. This data is tracked separately	The Ask Me! Survey meets Maryland DDA's needs, however Maryland is reviewing its quality plan to determine other ways to improve quality	Survey is administered by consumers through contract with The Arc of Maryland. Training on administering the survey is done by staff within the contracting agency	Yes, survey was developed and field-tested for reliability and validity under direction of Dr. Gordon Bonham, President of Bonham Research	Manual scoring	Physical wellbeing, Emotional wellbeing, Interpersonal relations, Material wellbeing, Social inclusion, Personal development, Self-determination, Rights	Self advocates helped develop and field tested survey and serve as interviewers	Provider agency results [from the Ask Me! Survey] are posted in an annual report on DDA website, for use by individuals and families as they consider which provider to engage for services.
MO	Missouri Quality Outcomes Measure Participant Survey” also known as Self Advocates & Families for Excellence (SAFE) survey, and “A Day in a Life”. NCI to be used	The Day in a life 18 months SAFE 6 months In process	SAFE tool is administered by peer volunteers	Not always easy to find volunteers to administer surveys throughout state	Yes, both tools meet needs	The SAFE survey is administered by peer volunteers and training is provided by the state employed Quality Assurance team leader. State Quality Assurance staff conducts the	Face validity. Reliability and other validity assessments have not been completed	The SAFE survey tool collects simple data currently does not have a specific scoring mechanism. A data base for results of process is in development. Results of Day in the Life process is	The domains are Safety, Health, Services and Staff, Money, and Rights. All of our QA data is summarized under these 5 domains. The Missouri Quality Outcomes tool contains 16	Self advocates can volunteer to administer SAFE survey	Family and guardians are encouraged to participate in either survey. They are always notified and guardians must sign the consent form for participation

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	along side of the current surveys.	for NCI with 7/07 start				Day in the Life visit		entered into a data base from which reports for trending can be obtained	outcomes for individuals served		
NC	NCI and state developed consumer satisfaction tool	Since 1999	Data is complete and useful and provides for face to face interviews with consumer	Can be costly since contracted interviewers are used	Yes	Trained interviewers are used. They are trained in actual tool, how to ask questions, and to be aware of evidence of any abuse or neglect	Yes	Manual	Same domains as listed above for NCI	None listed	Only if consumer is unable to respond for themselves.
ND	Systems Indicators was developed including material from NCI, Council Personal Outcomes and other sources. There are 3 versions depending on age and residential setting	Since 2001	It is automated and provides 100% sample in a 2 year cycle	None listed	Yes	Administered by Case Managers that are employees of Single State Medicaid Agency. They are trained in protocol by experienced users	It is considered to have face validity in that it was developed with extensive input and review by experienced professionals	Automated	Satisfaction with personal rights Activities, Facilities, Services Support personnel	There is no formal role in individual survey process. Statistical data is available to interested parties	Respondent may be family member, guardian, individual, or someone who knows individual best. Data is recorded regarding category of respondent

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NE	Quality of Life Questionnaire (Schalock/Keith) is used with people in community DD services Some private, non-profit ICFs/MR use the Council Personal Outcomes	Over 10 years	Promotes high self response rate	None listed	Yes, considering use of PES	State DD Service Coordinators with about one hour training	Yes	Manual	Satisfaction Competency Empowerment Social belonging Rights Relationships Economic security Growth and development Perception of well-being	Self advocates are interviewed and/or complete the survey	Up to two family members or others who know the person well may act as proxy for individuals with limited expressive or receptive communication abilities.
NJ	NCI	In process of being started	Low cost of training, cost effective and sustainable, reports available with comparisons between participating states	None listed	Not yet in use	Office of Quality Improvement Training to be done by teleconference	Yes	Automated	Same domains as listed above for NCI	Consumers respond to survey, if able	Family members are provided with Family Survey and may also be used as proxies during NCI Survey interview
NY *	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
OH	Individual Quality of Life [IQL] Review Tool was developed for use by ODMRDD	Since 2005	Consumer family and staff are all interviewed Focuses on routine/preventative healthcare, short and long term health risks from family	Difficult to get feedback from individuals who don't communicate verbally Occasionally difficult to arrange interviews with family members Size of tool is	Currently, yes	ODMRDD reviewers administer tool. State DD managers train staff to use tool and on review process. This is usually done in 1-2 days. Also, new reviewer will shadow	Tool has not gone through validity or reliability testing. Much of info on tool is hard data from records Because	Tool is filled in manually but currently there is no scoring instrument. Data from tool (each question has pre-determined list of responses) is inputted into	Demographics Health info Service delivery and QA Individual interview, Home visit Family/guardian/natural support interview	Interviewer completes one-on-one interview with individual and asks them series of questions about their feelings and preferences	Interviewer completes one-on-one interview with family/guardian or natural support and asks them series of questions about what the individual is

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			history and or lifestyle; follow-up at the end of review allows for any changes in service planning and health care based on input of consumer, family or staff	somewhat cumbersome		more experienced reviewer a few times before conducting reviews alone	reviewer also interviews individual, and other involved persons, OH can follow up to clarify concerns or conflicts that have surfaced.	spread sheet, and data is used for reporting generalized feedback. Info is used in annual reports Division of Community Services' QA office	Direct service staff interview		allowed to do
OK	NCI	Since 2001	State performance can be compared to other states providing supports	None listed	Tool presently meets needs	Administered by outside contractor	Yes	Automated	Same domains as listed above for NCI	Self advocates are interviewed during consumer survey	Family/guardians complete family survey
OR	Serious Event Review Team (SERT) System	Since Spring 2000	Standardized Incident reporting Ability to aggregate and review local and statewide information on serious events and significant licensing	Questions re quality of data input and lack of f/u documentation	Yes	State is responsible for offering training related to basic use and policy. The State offers technical assistance and maintains the web-based system.	Accuracy of data entry can affect reliability	There is no scoring. There are some "canned" reports that will identify top 10 incidents, providers, individuals based on frequency of incidents at	It covers health and safety assurance and can be used to identify need for provider training or risk tracking/ protocols to prevent serious events.	Self Advocates sit on DD Quality Assurance Committee that reviews SERT data periodically to offer feedback and advice about what to	Family Stakeholders sit on the DD Quality Assurance Committee that reviews SERT data periodically to offer feedback and advice about what to review and how

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			issues in electronic format					each program		review and how to make quality improvement using info from SERT system	to make quality improvement using info from SERT system
PA	National Core Indicators (NCI) and the Essential Data Elements which is an adaptation of the NCI	Since 1998	Provides comparative data on key quality indicators across states. NCI and EDE both provide information on key quality indicators that are relevant regardless of age, degree, type of disability or living arrangement. Both tools can be administered by people with disabilities and their families	None listed	Yes, just grappling with technology interface issues and needs for tweaking over time	EDE and NCI are administered statewide by independent monitoring teams with mainly people with disabilities and their families They conduct face to face interviews based on statewide guidelines and protocols Annual training is provided to interviewers	Yes	Automated	Same domains as listed above for NCI	Self advocates serve on Oversight Board and are interviewers	There is family/guardian survey that is administered through mail-in survey and telephone survey for NCI and EDE samples. Approximately 5,000 persons a year participate in EDE/NCI Survey.

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TX	NCI	Since 2005	NCI Tech. Asst. Aligns with CMS HCBS Quality Framework Covers many quality areas Can draw upon experiences of other states	Many indicators Hard to find interviewers Tools are only in English and Spanish	Yes for both	The state contracts this activity with NACES Plus Foundation for both tools	Yes for both	Both manual and automated for both tools	Same domains as listed above for NCI	Consumers helped choose NCI tool They also participated in mock training interviews Results are shared with external stakeholder groups	Same as self advocate role
	PES Elderly/ Disabled Version	Since 2005	PES can be used with people with cognitive limitations Identifies problem areas and measures impacts of interventions Extensive pre-testing and field testing PES	No proxy version Skip patterns are difficult to follow Limited TA No Spanish version - Difficult to find web resources					PES: Access to Care Choice and control Respect/ Dignity Community integration/ inclusion	PES – Same	PES - Same

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VA	Family/guardian survey	Since 2001	None listed	Some answers are provided by staff on behalf of individuals	Some, not all needs	Self report from family	No	Automated	Family involvement Health & safety Service reliability Case management Choice and access	Consumers assist w/answering tool	Families involved in development of survey tool and they fill out survey tool and report back.
WA	NCI	2000	Nationally normed, staff training is economical and tool is easy to use	None listed	Yes, all three meet state's needs	Regional QA managers for both NCI and Institutional Movers	Yes, all three tools are reliable and valid	Automated for all three tools and reports can be drawn from data	Same domains as listed above for NCI	Partnered with DDC, NCI and Institutional movers is done face to face using trained self advocates and family	Partnered with DDC, NCI and Institutional movers is done face to face using trained self advocates and family members
	Institutional Movers	2000	Follows a person first year after moving from institution-questions added to NCI						Movers adds questions re move from facility		
	Plan of Care Survey developed by WA	2002	Anonymous response from people and their families	not in depth tool		Case managers send to clients and families			POC only looks at process for developing a support plan	Support plan survey is completed by self advocates and family members	Support plan survey is only completed by self advocates and family members

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WI	DD Service Section Program Review Tool 5% of all consumers are sampled for review each year; all people leaving State Centers are reviewed within 30 days of discharge; and all people discharged from State Centers are reviewed annually until stable.	Waiver process for quality has been in use since early 1980's	The information contained in the outcome measures is useful to providers and counties. review process is quite comprehensive	Counties only receive feedback on very limited number of consumers each year	Yes	State Staff administer the tool.	Yes	Manual reporting, automated data	Health Residence Meaningful day Case management Guardian Community integration.	Participates in reviews, advisory and is seen and interviewed by state staff	Participates in the assessment and plan development, participates in reviews for quality, annually surveyed

Appendix 7

ANALYSIS OF QUALITY TOOLS FOR 27 MFP STATES

TOOL NAME	MEDSTAT PARTICIPANT EXPERIENCE SURVEY (PES)	QUALITY OF LIFE QUESTIONNAIRE (QOL)	NATIONAL CORE INDICATORS (NCI)	COUNCIL ON QUALITY AND LEADERSHIP PERSONAL OUTCOMES MEASURES (CQL)	ASK ME!
Description	<p>Thomson Med Stat group Participant Experience Survey (PES) is a series of population-specific interview tools that capture data that can be used to calculate indicators for monitoring quality within waiver programs. There is a version specific to the MR/DD population that was developed under a contract with CMS. The PES tools were developed to assist State's with quality management systems. Users' Guides provide guidance on survey administration and calculation of quality indicators. 51 performance indicators. Includes 8 "core questions" for participants with severe cognitive impairments.</p>	<p>Quality of Life (QOL) Questionnaire Schalock/ Keith- 40 item internationally validated survey with 8 domains</p>	<p>National Core Indicators (NCI) – developed by NASDDDS and HSRI The core indicators are the foundation for the project. The current set of performance indicators includes approximately 100 consumer, family, systemic, cost, and health and safety outcomes - outcomes that are important to understanding the overall health of public developmental disabilities agencies. Associated with each indicator is a source from which the data is collected. Sources of information include consumer survey (e.g., empowerment and choice issues) family surveys (e.g.,</p>	<p>Personal Outcomes Measures-consumer survey The Council on Quality and Leadership (CQL) used in many states as a part of an accreditation process for individual agencies rather than statewide.</p>	<p>Ask Me!© Survey is a collaborative project in Maryland between Schalock and Keith's QOL and the Signs of Quality, a booklet developed by People On the Go, the statewide self advocacy organization.</p> <p>It has been piloted beginning in 1997 and is mandatory for all DD funded agencies in MD for the past 5 years. 50 questions with 8 domains. Administered by The Arc of Maryland through a contract with MD Developmental Disabilities Administration</p>

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State Reported Strengths	Intent of interviews is not only to review consumer satisfaction but also to address provider issues and improve service delivery PES/ ED can be used with people with cognitive limitations Identifies problem areas and measures impacts of interventions Extensive pre-testing and field testing	Been in use for more than 15 years with extensive study and application around the world Survey has also been used on populations other than people with developmental disabilities to look at broader applicability of quality of life domains	satisfaction with supports), provider survey (e.g., staff turnover), and state systems data (e.g., expenditures, mortality, etc.) Provides comparison to other states' results. Data analysis done by HSRI Correlated with CMS assurances. Assesses regional and residential differences Allows for addition of state specific questions Self-response rate has consistently been 60-70%. Nationally normed, Staff training is economical Tool is easy to use Good technical assistance available Can compare results over time	Person centered Based on world recognized, valid tool Review uses both policy/ document Staff dialogue, observation and interviews with people who receive services Reliable data at individual and aggregate level which can help when people are looking for services Consistent way to gather info to make comparisons Easy and person centered	Uses only interviewers with disabilities High self response rate Information on agency results is made public Information can be used to improve agency quality assurance plans Measurements can be gathered by agency, by question, by domain or service type
State Reported Weaknesses	Focuses mainly on ADLs; but does not directly address support that included skill	Proxy responses have been shown to be different than self responses and the rate of self response	State-to-state comparisons take a number of months Cannot	Time intensive Issues with inter-rater reliability and IL did not	Does not capture important QA data, such as number of

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	<p>training, Although tool may identify deficit areas for these activities, it did not always identify why deficit existed. Main focus on services in home with few questions related to service provision outside home. PES based on experience of family member, not agency delivering ADL supports. Tool did not work for children. MR PES appears more institutionally based. Many consumers receive hourly supports and tool did not provide accurate or relevant data for that purpose. No proxy version. Skip patterns are difficult to follow. Limited technical assistance available. No Spanish version. Difficult to find web resources.</p>	<p>across people with the most severe cognitive disabilities is lower</p>	<p>guarantee interviewer objectivity. Have not been able to trend provider workforce info. Many indicators. Tools are only in English and Spanish.</p>	<p>believe benefits of survey were worth outlay of resources. Hard to do w/o good tracking systems. Initial CQL training costly but having internal staff certified is less costly.</p>	<p>incidents and licensing issues. Is subjective from perspective of person answering survey.</p>

TOOL NAME	MEDSTAT PARTICIPANT EXPERIENCE SURVEY (PES)	QUALITY OF LIFE QUESTIONNAIRE (QOL)	NATIONAL CORE INDICATORS (NCI)	COUNCIL ON QUALITY AND LEADERSHIP PERSONAL OUTCOMES MEASURES (CQL)	ASK ME!
MFP states using tool	<p>PES MRDD used in Iowa, has been used in past in Arkansas, Ohio and parts of Wisconsin</p> <p>PES E/D version used in TX alongside NCI</p>	Used in Nebraska and elsewhere internationally	14 (AR, CT, DE GA, HI, KY, MO, NC, NJ, OK, PA, TX, WA) of the current MFP states with MR/DD target population and parts of CA are using NCI IL, IA, NE, VA and IN used to participate in NCI	DC uses, LA uses in parts of the state and survey was used, but discontinued, in Illinois	Used in MD and elsewhere internationally
Domains	<p>Choice and control Respect and dignity Access to care Community integration</p> <p>The survey can be used to calculate 51 performance indicators, within these priority areas, for quality monitoring and intervention. The indicators can be calculated for the entire sample, or for different sub-samples, such as program participants residing in different counties or served by different providers, and compared across groups</p>	<p>Satisfaction Competency Empowerment Social belonging Rights Relationships Economic security Growth and development Perception of well-being</p>	<p>Consumer Outcomes; System Performance; Health, Welfare & Rights; Staff Stability and competence; Family Indicators; Case Management</p>	<p>Rights and protection Dignity and respect Protection from abuse, neglect, mistreatment, and exploitation Best possible health Safe environments Staff resources and supports Positive services and supports</p>	<p>Physical wellbeing Emotional wellbeing Interpersonal relations Material wellbeing Social inclusion Personal development Self-determination Rights</p>

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Reliability and Validity	Extensive field testing for reliability and validity	Extensive testing for reliability and validity Cronbach's alpha was used to test reliability and exploratory factor analyses were used to test validity (i.e. factor structure). Results: Data indicated that the reliability and factor structure was similar to that reported in the questionnaire's standardization manual and consistent with that reported in a number of Anglo-Saxon countries Research studies offer additional support for the valid use of the QOL-Q with Spanish-speaking populations, as well as others	The NCI program has been tested and refined in more than 30,000 assessments of individual outcomes The consumer interview consistently yields high self-response. Response types are mixed so that fixed response patterns are not facilitated. Consistency checks with recurring items are built into the survey. Basic reviews and psychometric testing has been conducted on the NCI to establish its reliability and validity NCI data are gathered with a common instrumentation package has been shown to meet accepted standards as being both valid and reliable.	Tool, as adapted for states, is based on internationally reliable and valid set of quality outcomes.	Survey was developed and field-tested for reliability and validity under direction of Dr. Gordon Bonham, President of Bonham Research

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Who administers	<p>Support brokers, counselors, volunteers, researchers, state program staff, etc.</p> <p>Since the survey asks about the case manager it may be awkward for them to ask the questions</p>	State DD Service Coordinators in NE	Support brokers, self advocates, family members, case managers, state caseworkers, QMRP or QDDP's, Regional QA managers	Team Leaders or QMRPs at ICFs/DD in LA, district staff in DC	Trained self advocates
Training and time required to administer	<p>Users guide has a section for selecting and training interviewers</p> <p>Each survey version is designed to be conducted as a face-to-face interview, lasting approximately thirty (35) minutes.</p>	One hour staff training and survey takes about 30 minutes	<p>The instrumentation is accompanied by a standard training program for interviewers, including training manuals, presentation slides, training video, scripts for scheduling interviews, lists of frequently asked questions, picture response formats, and additional resource materials on interviewing persons with disabilities. A sampling manual is also provided to state teams as part of the training program.</p>	Intensive staff training required	<p>Self-advocates apply for a position as Ask Me!</p> <p>Interviewer and are screened for skills and aptitude for position. All interviewers receive multi day training with look behind reviews to make sure they are properly following survey guidelines.</p>

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Manual or automated scoring	<i>PES MRDD Software</i> automates data collection and analysis for the PES MRDD tool released in 2003.	Manual	Manual or automated	Manual or automated	Manual
Self advocate role	Consumer feedback on quality of services/supports Not developed specifically for consumer-directed programs, but applicable Replacement of Likert-type response categories with primarily dichotomous (“yes/no”) response One idea per item Stays away from hypothetical questions Stay away from sound-alike words (“choose”	Self advocates are interviewed and/or complete the survey	Consumer survey component Self advocates are used as interviewers in some NCI states	Interview is done with the consumer	Self advocates helped develop and field tested survey and serve as interviewers Use of multiple answering modalities with use of positive, negative and neutral faces, e.g. pointing, sign language, speaking and writing has increased self advocate participation

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Family/ guardian role	<p><i>sounds like "shoes")</i> Simple responses best (Yes/No)</p> <p>Interviewer comments at the end of the survey allow for mention of other people beside the consumer that participated in the interview</p>	Up to two family members or others who know the person well may act as proxy for individuals with limited expressive or receptive communication abilities.	Family Survey component Section II may be answered by someone who knows the individual well on his or her behalf.	Families are involved in interview when more info is needed	Provider agency results [from the Ask Me! Survey] are posted in an annual report on DDA website, for use by individuals and families as they consider which provider to engage for services