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**Assessing the Face, Content, and  
Construct Validity of the Florida  
Questionnaire for  
Situational Information:  
Observations of Two Expert Panels**

January 30, 2008

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# **Assessing the Face, Content, Construct and Validity of the Florida Questionnaire for Situational Information: Observations of Two Expert Panels**

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<p>All opinions expressed herein are solely those of the authors and do not reflect the position or policy of the Florida Center for Inclusive Communities, UCEDD</p>
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This report was prepared by the Human Services Research Institute (HSRI) under subcontract to the Florida Center for Inclusive Communities (FCIC), a University Center for Excellence in Developmental Disabilities at the University of South Florida. FCIC engaged HSRI to study the face, content and construct validity of the Florida Questionnaire for Situational Information (QSI) on behalf of the Florida Agency for Persons with Disabilities (APD). The QSI is used to assess individuals with developmental disabilities served by APD. This study completes one task associated with a larger study designed to address APD requirements mandated by the passage of Senate Bill 1124.

In 2007, the Florida Legislature passed Senate Bill 1124, requiring the APD to “redesign” the state home and community-based services system. This task includes establishing a new reimbursement system for developmental disability service payments and confirming the validity of the QSI. In response, the agency contracted with the FCIC to study the psychometrics of the QSI.

Examination of the QSI's psychometric properties includes completion of several studies to assess: (a) face, content, and construct validity; (b) item characteristics; (c) inter-rater reliability; (d) test-retest reliability; and (e) concurrent validity between the QSI and the SIS. Subsequently, the University of South Florida subcontracted with HSRI to study the face, content, and construct validity of the QSI's three scored scales: *Functional Status*, *Behavioral Status*, and *Physical Status*.

Study Questions
Does the QSI measure what it intends to assess?
Do items represent what is being measured in each scale?

In this study, and as cited in the scope of work outlined by APD, face validity refers to the extent to which a test appears to measure what it is intended to measure. Likewise, content validity refers to the extent to which items in a scale represent the content that is being measured. Finally, construct validity is the degree to which a test measures an intended hypothetical construct. Typically, construct validity takes time to assess, involving complementing studies to compare the measures' performance against similar tools (e.g., through convergent and divergent validity studies and others) to assess its practical application. These definitions are commonly acknowledged in research literature<sup>1</sup>. If a test has these three types of validity, it will include items that are recognized to be representative of the targeted subject area(s).

This report documents the activities, findings, and conclusions associated with this study, and is organized into the following sections:

- A **Brief Description of the QSI** provides a description of the QSI's administration process, domains, and scoring.
- The **Methods** section provides an overview of the methods that were applied to complete the study.

<sup>1</sup> Allen, M.J., & Yen, W.M. (2002). *Introduction to Measurement Theory* (Rev. ed.). Long Grove, IL: Waveland Press.

- An analysis of the study results are presented in the **Findings** section, which is organized according to the two panels of experts that reviewed the QSI.
- Finally, the **Conclusion** section offers summary observations regarding study findings.
- Full expert comments are located in a separate document available from APD.<sup>2</sup> Two panels of nationally recognized field content experts and self-advocates reviewed the QSI to complete this study. Each panel responded to a series of questions about the QSI. Their responses are summarized in this supplemental report.

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### Brief Description of the QSI

The Florida Questionnaire for Situational Information (Version 4.0) is a 43-page questionnaire containing several scales designed to “gather key information about a person that will describe his or her life situation for the purpose of planning supports over a 12-month period. These descriptions reflect a person’s needs for assistance in order to adjust to life changes while living, working, fulfilling valued roles, and participating in his/her community” (QSI Version 4.0, p. 2). This tool is currently being used in Florida by the APD to assist in developing support plans for people with intellectual and developmental disabilities of all ages. The QSI is part of a broader process to develop support plans that includes the preferences of the individual as well as information from other sources (QSI Version 4.0, p. 2).

The QSI was developed from Florida’s previous assessment tool, the *Florida Status Tracking Survey*, which was largely compiled from several needs assessment tools developed twenty years ago in Tennessee and Oklahoma. The tool has been used since 2008 to assess over 15,000 individuals by 75 QSI administrators hired and trained by APD. Administrators are trained using a 19-page *Training Manual* and a 36-page *Administrative Guide* that provide guidance on how to conduct interviews and obtain information. Once trained, QSI administrators gather information from several sources including interviews with the individual, caregivers, or health care professionals, and review of personal records (e.g., recent assessments, medical records, school records, previous support plans). This information is recorded in the following six areas:

1. The *Life Change and Adjustment Scale* lists 20 items, each with an associated point value, selected according to an individual’s experience over the past 12 months. Six additional items request information regarding symptoms of distress, life changes expected over the next 12 months, and other information.
2. The *Community Inclusion and Valued Adult Roles* section lists 15 items that are rated according to five levels indicating “how much personal support the person requires (both now and in the future) in order to participate actively in his or her local community” (QSI, Version 4.0, p.10). Level “1” represents no need for support; levels “2” and “3” represent

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<sup>2</sup> Agosta, J., Daignault, J., Smith, D., Fortune, J., (2009). *Direct Expert Panel Comments*. For copies of this report, contact the Agency for Persons with Disabilities in Tallahassee, Florida.

increasing need for support; and levels “4” and “5” represent the greatest level of need for support.

3. The *Employment* section includes three “Yes” or “No” items related to working.
4. The *Functional Status* section includes 11 items that focus “on a person’s need for assistance during the normal course of a routine day, including sight, hearing, communication, and ambulation” (QSI Version 2.0 Administration Guide, p. 15). Items in this section are rated according to five levels (0 to 4). Level “0” represents no need for assistance; levels “2” and “3” represent increasing need for assistance; and level “4” represents the greatest need for assistance.
5. The *Behavioral Status* section includes eight items related to “interventions used to address problems with behavior” over the past 12 months (QSI Version 4.0, p. 22). This section is also scored according to five levels (0 to 4) that represent increasing levels of intervention. The behavioral area measures level of intervention to address the following behaviors: (a) hurtful to self/self-injurious behaviors, (b) aggressive/hurtful towards others, (c) destructive to property, (d) inappropriate sexual behavior, (e) running away, and (f) other behaviors that may result in separation from others.
6. The *Physical Status* section contains 12 physical health items and nine items related to medical concerns, including an extensive list of medical conditions. This section is concerned with “life situations and physical conditions that may pose a need for medical interventions or health care” (QSI Version 4.0, p. 30). Items are similarly rated from “0” to “4.”

Each area is intended to gather specific information for the purpose of planning supports. However, only the *Functional Status*, *Behavioral Status*, and *Physical Status* scales are used to produce an individual’s overall score. **These scales are the target of this study.**

The QSI is scored using an electronic weighting system. Results are entered into a protected and secure Internet web site, where they are weighted and scored using a computer program. Each of the sub-sections is scored independently using specific rules and scoring criteria. Scoring and results from the mainframe are deliberately separated from the tool’s administrator to prevent attempts to influence the scores. Once the score has been processed, the level of support is determined. To do so, the assessor uses a table provided by APD that cross tabulates scores from the *Functional*, *Behavioral* and *Physical* scales to estimate the individual’s level of assistance.

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## Methods

To complete this study’s objectives, HSRI organized two panels of experts to review the tool: a self-advocate expert panel and a field content expert panel. Brief biographies of each expert panel member are included in Appendix A.

The self-advocate expert panel includes five nationally recognized self-advocates selected for their leadership in the self-advocacy movement, participation in self-determination initiatives,

and experience with developmental disability policy. Likewise, the field content expert panel includes five consultants selected for their expertise in applied psychometrics, developmental disability policy, and evaluation and assessment methodologies.

The experts include:

**Self-Advocate Experts**

Betty Williams

Daylin Ward

Teresa Moore

Tricia Jones

Ricky Broussard

**Field Content Experts**

Garth Eldredge

Yona Lunsky

Wanda Seiler

Rodney Realon

Don Severance

**Methods**

- Self-advocate expert panel review
- Field content expert panel review
- HSRI analysis

Reviews were completed during a six-week period in September and October, 2008. A packet containing the QSI (Version 4.0), the Training Manual, and a brief description of its history was mailed to each panel member along with a letter describing the purpose of the study, and instructions to complete the review.

Self-advocate experts were asked to read the documents and participate in a series of four teleconferences in September and October. During the first teleconference, HSRI staff reviewed the materials to be sure they were understood, explained the purpose of the assessment, and answered related questions. During the next two calls, HSRI staff interviewed the self-advocate experts about the QSI and recorded their observations. These calls lasted approximately two hours each. A fourth call was planned. Panel members, however, were not available to participate during the prescribed six-week time period.

Self-advocate experts were asked four questions during the interview process:

1. Does this question relate to the topic area?
2. Is this question relevant to supports that people with ID/DD need to be successful?
3. Is people first language used?
4. Are the questions worded respectfully?

Similarly, field content experts were asked to examine the materials and respond independently to five questions, compile their responses, and submit them to HSRI. The questions included:

1. Does the test measure what it set out to assess?
2. Are the scale domains accurately defined?
3. Is this the type of behavior that should be included in the scale?
4. Is the test consistent with current knowledge and best practices?
5. Are there any other behaviors that should be included in this scale?

After the expert panels completed their review of the QSI, HSRI staff compiled, analyzed, and interpreted the results to develop our findings.

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## Findings

Our findings are presented below according to the questions we asked each panel of reviewers. Responses from the self-advocate expert panel are presented first, followed by responses from the field content expert panel. As previously mentioned, interview notes resulting from the self-advocate expert teleconferences and observations made by the field content experts are found in a separate document.

### Self-Advocate Expert Review

Individuals on the self-advocate expert panel bring a unique and valuable perspective to the study. They are people with intellectual and developmental disabilities and service recipients. Their observations regarding the three targeted scales are presented below by interview question.

#### 1. Does this question relate to the topic area?

The panel agrees that items in the targeted scales are consistent with the intended targets. Panel members, however, comment that the scales do not address individual interests or goals and related needs for support.

- The panel observes that the scales do not appear to address “what is important to the person,” or “what support a person needs to reach their goals.” Further, the administration manual and guide do not suggest these types of conversations occur. Yet, self-advocate experts agree that personal preferences and goals should be the basis of individual support plans.
- While panel members agree questions in the targeted scales relate to the topic areas, they are concerned that the way a person is rated against some items may not provide enough information “to figure out exactly what a person needs.” For example, several items in the *Functional Status* scale combine physical and cognitive issues, whereas self-advocate experts agree, these should be addressed separately. “You can understand but need physical assistance. Or you can need prompts but not need physical assistance. Or you could need both. The language seems to assume that a person would always need both types of assistance.” Additionally, consideration should be given to environmental factors. “A person may or may not use devices depending on the environment” and “may need more or less support in certain situations or under certain circumstances.”

#### Self-Advocate Expert Questions

1. Does this question relate to the topic area?
2. Is this question relevant to supports that people with intellectual or developmental disabilities need to be successful?
3. Is people-first language used?
4. Are the questions worded respectfully?



## 2. Is this question relevant to supports that people with intellectual or developmental disabilities need to be successful?

Self-advocate experts expressed concerns that the three targeted scales may not be relevant to supports that people need to be successful. In fact, the scales rather seem built on the expectation of deficits or anomalies and focus on the level of intervention needed to manage what is broken. Self-advocates observe that:

- Safety from harm or exploitation is an important issue to self-advocates. However, item 23 (Self-protection) focuses on staff interventions rather than what people need to keep themselves safe. For example, the administrator must rate “special precautions and/or supervision currently in place” to protect the person from harm. A score on this item would indicate that varying degrees of prompts, physical assistance, restrictions, or supervision would be provided. However, self-advocate experts agree that individuals need to be empowered with skills and knowledge – not prompts, physical assistance, restrictions, or supervision – to successfully keep themselves safe. “What skills or information does the person need to make choices to keep him or herself safe?”
- Self-advocates also agree that people need to know how to report abuse or exploitation if it happens. One self-advocate commented, “It’s so important for people to feel safe in their own home and to be able to tell someone when no one else is around.”
- Additionally, personal information is gathered from sources other than the individual to complete the targeted scales. Self-advocate experts agree that people should “have a say” about the supports they receive. Individuals should also “have a chance to verify the information before the assessment is complete.

## 3. Is people first language used?

People first language is a respectful way of communicating with and about people with disabilities. It includes, describing people in ways that recognize their capabilities as well as their needs for assistance or support, and presenting information in ways that people with disabilities are most likely to understand. Do the three scales use people first language? In short, self-advocate experts say, “it is not people first friendly.”

- Self-advocates understand that the scales are written in language for professionals or medical personnel and the tool is intended to be administered by a professional to individuals, families, or others. However, they recognize that the items are deficit-based. They address “what’s wrong with you” rather than “our capabilities” For example, items from the *Functional Status* section:
  - Item 15 (Hearing) “The person has a hearing impairment that MINIMALLY impacts functioning” rather than “ask the person what works best for them in a quiet place, a noisy place, and what they like or don’t like.”
  - Item 16 (Eating) “Requires INTERMITTENT physical assistance” instead of can eat with support.

- Item 18 (Transfers) “needs PHYSICAL ASSISTANCE” rather than can transfer with assistance.
- Item 19 (Toileting) “MINIMAL supervision or adaptation is required” rather than can use the toilet with support or adaptation.
- Item 21 (Dressing) “MINIMAL SUPERVISION OR ASSISTANCE IS REQUIRED” rather than individual can dress with assistance.
- Item 24 (Ability to Evacuate place of residence) “Minimal supervision or adaptation is required” rather than can evacuate with assistance or adaptation.
- Finally, panel members agree, the scales contain “too many words” and are “too long.” These characteristics pose a particular challenge to administering the tool. “Administrators need to make sure that their introduction to the assessment is very welcoming.” People often feel judged during the assessment process and need to be reassured that information will be used “to provide appropriate supports – the services they need.”

#### 4. Are the questions worded respectfully?

Self-advocate experts do not consider the language used in the targeted scales to be respectful of the people they are intended to assess. Several issues raised above contribute to this problem. Primarily, the outdated paradigm that the scales are built on lends items to language that describes supporting people as if they are passive and need to be “fixed,” rather than active and empowered. For example, Item 23 is titled “Self-protection”, yet the “supports” described in the rating scale are what others can do to the person (“requires supervision,” “not allowed to go certain places”) rather than what the individual can do to protect him or herself.

#### Field Content Expert Review

Summary observations offered by the field content experts are provided below according to the five questions posed. For each question, observations are organized according to the face, content and construct validity of the targeted scales and comments related to scoring and weighting.

#### Field Content Expert Questions

1. Does the QSI measure what it is intended to assess?
2. Are the scale domains accurately defined?
3. Is this the type of behavior that should be included in this scale?
4. Is the test consistent with current knowledge and best practice?
5. Are there any other behaviors that should be included in this scale?

#### 1. Does the QSI measure what it is intended to assess?

The QSI is intended “to gather key information about a person that will describe his or her life situation for the purpose of planning supports over a 12-month period” (QSI Version 4.0, p. 2). Responses regarding how well the tool measures each of the three targeted content areas varied widely. The majority of reviewers agree that the targeted scales measure what they intend to assess, however, suggested improvements were described in several areas.

To contrast, one of the five reviewers found that the targeted scales do not measure what they set out to assess due to a combination of missing content and scoring issues.

#### Face, Content, and Construct Validity

- The targeted scales have similar domains found in the *Individual Client and Agency Planning* (ICAP) scale and *Supports Intensity Scale* (SIS) and “gather extensive information about medical information, far exceeding the ICAP or the SIS.”
- According to one reviewer, the scales appear to be based on the “medical model.” “It is not clear how information in the first section is used because most of the support computations (are based on the three targeted scales). This is a major concern. It says at the start of the QSI that it is designed to gather key information to plan supports for valued community participation. But participating in the community is about much more than adaptive daily living skills such as toileting, feeding, ambulation. This strikes me as a bit ‘old school’ and not in line with current ‘person centered philosophy’.”
- Another content expert states that the scales appear to measure only “care for individuals based on personal care and safety, behavior, and medical needs.” Further, “relative to the philosophy of services, the concern is that the instrument measures basic ‘care’ support needs, not habilitative needs.”
- One reviewer expressed concern regarding the definition for a score of 4 in Item 22 (Communication), under the *Functional Status* section. “If we embrace the philosophy that all people can and do communicate, if by a smile, a grimace, a behavior, it seems unlikely and unproductive to state, ‘The person has NO IDENTIFIED [sic] METHOD TO COMMUNICATE...’”

#### Scoring and Weighting

- The scoring levels in the targeted scales tend to merge the concepts of functional limitations and adaptive behavior in a way that doesn’t clearly identify either construct. “In general, functional limitations relate to physical conditions, while adaptive behavior applies to the ability to perform certain tasks which, logically, may be impacted by a single functional limitation or a combination of functional limitations.”

For example, Item 16 Eating, under *Functional Status*. Consider a person with Prader-Willi Syndrome who requires extensive supervision while eating to ensure that non-food, raw or excessive food (potentially from the plates of others) is not consumed during mealtimes. A score of ‘0-Eats independently’ would not be reflective of this person’s support needs, but it appears that the other scores are reserved to describe a person who has motor (arm/hand) or other physical (swallowing) limitations to eating. Additionally, presuming that the scoring (0 – 4) is indicative of intensity of support needs, a score of 4 on this item may not be indicative of more intense support needs than a score of 3.

This may also be true of Item 18 (Transfers) also from the *Functional Status* section. A score of 3, by its definition would require staff support of at least two people, but a score

of 4 would require lift equipment/procedures that could be safely carried out by a single staff person. These issues appear to persist, in varying degrees, within several items in this section.”

## 2. Are the scale domains accurately defined?

Reviewers generally agree that the three scored domains are defined well enough to collect relevant information. However, there is potential for improvement. Expanding and refining elements within each scale would increase the depth of information collected and reduce challenges to scoring. Overall, reviewers suggest that the domains could be improved to address life situations of individuals of all ages who function in a wide range of settings including the family home, an individual's own home, competitive employment, and community life.

### Face, Content, and Construct Validity

- One reviewer noted that the *Behavioral Intervention and Support Status* section “appears to be comprehensive and is similar to sections commonly found in other nationally recognized assessment tools including the ICAP and the SIS.” However, this section does not collect data regarding “type, frequency, and severity of behavior. Yet, this information is directly related to support needs and is critical to individualized planning.” Further, the (behavioral scale) “collects information on prompts, instructions, and redirection, however these approaches do not aide in decreasing or eliminating maladaptive behavior. Consequently, the need for or use of these strategies is not a reliable indicator of individual support needs.”
- The *Physical Status* section is comprehensive and addresses critical issues, however, the scale should be expanded to include other areas of physical health such as aging and health promotion. For example, one reviewer notes, “This population will experience challenges related to aging, and they do not appear to be addressed in this instrument. Those who are aging will typically require additional services as their physical conditions deteriorate.”
- Another expert notes that the tool “tends to measure basic care needs such as toileting and feeding, yet omits information related to habilitative needs such as managing money or reading and writing.”
- Several reviewers agree that while Item 44 (Assistance in Meeting Chronic Health Care Needs), under the *Physical Status* section, addresses critical issues, its complexity poses a challenge to gathering this data. One reviewer commented that Item 44 “requires the reviewer to document within the QSI chronic conditions not captured elsewhere in the survey. Even with training, completing this list may be beyond the scope of non-medical personnel.”

### Scoring and Weighting

- Reviewers note scoring challenges due to very broad or very narrow distinctions between scoring levels. For example, one expert described difficulty in determining the

difference between Levels 3 and 4 in the *Behavioral Intervention and Support Status Section*. “Level 3 describes frequent restrictions of the person’s movement, while Level 4 describes the use of physical, mechanical, and/or chemical restraint or protective equipment. Both levels restrict movement. The only difference appears to be frequency which may need to be defined to determine the appropriate score. Additionally, Level 4 implies more than frequent restraint, which raises ethical considerations warranting exploration of an alternative approach.”

- Conversely, another expert describes too great a distinction between levels using the scoring levels in Item 25 (Hurtful to Self/Self-injurious Behavior) from the *Behavioral Intervention and Support Status Section* as an example. There appears “to be quite a jump from level 2 to level 3. Few cuts (or other tissue damage) will heal in 48 hours although first aid is adequate for treatment.”
- One field content expert expressed concern that the targeted scales include only selected items in an individual’s overall score and uses a complex scoring system. The expert noted that, “with the small number of items and relatively complex scoring/weighting system, it would not take many items scored in a similarly biased manner to significantly affect the person’s overall score. Other traditional instruments used in this manner generally have more items and are likely less affected by bias in the information used to score the items.”
- Another reviewer shares this concern. In the *Behavioral Intervention and Support Status Section*, several items related to supports are not used to determine a behavioral raw score. The reviewer noted, “for example, scores from items 32-36, which look at outcomes of behavior (i.e., injuries or the use of various restraints), are used to determine a behavioral raw score, whereas items 25-31, that specifically look at supports a person needs are not used.”

### **3. Is this the type of behavior that should be included in the scale?**

As previously mentioned, reviewers agree that items represent a narrow definition of the three targeted scale domains. Consequently, the scoring system appears to be biased towards individuals with greater support needs.

#### Face, Content, and Construct Validity

- The scales seem to be well designed as they contain similar behavioral and medical need items to the ICAP and SIS. However, as commented on by one reviewer, “unlike traditional adaptive behavior scales, the targeted scales are not based on a developmental model and do not require a range of behaviors to assess a person’s overall developmental growth.” Thus, the scales simply “measure needed supports outside the context of a developmental model.”
- Similarly, another reviewer comments, “the constructs are very basic and the items chosen appear to be the most salient aspects of those constructs. (They do) appear to be biased toward persons with very high needs and may not provide sufficient measures

of supports that would better discriminate the needs of persons with relatively few needs regarding functional, behavioral, or physical functioning.”

- The *Behavioral Intervention and Support Status Section* includes two items regarding follow up consultation by a professional. However, one expert observed “it is unclear how the assessor will decide which kind of specialist should be involved if there are behavior concerns. In most situations, the person would most likely benefit from a team of professionals rather than designating the problem as discipline specific and suggesting only one professional.”

#### Scoring and Weighting

- Level of need is determined by scoring on a small number of items within narrowly defined *Functional, Behavioral, and Physical Status* scales. One expert stated that, “due to the few items in the scales (eleven items on the *Functional Status* scale, six items on the *Behavioral Intervention and Support Status* scale and 23 items on the *Physical Status* scale), the internal reliability and thus, the validity of the scales would likely be limited. The potential error of a few items in a consistent direction would provide a significant error in the measurement of the overall scale construct.”

#### **4. Is the QSI consistent with current knowledge and best practice?**

While the tool includes scale found in similar assessment instruments, reviewers found that the tool is not consistent with best practice, primarily due to its deficiency-based approach to assessing support needs. Additionally, the narrow scale are not consistent with current knowledge and practice that promote individual choice, self-determination, and inclusive community life.

#### Face, Content, and Construct Validity

- The QSI has scale similar to other nationally recognized instruments, such as the SIS and the ICAP.
- However, the targeted scales reflect a deficiency-based approach to identifying support needs. This is exemplified in the instrument’s narrow definition of scale that focus on basic care needs and less integrated settings. For example, one reviewer stated that the targeted scales “seem to be based on clinical judgment of a reviewer who presumably has the information available to him/her. I can understand the availability of such information for someone living in an institutional setting but I have doubts about how accessible such information would be when someone is living in the community with more limited support or family.”
- According to one content expert, the *Functional Status, Behavioral Status, and Physical Status* scale “are the proper areas to be looking at when determining the level of support however; the areas as they currently exist appear to be inadequate for determining level of need.
- However, the scales are based on an out-of-date paradigm. One reviewer notes, “There are problems with utilizing a tool that was created for a different purpose and under a

different philosophy than what is being proposed now. I have concerns that advocates may not find the interview process as respectful and simple as it could be.”

- When compared to other instruments, review found that the targeted scales are lacking in their organization, what they are measuring, and how they are measuring items. One reviewer stated, “the three subscales used to determine the level of support rating are not accurately defined and are in need of expansion and refinement.”

#### Scoring and Weighting

- As previously noted, the targeted scales do not measure habilitative supports. However, one reviewer noted that current practice suggests that “the goal of services to persons with developmental disabilities is to maximize their independence. Therefore, independence and level of developmental disabilities system supports are inversely related.”
- Scoring of some items seems to promote the use of psychotropic medications to support people with complex support needs. One reviewer states, “For the item on ‘Use of Psychoactive Medications’, the scoring system assumes increased use of psychotropic medication is related to higher need. The assumption is that more complex problems lead to the need of increased medications. But it also infers that the benefit of this increased medication is less than the cost of providing services with persons with more complex needs. It also could be read to argue that the cost of providing increased medication is greater than the benefit gained. This scoring system could also encourage increased use of psychoactive medication, versus greater emphasis on other methods of addressing these needs, as increased use of medications would be scored as the person having greater needs. Increased use of other therapeutic methods would not change the scoring, regardless of their relative efficacy.”

#### **5. Are there any other behaviors that should be included in this scale?**

Reviewers agree that other data should be included in the scales to obtain needed information for to aid in support planning activities. All of the reviewers found a need for either clarification of items within the targeted scales, or a need for additional items.

#### Face, Content, and Construct Validity

- A reviewer comments, “there are a number of items that should be considered for inclusion if the (scales are) going to be used to determine a person’s level of support need and related funding. In addition to items mentioned above, where a person lives, the presence of natural supports, the ability to occupy free time, the use of adaptive equipment/augmentative communication device, and, the presence of a psychiatric disorder need to be considered.”
- Other reviewers commented that the targeted scales do not capture an accurate picture of issues such as addiction problems or mental health issues. These issues are important due to their prevalence among people with intellectual and developmental

disabilities. Currently, these items seem to be addressed only through the review of current medications which may be linked to issues around mental health.

- As previously noted, issues related to aging “do not appear to be addressed in this instrument.”
- Reportedly, the QSI is administered to children as well as adults. However, several reviewers agree the targeted scales should be further adapted for use with children. For example one reviewer commented that, “how we score functional items for children might (be different than adults). We would expect less of a child than an adult. Furthermore, how we care for a small person is different than how we care for an adult. The questionnaire may need to be modified for young people. In particular, the items on work may need to focus on school and recreational activities, and involvement with family. Another expert adds, “Additional questions are needed about learning opportunities for children and adults as it relates to academics or learning competitive work skills.”
- One expert notes, the targeted scales, in many situations, omit important information that should be used for support planning. The following items are used as examples:
  - “Item 15 (Hearing; *Functional Status* section) does not include any mention of the use of sign language.
  - Item 23 (Self-protection; *Functional Status* section) addresses self protection, but what of the person who needs supervision because the individual exploits others?
  - Item 25 (Hurtful to Self/Self-injurious Behaviors; *Behavioral Intervention and Support Status* section) addresses self injurious behaviors. Could this item address the level of training required of the staff to deal with problem behaviors?
  - Item 26 (Aggressive/Hurtful to Others; *Behavioral Intervention and Support Status* section) addresses aggressive behavior to others. Could an example of target behaviors include spitting? How about other verbal aggression such as yelling and screaming at others? Is there any attempt to address the intensity of the behavior?
  - Item 30 (Other Behaviors that May Result in Separation from Others; *Behavioral Intervention and Support Status* section): “I do not see any mention of depression and or withdrawal which is often a problem with this population.
  - Items 38 (Seizures; *Physical Status* section) and 39 (Antiepileptic Medication Use; *Physical Status* section) address seizure activity. It appears that one could ask the question, is there evidence of seizure activity? If so, is it controlled and how? There are individuals who control seizures with Vegas Nerve Stimulators. Is this an item that should be included in the levels discussed?”
- Another field content expert comments on items related to the *Physical Status* section,



- “Item 32. Not sure why suicide threat has same rating as serious self injury. It would depend on how serious the threat is. Also not sure why sleep disorder is under injury caused by self-injurious behavior.
- Item 33. Not sure why sexual misconduct requiring unprotected sex is here. Is unprotected sex a form of injury caused by aggression to others?
- Item 34. For level 2, it is unlikely that someone would be restrained for an urgent medical procedure at least once monthly. Level 2 examples could therefore be captured within level 1.
- Item 35. The difference between severity levels 2-4 is not meaningful. It is easy to measure but within a year, there should be a broader range. As well, it needs to be clear what emergency drug means. If it is an injectable antipsychotic that can only be administered in hospital, this is very different than a staff person administering a PRN med such as an anxiolytic in the home when client appears distressed or anxious.
- Item 36. Psychotropic meds are scored within behavior and physical status. Should this be the case? Again, it is not clear where PRN medications belong. Are they emergency meds? Or should they be considered in #36?
- Item 37. If there is an acute disturbance on a particular month where there are for example 2 or more episodes, does this get the same score as someone who has a recurrent problem each month?
- Items 38-44 are very medical in nature. Again, I would want to know how the questions are asked. I do not think this level of information will be available from individuals and families without strong documentation or nursing support.
- Item 43. I would want to select conditions here for administrative purposes. As it reads now, it just documents that there is a condition but does not specify which condition. This is done for item #44 and makes sense.
- Items 45-50. I like the idea of trying to track number of injuries, planned and unplanned medical visits, as well as absenteeism due to illness. I am not sure about the decisions for the levels per item (how do we know that they are truly Likert scale?).
- Item 50. Not clear whether this refers to missing days in one month for an acute and resolved illness versus if there are repeated illnesses that result in missing school or work.”

#### Scoring and Weighting

- In the *Functional Status* section one expert commented that the “authors of the QSI have selected 6 items to determine a functional raw score (eating (#16), ambulation (#17), transfers (#18), toileting (#19), assistance (#44), and day’s missed-illness (#50). This

area addresses many critical areas but fails to address items such as meal preparation, taking care of laundry, transportation, social skills, or use of community services.”

- The scale should be validated to address the needs of individuals of all ages in a wide range of residential settings. One reviewer noted that “...it is important to validate (the QSI) again with a community sample of individuals for whom the assessment is intended. If it is intended for individuals living alone, with families with limited support, and if it is intended for younger people not currently using adult services, then the tool needs to be tested and weighting needs to be revisited and validated with this new sample.”
- 

### Conclusion

The purpose of this study is to assess the face, content and construct validity of three scales within the QSI (i.e., the *Functional Status*, *Behavioral* and *Physical* scales). Overall, given the reviews offered by two panels, we conclude that:

- Regarding face validity, the three scales do appear to measure what is intended. Reviewers generally agreed that the items in each scale do refer to the topic area targeted.
- Regarding content validity, the items in each scale are representative of the topic areas. Reviewers, however, sometimes observed that the scales could be expanded to cover additional ground within a topic area. On balance, however, the reviewers indicate that the items within each scale amply cover essential aspects within each targeted area.
- Regarding construct validity, panel observations offer some support for the scales, but only modestly so. Construct validity for any measure is developed over time as a preponderance of evidence builds to illustrate that the measure is aligned with a targeted hypothetical construct, such as “the need for assistance or support.” To determine the construct validity of these three scales additional work is needed to assess, for instance, how well the scales compare to other tools that measure similar constructs. Ultimately, these three QSI scales might be assessed to determine if the results generated from their use actually contribute to the larger intents of the QSI.

This study, however, does offer some support for the construct validity of the three scales. First, the two panels generally agreed that the scales have ample face and content validity. Without such validity, the scales could not have construct validity. Second, panel experts often observed that the scales compared well with similar scales within the SIS and ICAP. Comments like these raise expectations that, if tested systematically, the QSI scales would be found to have some level of *convergent validity* with corresponding SIS and ICAP scales. If so, this would strengthen arguments for the construct validity of the QSI scales.

Beyond these summary observations, however, both expert panels agree that the three QSI scales have several shortcomings. In its current iteration, the instrument presents many opportunities for improvement to increase its validity and utility in determining assistance and

support needs. Two related primary concerns were raised concerning the language used and associated approaches for collecting information:

- The scales seem premised on a deficit-based or medical model whereby the intent is to find out what is wrong or broken about an individual and/or the support needed to manage an anomaly. One reviewer referred to the approach as “old school.” Self-advocates observed that the approach reflects an historical perspective of people with disabilities as incapable rather than capable. To contrast, panel experts, prefer approaches to collecting information that focus more directly on the support or assistance individuals need to lead and control their lives. The difference may seem subtle. After all, if an individual requires help with completing daily activities or routines, there is no getting around that simple truth.

Yet, going forward, APD seeks to establish service responses that promote community integration and self-direction. As a result, how information is collected is as important as what is collected.

In this regard, the panel experts, and especially the self-advocates observe that the scales could be improved by restructuring items and using language to emphasize a greater expectation of self-direction and eventual self-reliance.

- The scales sometimes reflect out-dated ways of supporting individuals within community systems. Clearly, the 20 year history of the tool gives the QSI scales some of their most trusted individual questions. This background, however, also embeds within the scales out-dated items and likewise lacks means to assess support needs related to diverse community living options. Panel members, for instance, sometimes observed that the scales seem to be geared toward segregated service settings, and so slight reference to more progressive approaches that emphasize community integration.

In essence, the field has evolved to embrace new approaches to supporting individuals, while the design and structure of the QSI scales, though of ample face and content validity, have not made the paradigm shift with the field. With time, the measure can only grow more out-dated, especially as individual service plans grow increasingly diverse to support a widening array of community living preferences. Further, keep in mind that presently about 72% of those served by APD reside home with families and another 8% live on their own with support. As a result it is also fair to reflect on whether or not the QSI scales presently take into account this circumstance.

Overall, despite these shortcomings, the QSI scales plainly measure the constructs they are intended to measure. If APD plans on using these scales into the future, however, it should make changes to improve the language used and align the scales more closely with the progressive best practices that APD seeks to fund.

To do so, APD should start with convening a group of self-advocates charged with offering guidance over how the language used in the scales might be altered to honor “people first” principles and emphasize capability over deficits.

Next, and more difficult, APD should consider what types of supports it seeks to maintain or encourage going forward across the state. Then, by taking such vision into account, APD staff will be better positioned to alter language, add or subtract scale items, or otherwise alter scale design.

In summary, the reviewers, as a group, agree that the three scales within the QSI possess ample face and content validity, and potential for achieving construct validity. APD, however, should consider revising the scales to align its content and design more closely with present best practices.

# **Appendix A**

## **Descriptions of QSI Reviewers**

## Appendix A

### Descriptions of QSI Reviewers

HSRI consulted 10 experts to review the QSI. These experts participated on two panels; the self-advocate expert panel and the field content expert panel. Individuals were chosen to review the QSI based on their experience and accomplishments related to applied psychometrics, evaluation, and developmental disability service systems. Brief descriptions of the self-advocate experts and field content experts are provided below.

#### Self-Advocate Experts

**Ricky Broussard** is a self-advocate residing in Texas. Ricky has been very active within the advocacy world as a self-determination trainer, working with providers and agencies, and active SABE board member representing TX, OK, and LA and was previously the President for Texas Advocates.

**Teresa Moore** is a self-advocate living in Arizona. Teresa has worked in self-advocacy in many capacities, and continues to work on making lives better for persons with disabilities. Currently, Teresa works as a coordinator for a statewide self-advocacy coalition. She works to build advocacy in areas across the state, and in strengthening the coalition over time. In the past, Teresa was also one of the first members of *The Riot!* a publication written by self-advocates for self-advocates.

**Patricia Jones** is a self-advocate living in Arizona, and has been an active member in advocacy for the past 11 years. Patricia currently holds the position of Southern Regional Coordinator for Advocacy in Arizona, and serves as a member of the Governor's Council for Developmental Disabilities. Patricia has also participated in SABE and People First of Arizona. Patricia has worked to move people with developmental disabilities out of institutions and into the community, and empower them.

**Betty Williams** has been involved in the self-advocacy movement since the early 1990s. Betty saw a need to help people speak up for themselves and is a pillar in the self-advocacy movement. Betty is the Vice-Chair of Self-Advocates Becoming Empowered (SABE) a national self-advocacy organization; she is also the President of Self-Advocates of Indiana. Self-Advocates of Indiana have gone to institutions to talk to people about living in the community and what options they have in life. Betty also coordinates Consumer Education and Training for the Arc of Indiana.

**Daylin Ward** is a self-advocate residing in Vandalia, Illinois. Daylin currently works with the Illinois Self-Advocacy Alliance (ISAA) and has been doing so for the past two years, he has also worked with Illinois Voices for one year. Daylin has become a strong member of the self-advocacy community, and has strived to help persons with developmental disabilities have a stronger voice in policymaking.

## Field Content Experts

**Garth M. Eldredge, Ph.D.** is a Professor Emeritus at the Utah State University and has worked in university settings for the past 36 years. Dr. Eldredge is an expert in functional assessment and applied psychometrics. While at Utah State, his research focused on the areas of vocational evaluation, adaptive behavior for adults with developmental disabilities, community employment, rehabilitation of persons with chronic mental illness, and nationally acclaimed distance education.

**Wanda Seiler** served as the Director of the South Dakota Division of Developmental Disabilities for eight years. South Dakota was the first state to create and implement a cost-based individual resource allocation (IRA) system (*Service Based Rates* or SBR) as a reimbursement methodology for home and community-based developmental disability services. Ms. Seiler led several initiatives to refine information sources used by SBR, improving stakeholder confidence in individual needs assessment data and cost and utilization information. SBR owns the highest statistical validity (R squared = .8) of any IRA model in the nation. Wanda is now a Senior Consultant with the Rushmore Group, LLC and has a baccalaureate degree from South Dakota State University.

**Rodney E. Realon** has a master's degree from Drake University. He has worked in the state of North Carolina for approximately 30 years. He worked as a licensed staff psychologist from 1979 through 2000 in two Developmental Centers. In July 2000, Mr. Realon began working in the Division of MH/DD/SAS Central Office, where he coordinated a variety of major initiatives and provided leadership and assistance in ensuring that individuals with developmental disabilities are reliably assessed using the NC-SNAP (co-author). He also coordinated research on resource allocation and managed the analysis and coordinator of data systems. He has provided services to a broad range of populations including persons with co-occurring disorders (MR/MI), persons with Autism, toddlers, geriatric, and non-ambulatory medically fragile individuals. In June 1994 Rod achieved the title of Fellow in the American Association on Intellectual and Developmental Disabilities (formerly AAMR).

**Donald D. Severance** is currently a Disabilities Services Coordinator with the Nebraska Division of Developmental Disabilities. He is primarily responsible for the *Objective Assessment Process*, Nebraska's method of determining individual budget amounts for persons in services as well as their quality improvement plan, eligibility determinations and evaluation methodology. He has a Masters degree in Psychology, and has 30 years of experience in the field of developmental disabilities related to test theory, psychometric methods, multivariate statistics, and evaluation methods.

**Yona Lunsky, Ph.D.** is an Assistant Professor at the University of Toronto, Centre for Addiction and Mental Health in the Dual Diagnosis Program. Yona is an expert in developmental disabilities especially mental health in DD and has done some work recently in Ontario province using assessment tools. A prolific author and reviewer she has published 38 articles in her career. Recent awards include the Canadian Institute of Health Research New Investigator Award, Ontario Mental Health Foundation New Investigator Award, and International Association for the Scientific Study of Intellectual Disabilities Stevens-Shapiro Memorial Research Fellowship. Her Ph.D. was awarded at Ohio State University.