



**Office for People With
Developmental Disabilities**



The Coordinated Assessment System (CAS):

Validating the CAS in New York State

October 2017



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Executive Summary

The Office for People With Developmental Disabilities (OPWDD) began the process of choosing a new assessment instrument in 2011 by forming a committee in partnership with stakeholders, including people with intellectual and/or developmental disabilities (I/DD), their families and representatives from the provider community. This group, known as the Access and Design Committee, developed recommendations which stressed the need for a person-centered assessment instrument that identifies the strengths of the person, the needs of the caregiver, could be used for care planning at the individual level, and would be useful for system level planning. In 2015, OPWDD created the Coordinated Assessment System (CAS) by utilizing the interRAI Intellectual Disability (ID) instrument as its foundation and by creating supplements (i.e., Medical Management, Mental Health, Substance Use, Forensic, Children) specific to areas of need identified by stakeholders.

The research that provides evidence of the interRAI ID instrument's validity was conducted in Canada, where the instrument was developed. Given that New York State serves a diverse population of people with I/DD through a wide range of services, OPWDD sought to replicate and expand upon the research performed by interRAI to test that the instrument retained its solid measurement properties when applied to the population of people receiving services from OPWDD. This report contains information on the evaluation activities completed.

Evaluation activities took place in two parts. First, OPWDD conducted an agency case study, which solicited feedback from people assessed, their families and providers about the person-centered administration process utilized by the CAS. Second, OPWDD and the Center for Human Services Research (CHSR) at the University at Albany conducted a formal validity study on the interRAI scales within the CAS instrument. Through the New York State validity study, OPWDD sought to:

- test the interRAI scales within the CAS measuring underlying constructs – for example, the ability of the Activities of Daily Living-Hierarchy Scale (ADL-H) to measure a person's functional performance via evaluation of internal consistency and convergent and discriminant validity (i.e., construct validity);
- test the correspondence of the interRAI scales within the CAS to scales within other instruments which claim to measure similar constructs (i.e., concurrent validity); and
- test the interRAI scales within the CAS for sensitivity in differentiating people with different diagnoses and in different settings (i.e., criterion validity).

For almost every single type of validity under scrutiny in this study, the interRAI scales within the CAS performed well. In the area of internal consistency and construct validity, all scales investigated had a Cronbach's alpha of 0.7, a threshold that is often used as a benchmark to evaluate internal consistency, except for the Aggressive Behavior Scale (ABS) which measures a range of behaviors. Evidence of convergent and discriminant validity was demonstrated by high mean correlations for items contained in different, but related, scales. Similarly, low mean correlations were present for items



belonging to scales that measure very different constructs. Specifically, the ABS scale items had low correlations, on average, with the items contained in the other interRAI scales within the CAS likely due to those scales focusing on constructs such as communication, cognition and performance of skills. This finding is consistent with prior research at OPWDD during the development of the Developmental Disabilities Profile-2 (DDP-2) demonstrating that skills and behaviors are two distinct constructs.

In the area of concurrent validity, the interRAI scales within the CAS proved highly correlated to scales contained within two other assessment instruments, the Developmental Disabilities Profile-2 (DDP-2) and the Inventory for Client and Agency Planning (ICAP), which measure similar underlying constructs.

In the area of criterion validity, the interRAI scales within the CAS were able to differentiate people in different service settings and with different diagnoses. For example, generally people in more intensive support settings scored as having higher needs on scales, as one would expect. Likewise, people with more severe diagnoses of an intellectual disability (ID), scored as having higher needs on scales that measure living skills.

The following report outlines the evaluation process for the CAS instrument and the interRAI scales within the CAS, including the research hypotheses, methods and instruments used in the validity study, and analysis activities and results.



Overview

Background

In 2011, the New York State Office for People With Developmental Disabilities (OPWDD) engaged stakeholders in the process of identifying the elements necessary to support a systemic change from fee for service to a managed care service delivery system. Such a change would allow for better coordination of care and provision of supports to the people that OPWDD serves. One area of focus for stakeholders was the review and identification of a needs assessment instrument that would best align with a person-centered service delivery system.

At the time of stakeholder engagement, OPWDD was using the Developmental Disabilities Profile-2 (DDP-2) assessment. This instrument was developed by OPWDD and used for service planning and resource allocation in New York State and was adopted by other states for similar uses. The DDP-2 evaluates a person's areas of need such as medical, behavioral, activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Stakeholders and OPWDD evaluated various assessment instruments and decided that there were critical elements not covered in the DDP-2. Specifically, information was lacking about the risks that caregivers face that could affect their ability to continue providing care, known as caregiver stability. The DDP-2 was also criticized for having limited information about a person's strengths and goals. Finally, areas for improvement that stakeholders identified in the assessment administration process included:

- having the person participate in the assessment process (also known as a person-centered administration process);
- administering the instrument by a conflict-free entity; and
- having consistent and intensive assessor training.¹

After extensive research and stakeholder engagement effort, OPWDD chose the interRAI Intellectual Disability (ID) assessment instrument. This instrument was selected for two main reasons. First, the instrument met all of the criteria identified by stakeholders that were deemed relevant to the assessment of a person's needs. Secondly, the instrument met the necessary rigor in the person-centered administration process.

As background, interRAI is a network of researchers from around the world that works to promote evidence-based policy and decision-making by collecting high-quality data.² interRAI has developed a set of comprehensive assessment instruments that evaluate the needs of people in different types of care settings.³ The instruments center on the issues and needs of distinct populations (e.g., those

¹ New York State Office for People With Developmental Disabilities, *Assessment Tools Technical Workgroup Report*, By Jerry Huber, et al., (Albany, NY: OPWDD, 2011), 9-13.

² "The interRAI Organization: Who We Are," interRAI, <http://interrai.org/organization.html>, accessed August 31, 2016.

³ "Instruments: An Overview of the interRAI Suite," interRAI, <http://interrai.org/instruments.html>, accessed August, 31, 2016.



with an intellectual disability), yet, they contain a “core” set of items which have identical definitions, data collection conditions and ratings.⁴

In collaboration with interRAI and stakeholders, OPWDD revised the instrument with language specific to New York State and created five supplements from the interRAI suite of items (i.e., Children, Forensic, Medical Management, Substance Use and Mental Health) to further identify the needs of people served by OPWDD. The result was the Coordinated Assessment System, CAS, an assessment instrument for use with people with intellectual and/or developmental disabilities (I/DD) eligible to receive services from OPWDD.

The selection of the interRAI ID instrument and subsequent development of the CAS aligns with the use of interRAI assessment instruments by other New York State agencies (the Department of Health and the Office of Mental Health) providing supports for people in need of care for more than 120 days, which is also defined as people in need of long-term services and supports (LTSS). Since all interRAI assessment instruments contain a common core data set, the use of the interRAI assessments across service systems allowed New York State to adopt a core standardized assessment for all people in need of LTSS. The use of a core standardized assessment will allow New York State, for the first time, to have the ability to evaluate and compare the needs of people receiving LTSS across different service systems (e.g., DOH, OPWDD, OMH). This will help to break down the silos between systems providing LTSS in New York State. The development of a core standardized assessment for people with LTSS needs was also a requirement for states utilizing Federal Balancing Incentive Program (BIP) funding for Medicaid redesign allocated under the Affordable Care Act.⁵

Two-Step Evaluation Process

OPWDD undertook a two-step process of evaluation of the CAS in order to test that it met the requirements of an assessment instrument as outlined by the stakeholders prior to implementation. The first step was the review of the CAS’ person-centered administration process (i.e., the inclusion of the person in an assessment interview/observation), which was part of an agency case study. It was important for OPWDD to evaluate if the CAS achieved its goal of being person-centered by including the person in the administration, completing the CAS at a time and location of the person’s choosing, and utilizing a conversational approach for gathering information about the person’s strengths, interests, goals and needs.

The second step was to define and conduct a validity study in order to test appropriateness for the diverse population of people served by OPWDD and add to the body of research associated with the interRAI ID assessment instrument, including its core data set. The design, process and results of the validity study are the focus of this paper.

⁴ Ibid

⁵ New York State Department of Health, *The New York State Balancing Incentive Program Work Plan*, (Albany, NY: DOH, 2014), 6, 27-31, Appendix B.1 through B.6.



Agency Case Study

The testing of the CAS' person-centered administration process was conducted as part of a case study in 2013. Nineteen (19) agencies across New York State were selected for, and agreed to, participation in the case study. These agencies were either OPWDD Compass agencies or met specific high performing criteria to be included in the case study.⁶ Four hundred and twenty-two (422) CAS assessments, for both children and adults, were completed as part of the case study. The core CAS was administered to all participants and an additional children's supplement was completed for those under the age of eighteen (18). Surveying and evaluation processes concluded in May 2014. As part of the evaluation process all participants and/or their families (n=422) were surveyed and asked to report on their satisfaction with their inclusion in the assessment administration process. One hundred and forty-one (141) surveys were returned resulting in a 33% return rate. Sixty-one percent (61%) of responders reported being very satisfied with the assessment administration process, 19% reported being somewhat satisfied, 17% reported neither satisfied nor dissatisfied, and 3% reported either somewhat dissatisfied (2%) or very dissatisfied (1%). Therefore, we can conclude that most people were satisfied with the person-centered assessment administration process (i.e., the inclusion of the person in an assessment interview/observation).

In addition to evaluating the administration process, OPWDD elicited feedback from providers about the efficacy of the CAS summary output for support planning purposes. (Upon completion, the CAS generates a personal summary as well as summaries specific to medications and any completed supplements.) These summaries are designed to be used by the person and his/her care planner to develop an appropriate support plan. Surveys completed by each of the nineteen (19) agencies indicated 84.2% believed that the CAS summary output would be helpful in the development of a support plan for someone that they did not know.⁷

Validity Study

Upon verifying that the CAS met the person-centered administration standard and achieved a high rate of satisfaction from case study participants, OPWDD proceeded with its evaluation by conducting a validity study. The validity study is designed as an evaluation of whether the interRAI scales within the CAS measure what they claim to measure (e.g., the functional skills and needs of people). While the foundational interRAI ID instrument was validated by interRAI, OPWDD chose to build upon interRAI's existing research prior to systemic implementation in New York State. OPWDD believes that the research conducted in New York State contributes to the interRAI validation work in the following ways:

⁶ New York State Office for People With Developmental Disabilities, *People First Waiver Case Study Proposal* (Albany, NY: OPWDD, 2012), 1-14.

⁷ Katherine Bishop, "OPWDD Validity Study Update, Results of the Case Study Agencies Final Programmatic Survey, and CAS Summaries Satisfaction Surveys," (presentation, Case Study Stakeholder Meeting, Albany, NY, September 30, 2014).



- The OPWDD study focused on a larger sample size (n= 1,129) than the one completed by interRAI. Previous research was conducted with a smaller sample (n=160) of people in Canada by Martin, Hirdes, Fries and Smith (2007), herein called Martin et al. (2007).⁸
- The capacity to collect assessments on large numbers of people allowed for the inclusion of people with a range of intellectual and/or developmental disabilities, reflective of the people served by OPWDD, whereas previous research by Martin et al. (2007) focused primarily on people with an intellectual disability.⁹
- People receiving the continuum of residential services available in New York State were included in the study. Martin et al., (2007) focused on people living in one type of residential setting, whereas OPWDD included people receiving a range of residential supports from people living in developmental centers (higher intensity of services) to people living in supportive apartments or at home with their family (lower intensity of services). OPWDD similarly included people receiving a range of day services from people attending day habilitation programs (higher intensity of services) to people utilizing supported employment supports (lower intensity of services).

As a result of including a large and diverse group of people receiving various services, the Center for Human Services Research (CHSR) at the University at Albany and OPWDD were able to examine systematic patterns that test the validity of the interRAI scales within the CAS. The inclusion of a diverse group of people was important to OPWDD leadership and its stakeholders, both of whom were interested in determining whether the interRAI scales within the CAS could be sensitive enough to capture the range of needs of a person receiving services through OPWDD.

All validity study research was approved by the Institutional Review Board (IRB). The IRB is the board responsible for reviewing research involving people in order to ensure their rights are protected. As part of the IRB application and approval process, the application was shared, reviewed and approved by the Willowbrook Consumer Advisory Board (WCAB).

Description of Validity Study

Hypotheses

Many of the interRAI tools, including the Intellectual Disabilities (ID) instrument, have scales that are embedded and purport to measure a person's abilities and behavioral needs. interRAI scales within the CAS will be the focus of OPWDD's validity study, as having a reliable way to measure the abilities and behavioral needs of people is important in supporting high-level service planning activities. While the case study allowed OPWDD and participating agencies to explore the CAS' person-centered

⁸ Lynn Martin, John P. Hirdes, Brant E. Fries and Trevor Smith, "Development and Psychometric Properties of an Assessment for Persons With Intellectual Disability—The interRAI ID," *Journal Of Policy & Practice In Intellectual Disabilities* 4, no. 1 (March 2007), 24.

⁹ Martin, "Development," 26.



administration process, the methods of the validity study were designed to test hypotheses, and the results of the tests would either support the validity of the interRAI scales within the CAS or not.

Using scales developed by interRAI, OPWDD proposed hypotheses for the validity study:

1. interRAI scales within the CAS measure an underlying construct, such as a person's ability to complete activities of daily living (ADLs). The items that make up a scale should be highly correlated, meaning there is a relationship between items within a scale. For example, all items included within the Activities of Daily Living-Hierarchy (ADL-H) Scale should have a relationship to one another (be correlated) since they are all supposed to measure the person's ability to complete ADLs. When strong correlations between items within the same scale exist, the scale is said to have internal consistency.
2. interRAI scales within the CAS that measure related constructs (such as a person's communication and ability to perform ADLs) are expected to contain items that are highly correlated. Similarly, those scales that measure very different constructs (such as the person's behavior and communication) are expected to contain items that are not highly correlated. Determining whether scales are measuring both distinct and overlapping constructs, is referred to as convergent and discriminant validity.
3. Scales that measure similar constructs, such as ADLs, should be highly correlated (have a relationship) across the different assessment instruments included in this study. Finding high correlations among scales contained in different instruments, which purport to measure the same underlying construct, is referred to as concurrent validity.
4. interRAI scales within the CAS should measure people in settings with higher intensity supports as having higher levels of need compared to people in settings with lesser intensity supports. This provides evidence of criterion validity.
5. interRAI scales within the CAS should measure higher levels of need for people with more significant cognitive impairments and/or other types of diagnoses/behavioral challenges typically associated with the person's need for more support. This too provides evidence of criterion validity.

Detailed hypotheses that describe expectations for each scale and population group included in this study are outlined and explained in the “Analysis & Results” section of this paper. However, OPWDD wanted to outline the overarching hypotheses, which guide each specific hypothesis, so the reader can understand the necessity of the methods described in the following section.

Methods for the Validity Study

The methods used for the validity study were developed by OPWDD staff and the Center for Human Services Research (CHSR) at the University at Albany. Consultation with an outside reviewer from Western Michigan University with expertise in evaluation, measurement and research was sought before



the methods were finalized. As already mentioned, the focus of the validity study was on scales associated with the interRAI Intellectual Disability (ID) assessment, as it is the foundational instrument for the Coordinated Assessment System (CAS).

OPWDD sought to conduct a study that was inclusive of the diverse population of people receiving services in New York State and was similar to the one completed by Martin et al. (2007). To do this, OPWDD utilized a random sample of adult (age 18+) service recipients in the OPWDD system. Also included in the study were relatively small groups of people (age 18+) that were selected strategically. These smaller sample groups of people were selected in order to test that the instrument was sensitive enough to measure people with a range of skills, abilities and challenges.

Two other assessment instruments were chosen as comparative criteria for the validity study: the Developmental Disabilities Profile-2 (DDP-2); and the Inventory for Client and Agency Planning (ICAP). The DDP-2 was selected as it is OPWDD's current assessment instrument and the embedded scales have already demonstrated that they distinguish a person's needs among OPWDD service recipients. The ICAP was selected as it is in widespread use in the field of developmental disabilities and has a body of work associated with it that demonstrates its sound psychometric properties. Each of these tools is described below.

Coordinated Assessment System

The Coordinated Assessment System (CAS) is comprised of the interRAI Intellectual Disability (ID) instrument and additional supplements developed from items in the interRAI assessment suite. For the purposes of this study, the interRAI ID Cognitive Performance Scale (CPS), Activities of Daily Living-Hierarchy (ADL-H) Scale, Instrumental Activities of Daily Living-Capacity (IADL-C) Scale, Communication Scale (CS), and Aggressive Behavior Scale (ABS) from the interRAI ID instrument were evaluated. Detailed descriptions of each of these scales can be found in Appendix A.

The CAS utilized a person-centered administration process. Participants, when able, selected the time and location of their assessment interview/observation. In-person interviews and/or observations of the person took approximately 1 to 1.5 hours, though instances of longer interviews did occur based on the person's interest and ability to participate. Subsequent interviews were also conducted with a person(s) who knew the participant well. This person(s), known as the knowledgeable individual, needed to meet the following requirements: has known the participant for a minimum of three months; sees the participant at least on a weekly basis; and has spent time with the participant within three days of the assessment interview/observation. Family members and/or advocates, who may not have met the definition of a knowledgeable individual, were also interviewed as available and interested in participation. These interviews were completed either in-person or over the phone and were separate and distinct from interviews required for the other assessment instruments [Inventory for Client and Agency Planning (ICAP) and Developmental Disabilities Profile-2 (DDP-2)].

In addition to the interviews, the assessors completed a records review in order to answer, or code, specific items in the CAS (i.e., diagnosis of developmental disability) and to verify, when needed, information gathered from the interviews. Should an assessor need to use professional judgment when



completing an item, information from *all* sources (i.e., interview/observation with the participant, interview with knowledgeable individual(s), interview with family members/advocate and the records review) was used to make an informed decision. Additionally, assessors had regular contact with OPWDD staff designated as the study's key personnel to resolve any questions and to ensure accuracy of coding based on the design of the instrument. Coding of items for each assessment was recorded directly into the electronic format of the CAS.

Developmental Disabilities Profile-2

The New York State OPWDD Program Research Unit developed the Developmental Disabilities Profile-2 (DDP-2), in partnership with voluntary agencies, over thirty years ago. The DDP-2 was developed as a simple and fast instrument that, at the time, was thought to contain enough information to support service planning. The DDP-2 performed well in tests for validity and reliability.¹⁰

Since its development, the DDP-2 has been the primary assessment instrument used by OPWDD to assess people who receive supports and services, including determining the person's relative level of need and tracking changes in need. For assessment purposes, the DDP-2 produces seven indices and three broad factor scores. The indices are intended as measures of specific abilities or attributes, while the factor scores simply combine multiple indices into a singular measure of a person's limitations within a broad conceptual area. The seven indices include: Level of Self-Care (Self-Care); Daily Living Skills; Communication Skills; Cognitive Functioning (Cognitive); Motor Functioning; Frequency of Behavioral Problems (Behavior Frequency); and Behavior Consequences, and are further described in Appendix B. Three DDP-2 factor scores are intended to provide a broader conceptual measure of the assessed person's limitations and include the Adaptive Limitation Factor, the Maladaptive Behavior Factor, and the Health/Medical Problems Factor. A list of all DDP-2 indices and factors utilized in this study can be found in Table 2. Further detail on each of the indices and factors is included in Appendix B.

The DDP-2 administration was completed with a person(s) that knew the participant well in accordance with its design. The knowledgeable individual identified for the CAS administration (see criteria in this section under "Coordinated Assessment System") was the person interviewed for the DDP-2 along with others, if needed. The DDP-2 interview was separate and distinct from interviews required for the other assessment instruments [Inventory for Client and Agency Planning (ICAP) and CAS]. Interviews were completed either in-person or over the phone and took between 30 minutes to one hour. A records review was completed for verification of information as necessary (i.e., diagnosis of developmental disability). Coding of items was based on the interview(s) and records review verification. Paper forms were utilized for the DDP-2 completion and subsequent data entry into the OPWDD data systems was completed by key study personnel. The DDP-2 information collected via this study was kept separate and distinct within the OPWDD data systems from the DDP-2 information collected per normal course of business.

¹⁰ New York State Office of Mental Retardation and Developmental Disabilities, *Final Report: The Developmental Disabilities Profile: Final Report on the Design, Development and Testing of the Core Instrument*, By M. Craig Brown, et al., (Albany, NY: OMRDD, 1986), 14-18.



Inventory for Client and Agency Planning

The Inventory for Client and Agency Planning (ICAP) is a comprehensive, structured instrument designed to assess the status, adaptive functioning and service needs of people with developmental disabilities. Although the ICAP has not previously been used by OPWDD for assessment, it is a known, established tool with scales that have undergone previous statistical testing and is generally accepted within the field of developmental disabilities.¹¹

The ICAP consists of 4 broad domains (i.e., Motor Skills, Social and Communication Skills, Personal Living Skills and Community Living Skills). The additional domain, Broad Independence, is a summary of all the domains that measure a person's overall ability to function independently. In addition to the domains, the ICAP has four indices (i.e., Internalized Maladaptive Index, Asocial Maladaptive Index, Externalized Maladaptive Index and General Maladaptive Index). For the purposes of this study, the focus is on the ICAP scales that are intended to capture concepts similar to those used by the CAS. A list of all ICAP domains and indices utilized in this study can be found in Table 2. Further detail on ICAP indices and domains are contained within Appendix C.

The ICAP administration was completed with a person(s) that knew the participant well in accordance with its design. The knowledgeable individual identified for the CAS administration (see criteria in this section under “Coordinated Assessment System”) was the person interviewed for the ICAP and others if needed. The ICAP interview was separate and distinct from interviews required for the other assessment instruments (DDP-2 and CAS). Interviews were completed either in-person or over the phone and took approximately half an hour. A records review was completed for verification of information as necessary (e.g., diagnosis of developmental disability). Coding of items was based on the interview(s) and records review verification. Paper forms were utilized for the ICAP completion and then subsequent data entry by staff at the Center for Human Services Research (CHSR) at the University at Albany into a secure system for analysis.

Validity Study Process

Training of Assessors

OPWDD had a cadre of assessment staff who were hired in 2012 prior to the case study and validity study. Additional OPWDD assessment staff were hired for the validity study data collection and supervised by OPWDD key study personnel. The OPWDD assessors, herein referred to as assessors, all met the following minimum qualifications: a Bachelor’s degree or higher in a Human Services Field; and a minimum of one year, post-education experience working directly with people with an intellectual and/or developmental disability.

¹¹ Robert H Bruininks, Bradley K. Hill, Richard F. Weatherman and Richard W. Woodcock, *Examiner's Manual: Inventory for Client and Agency Planning*, (Itasca, IL: Riverside Publishing Company, 1986).



Assessors were provided approximately four weeks of in-person training on the proper administration of the CAS, DDP-2, ICAP and research study protocols between July 2014 and December 2014. All training was provided by either the OPWDD Principal Investigator, Co-Investigator, and/or other OPWDD key study personnel, unless otherwise noted below. Refresher courses were provided in-person and via video conference throughout the duration of the study.

Fundamental trainings included:

- assessment instrument administration (in-person training);
- education on how to conduct research developed by the Collaborative Institute Training Initiative (CITI) (online training); and
- study protocols and procedures (in-person training).

Prior to data collection, assessors completed a minimum of four practice sessions per assessment instrument with volunteers who had developmental disabilities and/or staff in accordance with each assessment's administration protocols. OPWDD key study personnel provided review and feedback of practice sessions to ensure proper administration and coding of each instrument. See Appendix D for a comprehensive listing of all assessor trainings and descriptions.

If the assessors had questions after the trainings were completed, they were instructed to email OPWDD key study personnel via a centralized email process. The OPWDD Principal Investigator, Co-Investigator and/or the OPWDD key study personnel reviewed the questions and provided responses either by email or telephone. When assessors identified questions that were relevant to all staff, as opposed to an individual case, the OPWDD key study personnel and/or the Investigators held telephone or video conferences with all assessors to provide guidance and to further reinforce key concepts.

Sample Selections, Methods and Sizes

In order to test the validity study hypotheses and accomplish the planned analysis, the assessors administered the CAS, DDP-2 and ICAP assessments for all study participants between November 2014 and February 2016. The study was comprised of people in one large Random Sample group as well as people in 20 groups of interest, which are identified in Table 1.

Random Sample Group

When collaborating on the design of the study, the Center for Human Services Research (CHSR) at the University at Albany recommended a random selection of a minimum of 200 people for inclusion in the study. This sample was composed of adults, eighteen (18) years of age or older, selected from OPWDD's Tracking and Billing System (TABS), who had been determined eligible for OPWDD services, and were receiving at least one service at the time selection occurred. The data collected from the people in the Random Sample group were used to:

- test for the internal consistency of the interRAI scales within the CAS (find correlations between items within the same scale/measure);



- test for convergent and discriminant validity (determining whether scales are measuring both distinct and overlapping concepts using correlations between the interRAI scales within the CAS); and
- test for concurrent validity (find correlations between scales/measures contained in different instruments).

Groups of Interest

In order to better represent the diverse population that OPWDD serves, additional people in groups of interest were included in the study for separate analysis. A target sample size of approximately sixty (60) people per group was determined appropriate for the study given both the significant cost of conducting field assessments and the amount of data needed to support analyses. In all but three (3) of the groups of interest, the target sample size was met. For the people in the comparison group ($n=51$), people receiving supported employment services ($n=46$) and for people with a diagnosis of Prader-Willi Syndrome ($n=35$), the data collection period was concluded before achieving the target size. Due to the lengthy data collection timeframe and the significant resources in terms of costs and staffing required to complete recruitment and review documentation for inclusion in each group of interest, the decision was made to stop assessments for groups that did not meet the target sample in order to make progress in data collection for other groups.

Criteria for inclusion within a particular group were established and OPWDD then randomly selected a sample of people that fit the criteria for inclusion. Similar to the people selected for the Random Sample, inclusion for selection in a group of interest required the person to be an adult, age eighteen (18) years of age or older, eligible to receive services from OPWDD, and in receipt of a minimum of one service in addition to meeting criteria that defined the particular group. A sample of people was selected for each of the groups except for five (5) groups, which already had sufficient presence of people within the Random Sample to meet the target of sixty (60) people per group. This is documented in Table 1 as "No caseload required."

Table 1 lists groups of people identified in 2014 desired for inclusion in the study, the sample size, and the month and year in which each group of interest was provided to assessors as part of their caseloads. The specific criteria for inclusion in each group of interest is contained in Appendix E. Scores for the various scales, developed by interRAI and contained within the CAS, were calculated for each of the groups of interest. Information on group scores is contained within the section "Criterion Validity – Analysis of Groups of Interest," where scale scores for different groups are compared. Statistics for one group of interest, people with an autism spectrum disorder (ASD), are presented in the "Descriptive Statistics for Persons with and Autism Spectrum Disorder Group" section of this paper as opposed to being included in the "Criterion Validity-Analysis of Groups of Interest." Due to the designation as a spectrum disorder, one that encompasses people with and without intellectual disabilities and language impairment per the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V)*, OPWDD did not develop a specific hypothesis for this group of interest relative to how their scale scores would compare to other groups of interest. For this large and growing population, OPWDD calculated descriptive statistics for the group, which are presented immediately following the statistics for the Random Sample group.

**Table 1. Selected Groups of Interest**

Group of Interest:	n	Caseload Issue Date
Persons in the Random Sample	275	November 2014
Persons with Autism Spectrum Disorder	83	February 2015
Persons with Neurological Impairment ⁱ	0	February 2015
Persons with Prader-Willi Syndrome	35	February 2015
Persons with a Sensory Impairment	62	February 2015
Persons living in a Developmental Center (DC)-Not Forensic Unit	64	April 2015
Persons with a Forensic Background	59	April 2015
Persons living in an Intermediate Care Facility (ICF)	63	May 2015
Persons living in a Supportive Individualized Residential Alternative (IRA)	61	May 2015
Persons with Severe Intellectual Disability (ID)	75	May 2015
Persons with Profound Intellectual Disability (ID)	104	May 2015
Persons receiving a Prevocational Service	60	June 2015
Persons receiving a Supported Employment Service	46	June 2015
Persons who have had a Restrictive Intervention (Behavioral Challenges)	62	September 2015
Persons who are Medically Frail	72	September 2015
Persons in the Comparison Group	51	November 2015
Persons with Mild Intellectual Disability (ID)	108	No caseload required
Persons with Moderate Intellectual Disability (ID)	73	No caseload required
Persons with Dual Diagnosis (Developmental Disability & Mental Health Diagnosis)	117	No caseload required
Persons receiving a Day Habilitation Service	60	No caseload required
Persons living in Supervised IRA	87	No caseload required

ⁱIn the original research design, people with a neurological impairment were included as a group of interest. However, this group of interest was dropped from the design in August of 2015 when the OPWDD research team determined that this group of people was too heterogeneous to verify documentation confirming a neurological impairment.

Data Collection

Consent

Before assessment could begin, assessors followed specific study protocols to obtain consent for participation in research. The assessor initiated the consent process by contacting one of the service providers for the identified potential participant. The assessor asked if the person had a legally authorized representative (LAR) and whether that LAR was a legal guardian as determined by a New York State Surrogate Court. If the person had a legal guardian, the assessor was directed to obtain consent for participation in research from the legal guardian and assent from the potential participant, if capable (assent from a person that was capable was required in addition to consent from the legal guardian). For potential participants with a LAR (who is not a legal guardian) assessors made a determination, based on a process outlined in the study protocols, about the potential participant's ability to provide informed consent for participation in research (see Appendix F). If the person was



found capable of consenting for participation in research, and he/she wanted to participate in the study, assessors documented this consent and began assessments shortly thereafter. When potential participants with LARs (who are not legal guardians) were determined not able to provide consent for participation in research, but seemed open to being in the study, the assessor contacted the LAR to obtain the consent. If consent to participate in research was obtained from the LAR, then assent from the participant was obtained, if capable (assent from a person that was capable was required in addition to consent from the LAR). Potential participants with no LAR must have been found capable to provide consent for participation in research and provided consent in order to be included in the study.

Participation

Assessments began in November 2014 and continued until February 2016 across New York State. There were 1,129 people who participated in the study and whose information was included in the analyses provided in this report and 788 who were contacted about participation, but declined. Other reasons, beside declination, that a person may not have been included in the study were:

- the assessor was unable to contact the person/LAR after three attempts (n=108);
- the person withdrew from the study after consent to participate in research was obtained (n=11); and
- upon documentation review, there was not supporting evidence to include the person in the specific group of interest for which he/she was selected (n=215).

Assessment Instrument Administration Protocol

As noted earlier, three instruments were administered during the study: the Coordinated Assessment System (CAS); the Developmental Disabilities Profile-2 (DDP-2); and the Inventory for Client and Agency Planning (ICAP). A detailed description of each instrument, including administration requirements, is located in the “Methods for the Validity Study” section of this paper. Each participant in the study was assigned an order in which to have the three instruments administered to help prevent the possibility of “order effects.”¹² Order effects refer to the impact the order of the instrument (i.e., CAS, DDP-2, ICAP) administration has on influencing a participant’s response. To reduce this effect, the order of instrument administration was randomly assigned to each study participant. Reviewing or using a previously completed study assessment to assist in the completion of another study assessment was not permitted via the study protocols. Assessors were instructed to complete all three assessments within a two-week period. These instructions were communicated during in-person assessor training and reinforced during follow-up telephone and video conferences that occurred throughout the study.

Analysis & Results

The study consisted of four major analyses in order to test the hypotheses posited by OPWDD regarding the interRAI scales within the CAS. These hypotheses, as outlined in the “Description of

¹² As of 7/19/2017, an overview of order effects can be found via the following website:
<https://psychology.iresearchnet.com/social-psychology/social-psychology-research-methods/order-effects/>



Validity Study-Hypotheses" section of this paper, are specific to OPWDD achieving its purposes of testing whether the interRAI scales within the CAS are appropriate for the diverse population served in New York State by OPWDD and thereby adding to the body of research associated with the interRAI Intellectual Disabilities (ID) instrument. The analyses completed for this study were:

- assessment of internal consistency of interRAI scales within the CAS;
- assessment of convergent and discriminant validity;
- assessment of concurrent validity; and
- assessment of criterion validity for interRAI scales within the CAS.

Each of these different assessments are associated with specific types of evaluation methods (i.e., statistics and statistical tests). Table 2 contains the different types of evaluations examining various scales with the relevant method.

**Table 2. Types of Evaluation**

Type of Evaluation	Scales Included in Evaluation	Reason for Particular Scales Evaluation	Test/Evaluation Method
Internal Consistency	interRAI scales within the CAS: Activities of Daily Living-Hierarchy (ADL-H) Scale, Communication Scale (CS), Aggressive Behavior Scale (ABS)	Duplication of scales included in Martin et al. (except for the Depression Rating Scale) with the addition of the Communication Scale	Cronbach's Alpha to test for correlations of items within a scale measuring the same construct
Convergent and Discriminant Validity	interRAI scales within the CAS: Activities of Daily Living-Hierarchy (ADL-H) Scale, Communication Scale (CS), Aggressive Behavior Scale (ABS)	Includes the same scales as the internal consistency analysis to test the extent to which scales measure the same or different underlying constructs	Mean inter-item correlations to test for high and low correlations across interRAI scales within the CAS
Concurrent Validity	ICAP: Community Living Skills Domain, Personal Living Skills Domain, Social and Communication Skills Domain, Externalized Maladaptive Behavior Index DDP-2: Self-Care Index; Cognitive Index; Daily Living Skills Index; Communication Skills Index; and Maladaptive Behavior Factor interRAI scales within the CAS: Activities of Daily Living -Hierarchy (ADL-H) Scale; Cognitive Performance Scale (CPS); Instrumental Activities of Daily Living-Capacity (IADL-C) Scale; Communication Scale (CS); Aggressive Behavior Scale (ABS)	Any scales that were described as measuring similar constructs across instruments were included	Squared Correlation Coefficients between two similar scales across different instruments (Spearman's Rho)
Criterion Validity	interRAI scales within the CAS: Activities of Daily Living-Hierarchy (ADL-H) Scale, Instrumental Activities of Daily Living-Capacity (IADL-C) Scale, Aggressive Behavior Scale (ABS)	The three scales under investigation cover fundamental areas of need for people with intellectual and/or developmental disabilities (I/DD)	Kruskal-Wallis H Test to test for presence of significant differences among many groups, descriptive statistics (boxplots), Dunn's Tests to test for differences between two different groups of interest out of many possible groups, Wilcoxon Rank-Sum Test to test for presence of significant differences between the Comparison group and one other group



Descriptive Statistics for the Random Sample

Descriptive Statistics for each of the interRAI scales within the CAS focused on in this study are contained within Table 3 and Table 4 [i.e., Aggressive Behavior Scale (ABS), Communication Scale (CS), Cognitive Performance Scale (CPS), Activities of Daily Living Scale-Hierarchy (ADL-H) Scale, Instrumental Activities of Daily Living-Performance (IADL-P) Scale and Instrumental Activities of Daily Living-Capacity (IADL-C) Scale]. In each table the percentage of people associated with different scores is shown along with the median as is appropriate for ordinal data. OPWDD exceeded the 200 target number of people to be assessed in the Random Sample group, as recommended by the Center for Human Services Research (CHSR) at the University at Albany, by 75 people. Note that the ABS was computed for 274 people out of 275 people, due to a missing item contained within the ABS for one person.

As a check that the random sample is roughly reflective of the people enrolled in OPWDD services, OPWDD compared the following DDP-2 data recorded in the Tracking and Billing System (TABS):

- the Maladaptive Behavior Factor score (a score that measures the frequency and consequences of behavioral challenges) with the ABS; and
- the level of intellectual disability (ID) with the CPS.

Table 3. Descriptive Statistics for the ABS, CS, CPS and ADL-H interRAI Scales Within the CAS

Scales	Number of items in scale	Median	Number and Percentage of People by Scale Score												
			0	1	2	3	4	5	6	7	8	9	10	11	12
ABS	4	0	156 56.9%	36 13.1%	31 11.3%	24 8.8%	15 5.5%	6 2.2%	5 1.8%	0 0.0%	0 0.0%	0 0.0%	1 0.4%	0 0.0%	0 0.0%
CS	2	2	76 27.6%	37 13.5%	34 12.4%	31 11.3%	34 12.4%	14 5.1%	34 12.4%	6 2.2%	9 3.3%				
CPS	4	2	49 17.8%	64 23.3%	73 26.5%	23 8.4%	20 7.3%	34 12.4%	12 4.4%						
ADL-H	4	1	118 42.9%	61 22.2%	20 7.3%	34 12.4%	14 5.1%	16 5.8%	12 4.4%						

As an example of how to read Table 3, the statistics are based on 275 people, except for the ABS (274 as previously noted). The Activities of Daily Living Hierarchy (ADL-H) Scale, for example, has four (4) items that are included in the scale. These four items are computed into a 7-point scale described by the following categories ordered from the lowest need to the highest need: independent (0); supervision (1); limited assistance (2); extensive assistance (3); maximal assistance (4); dependent (5); and total dependence (6).¹³ The median ADL-H score was one (1) (supervision) meaning that at least half of the people in the random sample were associated with a score of zero (0) (independent) or one (1)

¹³ Lynn Martin, John P. Hirides, Brant E. Fries and Trevor Smith, "Development and Psychometric Properties of an Assessment for Persons With Intellectual Disability—The interRAI ID," *Journal Of Policy & Practice In Intellectual Disabilities* 4, no. 1 (March 2007), 25.



(supervision). In fact, nearly two thirds of the people in the study (65.1%) scored zero (0) (independent) or one (1) (supervision) on the ADL-H Scale.

The Cognitive Performance Scale (CPS) is composed of four (4) items, which, when used together, result in a 7-point scale described by the following categories ordered from the lowest need to the highest need: intact (0); borderline intact (1); mildly impaired (2); moderately impaired (3); moderately to severely impaired (4); severely impaired (5); very severely impaired (6).^{14,15} The median score was two (2) (mildly impaired) and almost half of the people in the random sample (49.8%) scored a one (1) (borderline intact) or two (2) (mildly impaired) on the CPS (see Table 3 above). This indicates that close to half of the people in the random sample have borderline to mild cognitive impairment. These results align with adults currently receiving services from OPWDD, since almost half (44.4%) of the population have a diagnosis of a mild intellectual disability reported via the DDP-2.

The other two scales within Table 3 are the Communication Scale (CS) and the Aggressive Behavior Scale (ABS), containing two and four items, respectively. The ABS is based on four (4) items: verbal abuse, physical abuse, socially inappropriate or disruptive behavior, and resistance to care. Scale scores range from zero (0) to twelve (12) with higher scores indicative of greater frequency and diversity of aggressive behavior. A score of one (1) to four (4) on the ABS indicates mild to moderate aggressive behavior, whereas scores of five (5) or more represent the presence of more severe aggression.¹⁶ The median ABS score was zero (0); 56.9% of people were associated with this score (see Table 3). Comparing this result to the overall OPWDD adult population, we see that 78% of people are associated with low behavior scores, based upon reported DDP-2 data.

The Communication Scale (CS) is based on two (2) items which result in a 9-point scale where scores range from intact (0) to very severe impairment (8).¹⁷ The median CS score was two (2) (mild impairment). CS scores were distributed fairly evenly between scores of (1), (2), (3), (4), and (6) (from 11-13.5%) indicating a range of communication abilities across the random sample (see Table 3 above). About 5.5% of people scored a (7) or an (8) on the CS, demonstrating severe or very severe challenges communicating with others (see Table 3 above).

interRAI developed two scales to measure a person's abilities and needs in the area of instrumental activities of daily living (IADLs). The first scale, the Instrumental Activities of Daily Living-Capacity (IADL-C) Scale, measures the *person's capacity* to complete a specific task (even if it was not performed within the timeframe of the assessment). The second scale, the Instrumental Activities of Daily Living-Performance (IADL-P) Scale measures the *person's ability to perform* a specific task within a required three (3) day timeframe. Both scales include the same seven (7) items, with the only difference being that the IADL-P scale also allows for an assessor to code an item as "Activity Did Not Occur." For

¹⁴ Lynn Martin, John P. Hirdes, Brant E. Fries and Trevor Smith, "Development and Psychometric Properties of an Assessment for Persons With Intellectual Disability—The interRAI ID," *Journal Of Policy & Practice In Intellectual Disabilities* 4, no. 1 (March 2007), 25.

¹⁵ Note: Terminology used to describe the scales originates from the interRAI ID instrument.

¹⁶ Lynn Martin, John P. Hirdes, Brant E. Fries and Trevor Smith, "Development and Psychometric Properties of an Assessment for Persons With Intellectual Disability—The interRAI ID," *Journal Of Policy & Practice In Intellectual Disabilities* 4, no. 1 (March 2007), 25

¹⁷ interRAI. Scales: Status and Outcome Measures. interRAI. <http://www.interrai.org/scales.html>, accessed June 29, 2017.



example, should an activity, such as shopping, not be performed during the three (3) day timeframe, the assessor would code the item used in the IADL-P scale as “Activity Did Not Occur.” However, the person’s capacity to complete shopping would be coded for in the IADL-C item for shopping.

Both scale scores range from zero (0), which indicates independence in all of the eight activities considered, to forty-eight (48), which indicates total dependence in all eight activities. The coding of “Activity Did Not Occur” for items within the IADL-P prevents the scale score from being calculated using items from the IADL-P scale only. In instances where “Activity Did Not Occur” is coded as a response, comparative items from the IADL-C are substituted into the IADL-P scale score calculation, per interRAI’s methodology, which recognizes that not all activities occur during the prescribed timeframe. The IADL-C scale score is calculated solely based on the coding associated with the IADL-C and substitution of a comparative item from the IADL-P scale is never needed since it is a measurement of the person’s capacity to perform each task.

In order to decide which scale to use for the study, or both, the researchers at the Center for Human Services Research (CHSR) at the University at Albany and the OPWDD research team considered the following information:

- close to half of the people assessed (n=129) for the study’s random sample had at least one (1) item in the IADL-P scale coded as “Activity Did Not Occur” resulting in the need to substitute a comparative item or items from the IADL-C scale; and
- the scales that measure instrumental activities of daily living (IADLs) in the comparative instruments, the DDP-2 and the ICAP, measure capacity as opposed to performance.

Upon review of these factors, the decision was made to evaluate the IADL-C scale for the purposes of this paper as it provides a consistent set of items within the scale and is similar to those scales in the other instruments included in this study, which also focus on capacity. However, descriptive statistics are provided for the IADL-P for the Random Sample group.

The median IADL-C score was 28 and the median IADL-P score was slightly higher at 31 (see Table 4 below). The random sample contained people who reached the minimum (0) and maximum (48) scores for both scales. Three quarters of the people in the random sample scored below 40 and 41 for the IADL-C and IADL-P, respectively. Overall, these two scales show very similar distributions, which, can be partly attributed to measuring similar constructs and partly attributed to the construction of the IADL-P scale itself, which uses response codes associated with the IADL-C when an activity does not occur within the required three (3) day timeframe.

Table 4: Descriptive Statistics for the IADL-C and IADL-P interRAI Scales Within the CAS

Scales	Number of People	Number of Items	Median	Sample Minimum	Sample Maximum	25th Percentile	75th Percentile
IADL-C	275	7	28	0	48	12	40
IADL-P	275	7	31	0	48	16	41



Sections of this report related to testing for solid psychometric properties in terms of internal consistency, construct validity and concurrent validity, use the Random Sample group as the foundation of the analysis. The descriptive analysis contained in this section is provided to demonstrate the diversity in skills and behavioral challenges present within the random sample.

Descriptive Statistics for the Persons with an Autism Spectrum Disorder Group

Descriptive Statistics for each of the interRAI scales within the CAS focused on in this study and applied to the persons with an Autism Spectrum Disorder group are contained within Table 5 and Table 6 [i.e., Aggressive Behavior Scale (ABS), Communication Scale (CS), Cognitive Performance Scale (CPS), Activities of Daily Living-Hierarchy (ADL-H) Scale, and Instrumental Activities of Daily Living-Capacity (IADL-C) Scale]. In each table, the percentage of people associated with different scores is shown along with the median, as is appropriate for ordinal data. Below is a review of the results on these scales for persons with an autism spectrum disorder. The descriptive statistics for the Random Sample group are provided and can be used as a contextual reference.

Table 5. Persons with an Autism Spectrum Disorder Group - Descriptive Statistics for the ABS, CS, CPS, and ADL-H interRAI Scales Within the CAS

Scales	Number of Items in Scale	Median	Number and Percentage of People by Scale Score												
			0	1	2	3	4	5	6	7	8	9	10	11	12
ABS	4	1	33 39.8%	11 13.3%	11 13.3%	12 14.5%	7 8.4%	4 4.8%	2 2.4%	0 0.0%	2 2.4%	0 0.0%	1 1.2%	0 0.0%	0 0.00%
CS	9	3	15 18.1%	13 15.7%	10 12.1%	6 7.2%	9 10.8%	11 13.3%	17 20.5%	1 1.2%	1 1.2%				
CPS	4	2	6 7.2%	21 25.3%	17 20.5%	13 15.7%	13 15.7%	12 14.5%	1 1.2%						
ADL-H	4	1	22 26.5%	29 34.9%	15 18.1%	16 19.3%	0 0.0%	0 0.0%	1 1.2%						

Table 6: Persons with an Autism Spectrum Disorder Group - Descriptive Statistics for the IADL-C interRAI Scales Within the CAS

Scale	Number of People	Number of Items	Median	Minimum	Maximum	25th Percentile	75th Percentile
IADL-C	83	7	34	0	48	21.5	38

People with an autism spectrum disorder tended to have scores that reflect higher needs, as measured by the interRAI scales within the CAS, in the areas of behavioral challenges (ABS), communication (CS) and instrumental activities of daily living (IADL-C) as compared to the Random Sample group. About 40% of people in the Autism Spectrum Disorder group are associated with a score



of zero (0) and the median score was one (1) on the Aggressive Behavior Scale (ABS) whereas 56.9% of the Random Sample group had a score of zero (0), which also represented the median for this group. The median score on the Communication Scale (CS) for the Autism Spectrum Disorder group was three (3) and the scores on the CS are well distributed across all of the values, with only one person scoring a seven (7) and one person scoring an eight (8) for a total percentage of 2.4. Comparatively, the median score for the Random Sample group on the CS was two (2) and scores of seven (7) and eight (8) represented 5.5% of the Random Sample group. The median for the Instrumental Activities of Daily Living-Capacity (IADL-C) Scale for the people with an autism spectrum disorder was 34, the 25th percentile was 21.5 and the 75th percentile was 38. By comparison the IADL-C median for the Random Sample group was 28, the 25th percentile was 12 and the 75 percentile was 40.

Similarities exist between the Random Sample group and the Autism Spectrum Disorder group when comparing the scores on the Cognitive Performance Scale (CPS) and Activities of Daily Living-Hierarchy (ADL-H) Scale. The median score on the Cognitive Performance Scale (CPS) for the Autism Spectrum Disorder group was two (2) (mildly impaired) and, as in the case with the Communication Scale (CS), the scores were distributed across all of the various values, with only one person associated with the highest possible score (1.2%). The Random Sample group also had a median score of two (2) and 4.4% of that group had the highest possible score on the CPS. With respect to the ADL-H scale both the Autism Spectrum Disorder group and the Random Sample group had a median of one (1). Again, these descriptive statistics are provided since the Autism Spectrum Disorder group was not associated with a specific hypothesis, as were the other diagnostic groups, due to expected variation in skill performance that would be anticipated from spectrum disorders.

Internal Consistency

When items are used together to form a scale they should have internal consistency. Internal consistency relates to the correlation between different items that should all measure the same general concept. For example, items in the Activities of Daily Living-Hierarchy (ADL-H) Scale should all measure a person's general ability to complete daily living activities. There are several ways to measure internal consistency and Cronbach's Alpha is one commonly used measure. Cronbach's Alpha was used to assess the internal consistency of interRAI scales within the CAS listed below. Cronbach's Alpha is a classic measure of composite reliability; a high value is indicative of a scale composed of items that are measuring the same broad concept. Scales with strong correlations between items provide evidence of measuring the same underlying construct and will have a high value for Cronbach's Alpha. This measure was calculated for the following interRAI scales within the CAS:

- the Activities of Daily Living-Hierarchy (ADL-H) Scale (intended to measure a person's functional performance);
- the Communication Scale (CS) (intended to measure a person's communication capabilities); and
- the Aggressive Behavior Scale (ABS) (intended to measure a person's level of aggressive behavior).



Although similar analysis on Cronbach's Alpha have been conducted for the interRAI ID assessment that serves as the basis for the CAS, these additional coefficient calculations help to confirm that internal consistency has been maintained when measurement occurs based on the population that OPWDD serves.

Table 7 contains Cronbach's Alpha values for the interRAI scales within the CAS assessed for internal consistency.

Table 7. Cronbach's Alpha Values for interRAI Scales Within the CAS

interRAI Scales within the CAS	Cronbach's Alpha
Activities of Daily Living- Hierarchy (ADL-H) Scale	0.902
Communication Scale (CS)	0.874
Aggressive Behavior Scale (ABS)	0.506

Though there is a range of suggested cut-points for what Cronbach's Alpha values are considered acceptable, a value greater than .70 is considered indicative of an internally consistent measure. With the exception of the Aggressive Behavior Scale (ABS) ($\alpha=.506$) the interRAI scales within the CAS that were evaluated with this statistic meet this standard with the Activities of Daily Living-Hierarchy (ADL-H) Scale achieving an $\alpha=.902$, and the Communication Scale achieving an $\alpha=.874$.

Unlike the other scales, the Aggressive Behavior Scale (ABS) includes a diverse set of items which may impact its internal consistency resulting in an alpha value not as strong as the other scales under investigation. The items included in the ABS (i.e., verbal abuse, physical abuse, resisting care and socially inappropriate or disruptive behavior) all center around very different types of behavior that affect care planning. For example, it is very possible that a person who engages in verbal abuse does not engage in physical abuse. These behaviors are very different from one another, and therefore there might not be a strong relationship between the items and concepts in the scale (e.g., resisting care and physical abuse, socially inappropriate or disruptive behavior and aggression), which would affect the alpha value for the ABS. While the CAS contains other items that are indicative of aggressive behavior, since these items are not contained in the ABS, they were outside the scope of this evaluation which focused on the established interRAI scales within the CAS.

Construct Validity - Convergent and Discriminant Validity

The assessment of convergent and discriminant validity involves determining whether or not scales are measuring both distinct and overlapping concepts. For this study, convergent and discriminant validity were analyzed by comparing the average inter-item correlation between the components of the interRAI scales within the CAS. Whereas the calculations for Cronbach's Alpha focus on correlations for items within the same scale, the calculations associated with convergent/discriminant validity focus on the average correlations for items across two different scales. Extremely low correlations indicate little convergent validity between the interRAI scales within the CAS, meaning there is some evidence that the two scales under investigation are measuring different



concepts. This intuitively makes sense because items that are subsumed under two different scales that purport to measure very different things (e.g., behaviors and skills) would not be expected to correlate strongly to one another. Low correlations would provide some evidence that the two scales are probably measuring very different underlying constructs.

On the other hand, extremely high mean inter-item correlations indicate little discriminant validity, meaning that the items that make up different scales are highly related and possibly measuring similar concepts.

Figure 1 is a matrix of mean inter-item correlations. As an example of how to read the matrix, the mean inter-item correlation between the Activities of Daily Living-Hierarchy (ADL-H) Scale and the Communication Scale (CS) is .55, suggesting that the items that make up the ADL-H scale and the Communication Scale, are moderately to strongly correlated.

The weakest correlations occur between the Aggressive Behavior Scale (ABS) and the other scales. In fact, the ABS has essentially no correlation with any of the other scales (correlations of .03 and 0.07). This is not surprising since the ABS measures something very different than activities of daily living skills and communication skills. These results support the idea that there are different underlying concepts being measured by the interRAI scales contained within the CAS. The ADL-H Scale and the Communication Scale are related to skills while the ABS is not associated with a person's abilities.

Figure 1. Correlations for Items Within and Across Scales

Mean Correlation Among Items	Activities of Daily Living-Hierarchy Scale	Communication Scale	Aggressive Behavior Scale
Activities of Daily Living-Hierarchy Scale	.73		
Communication Scale	.55	.78	
Aggressive Behavior Scale	.03	.07	.22

Concurrent Validity

One means of determining the validity of the interRAI scales within the CAS was through comparison with existing, established scales contained within the Developmental Disabilities Profile- 2 (DDP-2) and the Inventory for Client and Agency Planning (ICAP). This study utilized a concurrent validity approach, examining the relationship between scale scores from three assessment instruments that have been administered around the same time. Ideally, the CAS should produce scoring that is relatively similar to that of scales contained within the DDP-2 and the ICAP. Intuitively, this makes sense: scales that measure similar concepts – such as adaptive behavior – should have scale scores that are



moderately to highly correlated, meaning that people who score as having strong adaptive skills on one instrument's scale should also score as having strong adaptive skills on the other.

DDP-2 and CAS

Based on the random sample data, Figure 2 (below) contains the r_s^2 matrices between the interRAI scales within the CAS and DDP-2 measure. Spearman's Rho, squared (r_s^2), is reported in Figures 2 and 3, as a measure of association that ranges from 0-1 and can be interpreted as the proportion of shared variance between the measures. A priori we would expect several scale/measure pairs to be related. These sets of scales/measures include:

- interRAI's Activities of Daily Living-Hierarchy (ADL-H) Scale within the CAS and the DDP-2's Self Care Index ($r_s^2=.76$);
- interRAI's Cognitive Performance Scale (CPS) within the CAS and DDP-2's Cognitive Index ($r_s^2=.59$);
- interRAI's Instrumental Activities of Daily Living-Capacity (IADL-C) Scale within the CAS and DDP-2's Daily Living Skills Index ($r_s^2=.87$);
- interRAI's Communication Scale (CS) within the CAS and DDP-2's Communication Skills Index ($r_s^2 = .56$); and
- interRAI's Aggressive Behavior Scale (ABS) within the CAS and DDP-2's Maladaptive Behavior Factor ($r_s^2=.33$).

These pairs are greyed out in Figure 2 so the reader can easily identify which pairs were identified a priori by OPWDD.

Upon review of the hypothesized relationships, in all but the Aggressive Behavior Scale (ABS), the r_s^2 exceeds .5 indicating a large proportion of shared variance between the interRAI scales within the CAS and existing scales within the DDP-2. As an example of how to interpret an r_s^2 value, one would say 66% of the variance in the DDP-2's Daily Living Skills Index is associated with the Activities of Daily Living-Hierarchy (ADL-H) Scale, which is substantial. All of the pairs under examination except one have large shared variances, which provides evidence of concurrent validity.

Furthermore, in most cases the interRAI scales within the CAS under investigation are very highly associated with the DDP-2 measure with which it was paired a priori. For example, the ABS correlated most highly with the DDP-2's Behavior Frequency Index ($r_s^2 = .40$) (not shown in Figure 2 as it is a subset of the Maladaptive Behavior Factor) and the Maladaptive Behavior Factor ($r_s^2 = .33$) compared to any other indices or factors within the DDP-2. Likewise, the Communication Scale (CS) correlates most highly with the DDP-2's Communication Skills Index, as well as, the DDP-2's Adaptive Limitations Factor ($r_s^2 = .59$) (not shown in Figure 2), which contains the DDP-2's Communication Skills Index. The ADL-H Scale and the DDP-2's Self Care Index had the strongest association when examining the ADL-H Scale against any other DDP-2 measure ($r_s^2=.76$). This makes sense as they both purport to measure basic skills that are required in order to care for one's self on a daily basis such as eating and getting dressed.



Figure 2. Squared Correlation Coefficient (r_s^2) Matrices Between the interRAI Scales Within the CAS and DDP-2 Indices/Factors

Squared Correlation Coefficient (r_s^2)		interRAI Scales within the CAS				
		Activities of Daily Living-Hierarchy (ADL-H) Scale	Cognitive Performance Scale (CPS)	Instrumental Activities of Daily Living – Capacity (IADL-C) Scale	Communication Scale (CS)	Aggressive Behavior Scale (ABS)
DDP-2 Indices / Factors	Self-Care Index	.76	.57	.77	.51	.01
	Cognitive Index	.49	.59	.62	.51	.02
	Daily Living Skills Index	.66	.64	.87	.55	.01
	Communication Skills Index	.41	.58	.55	.56	.01
	Maladaptive Behavior Factor	.02	.03	.03	.02	.33

ICAP and CAS

Figure 3 (below) contains the r_s^2 matrices between the interRAI scales within the CAS and ICAP scales. As in the previous section, OPWDD identified scales contained within the CAS and the ICAP that would be expected to be highly correlated because they are identified as measuring similar constructs. A priori we would expect these high correlations between:

- interRAI Activities of Daily Living-Hierarchy (ADL-H) Scale within the CAS and the ICAP's Personal Living Skills Domain ($r_s^2 = .73$);
- interRAI Communication Scale (CS) within the CAS and the ICAP's Social and Communication Skills Domain ($r_s^2 = .55$);
- interRAI Aggressive Behavior Scale (ABS) within the CAS and the ICAP's Externalized Maladaptive Index ($r_s^2 = .40$); and
- interRAI Instrumental Activities of Daily Living-Capacity (IADL-C) Scale within the CAS and the ICAP's Community Living Skills Domain($r_s^2 = .79$).



Figure 3. Squared Correlation Coefficient (r_s^2) Matrices Between the interRAI Scales Within the CAS and ICAP Scales

Squared Correlation Coefficient (r_s^2)		interRAI Scales Within the CAS				
		Activities of Daily Living-Hierarchy Scale (ADL-H)	Cognitive Performance Scale (CPS)	Instrumental Activities of Daily Living-Capacity Scale (IADL-C)	Communication Scale	Aggressive Behavior Scale (ABS)
ICAP Scales	Community Living Skills Domain	.59	.65	.79	.59	.01
	Personal Living Skills Domain	.73	.57	.86	.48	.01
	Externalized Maladaptive Index	.01	.01	.01	.01	.40
	Social and Communication Skills Domain	.54	.62	.70	.55	.01

As was the case with the comparisons between the DDP-2 and interRAI scales within the CAS, scales that measure skills tend to correlate strongly. Similarly, the External Maladaptive Index embedded in the ICAP correlated most strongly with the ABS. Note that since there is not a scale specific to cognition within the ICAP, OPWDD did not have an expectation about which ICAP scale would correlate most strongly with the CPS. Instead, as would be expected, the ICAP scales that relate to performance have high shared variances with the CPS as compared to the Externalized Maladaptive Index, which is associated with behavior (see the r_s^2 values in Figure 3).

In summary, high correlations between the interRAI scales within the CAS and those contained in the DDP-2 and ICAP are evidence that the interRAI scales within the CAS are measuring the similar concepts as those measured in the other two assessment instruments.

Criterion Validity - Analysis of Groups of Interest

Another area of interest is how the *actual* scale scores differ between groups versus how they are *expected* to differ between groups. This is another way to check the validity of the instrument. Twenty groups of interest were selected for analyses; seven based on the service delivery environment, and thirteen based on diagnosis/clinical groupings. These groups of interest (herein referred to as groups) were previously noted in the “Sample Selections, Methods and Sizes-Groups of Interest” section of this paper and are described in Appendix E. Groups of people were identified in order to ensure that many types of service settings, from more intensive to less intensive, were represented in the study. People who are served in more intensive service settings are expected to have adaptive skill scores that reflect fewer skills compared to those in less intensive service settings. Though there is a diversity of people within any given service, it is still expected that there will be patterns across service settings.



Groups of people with various types of diagnoses and/or behavioral challenges were also evaluated to see if scale scores differ by group. For example, with scales that measure skill (i.e., activities of daily living, instrumental activities of daily living) it is expected that scale score patterns change as the level of intellectual disability (ID) varies. People with a more severe ID diagnosis are expected to have scale scores that indicate fewer skills than others with a milder ID diagnosis.

For people in various service settings and with different levels of intellectual disability (ID), differences in scale scores were investigated with a three-step approach:

1. Statistical differences in scale scores were identified first using the Kruskal-Wallis H Test, appropriate for use when checking for statistically significant differences between two or more groups on the ordinal interRAI scales within the CAS under investigation. A positive finding on the Kruskal-Wallis H Test (KW Test) indicates that at least one of the groups under investigation is statistically different than another group. The KW Test is an omnibus test that informs the researcher about whether more specific testing is warranted.
2. After the KW Test, boxplots are presented in order to show the distribution of scale scores for different groups. The boxplots present the scale scores associated with the 25th, 50th (median) and 75th percentiles for any given scale by group. Dots that extend above the 75th percentile line and below the 25th percentile line show the distribution of the remaining scores not included in the interquartile range (25th through 75th percentile).
3. Lastly, more specific testing, using Dunn's Tests, was completed in order to identify whether a statistical difference existed between two specific groups. While the KW Tests simply reveal whether a significant difference exists among any of the groups under consideration, the Dunn's Tests refine the analysis by finding exactly where some of these differences exist. OPWDD identified specific pairs within the service setting groups and the diagnostic/clinical groups of interest for evaluation. Continuing with the example of anticipated differences in skill by level of ID, the methods used in this paper required that first the Kruskal-Wallis H Test be employed to test whether *any* significant differences in Activities of Daily Living-Hierarchy (ADL-H) Scale scores exist across all levels of ID from Mild to Profound. A positive finding using the Kruskal Wallis H Test suggests that there is at least one significant difference in pairs of the ID groups in the analysis. In order to find where these differences exist, Dunn's Tests were conducted to identify which pairs have a significant difference in ADL-H Scale scores.

The three-step approach is repeated in the first three analyses:

- “Results and Evaluation for Groups of People Living in Various Residential Settings;”
- “Results and Evaluation for Groups of People Receiving Supports in Various Day Service Settings;” and
- “Results and Evaluation for Groups of People with Different Intellectual Disability (ID) Diagnosis Levels.”



The approach for the last analysis is slightly different as each diagnostic/clinical group is tested against one comparison group, and an omnibus test (Kruskal-Wallis H Test) is not required. Therefore, this section contains descriptive statistics (boxplots) and the results of the Wilcoxon Rank-Sum Tests used to test for differences between groups.

- “Results and Evaluation for Groups of People with Various Diagnoses/Clinical Presentations and/or Behavioral Challenges.”

By the end of the analysis and presentation of results related to criterion validity, it will be clear that, overall, the interRAI scales within the CAS are able to differentiate groups of people:

- receiving services in a variety of settings (specifically, residential and day);
- having different severity levels of intellectual disability;
- having certain diagnoses versus people without these diagnoses; and
- having behavioral challenges versus people without these types of challenges.

Results & Evaluation for Groups of People Living in Various Residential Settings

OPWDD posited several general hypotheses when entering into this study, previously stated in the “Description of Validity Study – Hypotheses” section of the report. In this section, OPWDD applies the general hypothesis, “interRAI scales within the CAS should measure people in settings with higher intensity of supports as having higher levels of need compared to people in settings with lesser intensity supports” to people in residential settings to arrive at Hypothesis 1.

Hypothesis 1: People receiving supports in what have traditionally been referred to as “more intensive” residential settings are expected to show scores that reflect fewer abilities to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs), and potentially more behavioral challenges, as measured via the scales developed by interRAI and used in the CAS.

OPWDD expected all scores on the Activities of Daily Living-Hierarchy (ADL-H) Scale, Instrumental Activities of Daily Living-Capacity (IADL-C) Scale, and the Aggressive Behavior Scale (ABS) to decrease, which is indicative of people having more skills or fewer behavioral challenges, as one moves across the continuum of residential settings towards less intensive settings:

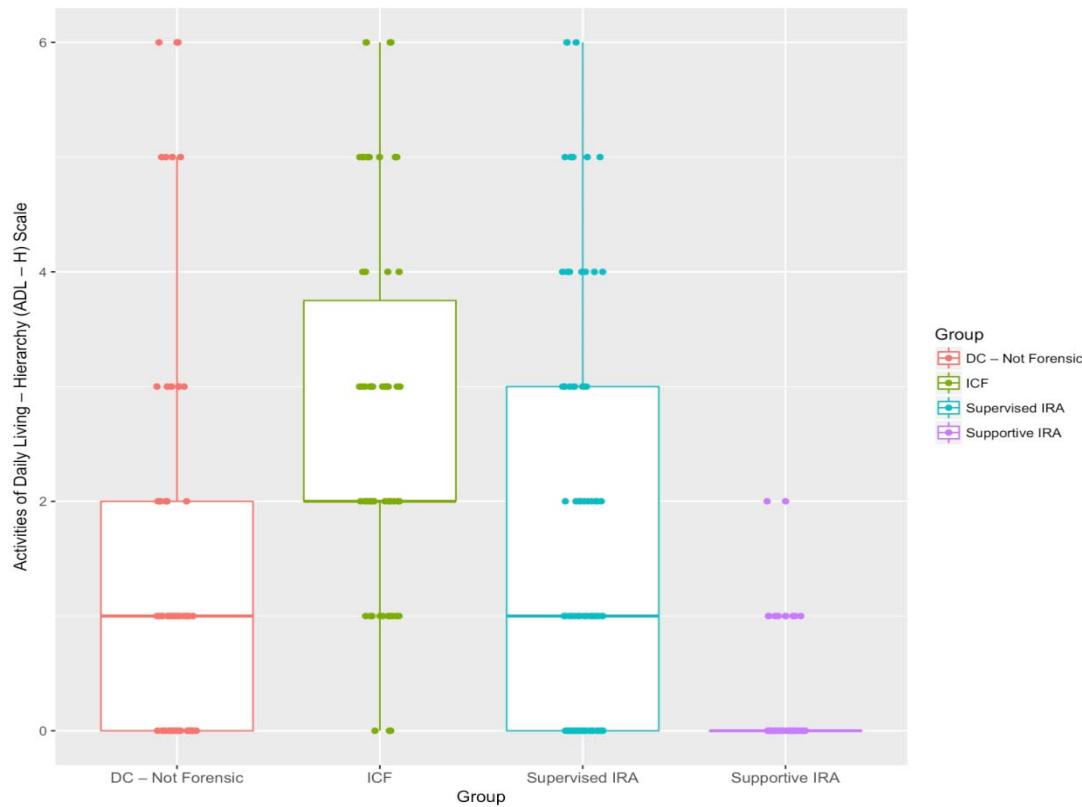
- Developmental Center (DC) – Not Forensic Units;
- Intermediate Care Facility (ICF);
- Supervised Individualized Residential Alternative (IRA); and
- Supportive Individualized Residential Alternative (IRA).

For the analysis of residential service settings, the Kruskal-Wallis H Test revealed that scores do change with residential setting [ADL-H ($H(3) = 90.83, p < .05$), IADL-C ($H(3) = 136.11, p < .05$) and ABS ($H(3) = 22.87, p < .05$)]. Figures 4 through 6 contain boxplots for each of the residential groups for the three (3) scales. Tables 8 through 10 contain the results of the Dunn’s Tests, used to test whether there



were statistically significant differences between groups of people living in two different types of residential settings.

Figure 4. ADL-H Score by Residential Setting



As shown in Figure 4, people living in a DC-Not Forensic Unit had a median ADL-H Scale score of one (1), the 75th percentile scored a two (2) and the 25th percentile scored a zero (0). As a reminder, the ADL-H scale ranges from zero (0) to six (6), with six (6) representing total dependence. Further detail about the ADL-H scale can be found in Appendix A. For three (3) of the groups, DC-Not Forensic Unit, ICF and Supervised IRA, the scores ranged from the highest to lowest possible scores on the scale. People living in a Supportive IRA had low ADL-H scores, with the 75th percentile falling at a score of zero (0), which indicates strong activities of daily living (ADLs) skills. Note, that the median and the 25th percentile for the people in the ICF group is equal to two (2). Similarly, the boxplot representing the scores for people in a Supportive IRA is collapsed because the 25th percentile, median and 75th percentile all equal zero (0).

Table 8. Differences in ADL-H Scale Scores for People Living in Various Residential Settings

	Z	p adj
Residential Setting Pairs		
ICF vs DC-Not Forensic Unit	5.09	0.000
Supervised IRA vs ICF	-4.19	0.000
Supportive IRA vs Supervised IRA	-6.02	0.000



The Dunn's Tests revealed statistically significant differences in scale scores ($p < .05$) between groups, even for people who live in settings that are “adjacent” to each other on the continuum of residential services. While it is not surprising that the analysis would reveal statistically significant differences when comparing people living in residential settings that are quite different in support intensity [i.e., Intermediate Care Facility (ICF) compared to Supportive Individualized Residential Alternative (IRA)] the finding of statistically significant differences between people living in residential settings “adjacent” to each other is noteworthy. The comparison of people living in Supervised IRAs and Supportive IRAs, and the comparison of people living in ICFs and Supervised IRA settings, are both statistically significant. Returning to the point about expecting larger, statistically significant differences for people living in settings that are not adjacent on the continuum, there is, in fact, a large difference in ADL-H scores when comparing scores for people living in ICFs versus Supportive IRA settings, as shown in Figure 4. People living in an ICF tend to score higher than people living in a Supportive IRA which is statistically significant ($p < .05$) and indicates that people living in an ICF are associated with having less independence with regard to their ADLs.

The results of the comparison between people living in a Developmental Center (DC)—Not Forensic Unit and those living in an ICF also yielded statistically significant differences. The low p values contained in Table 8 suggest that the differences between the groups are statistically significant and arise from real differences in scores among groups rather than through choosing samples that happen to be different from one another by chance. On average, people living in an ICF tended to score higher on the ADL-H scale than people living in a DC-Not Forensic Unit. That means people living in an Intermediate Care Facility (ICF), on average, have an ADL-H score that indicates more dependence compared to people living in DC-Not Forensic Unit. Given OPWDD’s recent efforts to integrate people living in developmental centers (DC) into community settings, except for people with the most significant behavioral challenges, this is not a surprising result. People living in the DC-Not Forensic Units may have more independence with ADLs, but struggle with behavioral challenges, while people living in ICFs may have medical needs that prevent them from performing ADLs such as personal hygiene, toilet use, mobility and eating.

An analysis of the Instrumental Activities of Daily Living-Capacity (IADL-C) Scale completes the examination of scales evaluating a person’s skill by residential setting (Figure 5 and Table 9). Similar patterns were found as those that resulted from the ADL-H analysis (Figure 4 and Table 8). The Kruskal-Wallis H Test revealed that scores change according to the type of residential setting, [IADL-C H(3) = 136.11, $p < .05$]. Figure 5 and Table 9, respectively, contains a boxplot of the distributions and the results of testing for differences between specific residence types.

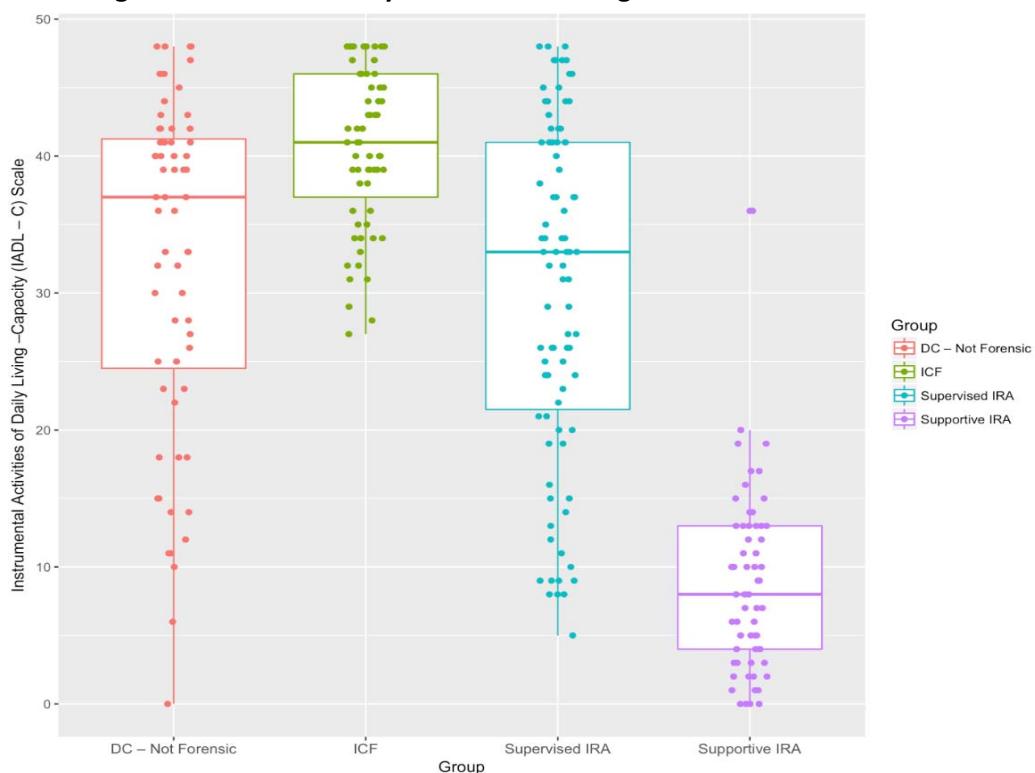
**Figure 5. IADL-C Score by Residential Setting**

Figure 5 contains the boxplots for the four different types of residential settings included in this study. People living in a Supportive IRA have a median of eight (8) for the IADL-C Scale score, while the median scores for the other residential groups are all higher than thirty (30). People living in ICFs, Supervised IRAs and DC- Not Forensic Unit all show scores reaching the maximum of forty-eight (48). Only people living in a DC-Not Forensic Unit or Supportive IRA are associated with the minimum score of zero (0), which indicates strong instrumental activities of daily living (IADLs) skills.

Once again, we see that people living in ICFs have higher scores (indicating more dependence), on average, than those in Supervised IRA settings. People in Supervised IRAs have higher scores than people living in a Supportive IRA. Differences in scores are statistically significant, as evidenced by the low p value for the last two residential pairs in Table 9.

Table 9. Differences in IADL-C Scale Scores for People Living in Various Residential Settings

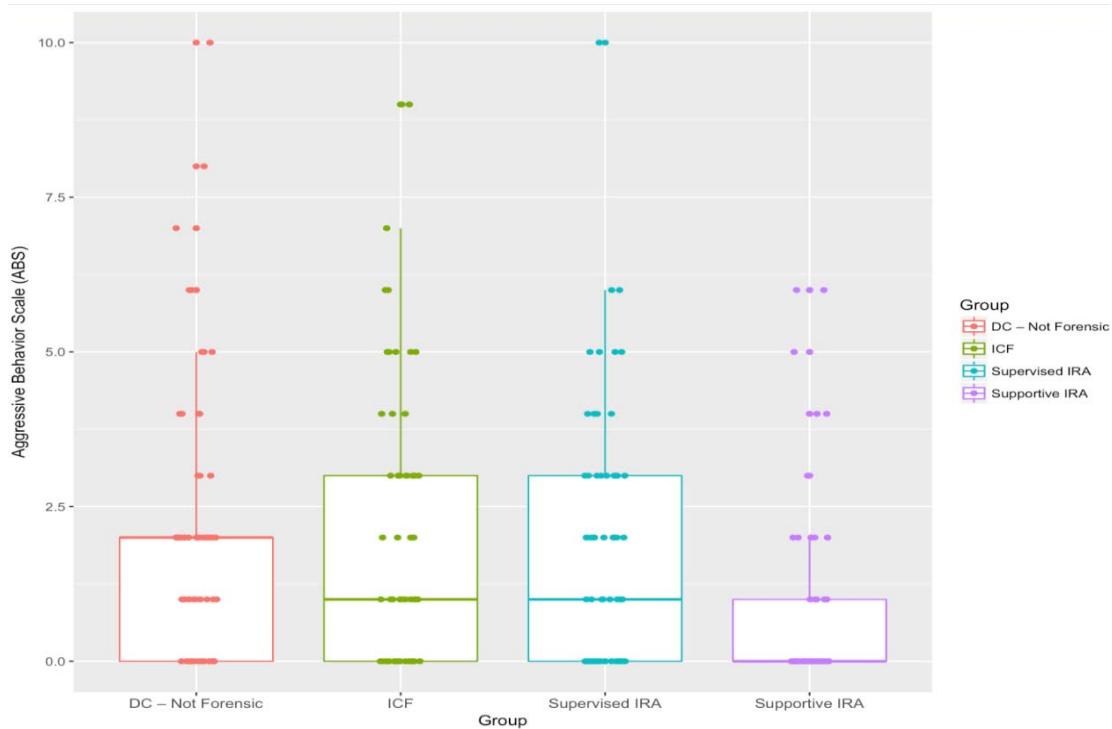
Residential Setting Pairs	Z	p adj
ICF vs DC-Not Forensic Unit	3.29	0.004
Supervised IRA vs ICF	-4.47	0.000
Supportive IRA vs Supervised IRA	-7.74	0.000



As shown, people living in a Developmental Center (DC)-Not Forensic Unit have IADL-C scale scores that indicate more abilities when compared to people living in ICFs. The same explanation provided previously regarding the results of the ADL-H Scale, that those living at a DC-Not Forensic Unit are more likely to have behavioral challenges, but may be able to accomplish a variety of living skills, may be applicable here too. Differences between people living in ICFs and DC-Not Forensic Unit are statistically significant.

The Aggressive Behavior Scale (ABS) scores were reviewed across people living in residential settings to examine whether those scores show expected differences. The Kruskal-Wallis H Test revealed that scores change according to the type of residential setting, [ABS ($H(3) = 22.87, p < .05$)].

Figure 6. ABS Score by Residential Setting



Across all residential settings the 75th percentiles for ABS scores are within the range of mild to moderate aggression (1 - 4), as shown in Figure 6. Medians all fall at one (1) or below. People living in Supportive IRAs are generally associated with the lowest ABS scores, which are indicative of fewer behavioral challenges.



Table 10. Differences in ABS Scores for People Living in Various Residential Settings

	Z	p adj
Residential Setting Pairs		
ICF vs DC-Not Forensic Unit	-0.46	0.643
Supervised IRA vs ICF	-1.34	0.216
Supportive IRA vs Supervised IRA	-2.86	0.008

The results of Dunn's Tests comparing people living in adjacent residential settings are contained in Table 10. Two of the p values (associated with the first two pairings) did not reach the threshold necessary to achieve statistical significance. However, a comparison of people living in Supervised IRAs and Supportive IRAs demonstrated that people in Supervised IRAs scored higher on the ABS scale, in general, indicating more behavioral needs. The ABS scale does show other statistically significant scores for people living in residential settings that are further apart on the residential continuum (non-adjacent), and these differences are in the expected direction (these results are not shown in Table 10). Specifically, people living at DC-Not Forensic Units and ICFs have higher scores, on average, compared to people living in Supportive IRA settings ($Z = -4.37$, $p < .05$ and $Z = -3.89$, $p < .05$, respectively). While the ABS did not provide statistically significant differences between the DC-Not Forensic Units and ICFs, this could be due to the fact that items that are reflective of behaviors that may result in the need for higher intensity supports (i.e., destructive behavior, self-injurious behavior) are contained elsewhere in the CAS. Since these types of items were not contained in the ABS or any other interRAI scales within the CAS, the testing of these items was outside the scope of this study.

Summary for Groups of People Living in Various Residential Settings

This analysis began with the specific hypothesis that people receiving supports in what have traditionally been referred to as “more intensive” residential settings are expected to show scores that reflect fewer abilities to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs) and potentially more behavioral issues. The results of the analysis support this expectation by showing that people living in homes with more intense supports are, in general, associated with less ability in completing everyday living activities independently. As a result, there is evidence that the interRAI scales within the CAS measuring living skills (ADL-H and IADL-C) are sensitive enough to differentiate between people living across different types of residential settings.

Only one significant difference emerged for the Aggressive Behavior Scale (ABS) when OPWDD tested people living in “adjacent” residences on the residential continuum. However, when comparing ABS scores for people living in very different types of residences (non-adjacent on the residential continuum), such as people living in DC-Not Forensic Units and people living in Supportive IRAs, significant differences do emerge in the expected direction. Given the fact that there are many people living in OPWDD residences with no behavioral challenges, it is reasonable that this scale may yield similar scores across some of the different residential settings. A better test for the sensitivity of the ABS would be to ensure that groups of people who are identified as having behavioral challenges yield different scale scores compared to those who are specifically identified as not having behavioral



challenges. OPWDD did collect data necessary to make that comparison and the results will be explored in the section titled “Results & Evaluation for Groups of People with Various Diagnoses/Clinical Presentations and/or Behavioral Challenges.”

Results & Evaluation for Groups of People Receiving Supports in Various Day Service Settings

OPWDD posited several general hypotheses when entering into this study, previously stated in the “Description of Validity Study-Hypotheses.” In this section, OPWDD applies the general hypothesis, “interRAI scales within the CAS should measure people in settings with higher intensity of supports as having higher levels of need compared to people in settings with lesser intensity supports” to people in day settings to arrive at Hypothesis 2.

Hypothesis 2: People receiving supports in what have traditionally been referred to as “more intensive” day service settings are expected to show scores that reflect fewer abilities to perform Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) and potentially more behavioral issues as measured via the scales developed by interRAI and used in the CAS.

OPWDD expected all scores on the Activities of Daily Living-Hierarchy (ADL-H) Scale, Instrumental Activities of Daily Living – Capacity (IADL-C) Scale, and the Aggressive Behavior Scale (ABS) to decrease, indicating people have more skills or fewer behavioral challenges as one moves across the continuum of day service settings (ordered by highest level of intensity of service to lowest):

- day habilitation;
- prevocational; and
- supported employment (SEMP).

The Kruskal-Wallis H Test revealed that the skills scores do change with day setting [ADL-H ($H(2) = 37.85$, $p < .05$), IADL-C ($H(2) = 62.23$, $p < .05$)], while the analysis suggests that statistically significant differences in ABS scores across day settings are not present [$ABS (H(2) = 5.59$, $p = 0.061$] . Figures 7 through 9 contain the distributions for the three (3) different scales for each of the three (3) day service groups. Tables 11 and 12 contain the results of the Dunn’s Tests, used to test whether there were statistically significant differences in scale scores for people living in different pairs of day settings. The results of the Dunn’s tests for the ABS are not provided, given that the Kruskal-Wallis H Test indicated there are no statistically significant differences between any of the day settings.

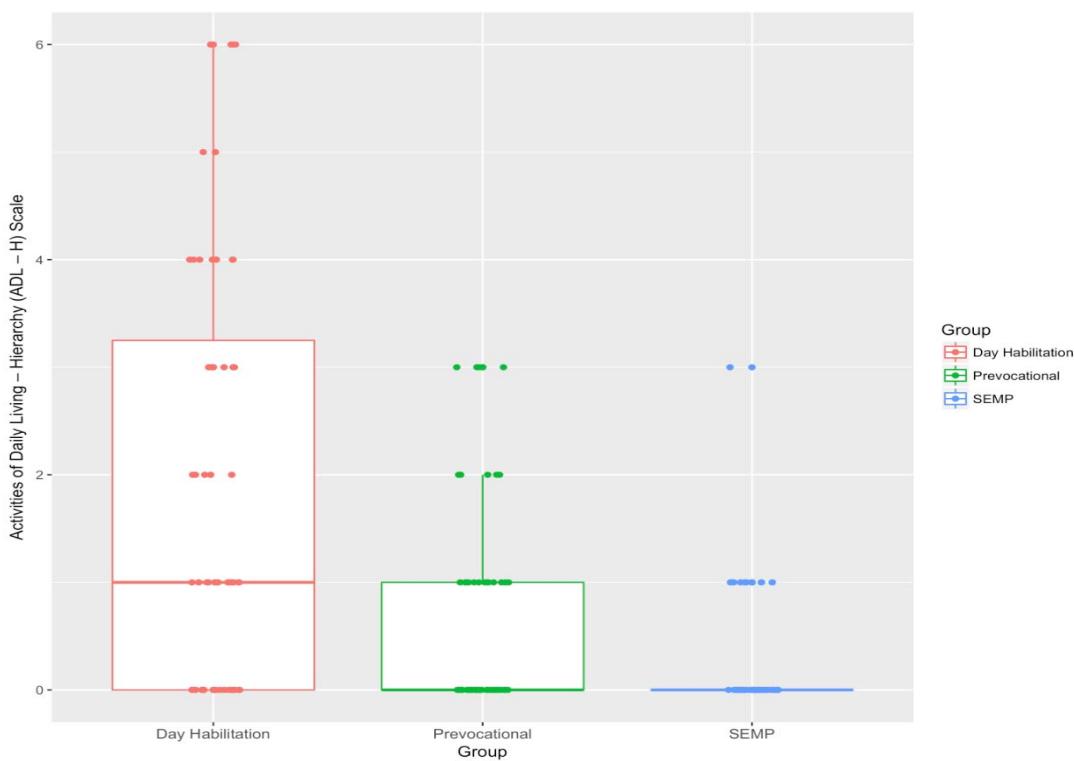
**Figure 7. ADL-H Scale Score by Day Setting**

Figure 7 shows that people in the Day Habilitation group are diverse in ability in ADLs, with the 75th percentile at three (3) and the 25th percentile being zero (0). The majority of people in the Supported Employment (SEMP) group are associated with a score of zero (0), suggesting that most people in this group were able to accomplish ADLs with complete independence. The median score for people in the Prevocational group, like the SEMP group, is also zero (0). However, the distribution of scores for people in the Prevocational group includes more people who have a higher ADL-H score.

Table 11. Differences in ADL-H Scale Scores for People Receiving Services in Various Day Settings

	Z	p adj
Day Service Setting Pairs		
Prevocational vs Day Habilitation	-3.91	0.000
SEMP vs Prevocational	-2.38	0.017

The low p values contained in Table 11 suggest that the differences between the groups are statistically significant and arise from real differences in scores among groups rather than through choosing samples for each group that happens to have some differences by chance.

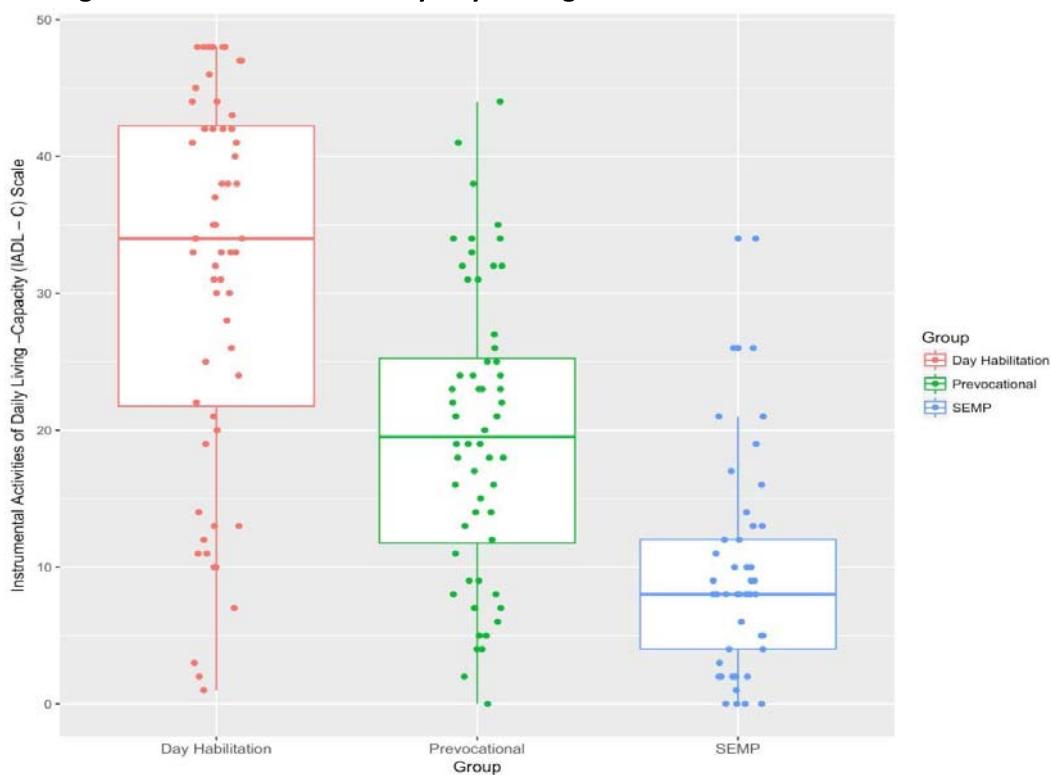
Figure 8. IADL-C Scale Score by Day Setting

Figure 8 contains the boxplots that depict the distribution in IADL-C scores for each of the three (3) day service groups. Once again, the Day Habilitation group has the largest spread in terms of the IADL-C scores and the highest median, the SEMP group has the lowest median score and the Prevocational group's median falls between the other two groups. The SEMP group has a smaller variation in scale scores compared to the other two groups with scores clustering more tightly around the median compared to the other groups.

Table 12. Differences in IADL-C Scale Scores for People Receiving Services in Various Day Settings

	Z	p adj
Day Service Setting Pairs		
Prevocational vs Day Habilitation	-4.05	0.000
SEMP vs Prevocational	-4.11	0.000

Table 12 contains the results of the Dunn's Tests, which confirm that the differences shown visually are statistically significant for groups that are adjacent on the day continuum.

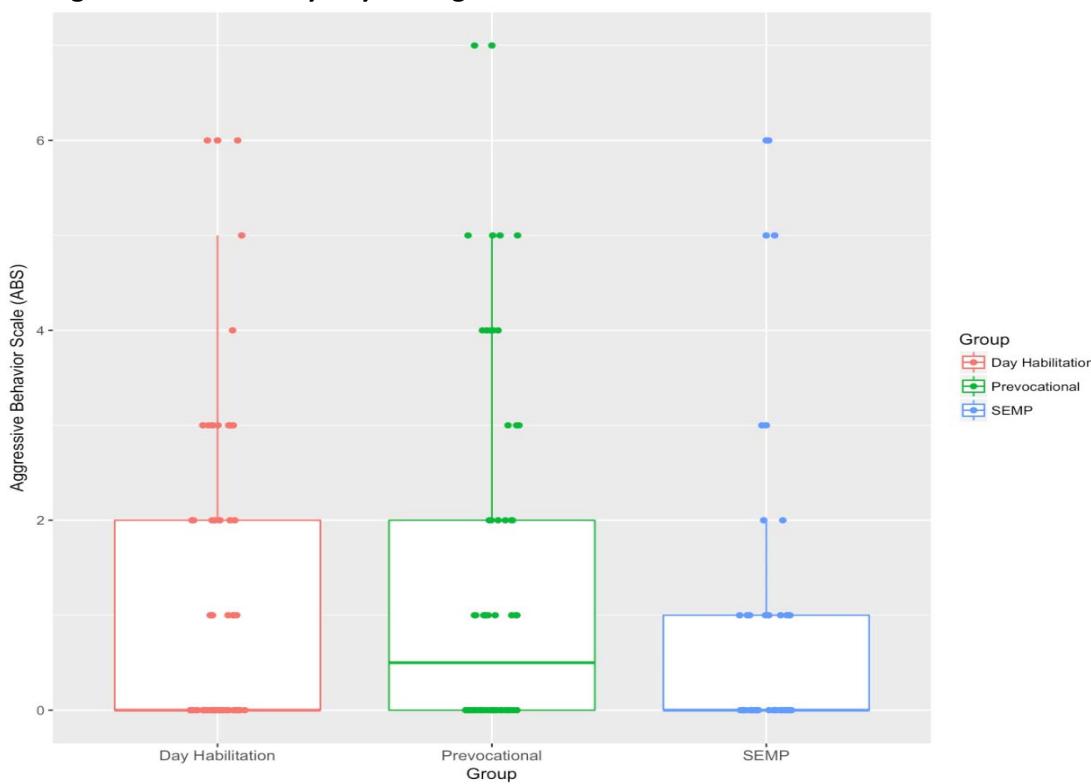
Figure 9. ABS Score by Day Setting

Figure 9 contains the boxplots depicting the distributions in the Aggressive Behavior Scale (ABS) scores for each of the three (3) day service groups. The Day Habilitation group and the Prevocational group share the same interquartile range, with the 25th percentile falling at zero (0) and the 75th percentile falling at two (2). The SEMP group's 25th percentile also falls at zero (0), as does the median, while the 75th percentile falls at one.

Summary for Groups of People Participating in Various Day Settings

This analysis began with the specific hypothesis that people receiving supports in what have traditionally been referred to as “more intensive” day settings are expected to show scores that reflect fewer abilities to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs). The results of the analysis support this expectation by showing that people in “more intensive” day services, in general, are associated with less ability in completing everyday living activities independently. People in the Day Habilitation group have scale scores that reflect having fewer skills than people in the Prevocational group. Similarly, people in the Prevocational group have scale scores that reflect having fewer skills compared to people in the Supported Employment (SEMP) group. As a result, there is evidence that the interRAI scales within the CAS measuring living skills (ADL-H and IADL-C) are sensitive enough to differentiate between people participating in the range of day services.



No significant differences exist between the different day settings with regard to the Aggressive Behavior Scale (ABS). The ABS is investigated further in the section titled “Results & Evaluation for Groups with Various Diagnoses/Clinical Presentations and/or Behavioral Challenges.”

Results & Evaluation for Groups of People with Different Intellectual Disability (ID) Diagnosis Levels

OPWDD posited several general hypotheses when entering into this study, previously stated in the “Description of Validity Study-Hypotheses.” In this section, OPWDD applies the general hypothesis, “interRAI scales within the CAS should measure higher levels of need for people with more significant cognitive impairments and/or other types of diagnoses/behavioral challenges” to people with different intellectual disability (ID) diagnosis levels to arrive at Hypothesis 3.

Hypothesis 3: People with a more severe intellectual disability (ID) diagnosis are expected to show scores that reflect fewer abilities to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs) as measured via the scales developed by interRAI and used in the CAS.

OPWDD expected all scores on the Activities of Daily Living-Hierarchy (ADL-H) Scale and Instrumental Activities in Daily Living Capacity (IALD-C) Scale to decrease, indicating people have more skills in the areas of ADLs and IADLs as one moves across the levels of ID (ordered by severity of ID):

- profound ID;
- severe ID;
- moderate ID; and
- mild ID.

The Kruskal-Wallis H Test revealed that scores do change with level of ID [ADL-H ($H(3) = 190.46$, $p<.05$), IADL-C ($H(3) = 222.56$, $p<.05$)]. Figures 10 and 11 contain the distributions for the two different scales for each level of ID. Tables 13 and 14 contain the results of the Dunn’s Tests, used to test whether there were statistically significant differences in scale scores between two different groups. Scores did decrease, as expected, for the ADL-H and the IADL-C scales, suggesting that people with more severe ID have comparatively fewer skills.

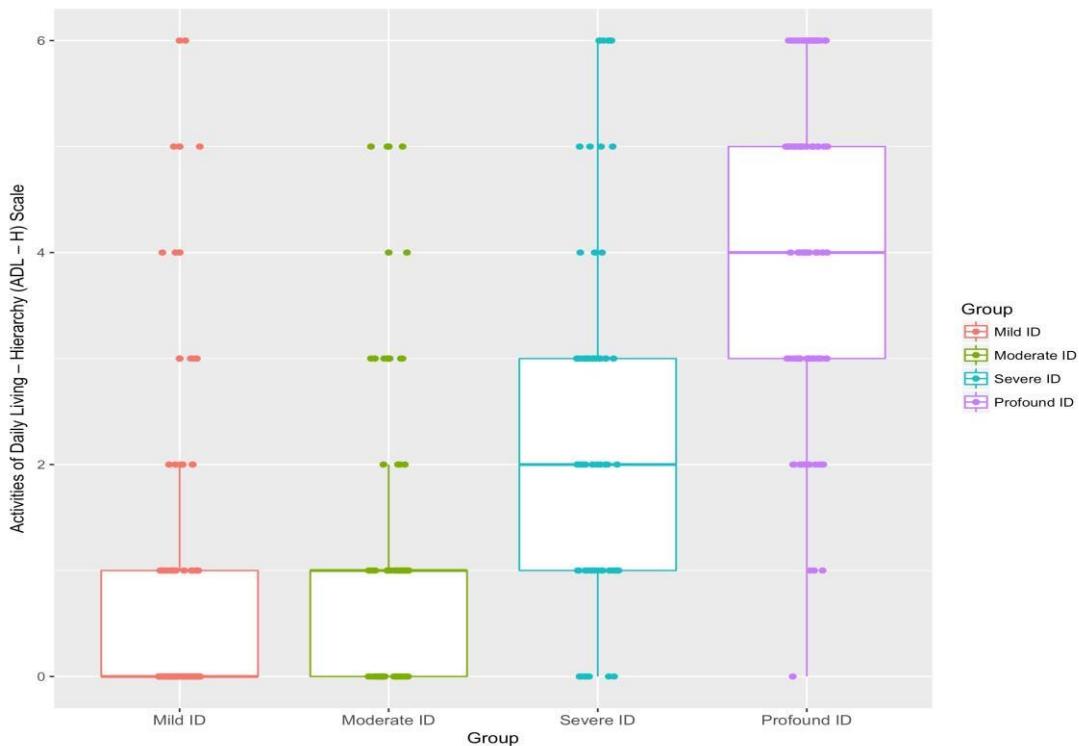
**Figure 10. ADH-L Scale Score by Intellectual Disability Group**

Figure 10 contains the boxplots depicting the distributions for the ADL-H scores for each level of intellectual disability (ID). Medians increase as the severity of the ID increases. Individuals with mild ID have a median of zero (0), while people with a moderate ID have a median score of one (1). The 25th percentile for both of these groups is zero (0). People with a severe ID or profound ID have a median ADL-H score of two (2) and four (4), respectively. The largest differences emerge among people with moderate, severe, and profound ID diagnoses. Intuitively, this is a reasonable result. People with mild and moderate ID are more likely to be similar in terms of their ability to complete basic activities of daily living (ADL) independently. Whereas, people with severe and profound ID are more likely to have support needs to accomplish ADLs that differ from one another and differ significantly from those with mild or moderate ID.

Table 13. Differences in ADL-H Scale Scores for Pairs of ID Severity

ID Severity Pairs	Z	p adj
Profound vs Severe	4.58	0.000
Severe vs Moderate	4.42	0.000
Moderate vs Mild	2.41	0.016

Table 13 contains the results of the Dunn's Tests. Significant differences were found between the groups of people with a mild ID versus a moderate ID diagnosis at the p < 0.05 level. Significant

differences were also found when comparing scores between the groups of people with severe ID and moderate ID, as well as when comparing scores between groups of people with profound and severe ID. The low p values contained in Table 13 suggest that the differences between the groups are statistically significant and arise from real differences in scores rather than through choosing samples that happen to have some differences by chance.

Figure 11. IADL-C Scale Score by Intellectual Disability Category

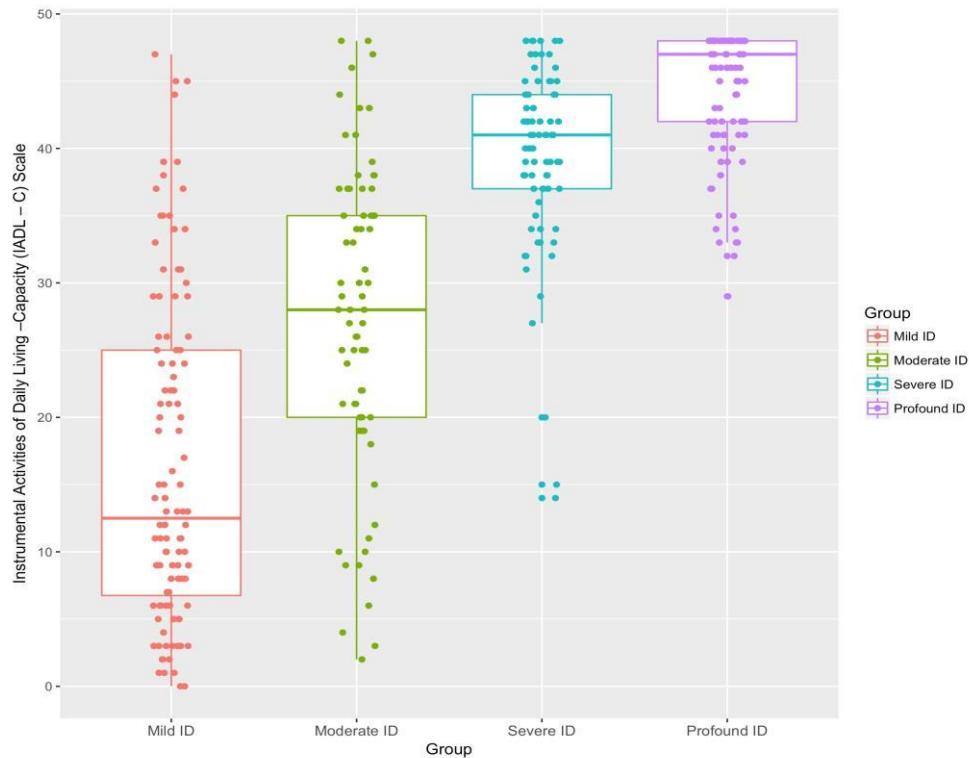


Figure 11 contains the boxplots depicting the distributions for the IADL-C scale for each of the groups with different levels of ID. The median scores increase as the severity of the ID increases, as expected. The median for the group of people with mild ID is the lowest of all groups and the median for the group of people with profound ID is the highest, which is indicative of needing extensive supports for instrumental activities of daily living skills. The groups of people with mild or moderate ID tend to have greater variability in their IADL-C Scale scores compared to the groups of people with severe or profound ID.

Table 14. Differences in IADL-C Scale Scores for Pairs of ID Severity

ID Severity Pairs	Z	p adj
Profound vs Severe	3.60	0.000
Severe vs Moderate	5.09	0.000
Moderate vs Mild	3.60	0.000



Table 14 contains the results of the Dunn's Tests, which suggest that people with different levels of intellectual disability show significant differences in IADL-C Scale scores at the $p < 0.05$ level. Statistically significant differences were found for each of the three comparisons.

Summary for Groups of People with Different Intellectual Disability (ID) Diagnosis Levels

These results support the general hypothesis that the interRAI scales within the CAS will measure higher levels of need and support for people with a more significant diagnosis of an intellectual disability (ID). Statistics (medians and percentiles) for both the ADL-H scale and the IADL-C scale vary in expected ways when looking across the continuum of ID, and differences in scores across groups were statistically significant.

Results & Evaluation for Groups with Various Diagnoses/Clinical Presentations and/or Behavioral Challenges

OPWDD posited several general hypotheses when entering into this study, previously stated in the “Description of Validity Study-Hypotheses.” In this section, OPWDD applies the general hypothesis, “interRAI scales within the CAS should measure higher levels of need for people with more significant cognitive impairments and/or other types of diagnoses/behavioral challenges” to people with various diagnoses/clinical presentations and/or behavioral challenges to arrive at Hypothesis 4.

Hypothesis 4: People with various diagnoses are expected to show scores that reflect fewer abilities to perform activities of daily living (ADLs) and instrumental activities of daily living (IADLs) and potentially more behavioral challenges in contrast to a group of people chosen based on a set of criteria that selects people with few cognitive, medical and behavior challenges – known in the study as the Comparison group.

A Comparison group was necessary to investigate differences in scale scores when there is no obvious continuum – as there was for residential and day services as well as level of intellectual disability (ID). In the absence of a continuum, OPWDD used a Comparison group of people to test scale scores against groups of people with various diagnoses, medical issues, and behavioral challenges (see Appendix E for definitions).

Specifically, OPWDD expected that the Comparison group would, on average, have lower scores on the Activities of Daily Living-Hierarchy (ADL-H) Scale and the Instrumental Activities of Daily Living – Capacity (IADL-C) Scale, indicating people have more skills, when compared against the following groups:

- people who are medically frail;
- people with a diagnosis of Prader-Willi Syndrome; and
- people with a sensory impairment.

Additionally, OPWDD expected that people in the Comparison group would, on average, have lower scores on the Aggressive Behavior Scale (ABS) compared to:

- people living in a developmental center (DC) with a forensic history or at risk for forensic involvement;
- people with a diagnosis of Prader-Willi Syndrome;
- people who have had a restrictive intervention (see Appendix E for definitions); and
- people with a dual diagnosis (developmental disability and psychiatric diagnosis).

As a reminder, a lower score on the ABS is associated with fewer behavioral challenges.

Figure 12. ADL-H Scale Score by Diagnoses/Clinical Presentations Group

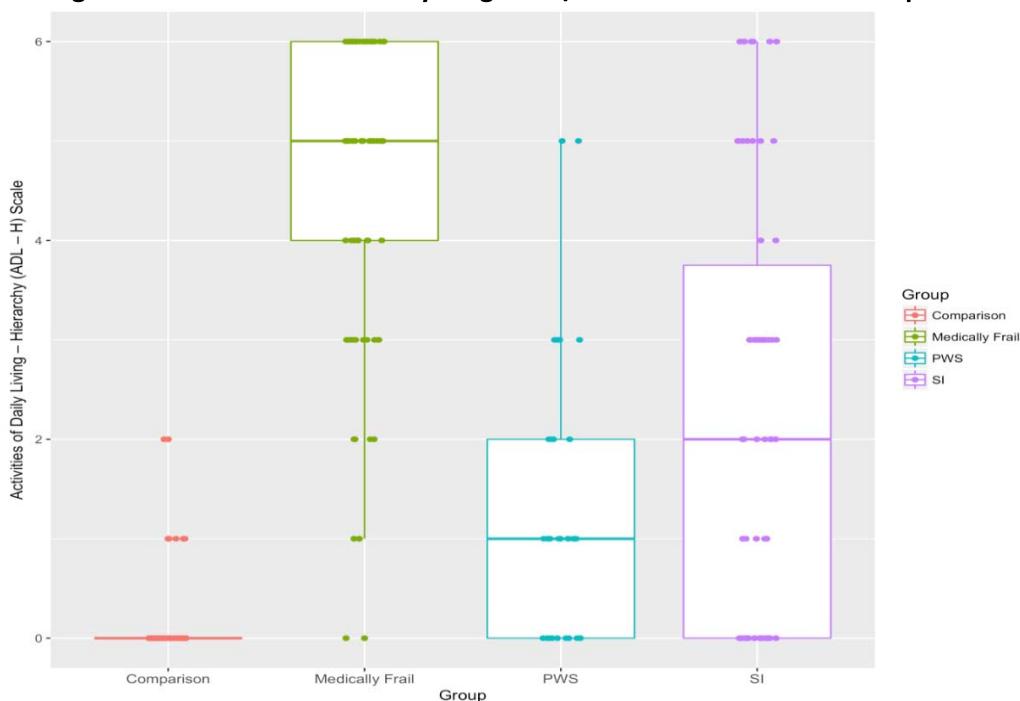


Figure 12 contains the boxplots depicting the distributions of ADL-H Scale scores for people in different Diagnoses/Clinical Presentations groups and for people in the Comparison group. Almost all of the people in the Comparison group have an ADL-H Scale score of zero (0), indicating total independence in activities of daily living. The people in the Medically Frail group tend to have much higher ADL-H Scale scores in contrast to the Comparison group. People in the Prader-Willi Syndrome group and the Sensory Impairment group also tended to have higher scores, which is indicative of needing more support to accomplish activities of daily living.



Table 15. Differences in ADL-H Scale Scores for People with Various Diagnoses/Clinical Presentations vs Comparison Group

	W	p
Medically Frail	3636	0.000
Sensory Impairment	2606	0.000
Prader-Willi Syndrome	1464	0.000

Table 15 contains the results of the Wilcoxon Rank-Sum Tests. Significant differences were found between people in the Comparison group and the Diagnoses/Clinical Presentations groups at the $p < 0.05$ level. The low p values contained in Table 15 suggest that the differences between the groups are statistically significant and arise from real differences in scores rather than through choosing samples that happen to have some difference by chance.

Figure 13. IADL-C Scale Score by Diagnoses/Clinical Presentations Group

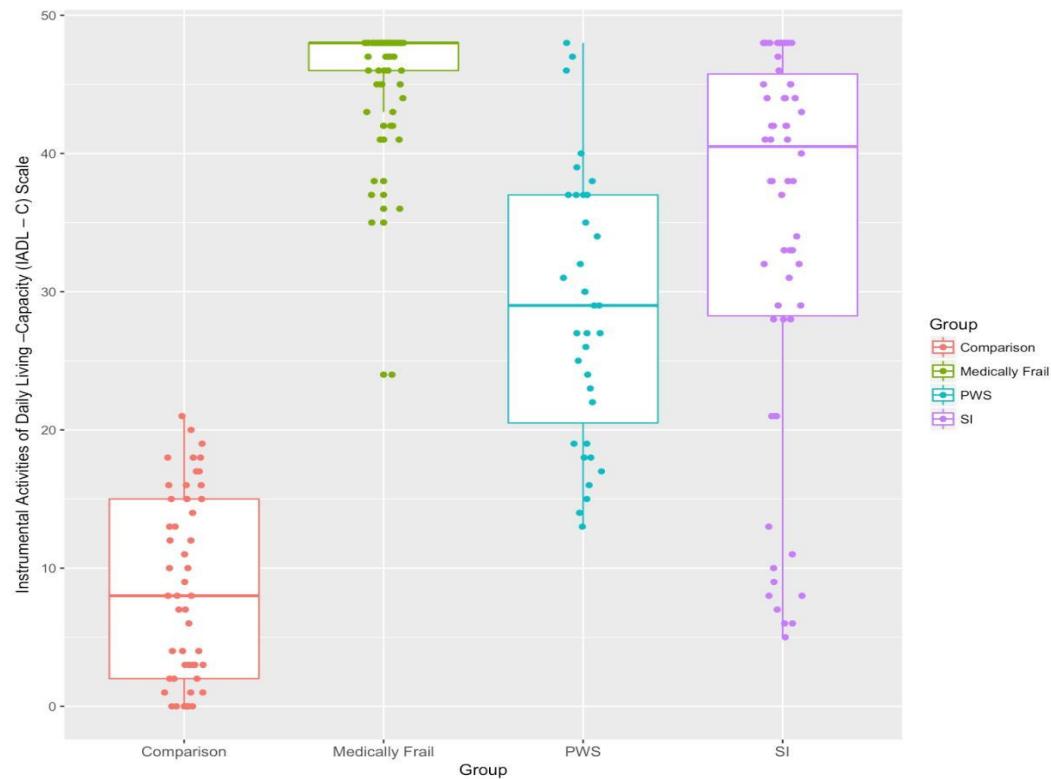


Figure 13 contains the boxplots depicting the distributions of IADL-C scale scores for people in different Diagnoses/Clinical Presentations groups and for people in the Comparison group. As in the case when examining ADL-H Scale scores, the Comparison group contains people who tend to have much lower scores than people in the other groups, which is indicative of more independence in instrumental activities of daily living. People in the Medically Frail group tend to score uniformly higher than people in the Comparison group. People in the Prader-Willi Syndrome group and Sensory



Impairment group generally have scores that fall between the Comparison and Medically Frail group's score distributions.

Table 16. Differences in IADL-C Scale Scores for People with Various Diagnoses/Clinical Presentations vs Comparison Group

	W	p
Medically Frail	3672	0.000
Sensory Impairment	2920	0.000
Prader-Willi Syndrome	1712	0.000

Table 16 contains the results of the Wilcoxon Rank-Sum Tests. Significant differences were found in IADL-C scores between people in the Comparison group and the Diagnoses/Clinical Presentations groups.

Figure 14. ABS Score by Diagnoses/Clinical Presentations Group

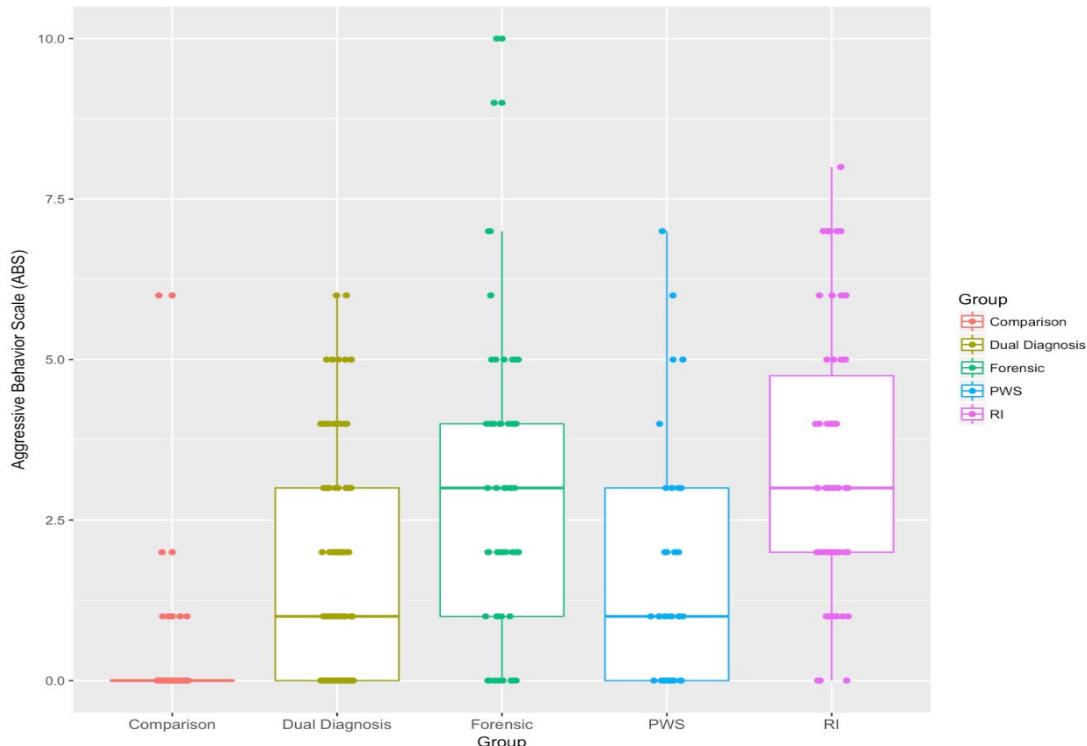


Figure 14 shows the distribution of ABS scores for all groups. Not surprisingly, large differences in ABS scores exist between the Comparison group and the group of people that were chosen because they had a Restrictive Intervention (RI).

Large differences are also present between the people in the Comparison group the Forensic group, which was the the group of people living in a designated forensic unit and/or living at a Developmental Center (Forensic group) due to their forensic risk. People in the Prader-Willi Syndrome



group and people in the Dual Diagnosis group also had differences from the Comparison group that were sizeable.

Table 17. Differences in ABS Scores for People with Various Diagnoses/Clinical Presentations vs Comparison Group

	W	p
RI	2995	0.000
Forensic	2631	0.000
Prader-Willi Syndrome	1447	0.000
Dual Diagnosis	4389	0.000

The last table, Table 17, contains the results of the Wilcoxon Rank-Sum Tests for the ABS scores, which show that differences between the Comparison group and other groups were statistically significant.

Summary for Groups of People with Various Diagnoses/Clinical Presentations and Behavioral Challenges

Differences in scales scores are evident for every test conducted in this section. With regard to the ABS, the Comparison group has lower scores, indicating fewer behavioral challenges compared to groups selected due to the presence of behavioral challenges, documented by the occurrence of a restrictive intervention, type of living situation, or clinical presentation. The differences in the ABS are important to highlight here as differences were sometimes not found based on the continuum of residential and day settings and level of intellectual disability. The tests conducted in this section were included to investigate whether groups with known behavioral challenges could be differentiated from a Comparison group using a scale that measures behavioral challenges. The differences between the Comparison and other groups, shown in the boxplots, is what one would expect when comparing these very different groups. Differences in scale scores were also significant for the ADL-H and IADL-C scales, with the groups of interest investigated in this section measuring as having less capacity to complete skills compared to the Comparison group.



Conclusion

The New York State Office for People With Developmental Disabilities (OPWDD) sought to design and implement a new needs assessment instrument for the purposes of:

- utilizing a person-centered assessment instrument to align with the person-centered delivery system;
- moving from fee for service to a managed care service delivery system; and
- achieving measurement of a person's needs that is conflict-free.

As such, the interRAI Intellectual Disability (ID) assessment instrument was chosen as it was a validated assessment of need for people with intellectual and/or developmental disabilities. The interRAI ID assessment also addressed critical elements identified by stakeholders as lacking from other needs assessment instruments: the inclusion of items specific to a person's strengths, goals and caregiver stability and a person-centered administration process. The interRAI ID became the foundational instrument for OPWDD's new needs assessment, the Coordinated Assessment System (CAS), which also includes supplements developed from the interRAI suite of instruments.

OPWDD believes that the analysis of the results of these studies on the CAS, summarized in this paper, provides evidence that it meets the objectives of its stakeholders for a valid, person-centered needs assessment instrument for use with people with intellectual and/or developmental disabilities. OPWDD also believes that the validity study has added to the body of research that shows that the interRAI scales within the CAS measure concepts of fundamental importance that are related to a person's level of independence. To test that, the interRAI scales within the CAS performed these concepts, the Center for Human Services Research (CHSR) at the University at Albany examined measures of internal consistency, convergent and discriminant validity, and concurrent validity. Overall, for each type of evaluation conducted, the interRAI scales within the CAS performed well. Internal consistency was achieved for the scales under investigation, except for the Aggressive Behavior Scale (ABS), which covers a range of behaviors. Evidence of convergent and discriminant validity was present via high mean correlations for items contained in different, but related scales. Similarly, low mean correlations were present for items belonging to scales that measure very different constructs (e.g. behavior challenges and adaptive living skills), as would be expected. When evaluating concurrent validity, strong relationships were found between the interRAI scales within the CAS and scales from different instruments [Developmental Disabilities Profile-2 (DDP-2), Inventory for Client and Agency Planning (ICAP)] measuring similar constructs.

Furthermore, the Center for Human Services Research (CHSR) at the University at Albany evaluated the criterion validity of the interRAI scales within the CAS. This evaluation was done to test whether the CAS differentiates between the diverse people served by OPWDD such as people receiving services in a range of settings and people with different diagnoses/clinical presentations and/or behavioral challenges. In most cases, significant differences emerged in scale scores among these groups, showing that the interRAI scales within the CAS are sensitive to differences in abilities among the people served by OPWDD.



The ability to make distinctions about people's needs in a systematic and standardized way is necessary to support global planning at the systems level within New York State and to support care planning at the individual level in order to serve people appropriately. The results of this study show that OPWDD's new assessment instrument, the Coordinated Assessment System (CAS), provides a solid foundation for these activities.



Appendix A : Composition of the Coordinated Assessment System (CAS) Scales

Scales

- *Cognitive Performance Scale (CPS)*: According to Martin (2007) the CPS is "... a predictive algorithm based on a decision tree that describes cognitive status. It uses four items: short-term memory, decision-making, expression, and self-performance in eating (Morris et al., 1994). The result is a 7-point scale where scores range from intact (0), borderline intact (1), mildly impaired (2), moderately impaired (3), moderately to severely impaired (4), severely impaired (5), to very severely impaired (6)." ¹⁸
- *Activities of Daily Living Hierarchy (ADL-H)*: According to Martin (2007) the ADL-H is "...a measure for ADL performance that classifies ADLs according to the stages at which they can no longer be performed, rather than simply summing the reduction in functioning (Morris, Fries & Morris, 1999). Based on four ADL items (i.e., personal hygiene, toilet use, mobility, and eating), an algorithm is used to compute a 7-point scale, ranging from independent (0), to supervision (1), to limited assistance (2), to extensive assistance 1 (3), and extensive assistance 2 (4), to dependent (5) and total dependence (6)." ¹⁹
- *Instrumental Activities of Daily Living (IADL-P & IADL-C)*: Two scales (Instrumental Activities of Daily Living – Performance (IADL-P) and Instrumental Activities of Daily Living – Capacity (IADL – C)) are used to measure a person's ability or capacity to live and function independently. Each scale is based on eight underlying activities: meal preparation, house work, basic finances, ability to manage medications, phone use, climbing stairs, shopping, and using transportation. The IADL – P measures a person's performance of these activities over a three (3) day time span. In instances where an activity did not occur (e.g. meal preparation) during these three (3) days, the assessors coded the item accordingly, i.e. activity did not occur. In these instances, the IADL-C response for the item (e.g. meal preparations) was substituted into the IADL-P calculation. The scale range is 0-48, with higher values indicating greater impairment and less ability to live independently. See the "Descriptive Statistics for the Random Sample" section of this paper for further details on these scales.
- *Communication Scale*: The Communication Scale is a summated scale that consists of two items, one item focuses on whether the person can make him/herself understood and another focuses on the extent to which the person has the ability to understand others. The score ranges from between 0 and 8.
- *Aggressive Behavior Scale (ABS)*: According to Martin (2007) the ABS is "...a summated scale indicating the level of aggression exhibited over the last three (3) days, based on four items: verbal abuse, physical abuse, socially inappropriate or disruptive behavior, and resistance to

¹⁸ Martin, "Development," 25.

¹⁹ Ibid.



care. Scores range from between 0 and 12, where higher scores indicate higher levels of aggression.”²⁰

²⁰ Ibid.



Appendix B : Composition of the Developmental Disabilities Profile- 2 (DDP-2) Indices and Factors

Indices

- *Level of Self-Care:* A measure of the assessed person's ability to care for himself or herself, based on eleven (11) items such as toileting, dressing, hygiene and eating. The index ranges from 1 – 100.
- *Daily Living Skills:* A measure of the assessed person's ability to independently complete ten (10) activities such as household chores, meal preparation, and managing money. The index ranges from 1-100.
- *Communication Skills:* A measure of the assessed person's ability to display receptive and expressive communication skills based on nine (9) items such as making self understood and understanding information. The index ranges from 1 – 100.
- *Cognitive Functioning:* A measure of the assessed person's ability to perform nine (9) basic cognitive performance skills such as counting, basic mathematical abilities and comprehension. The index ranges from 1 – 100.
- *Motor Functioning:* A measure based on the assessed person's demonstrated motor abilities and observed use or non-use of mobility assistance. This scale is based on ten (10) items such as walking, fine motor and gross motor skills. The index ranges from 1 – 100.
- *Frequency of Behavior Problems:* A measure based on the frequency that the assessed person engaged in ten (10) different maladaptive behaviors such as verbal abuse, physical abuse, property damage and elopement over a 12-month period. The index ranges from 1 – 100.
- *Behavior Consequences:* A measure of the severity of the assessed person's behaviors, based on six (6) different situational outcomes or program consequences such as the use of restrictive interventions and the need for specialized supports due to behavior. The index ranges from 1 – 100.

Factors

- *Adaptive Limitations Factor:* This factor is based on five underlying DDP-2 index scores: Level of Self-Care; Daily Living Skills; Communication Skills; Cognitive Functioning; and Motor Functioning. The score range is 0-500 with 0 indicating no areas of need and 500 indicating the highest level of adaptive need and limitations.
- *Maladaptive Behavior Factor:* This factor is based on the Frequency of Behavior Problems and Behavior Consequences Indices. The score range is 0-200 with higher scores indicating more frequent and severe behavioral issues.
- *Health/Medical Problems Factor:* This factor is intended to measure an overall concept of health for the assessed person. The score is based on medical conditions, seizure history, seizure prevalence, medications, the level of medical support the person receives, and the presence of specific medical outcomes. The range of scores is 0-31, with low scores indicating good physical health and higher scores indicating more severe health problems.



Appendix C: Composition of the Inventory for Client and Agency Planning (ICAP) Domains and Indices

Adaptive Behavior

The adaptive behavior section of the ICAP contains 77 items and is organized into four broad domains: Motor Skills, Social and Communication Skills, Personal Living Skills, and Community Living Skills. Each domain is summarized by a composite score which, taken together, then yields a composite adaptive behavior score.

Domains

- *Motor Skills Domain:* This domain measures both gross- and fine-motor skills of the assessed person.
- *Social and Communication Skills Domain:* This domain measures the person's ability to interact socially and to communicate through oral expression, signs, and written language.
- *Personal Living Skills Domain:* This domain measures a person's skills across five areas considered to be basic living skills: eating and meal preparation; toileting; dressing; self-care; and general domestic skills.
- *Community Living Skills Domain:* This domain focuses on higher-level and group living skills that are necessary in a workplace or communal living environment. The items underlying this score come from the areas of timeliness, money use and understanding value, work skills, and community orientation.
- *Broad Independence Domain:* This is a summary domain that is intended to measure a person's overall ability to function independently.

Maladaptive Behavior

Problem or maladaptive behavior is assessed along the following eight areas of behavior: hurtful to self, hurtful to others, destructive to property, disruptive behavior, unusual or repetitive habits, socially offensive behavior, withdrawal or inattentive behavior and uncooperative behavior. These items yield four maladaptive behavior index scores:

Indices

- *Internalized Maladaptive Index:* This index measures maladaptive behaviors that are inwardly directed by the person. The index captures data from three scoring areas: activities that are hurtful to one's self, unusual and repetitive behaviors and withdrawal. The scores for all ICAP maladaptive indices range from approximately -70 to +10, with scores below zero indicating problem behaviors outside the typical or expected spectrum.
- *Asocial Maladaptive Index:* This index measures maladaptive behaviors that are outwardly directed but passive or unpleasant in nature, as opposed to physical or aggressive. The underlying items in this index are drawn from the areas of socially offensive behavior and uncooperative behavior.



- *Externalized Maladaptive Index:* This index measures behaviors that are aggressive or physically directed at other people or things. It draws from the underlying conceptual areas of behaviors that are hurtful to others, the destruction of property and disruptive behaviors.
- *General Maladaptive Index:* This is a summary index that measures overall problem behaviors.



Appendix D: Assessor Trainings

Collaborative Institute Training Initiative (CITI)

The CITI training consisted of courses established by Collaborative Institute Training Initiative (CITI) whose mission is:

*"To promote the public's trust in the research enterprise by providing high quality, peer reviewed, web-based, research education materials to enhance the integrity and professionalism of investigators and staff conducting research."*²¹

Assessors were required to complete the following courses:

I. Introduction and History: Introduction to CITI Course

- a. Introduction: Introduction to Belmont Report and CITI Course
- b. History and Ethical Principles: This module provided an overview of unethical research cases that led to the development of codes of research ethics such as the Declaration of Helsinki or the Belmont Report in the United States (U.S.). In addition, this module discussed the ethical principles applied to research in the social and behavioral sciences, education and the humanities.
- c. Basic Institutional Review Board (IRB) Regulations and Review Process: This module contained a definition of the role, authority, and composition of the IRB as protector of human research subjects.
- d. Informed Consent: This module provided a definition of Informed Consent in research, differentiating between the process and the documentation of consent. It also described the complexities involved in obtaining and documenting consent in social and behavioral research.
- e. Conflicts of Interest in Research Involving Human Subjects: This module provided a definition of conflicts of interest and their relation to ethical concerns that arise in the context of research involving human subjects. It also discussed the rules established by the Department of Health and Human Services and the U.S. Food and Drug Administration regarding conflicts of interest and the disclosure requirements.
- f. RFMH/NYS DMH: This section provided an explanation of the role of the Research Foundation for Mental Hygiene (RFMH)/New York State Department of Mental Hygiene (NYS DMH) in the presentation of material in the modules and its maintenance. It also contained links to ethical codes and regulations regarding human subjects in research.

II. Vulnerable Subjects

- a. Belmont Report and CITI Course Introduction: Introduction to the Belmont Report and the CITI Course.
- b. Research with Children: This module described the definition of children in the context of federal regulations and provided a description of the regulations that have been developed to protect children in research with human subjects.

²¹ "Mission and History," *Collaborative Institute Training Initiative*, <https://www.citiprogram.org/index.cfm?pageID=30>, accessed August 31, 2016.



- c. Vulnerable Subjects – Research Involving Children: This module provided an overview of the historical involvement of children in biomedical research and how research excesses led to the passage of the National Research Act in 1974, which ultimately led to the development of regulation 45 CFR 46, Subpart D.
- d. Vulnerable Subjects – Research Involving Workers/Employees: This module explained why workers are considered a vulnerable population and what types of protections should be put in place when conducting research involving the workplace. Also, it explained how the Common Rule should apply to studies in the workplace.

III. Protecting Vulnerable Subjects

- a. Assessing Risk: This module explained the risks associated with participation in social and behavioral sciences research. It also discussed the difference between probability and magnitude of harm when assessing risk and provided an overview of strategies to minimize and manage risk.
- b. Privacy and Confidentiality: This module provided definitions of privacy and confidentiality. It also discussed some research methods that raise concerns about privacy and methods for ensuring confidentiality. Finally, this module provided an overview of relevant laws regarding privacy and confidentiality.
- c. Research and HIPAA Privacy Protections: This module discussed the Health Insurance Portability and Accountability Act (HIPAA) and its impact on data protection requirements for human subjects research.
- d. Internet Research: This module discussed the impact of the Internet on social, behavioral and educational research, as well as some of the issues that researchers must consider when using the Internet as a research tool and as an environment to study human behavior.

CAS Validity Study Protocols and Procedures

Assessors were required to complete in-person training on the validity study's protocols and procedures. Trainings included:

- Overview of the CAS validity study: An overview presentation and discussion of the purpose of the study, process flow and protocols.
- Research Ethics: A detailed presentation about the importance of ethical research with emphasis on consent and assent specific to people with intellectual and/or developmental disabilities.
- Study Protocols: A presentation that provided study work flows, documentation requirements and required protocols.
- Protocols for reporting allegations of abuse and neglect: Training on the responsibilities and procedures for safeguarding people that reported allegations of abuse and neglect as well as required reporting processes.
- Software Training: Training on the various systems and processes used to document study information.



Assessment Instrument Administration

Training on the OPWDD service delivery system and overarching principles critical to the administration of all assessment instruments was provided in person to all assessors.

- Overview of the OPWDD service system: Training to ensure familiarity and understanding of *all* services provided by OPWDD as well as frequently used terms and acronyms.
- Cultural Competency: Training focused on understanding the impact of culture when performing assessments.
- Interview skills: Intensive training on interviewing and gathering information specific to people with varying degrees of abilities based on their intellectual and/or developmental disability. Assessors participated in practice interview sessions with volunteers who had intellectual and/or developmental disabilities that included observation and feedback by key study personnel.

Coordinated Assessment System (CAS)

- Overview of interRAI: Presentation provided by interRAI via video conference about the organization, instrument development and the Intellectual Disabilities (ID) instrument.
- Administration principles: Training that reviewed the required administration steps including the person-centered interview/observation, interview of knowledgeable individual(s) and records review.
- Coding: Intensive training that reviewed the intent, definition, process for collecting data and recording options for each item.
- Group practice: Vignettes based on real life situations were reviewed and discussed with assessors as practice opportunities for coding.
- Practice Assessments: Practice assessments (at least four) with volunteers who had an intellectual and/or developmental disability in order to evaluate the assessor's interview skills and coding. This individual training provided the assessor with the opportunity to administer the CAS with key study personnel for feedback and review.
- Software training: Training provided in person and via video conference by the developer to understand the system used to record the CAS data.

Developmental Disabilities Profile-2 (DDP-2)

- Administration principles: Training that reviewed the required administration steps including the interview with a knowledgeable individual(s) and records review.
- Coding: Intensive training that reviewed the definition, process for collecting data and recording options for each item.
- Practice assessments: Practice assessments (at least four) with volunteer staff who work with people with an intellectual and/or developmental disability in order to evaluate the assessor's interview skills and coding. This individual training provided the assessor with the opportunity to administer the DDP-2 with feedback and review from key study personnel.

Inventory for Client and Agency Planning (ICAP)

- Administration principles: Training that reviewed the required administration steps including the interview with a knowledgeable individual(s) and records review. Definitions of terminology were reviewed to ensure understanding and accuracy as language has been updated since the development of the instrument.



- Coding: Intensive training that reviewed the definition, process for collecting data and recording options for each item.
- Practice assessments: Practice assessments (at least four) with volunteer staff who work with people with an intellectual and/or developmental disability in order to evaluate the assessor's interview skills and coding. This individual training provided the assessor with the opportunity to administer the ICAP with feedback and review from key study personnel.



Appendix E: Groups of Interest Definitions

The data source used for identifying people in each of the groups of interest was the OPWDD Tracking and Billing System (TABS) unless otherwise specified. A random sample of cases was pulled for each group of interest.

Refer to the table of groups of interest in the “Sample Selections, Methods, and Sizes-Groups of Interest” section of this paper for the sample size and dates that caseloads for each group were assigned.

Intellectual Disability (ID) Groups of Interest: Mild, Moderate, Severe and Profound:

Sufficient numbers of people with mild and moderate ID were in the Random Sample and no additional people were needed to meet the target sample size for the mild and moderate ID groups. Additional data was collected separate from the Random Sample group for people with profound and severe ID in order to meet the sample size needed for each group of interest.

OPWDD staff reviewed psychological evaluations/assessments with appropriate signatures (Ph.D. Psychologist, Licensed Clinical Social Worker or Licensed Psy.D) to confirm the diagnosis and level of ID. If the diagnosis could not be confirmed with appropriate documentation, the person’s assessments were not included in the analysis of the designated group of interest.

Autism Spectrum Disorder Group of Interest:

People with an autism diagnosis were included in the sampling frame. OPWDD staff reviewed psychological evaluations/reports/assessments or documentation from a physician’s evaluation with appropriate signatures to confirm the diagnosis of an autism spectrum disorder. If the diagnosis could not be confirmed with appropriate documentation, the person’s assessments were not included in the analysis of the designated group of interest.

Sensory Impairment Group of Interest:

People with the following noted sensory impairments were included in the sampling frame.
People who:

- have a severe loss or profound loss in hearing; and/or
- have a severe impairment in vision or worse (can't see faces/lines on which to write, only have light perception, have total blindness).

These rules were chosen to select for people with a sensory impairment(s) that is expected to affect services as per clinical judgment. OPWDD staff reviewed nursing consultation records, medication administration records, recent Individualized Service Plans(ISPs), recent comprehensive functional



assessments (CFA), and/or speech therapy reports with appropriate clinical signatures to confirm the diagnosis. If the diagnosis could not be confirmed with appropriate documentation, the person's assessments were not included in the analysis of the designated group of interest.

Prader-Willi Syndrome Group of Interest:

People with a Prader-Willi Syndrome diagnosis were included in the sampling frame. OPWDD staff reviewed medical records and/or genetic testing (when available) with appropriate clinical signatures to confirm the diagnosis. If the diagnosis could not be confirmed with appropriate documentation, the person's assessments were not included in the analysis of the designated group of interest.

Restrictive Intervention/Behavioral Challenges Group of Interest:

To qualify for inclusion in this group of interest, the person must have had a restrictive intervention utilized within the last quarter preceding the data extract in September 2015. The following restrictive intervention definition was used for inclusion in this group of interest:

Anyone participating in a service provided in a certified setting who had one or more of the following interventions:

- administration of medication to control behavior;
- use of a Time Out Room; and/or
- physical intervention other than guiding/touch control (e.g. one-person take down, seated control to supine control, individual-specific restrictive technique).²²

This information was obtained from the OPWDD Restrictive Intervention Application (RIA), which houses data about restrictive interventions for people receiving services in certified settings.

Medically Frail Group of Interest:

To qualify for inclusion in this group of interest, the person must have met all the following criteria prior to the data extract in September 2015:

- live in an Intermediate Care Facility (ICF) over the past year;
- not had a restrictive intervention (see above definition) applied in the last quarter; and
- hospitalized for a medical need at least twice in the past year.

²² New York State Office for People With Developmental Disabilities, *Restrictive Intervention Application (RIA) Instructions*, Albany, NY: OPWDD, 2012, <http://www.opwdd.ny.gov/node/2311>, accessed on August 31, 2016.



The data sources to identify the people in this group of interest included: EMedNY, a New York State Medicaid Claims database, TABS and RIA (see above definitions).

Dual Diagnosis Group of Interest:

Sufficient numbers of people with a dual diagnosis (i.e. developmental disability and a psychiatric diagnosis) were in the Random Sample group and then included for this specific group of interest. To qualify for inclusion in this group, the person must have had a designation of a psychiatric diagnosis.

OPWDD staff reviewed psychological evaluations/assessments, behavior support plans, medication administration records, and psychological summaries/consultations with appropriate signatures to confirm the diagnosis. If the diagnosis could not be confirmed with appropriate documentation, the person's assessments were not included in the analysis of the designated group of interest.

Neurological Impairment Group of Interest:

In the original research design, people with a neurological impairment were included as a group of interest. However, this group of interest was dropped from the design in August of 2015 when the OPWDD research team determined that this group of people was too heterogeneous to verify documentation confirming a neurological impairment.

Living at a Developmental Center with a Forensic History or at Risk for Forensic Involvement Group of Interest:

To qualify for inclusion in this group of interest, a person must have been living in one of the following designated units at a Developmental Center that provides services to people with forensic histories or people at risk of forensic involvement at the time of the data pull in April 2015:

- Valley Ridge at Broome Developmental Center;
- Regional Intensive Treatment (RIT) and Center for Intensive Treatment (CIT) at Sunmount Developmental Center; and
- Brooklyn Developmental Center.

Living at a Developmental Center- Not Forensic Unit Group of Interest:

To qualify for inclusion in this group of interest, a person must have been living in one of the following settings that was designated as a Developmental Center-Not Forensic Unit at the time of the data pull in April 2015:



- Bernard Fineson Developmental Center (Queens); and
- Broome Developmental Center (excluding Valley Ridge).

These locations represented the Developmental Centers (defined as institutions) operated by OPWDD that would not be likely to serve people with a forensic history or forensic risk.

Living in an Intermediate Care Facility (ICF) Group of Interest:

An ICF, for purposes of this study, is defined as an institutional setting located in the community for people typically unable to care for their basic needs and who require heightened supervision and support²³.

To qualify for inclusion in this group, a person must have been living in an ICF at the time of the data extract in May 2015.

Living in a Supervised Individualized Residential Alternative (IRA) Group of Interest:

A Supervised IRA is defined as a community residential setting that provides 24-hour-a-day staff support and supervision.²⁴

Sufficient numbers of people living in a Supervised IRA were in the Random Sample group and then included for this specific group of interest.

Living in a Supportive Individualized Residential Alternative (IRA) Group of Interest:

A Supportive IRA is defined as a community residential setting that provides needs-based supports and services in the person's own home or apartment. The person is not in need of 24-hour-a-day staff support or supervision.²⁵

To qualify for inclusion in this group, a person would have to be living in a Supportive IRA at the time of the data pull in May 2015.

²³ "Residential Opportunities: Intermediate Care Facility," *New York State Office for People With Developmental Disabilities*,

http://www.opwdd.ny.gov/opwdd_services_supports/residential_opportunities/intermediate_care_facility, accessed August 31, 2016.

²⁴ "Residential Opportunities: Individualized Residential Alternative," *New York State Office for People With Developmental Disabilities*,

http://www.opwdd.ny.gov/opwdd_services_supports/residential_opportunities/individualized_residential_alternative, accessed August 31, 2016.

²⁵ Ibid



Supported Employment Group of Interest:

Supported employment is defined as a service that assists a person in identifying job interests, training for a position and providing assistance in learning and maintaining a job at, or above, minimum wage or for self-employment²⁶.

To qualify for inclusion in this group, a person had to be enrolled in a supported employment service funded by OPWDD at the time of the data pull in June 2015.

Prevocational Group of Interest:

Prevocational service is defined as a service that assists a person in developing skills necessary for employment.

To qualify for inclusion in this group, a person had to be enrolled in a prevocational service at the time of the data pull in June 2015.

Day Habilitation Group of Interest:

Day habilitation is defined as a service provided in the community or at a certified site in the community that teaches a person skills to increase his/her community integration, safety and independence.²⁷

Sufficient numbers of people receiving day habilitation services were in the Random Sample group and then included in this specific group.

Comparison Group of Interest:

The group of people identified as the Comparison group was selected in order to reflect people that have relatively few support needs. OPWDD defined this group as people who have a diagnosis of a mild intellectual disability (ID) and who participate in supported employment that can be described as competitive employment for at least 15 hours a week. The person also should not have had any of the following diagnoses documented on his/her DDP-2 data (completed separate from, and prior to, the study and recorded in the TABS system): Autism, Neurological Impairments other than ID, Prader-Willi Syndrome, Psychological Impairments, Epilepsy, Seizures or Cerebral Palsy. Additionally, the CAS, when completed, must not have triggered the Forensic Supplement for a person. Finally, the person must not

²⁶ New York State Office for People With Developmental Disabilities, *Transition Planning Employment and Meaningful Community Activities: A Guide for Students in Transition*, (Albany, NY: OPWDD, 2014), 1-2.

²⁷ Ibid



be medically frail as defined by living in an Intermediate Care Facility (ICF) and having more than two medical hospitalizations within a year's time frame from the data pull in November 2015.



Appendix F: Consent Protocol

Process

Assessors provided each potential participant with information about participation in research including:

- the types of questions that would be asked (e.g., your strengths, interests and needs);
- the inclusion of others in the assessment process (e.g., family members, staff);
- the review of the person's records; and
- other key elements of the study:
 - the goal of the study (i.e., to evaluate validity);
 - sharing of data with the OPWDD partners;
 - the contractual obligation of the OPWDD partners to ensure the person's privacy;
 - the results of the validity study would not impact a person's services; and
 - the person can stop at any time.

After the assessor explained information regarding participation in research, he/she would evaluate the potential participant's ability to understand the information by completing a nine (9)-question checklist (see "Capacity to Provide Informed Consent").

If the assessor did not believe that the person understood the information in one of the nine (9) areas on the checklist, then the person was considered not capable of providing informed consent to participate in research. In other words, the assessor needed to ensure that the potential participant had an understanding of all critical elements of providing consent to participate in research.

The checklist utilized by the assessors to determine capacity to provide informed consent to participate in research was approved by the Institutional Review Board (IRB) responsible for ensuring the protection of people included in research.



Capacity to Provide Informed Consent

Determined by the Assessor

This validity study involves no more than minimal potential risk. **Prior to beginning the validity study the assessor must obtain informed consent/assent from the person.** The assessor must make sure the person is capable of granting consent for this validity study. To determine if the person is capable of providing informed consent for this validity study, the following set of criteria has been established. The assessor **must** use these criteria to determine if a person has the ability to consent for the purposes of this validity study:

1. Does the person understand that he/she will be asked questions about his/her life, strengths, needs, and dreams as well as questions about some of his/her current and past behaviors?

Yes No

2. Does the person understand that others (such as family, staff, and friends) will be asked similar questions about the person's life, strengths, needs and dreams as well as questions about some of his/her current and past behaviors?

Yes No

3. Does the person understand that the assessor will be reviewing his/her medical and service records including his/her Individualized Service Plan (ISP)?

Yes No

4. Does the person understand the reason for the proposed validity study (looking at a new measure to assess a person and his/her service needs)?

Yes No

5. Does the person understand that the collected data will be shared with the Center for Human Services Research at the University at Albany (CHSR), Optumas and potentially, in the future, other businesses that may collaborate with OPWDD to help analyze the data for - rate rationalization?

Yes No





5. Does the person understand that as part of these businesses' contractual responsibility with OPWDD that they will be held to the same HIPAA and HITECH standards as OPWDD?

Yes No

6. Does the person understand that if he/she says "No" to the validity study there will be no change to his/her current services based on his/her decision?

Yes No

7. Does the person understand that if he/she says "Yes" to the validity study that there will be no change to his/her current services based on his/her decision?

Yes No

8. Does the person understand that he/she can stop participating at anytime with no penalties or repercussions?

Yes No

To be capable to give informed consent for this validity study the person must be able to understand all of the above questions and can answer "Yes" to all of the questions.

If the answer to any of the above questions is "No", the person should be deemed not capable of providing consent to participate in this validity study and should give his/her assent (if capable). If the person is capable of providing assent, consent by a legal guardian and/or LAR should only be sought if the person is assenting.

If the person is unable to provide consent the assessor will need to obtain consent from a legally authorized representative, or LAR, such as a court appointed legal guardian, actively involved spouse, parent, adult child or other actively involved family member, or Willowbrook Consumer Advisory Board (WCAB for class members). When the person is unable to provide consent then all consents must be sought from the above list in the order specified above. For example, if a person is not able to give consent and does not have a court appointed legal guardian, consent needs to be obtained from an actively involved spouse. If there is no actively involved spouse, then consent should be obtained from a parent. If there is no parent, then an adult child or actively involved family member may give consent.

If the person is unable to provide consent and does not have someone listed above the person will not be included in the validity study.

Name of person: _____ Date: _____

Capable of Consent: Yes No

Assessor's Name: _____



**LAR CONSENT TO PARTICIPATE IN RESEARCH**

Consent to Participate in OPWDD's CAS Validity Study

Title of Project: The Coordinated Assessment System (CAS) Validity Study**Principal Investigator:** Christine M. Muller, Ph.D.**Co-Investigator:** Diane Woodward, LMSW**Sponsor:** Office for People With Developmental Disabilities (OPWDD)

You have been identified as a Legally Authorized Representative for _____ who has been selected as a research participant for a study by the Office for People With Developmental Disabilities (OPWDD):

A *Legally Authorized Representative (LAR)* means an individual, or a judicial or other body authorized under applicable law, to consent **on behalf of** a person unable to provide his or her own consent and approval to serve as a potential research participant. As such, this Informed Consent Form requests your permission for _____ to take part in the research described below. Please read the information in this form and ask as many questions as you like. Please ask the OPWDD study staff, or assessor, to explain any words or information that you do not clearly understand. It is an important responsibility to give consent for another person to participate in any research.

The person named above is being asked to volunteer in the research study referred to as the Coordinated Assessment System (CAS) Validity Study. Before you consent on behalf of the person to participate in this validity study, it is important that you read and understand this form. It describes the purpose, procedures, benefits, risks, discomforts and precautions of the validity study. It also describes your right to withdraw the named person from the validity study at any time.



Purpose and General Plan of Research:

The Office for People With Developmental Disabilities, or OPWDD, is working on a validity study to see if a new tool is good to use in planning services for people with intellectual and/or developmental disabilities. The tool is called the Coordinated Assessment System, or CAS. The CAS looks at the strengths and weaknesses of people with intellectual and/or developmental disabilities. OPWDD's current assessment tool, the Developmental Disabilities Profile-2 (DDP-2) has not been updated for 30 years such that it has become clear that a new tool is needed that more completely describes people who need services.

We want to know if different people with the same types of strengths and needs answer questions on the CAS in the same way. We also want to know if people answer questions on the CAS in the same way as they do on other assessment tools. This is called validity. To do this we need to see if the answers people give are the same or different on three different tools. These tools are called the CAS, the Developmental Disabilities Profile-2, or DDP-2, and the Inventory for Client and Agency Planning, or ICAP.

We hope to be able to use the CAS to help make decisions about how much and what type of services people with intellectual and/or developmental disabilities should get based on their strengths and needs. This information will eventually inform payments for services. This is called rate rationalization.

It is your decision to provide consent on behalf of the person to join this validity study. Whatever you decide is OK and the current services that he or she gets will not change no matter what you decide.

Procedures Included in this Research: Should you provide consent on behalf of the person to participate in this validity study, an OPWDD study staff, also known as an assessor, will set up a date, time, and place to begin the interviews/observations. The assessor will talk to him/her, ask questions and/or observe the participant. It also means an assessor will talk to someone who knows _____ well, and ask him/her to answer questions about the participant.

The assessor will ask about the participant's physical and behavioral health (how he/she feels, mood and behaviors), relationships (friends, family and people he/she likes or doesn't like), and feelings about his/her life (what would he/she like to change and what would he/she keep the same). The assessor will also review the participant's life goals (what the person would like to be or want to do). If the participant is unable to answer these questions, the assessor will observe the participant and talk to others (e.g. family, staff, friends, etc.) in order to answer the questions on the CAS.

By providing consent on behalf of the participant you are also saying that assessors can look at the participant's medical and service records (e.g. Individualized Service Plan, or ISP, doctor's notes, etc.) to help answer some of the questions. Below is an attached HIPAA authorization form that you are also asked to approve.



Because there are a lot of questions for the participant to answer the interview may take several hours. If the participant gets tired he/she can stop for a while, or if needed, the interview/observation can also be done in several sessions or visits. Once the assessor has completed all three assessment tools for the participant, his/her answers will be shared with the Center for Human Services Research (CHSR) at the University at Albany. CHSR will be helping us see if the CAS is a good tool to use. In addition, everyone's assessments will be shared with Optumas, a business hired by OPWDD to help us figure out what type of services people with intellectual and/or developmental disabilities should get based on their strengths and needs. These two businesses understand that the answers to the tools are confidential. That means they will not give out answers to other people, and will only use the answers to help us figure out if the CAS is valid and if it can help us decide what services people should get. It is possible that, in the future, other businesses may receive the data collected through this study. If OPWDD does decide to contract with other businesses in the future, these businesses will be held to the same privacy and confidentiality standards as Optumas and CHSR, which are described under "Benefits/Risks".

If you provide consent on behalf of the participant to join the validity study, he/she will be entered into a drawing (like a raffle) where we will give away a total of twenty (20) \$25.00 gift cards. The participant does not need to answer all the questions to be part of the drawing. Only twenty (20) of roughly 1,000 people will win a gift card but by being in the drawing he/she will have a chance to win one of these gift cards.

Benefits/Risks: While there are no direct benefits for you or the participant from this validity study, we hope that there will be good that comes out of it for a lot of people. The validity study has few risks, but one of them is the chance that the participant's answers may be lost by OPWDD, one of our current business partners (CHSR and Optumas), who will be conducting data analysis using the interview data collected through the three tools or one of our potential future business partners. The laws that help make sure answers are kept safe and private are called the **Health Insurance Portability and Accountability Act (HIPAA)** and the Health Information Technology for Economic and Clinical Health Act (HITECH). Our two business partners, with whom we will share the participant's answers, have agreed to follow these laws as part of their contractual agreements with OPWDD. Our current business partners and any potential future business partners will be held to the same HIPAA and HITECH requirements as OPWDD. Compliance with these requirements increases the chances that the participant's information will be kept private. A HIPAA addendum follows this consent form for your review and approval.

One other risk of the validity study is that a participant may become tired due to the number of questions. If the participant is getting tired he/she is free to take a break, or ask the assessor to set up another meeting to finish answering the questions.

Alternatives to Participation: You get to decide if the person named above will be a participant in this validity study. If you say, "Yes," that is OK. If you say, "No," that is OK too. **No matter what you decide, there will be no change in the person's programs or services as a result of your decision.**



Ending Participation: If you said you wanted this person to be part of the validity study, you can still change your mind at any time and say that he/she must drop out or withdraw from the validity study. Removing the participant from the validity study at any time and for any reason is your decision. Neither you nor the participant will have any trouble or difficulty for changing your mind. The participant's name will still be entered in the drawing (like a raffle) for a chance to win one of the gift cards.

Voluntary Participation: You may decide if you want _____ to be part of this validity study. If you say "Yes" and then change your mind at any time while the validity study is going on, that is OK too. If you have any questions about this validity study, you can contact Christine M. Muller, Ph.D. or Diane Woodward, LMSW at OPWDD at (518) 473-9697. If you have questions about the rights of people who participate in research studies such as this validity study, you can contact Dr. Ed Jenkins, Chair of the Institutional Review Board at OPWDD (718-494-5117).

Confidentiality Statement: What you and the participant tell us is private and confidential. No one except the OPWDD study staff and their business partners will have access to the answers, *except when the law says we must share the answers*. Some legal advocacy organizations may be authorized by State Law to examine research records, but they cannot disclose any personal information without your permission.

The assessors, and all other OPWDD study staff, will keep each participant's information strictly private and confidential except if told about possible abuse or neglect of someone with a disability. All OPWDD staff are required by law to report possible cases of abuse or neglect while carrying out this validity study:

- **Abuse** is when anyone hurts a person with a disability on purpose.
- **Neglect** is when anyone does not help to protect or take care of a person with a disability.

All cases of abuse or neglect discovered must be reported to the assessor's supervisor. If necessary, an investigation may need to be conducted; this means other people will follow up and ask the participant and/or others about the possible abuse and/or neglect.

To help keep the participant's privacy, assessors have been trained on how to keep confidential paper and electronic information secure. *Computers with validity study data will be secured and protected by coded passwords.* All paper forms will be sent by secure mail (Federal Express) to OPWDD's Central Office and this information will be stored in a locked file cabinet. Only designated study staff will have access to the locked file cabinet.

Payments and Cost: There is no cost or guaranteed payment to you or the participant in this validity study.

**Consent to research participation:****Signature and Consent/Permission to be in the CAS Validity Study**

Before making the decision on behalf of the person regarding enrollment in this validity study you should have:

- Discussed this validity study with an assessor,
- Reviewed the information in this form, and
- Had the opportunity to ask any questions you may have.

You may change my mind at any time and say you no longer want this person to be part of the validity study. To do this you have to let the assessor know you no longer want the person to be in the validity study. The assessor will then write a letter to Christine M. Muller, Ph.D., the principal investigator, letting her know to remove the person from the study.

Although the Center for Human Services Research at the University at Albany and Optumas have agreed not to share the participant's information, you understand that once they have it, OPWDD is no longer the only agency to control that information. One of the other agencies and businesses may mistakenly give out some of the participant's health and clinical information and it may no longer be covered by the federal privacy laws and rules. This is also the case for any potential future partnerships with other businesses not specified here. However, you understand that the other businesses must act to protect the participant's information, so there is only a small chance that his/her information would be given out by mistake.

You may refuse to sign this form and your refusal to sign will not affect the person's ability to continue to receive any of his/her services or treatment.

Your signature below means that you have received this information, have asked the questions you currently have about the validity study and those questions have been answered. You will receive a copy of the signed and dated form to keep for future reference.



Participant's Legally Authorized Representative (Legal Guardian, Actively Involved Spouse, Parent, Child or Other Actively Involved Family Member or Willowbrook Consumer Advisory Board (WCAB):

By signing below, you indicate that you give permission for the named participant to take part in this validity study.

Signature of Participant's Legally Authorized Representative: _____

Date: _____ Time: _____

Printed Name of Legally Authorized Representative _____
(Signature of Participant's Legally Authorized Representative is required for people unable to give consent for themselves.)

Participant's Information:

Name of person approved for validity study participation:

Person's Address:

TABS ID: _____

Date of Birth: _____

Phone Number (If Known): (_____) _____

(Signature of Assessor Obtaining Consent)

(Date)

(Time)

I have fully explained the above including any risks or benefits, and believe the person above understands the nature and purpose of the validity study on behalf of the named person. I have offered to answer any questions relating to the validity study and have fully and completely answered all such questions.

(Print Name of Assessor Obtaining Consent)

(Date)



Attachment 1

**New York State Office for People with Developmental Disabilities
Authorization to Use or Disclose Health Information during a Research Study**

Protocol Number: 508 Principal Investigator: Christine Muller, Ph.D.

Name of Study: The Coordinated Assessment System (CAS) Validity Study

For use in the above study (the "Research"), you agree to allow the following individuals and entities to create, use and disclose Health Information about you as described below:

- Office for People With Developmental Disabilities (OPWDD)
- Your doctors, your other health care providers, and your service providers, if any, and
- The Principal Investigator and his/her staff (together "Researchers"). Researchers may include staff of the New York State Office for Persons With Developmental Disabilities, staff at the Center for Human Services Research at the University at Albany and the staff at Optumas and other future, business partners.

1. The Health Information that may be used and disclosed for this Research includes:

- All information collected during the Research as told to you in the Informed Consent Form.
- Health Information in your medical records which include the results of physical exams, medical history, diagnostic tests, or Health Information relating to a particular condition that is related to the Research.
- Additional information may include: Information included in your service records

2. The Health Information listed above may be used or disclosed to:

- Researchers at OPWDD who are involved in the study.
- Researchers and their staff at the following organizations involved with this Research: The Center for Human Service Research at the University at Albany
- Representatives of regulatory and government agencies, institutional review boards, representatives of the Researchers and their institutions to the level needed to carry out their responsibilities related to the conduct of the research.
- Other (family members or significant others, study buddies, outside agencies etc.) Specify: Family members, providers of service to the person, Optumas, future business partners



3. By giving permission to release your Health Information as described above, you understand that this information may be shared with individuals or companies outside of OPWDD. As stated in the consent form, OPWDD will share information collected through this research with our two business partners (The Center for Human Services Research at the University at Albany and Optumas) and may share information with other business partners in the future. These partners have signed (future business partners will sign) a business agreement, agreeing to follow the laws that protect your information from being shared which are called HIPAA and HITECH. The Center for Human Services Research at the University at Albany, Optumas, and any business partners OPWDD contracts with in the future will be held to the same standard as OPWDD to keep your information safe and private.

4. Please note that:

- You do not have to sign this Authorization form, but if you do not, _____ will not be able to participate in the study. You may change your mind at any time and for any reason. If you do so, _____ will no longer be allowed to participate in the study. If you withdraw this Authorization the research staff may still use or disclose Health Information they already have collected about _____ as needed to maintain the reliability of the research. Any request to withdraw this Authorization must be made in writing to:

Dr. Christine Muller

OPWDD

44 Holland Avenue, 5th Floor
Albany, NY 12229

- You will not have access to review _____'s Health Information documented in the assessment instruments during this study. However, OPWDD will provide public access to a report that describes the overall results of this research.

5. This Authorization does not have an end date.

6. You will be given a copy of this form after you have signed it.



I agree to the use and disclosure of Health Information about me as described above:

Signature of Legally Authorized Representative (LAR)

Date

Printed Name of Legally Authorized Representative (LAR)

Relationship of Legally Authorized Representative to Participant (if applicable)

We also asked you or your legally authorized representative to initial the statement below:

I have received a copy of the OPWDD IBR Notice of Privacy Practices.



**Office for People With
Developmental Disabilities**

Andrew M. Cuomo, Governor
Kerry A. Delaney, Acting Commissioner

Title of Project: The Coordinated Assessment System (CAS) Validity Study

Principal Investigator: Christine M. Muller, Ph.D.

Co-Investigator: Diane Woodward, LMSW

Sponsor: Office for People With Developmental Disabilities (OPWDD)

Purpose and General Plan of Research:

The Office for People With Developmental Disabilities (OPWDD), is working on a validity study to see if a new tool is good to use in planning services for people with intellectual and/or developmental disabilities. The tool is called the Coordinated Assessment System (CAS). The CAS looks at the strengths and weaknesses of people with intellectual and/or developmental disabilities. OPWDD's current assessment tool, the Developmental Disabilities Profile-2 (DDP-2) has not been updated for 30 years such that it has become clear that a new tool is needed that more completely describes people who need services.

We want to know if different people with the same types of strengths and needs answer questions on the CAS in the same way. We also want to know if people answer questions on the CAS in the same way as they do on other tools. This is called validity. To do this we need to see if the answers people give are the same or different on three different tools. These tools are called the CAS, the Developmental Disabilities Profile-2, or DDP-2, and the Inventory for Client and Agency Planning, or ICAP.

We hope to use the CAS to help make decisions about how much and what type of services people with intellectual and/or developmental disabilities should get based on their strengths and needs. This information will eventually inform payments for services. This is called rate rationalization.

It is your decision to join or not join this validity study. Whatever you decide is OK and the current services you get will not change no matter what you choose.





Procedures Included in this Research: If you agree to participate in this validity study, we will set up a date, time, and place to meet with you. You will help pick where and when you want to meet.

If you say you would like to help us, you will become part of the validity study. This means you will let OPWDD study staff, or assessors, talk to you and ask you questions. It also means you will let the assessor talk to someone who knows you well, and answer questions about you.

The questions the assessor will ask you are about your physical and behavioral health (how you feel, your mood and behaviors), your relationships (your friends, family and people you like or don't like), and how you feel about your life (what you would like to change and what you would like to keep the same). The assessor will also talk to you about your life goals (what you would like to be or want to do).

By saying you want to be part of this validity study you are also saying that the assessor can look at your medical and service records (your Individualized Service Plan, or ISP, doctor's notes, etc.) to help answer some of the questions. You will also be asked to sign a document where you give permission to the OPWDD assessors to look at your medical and service records. This document is called a HIPAA authorization. Below is the attached HIPAA Authorization form that you are also asked to approve.

Because there are a lot of questions for you to answer the interview may take several hours. If you get tired you can stop for a while, or if you need to, we can also do this in several sessions or visits. Once people in the validity study have answered the questions on the tools their answers will be shared with the Center for Human Services Research at the University at Albany (CHSR). They will be helping us see if the CAS is a good tool to use. In addition, everyone's answers to the questions will be shared with Optumas, a business hired by OPWDD to help us figure out what type of services people with intellectual and/or developmental disabilities should get based on their strengths and needs. These two businesses understand that your answers to the tools are confidential. That means that they will not give out your answers to other people, and will only use the answers you gave us to help us figure out if the CAS is a good tool and if it can help us decide what services people should get. It is possible that, in the future, other businesses may receive the data collected through this study. If OPWDD does decide to contract with other businesses in the future, and these businesses receive data from this study, these businesses will be held to the same privacy and confidentiality standards as Optumas and CHSR.

If you join the validity study, you will be entered into a drawing (like a raffle) where we will give away a total of twenty (20) \$25.00 gift cards. You do not need to answer all the questions to be part of the drawing. Only twenty (20) of roughly 1,000 people will win a gift card but by being in the drawing you would have a chance to win one of these gift cards.





Benefits/Risks: While there are no direct benefits for you from this validity study, we hope that there will be a lot of good that comes out of it for a lot of people. The validity study has few risks, but one of them is the chance that your answers may be lost by OPWDD, one of our current business partners (CHSR and Optumas), who will be conducting the data analysis using the interview data collected through these tools or one of our potential, future business partners. The laws that help keep your information safe and private are called the **Health Insurance Portability and Accountability Act (HIPAA)** and the Health Information Technology for Economic and Clinical Health Act (HITECH). HIPAA and HITECH require that OPWDD and our business partners must protect your personal information. One other risk of the validity study is that you may become tired due to the number of questions. If you find yourself getting tired you are free to take a break, or ask the assessor to set up another meeting to finish answering the questions.

Alternatives to Participation: You get to decide if you want to be part of this validity study. If you say, "Yes", that is OK. If you say, "No", that is OK too. **No matter what you say there will be no changes in the programs or services you are part of based on what you decide.**

Ending Participation: If you say you want to be part of the validity study, you can change your mind at any time and say you don't want to be part of it anymore. You do not have to keep doing it if you do not want to and may quit for any reason. You will not get in trouble for changing your mind. Your name will still be entered in the drawing (or raffle) for a chance to win one of the gift cards.

Voluntary Participation: You get to decide if you want to be part of this validity study. If you say "Yes" and then change your mind at any time while the validity study is going on, that is OK too. If you have any questions about this validity study, you can contact Christine M. Muller, Ph.D. or Diane Woodward, LMSW at OPWDD at (518) 473-9697. If you have questions about your rights as being part of this validity study you can contact Dr. Ed Jenkins, Chair of the Institutional Review Board at OPWDD (718-494-5117).

Confidentiality Statement: What you tell us is private and confidential. No one except the OPWDD study staff and their business partners will have access to the answers, *except when the law says we must share the answers*. Some legal advocacy organizations may be authorized by State Law to examine research records, but they cannot disclose any personal information without your permission.





The assessors, and all other OPWDD study staff, will keep each person's information strictly private and confidential **except** if told about possible abuse or neglect of someone with a disability. All OPWDD staff are required by law to report possible cases of abuse or neglect while carrying out this validity study:

- **Abuse** is when anyone hurts a person with a disability on purpose.
- **Neglect** is when anyone does not help to protect or take care of a person with a disability.

All cases of abuse or neglect discovered must be reported to the assessor's supervisor. If necessary, an investigation may need to be conducted; this means other people will follow up and ask you about the possible abuse and/or neglect.

To help keep your privacy, assessors have been trained on how to keep your confidential paper and electronic information secure. *Computers with validity study data will be secured and protected by coded passwords.* All paper forms will be sent by secure mail (Federal Express) to OPWDD's Central Office and this information will be stored in a locked file cabinet. Only designated study staff will have access to the locked file cabinet.

Payments and Cost: There is no cost or guaranteed payment to you for participating in this validity study.

Consent to research participation:

Signature and Consent to be in the CAS Validity Study

Before making the decision regarding enrollment in this validity study you should have:

- Discussed this study with an assessor,
- Reviewed the information in this form, and
- Had the opportunity to ask any questions you may have.

You may change your mind at any time and say you no longer want to be part of the validity study. To do this you have to let the assessor know that you do not want to be in the validity study any more. The assessor will write a letter to Christine M. Muller, Ph.D., the Principal Investigator, stating that you want to be removed from the validity study.

Although the Center for Human Services Research at the University at Albany and Optumas have agreed not to share your information you understand that once they have it, OPWDD is no longer the only agency to control of your information. One of the other businesses may mistakenly give out some of your health and clinical information and it may no longer be covered by the federal privacy laws and rules. This also holds for any potential future partnerships with other businesses not specified here. However, you understand that the other businesses must act to protect your information, so there is only a small chance that your information would be given out by mistake.





You may refuse to sign this form and your refusal to sign will not affect your ability to continue to receive any of your services or treatment.

Your signature below means that you have received this information, have asked the questions you currently have about the validity study and those questions have been answered. You will receive a copy of this signed and dated form to keep for future reference.

I, _____, give my consent to be part of this validity study

(Print Name)

under the conditions described above.

(Signature)

(Date)

(Time)

Participant's Information:

Name of person approved for validity study participation:

Person's Address:

TABS ID: _____

Date of Birth: _____

Phone Number (If Known): (_____) _____

(Signature of Assessor Obtaining Consent)

(Date)

(Time)

I have fully explained the above including any risks or benefits, and believe this person understands the nature and purpose of the validity study with sufficient capacity to consent (see attached Consent Capacity Checklist). I have offered to answer any questions relating to the validity study and have fully and completely answered all such questions.

(Print Name of Assessor Obtaining Consent)

(Date)





New York State Office for People with Developmental Disabilities
Authorization to Use or Disclose Health Information during a Research Study

Protocol Number: 508 Principal Investigator: Christine Muller, Ph.D.

Name of Study: The Coordinated Assessment System (CAS) Validity Study

For use in the above study (the "Research"), you agree to allow the following individuals and entities to create, use and disclose Health Information about you as described below:

- Office for People With Developmental Disabilities (OPWDD)
- Your doctors, your other health care providers, and your service providers, if any, and
- The Principal Investigator and his/her staff (together "Researchers"). Researchers may include staff of the New York State Office for Persons With Developmental Disabilities, staff at the Center for Human Services Research at the University at Albany and the staff at Optumas and other future business partners

1. The Health Information that may be used and disclosed for this Research includes:

- All information collected during the Research as told to you in the Informed Consent Form.
- Health Information in your medical records which include the results of physical exams, medical history, diagnostic tests, or Health Information relating to a particular condition that is related to the Research.
- Additional information may include: Information included in your service records

2. The Health Information listed above may be used or disclosed to:

- Researchers at OPWDD who are involved in the study.
- Researchers and their staff at the following organizations involved with this Research: The Center for Human Service Research at the University at Albany
- Representatives of regulatory and government agencies, institutional review boards, representatives of the Researchers and their institutions to the level needed to carry out their responsibilities related to the conduct of the research.
- Other (family members or significant others, study buddies, outside agencies, etc.) Specify: Family members, providers of service to the person, Optumas, future business partners

3. By giving permission to release your Health Information as described above, you understand that this information may be shared with individuals or companies outside of OPWDD. As stated in the consent form, OPWDD will share information collected through this research with our two business partners (The Center for Human Services Research at the University at Albany and Optumas) and may share information with other business partners in the future. These partners have signed (future business partners will sign) a business agreement, agreeing to follow the laws that protect your information from being shared which are called HIPAA and HITECH. The Center for Human Services Research at the University at Albany, Optumas and any business partners OPWDD contracts with in the future will be held to the same standard as OPWDD to keep your information safe and private.



**4. Please note that:**

- You do not have to sign this Authorization form, but if you do not, you will not be able to participate in the study. You may change your mind at any time and for any reason. If you do so, you will no longer be allowed to participate in the study. If you withdraw this Authorization, the research staff may still use or disclose Health Information they already have collected about you as needed to maintain the reliability of the research. Any request to withdraw this Authorization must be made in writing to:

Dr. Christine Muller
OPWDD
44 Holland Avenue, 5th Floor
Albany, NY 12229

- You will not have access to review your Health Information documented in the assessment instruments during this study. However, OPWDD will provide public access to a report that describes the overall results of this research.

5. This Authorization does not have an end date.**6. You will be given a copy of this form after you have signed it.**

I agree to the use and disclosure of Health Information about me as described above:

Signature of Participant

Date

Printed Name of Participant

We also asked you or your legally authorized representative to initial the statements below:

I have received a copy of the OPWDD IRB Notice of Privacy Practices.





Office for People With Developmental Disabilities

Andrew M. Cuomo, Governor
Kerry A. Delaney, Acting Commissioner

ASSENT TO PARTICIPATE IN RESEARCH STUDY

Title: The Coordinated Assessment System (CAS) Validity Study

Principal Investigator: Christine M. Muller, Ph.D.

Co-Investigator: Diane Woodward, LMSW

Sponsor: The Office for People With Developmental Disabilities (OPWDD)

What is a research study?

We are asking you to be in a research study. A research study is a way to learn about new ideas and helps us learn new things. This research study is called the Coordinated Assessment System (CAS) Validity Study.

Why are we doing this validity study?

1. We, the Office for People With Developmental Disabilities (OPWDD), are doing this validity study because we want to see if a new tool, Coordinated Assessment System or CAS, gives us good information to use in planning for services for people with intellectual and/or developmental disabilities.
2. We want to know if different people with the same types of strengths and needs answer questions on the CAS in the same way. We also want to know if people answer questions on the CAS in the same way as they do on other assessment tools. This is called validity.
3. OPWDD wants to see if the CAS can help make decisions about how much and what type of services people with intellectual and/or developmental disabilities should get based on their strengths and needs. This information will eventually inform payments for services. This is called rate rationalization.

What will happen in the study?

You will be meeting with an OPWDD study staff, or an assessor, who will ask you some questions about your life, moods and behaviors, health, friends, strengths, needs, and goals. The assessor may also ask to watch you doing an activity. The assessor will need to talk with someone that knows you well like a family member, guardian, friend, and/or a staff member. The assessor will ask to look at some of your records like your Individualized Service Plan (ISP), doctor's notes, and lists of medicines, if you take any.





Will I get paid to be in the validity study?

No, you will not get paid to be in the validity study. If you do decide to join the validity study you will be entered into a drawing (like a raffle) where OPWDD will give away a total of twenty (20) \$25.00 gift cards. You do not need to answer all the questions to be part of the drawing. Only twenty (20) of roughly 1,000 people will win a gift card but by being in the drawing you will have a chance to win one of these gift cards.

What are the good things that can happen from this validity study?

By being in this validity study, you can help us understand if the CAS finds out about people's strengths and needs.

What are the bad things that can happen from this validity study?

Because there are a lot of questions for you to answer this may take several hours and you may get tired. We have planned to keep all your information safe from being seen by people not working on the validity study. However, there is a small chance that some of your information could be given to people not working on this validity study.

Will anyone else know my answers from this validity study?

The assessor will keep each person's information strictly private and confidential except if told about possible abuse or neglect of someone with a disability. All OPWDD staff are required by law to report possible cases of abuse or neglect while carrying out this validity study:

- **Abuse** is when anyone hurts a person with a disability on purpose.
- **Neglect** is when anyone does not help to protect or take care of a person with a disability.

All cases of abuse or neglect discovered must be reported to the assessor's supervisor. If necessary, an investigation may need to be conducted; this means other people will follow up and ask you or other people about the possible abuse and/or neglect.

Some legal advocacy organizations may be authorized by State Law to examine research records, but they cannot disclose any personal information without your permission.

What else should you know about the validity study?

Being in the validity study is your choice. You can say "Yes" or "No". Either answer is OK.

No matter what you decide, there will be no change in your current programs or services.





If you say "Yes" and change your mind later that is OK. You can stop being in the validity study at any time. If you want to stop, please tell the assessor. He or she will write a letter and send it to Christine Muller, the person in charge of the validity study, to let her know that you do not want to be in the validity study any more.

Take the time you need to decide if you want to say "Yes, I want to be in the validity study" or "No, I do not want to be in the validity study." Ask us any questions you have. You can ask questions at any time.

You will get a copy of this form to keep.

Participant's Statement

The assessor has told me about the validity study. I had a chance to ask questions and the assessor answered my questions. I know I can ask questions at any time. I want to be in the validity study.

Name of Participant: _____

Signature of Participant (if able): _____

Date: _____ Time: _____

TABS ID: _____

Date of Birth: _____

Phone Number (If Known): (_____) _____

OPWDD Study Staff Person (Assessor) Obtaining Assent

This assent was (Circle all applicable):

- 1) Verbally explained to the person
- 2) Read by the person
- 3) Person was not able to assent (deferred to legal guardian or other legally authorized representative)
- 4) Person verbally dissented and will not be enrolled in the validity study
- 5) Person nonverbally dissented and will not be enrolled in the validity study

Name of Person Obtaining Assent

Signature of Person Obtaining Assent

Date: _____





Works Cited

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