



THE REVISED CLIENT DEVELOPMENT EVALUATION REPORT:
RELIABILITY AND VALIDITY OF THE
EVALUATION AND PERSONAL OUTCOMES ELEMENTS

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Overview of CDER Revision

The 2003 CDER revision addressed two needs that have become increasingly important as the Department of Developmental Services (DDS) focuses on efficient and effective delivery of services to consumers. The first is the need to provide useful and accurate information to Regional Centers about consumers' skills and challenges so that appropriate services and supports can be obtained. The second is the need to assess the outcomes of the services provided to consumers.

The Evaluation Element was substantially revised to assure that it provides useful information in a reliable manner. It was also condensed to accommodate new items that assess outcomes of services. The result is a 20-item measure. The first 14 items assess consumers' skills for daily living using a five-point scale. A low score indicates less skill, and a high score reflects a skill level that allows for independent action by the consumer. The remaining six items assess the frequency and/or intensity of challenging behaviors that make increased supervision or monitoring of the consumer necessary. These behaviors are also rated on a five-point scale, with a low score indicating the consumer is not able to control or eliminate challenging behaviors and a high score indicating these behaviors occur rarely or never.

The assessment strategy underlying the new Evaluation Element differs from the previous version. As shown in Appendix A, the original items provided response options that described the specific abilities or behaviors of consumers; the number of options ranged from four through nine. The revised items, shown in Appendix B, employ a standardized five-point scale through which persons who complete the assessment describe the level of ability or behavior. Since all possible behaviors would not be listed in the new format, the scale was developed so that each successive number on the scale indicates a new level of skill or, in the case of the challenging behaviors segment, an increased level of control over behaviors injurious to oneself or others. The new version of the Evaluation Element also encourages the test administrator to interview reliable informants to determine the most frequent behavior shown by the consumer in a specified time period, rather than relying solely on personal observation.

A new element, the Personal Outcomes Element, was developed to assess the outcomes of services and supports. It contains 26 items. The first 16 questions focus on indicators of integration, inclusion, access to health care, and productivity. The remaining 10 questions assess satisfaction and quality of life through an interview with the consumer. Appendix C lists the questions and response formats for the Personal Outcomes Element. The Personal Outcomes Element, too, uses a series of standardized scales through which the level or degree of an attribute is measured. In this portion of the revised CDER, four response options are always offered.

The revision of the Evaluation Element was conducted by researchers at California State University, Stanislaus in collaboration with DDS staff and regional center employees. The Personal Outcomes Element was developed over a six-year period in a collaborative effort involving DDS staff, the Service Delivery Reform Committee ¹ and researchers at California State University, Stanislaus. More detailed information about item development and revision is presented later in this report. A statewide evaluation of the reliability and validity of the revised CDER was conducted in 2002, demonstrating that it is a reliable and valid instrument. Information on these tests is also provided in this report.

Evaluation Element Revision

The revision of the Evaluation Element was guided by a number of goals. One was to alter the questions so the focus was more on consumers' abilities rather than their disabilities. Another goal was to make the measure more useful for service coordinators and staff at the regional centers. A third goal was to improve the ability of the instrument to yield reliable data. It was also essential that the new Evaluation Element be no longer than the original form; indeed, the goal was to reduce the length of the instrument.

A final consideration stemmed from the need to maintain continuity with existing CDER data, to allow continued tracking of consumer and system data. Particular emphasis was given to developing a new scale that would enable the reproduction of calculated variables, such as the Frankland Factor and Developmental Level. Thus, the researchers endeavored to construct new items that correlated as highly as possible with old items, unless the old items were imprecise or included confounding aspects.

Planning Research

A series of interrelated research projects provided the information used to select and revise Evaluation Element items for use in the revised CDER. Researchers at California State University, Stanislaus conducted these projects with the assistance and collaboration of staff in DDS Headquarters.

¹ The Service Delivery Reform Committee was convened by DDS in response to the Budget Act of 1998, which mandated reform of the community-based service delivery system through the implementation of a performance-based rate structure focused on consumer outcomes. The associated costs, coupled with the State's difficult fiscal situation, ultimately prohibited implementation of the reform recommendations made by this committee.

User Surveys

Surveys were distributed to regional center (RC) and developmental center (DC) employees, DDS Headquarters' staff, stakeholders and consumer advocates, researchers, and consumers' families. Respondents were asked to rate the value or importance of existing items and to describe, in an open-ended format, which items should be updated, revised, or deleted. A total of 107 surveys was returned: 24 from DC employees, 60 from RC employees, 11 from DDS staff, 4 from other state offices, 6 from researchers, and 1 from a family member. Overall, the respondents were well qualified to comment on the CDER. On a scale of 1 (low) to 5 (high), the average self-rating for familiarity with the CDER was 3.67 and that for frequency of using the CDER in work was 3.94.

The user survey data were used to select items to be included in the new Evaluation Element. First, questions that received high ratings were retained. Overall, items from the Emotional Domain were seen as most important, and these became part of the Challenging Behaviors segment of the new Evaluation Element. Questions related to ambulation, bowel and bladder control, toileting, eating, and safety awareness also received high ratings; these items formed the nucleus of the Daily Living Skills segment.

Second, the open-ended comments provided rich information about users' needs and about items that should be updated. Last, since Developmental Center employees rated the Evaluation Element as less valuable than other respondents and reported using it less often, the revised CDER focuses primarily on the needs of the regional centers.

Data Requests

Requests for CDER data from DDS Headquarters were analyzed to determine which questions were requested most often. A packet of 262 requests was provided for analysis, but only 236 requested information from the Diagnostic or Evaluation Elements: the remainder specified information from the Client Master File. Most of the requests were from a DDS staff person (62.4%), or regional centers (18.6%).

Information from the Evaluation Element was requested, either alone or in combination with Diagnostic information, in 43.7% of the requests. The results indicated that two sets of items were requested most frequently, primarily because they are part of calculated variables such as Preferred Program and the Frankland Factor. The first were items 34-39 and 45 of the Emotional Domain; these can be found in the Challenging Behavior segment of the new Evaluation Element. The second were items 14-20 and 22 of the Independent Living Domain. These items are part of the Daily Living Skills segment.

Scientific Literature Search

The CDER represents a valuable research resource on developmental disabilities. A review of published research dated prior to the year 2000 was conducted to determine if information used by researchers could be retained in the revised CDER. This effort identified 50 articles that referenced the CDER database. The analysis identified four items that were used in at least 30% of the studies referenced: Rolling and Sitting (Item 1), Hand Use (Item 2), Ambulation (Item 5), and Eating (Item 14). Only one of these items, Rolling and Sitting, was not retained in the revised CDER; it received a relatively low importance rating (2.77 out of 5) in the user survey.

Archival CDER Data

Existing CDER data were analyzed using the last report for each consumer. After dropping cases deemed not to be reliable, 159,440 were retained for analysis. A set of 79,726 cases was used for an exploratory analysis; the remaining cases were retained for confirmatory analysis at a later time.

A redundancy analysis was conducted to identify existing CDER items that could be combined or replaced with a single question as a means of creating a shorter measure. Tables were created to cross tabulate the entries for all possible pairs of elements in the same domain of the Evaluation Element. A total of 390 tables was generated. The results indicated little or no redundancy in the Motor and Cognitive Domains and only two redundant elements each in the Social and Emotional Domains. The strongest level of redundancy was within the Independent Living Domain.

Reliability and Validity Test of the Revised CDER

The revised Evaluation Element was completed for 809 consumers to test its reliability and validity. The sample was drawn from six regional centers; participants were randomly selected from consumers scheduled for yearly review. In keeping with instructions for the new form, service coordinators used reliable informants to collect information needed to answer each question. A subset of 368 consumers was randomly chosen for a second administration two to four weeks later.

Test-Retest Reliability

Data collected in the original administration correlated well with data collected several weeks later. As Table 1 illustrates, most correlations were very high, demonstrating strong test-retest reliability.

Table 1: Test-Retest Correlations for Evaluation Element Items

Item Number & Description		Test-Retest Correlation (Pearson r)	Concordance
Daily Living Skills			
1	Using Hands	.87	93.1%
2	Walking	.97	94.2%
3	Using a Wheelchair	.98	90.7%
4	Taking Medication	.90	82.1%
5	Eating	.95	88.6%
6	Toileting	.95	91.9%
7	Bladder and Bowel Control	.94	91.3%
8	Personal Care	.91	80.6%
9	Dressing	.93	84.7%
10	Safety Awareness	.90	81.7%
11	Focusing on Tasks and Activities	.86	76.9%
12	Verbal Communication	.92	84.7%
13	Nonverbal Communication	.86	82.9%
14	Social Interaction	.85	77.0%
Challenging Behaviors			
15	Disruptive Social Behavior	.76	75.7%
16	Aggressive Social Behavior	.75	84.3%
17	Self-Injurious Behavior	.61	88.1%
18	Destruction of Property	.72	88.8%
19	Running or Wandering Away	.75	89.3%
20	Emotional Outbursts	.79	75.6%

Correlations were lower for the Challenging Behaviors items (Items 15-20) than for the Daily Living Skills items (Items 1-14). One possible explanation for this pattern is that challenging behaviors tend to be more volatile than daily living skills, so that the lower correlations for Items 15-20 result from larger discrepancies in behavior between the first and second test administrations. This explanation would suggest that test-retest reliability is lower for the Challenging Behaviors items than for the Daily Living Skills items. However, an alternate explanation seems more likely. Unlike daily living skills, challenging behaviors tend to vary little across consumers; for example, most consumers (70.0%) do not exhibit any type of self-injurious behavior. In cases such as this, correlations are poor measures of the statistical overlap between two test administrations. A better measure is concordance, which describes the percent of cases in which the same response was given in both

test administrations. Concordance data are provided in the rightmost column of Table 1. These figures suggest that test-retest reliability is just as strong for the Challenging Behaviors items as for the Daily Living Skills items.

Internal Consistency of New Items

Two items were dropped before testing internal consistency because very few consumers were required to complete them. The first item, Using a Wheelchair (Item 3), applies only to consumers who cannot walk and rely on a wheelchair for ambulation. The second item, Nonverbal Communication (Item 13), is only completed for consumers who do not use words to communicate.

With these items eliminated from the analysis, the internal consistency (Cronbach's alpha) of the entire Evaluation Element was .84 (n = 484). Internal consistency was .93 (n = 531) for the Daily Living Skills items and .83 (n = 704) for the Challenging Behaviors items. These results indicate that summary scores created for these sections, and for the Evaluation Element as a whole, will be reliable.

Correlation with Original CDER Items

Responses to the revised CDER items were correlated with the items in the original CDER from which they were derived. In cases where the new item represented a combination of old items, correlations with each old item were calculated. Analyses indicated high correlations between most items in the revised CDER and corresponding items in the original form (see Table 2).²

Table 2: Correlation Between New and Existing Items of the Evaluation Element

Item Number & Description		Item Number(s) in Original CDER	Correlation(s) (Pearson r)
Daily Living Skills			
1	Using Hands	2	.64
2	Walking	5	.93
3	Using a Wheelchair	7	.85
4	Taking Prescription Medication	13	.83
5	Eating	14	.86
6	Toileting	15	.90

² In the reliability and validity test Challenging Behaviors items were scored so that high scores indicated high levels of these behaviors. That scoring has since been abandoned; the revised CDER now in use assigns high scores when consumers exhibit few challenging behaviors, and low scores when consumers exhibit many challenging behaviors. Thus, those consumers who are the most advanced and require the least supervision receive high scores, regardless of the question being asked. Correlations shown in this report are based on the current scoring system, not the one used in the original analysis.

Item Number & Description		Item Number(s) in Original CDER	Correlation(s) (Pearson r)
7	Bladder and Bowel Control	16 & 17	.87 & .83
8	Personal Care	18 & 19	.86 & .83
9	Dressing	20	.87
10	Safety Awareness	56	.66
11	Focusing on Tasks and Activities	55	.71
12	Verbal Communication	58, 62, & 66	.78, .83, & .79
13	Nonverbal Communication	59 & 60	.69 & .60
14	Social Interaction	27 & 28	.64 & .61
Challenging Behaviors*			
15	Disruptive Social Behavior	33	.56
16	Aggressive Social Behavior	34	.61
17	Self-Injurious Behavior	35 & 36	.46 & .47
18	Destruction of Property	38	.55
19	Running or Wandering Away	39	.65
20	Emotional Outbursts	45	.52

Table 2 includes several low correlations, but many of these result from a lack of variation in scores across a consumer, which limits the correlation that can be obtained. Accordingly, Table 3 lists the concordance scores for all correlations that were below .70 in Table 2. To accommodate the fact that the old and new rating scales have different ranges, concordance scores in Table 3 represent the percent of cases in which consumers received the most extreme scores on both the old and new items. It should be noted that this tends to underestimate the true level of concordance, because the calculation ignores intermediate ratings.

Table 3: Concordance of Extreme Scores for Items With Low Inter-Test Correlations

Item Number & Description		Item Number(s) in Original CDER	Concordance
Daily Living Skills			
1	Using Hands	2	78.4%
13	Nonverbal Communication	59	29.4%
13	Nonverbal Communication	60	23.8%
14	Social Interaction	27	21.8%
14	Social Interaction	28	20.8%
Challenging Behaviors			
15	Disruptive Social Behavior	33	39.6%

Item Number & Description		Item Number(s) in Original CDER	Concordance
16	Aggressive Social Behavior	34	59.8%
17	Self-Injurious Behavior	35	74.0%
17	Self-Injurious Behavior	36	73.3%
18	Destruction of Property	38	73.2%
19	Running or Wandering Away	39	73.2%
20	Emotional Outbursts	45	30.4%

Table 3 indicates that Items 13-16 and 20 in the revised CDER do not correspond well with their counterparts in the original form. These low levels of concordance are not surprising; they result from intentional changes introduced to provide more precise and reliable measurement by the new items. The differences between these and the original items are described below.

1. Item 13, Nonverbal Communication, combines expressive and receptive nonverbal communication. These were assessed separately in the original form, but were combined in the revised CDER because consumers require both skills to communicate effectively with others. Furthermore, the response options for the original items did not clearly differentiate between the two highest ratings; the second-highest rating could be interpreted as indicating a level of functioning comparable to, or even more advanced than, the level of functioning corresponding to the highest rating. This ambiguity was corrected in the revised item.
2. Item 14, Social Interaction, combines two items from the original form that pertained to social behavior. The new operational definition expanded the concept of interaction to allow behavior in small groups to be considered. In addition, the skill of maintaining interactions was added to the response format to capture more advanced skill levels.
3. Item 15, Disruptive Social Behavior, was changed to allow a wider range of behaviors to be considered as disruptive. This was accomplished by providing a conceptual definition of the category, rather than listing behaviors to be considered.
4. Item 16, Aggressive Social Behavior, differs from the original item in two ways. First, it provides a narrow operational definition (behavior that harms or has the potential of harming others), whereas the original item allowed the examiner to consider any behavior he or she perceived to be aggressive. Second, the new response format is more inclusive in that it reflects frequency of aggression as well as severity.

5. Item 20, Emotional Outbursts, was formerly titled “Temper Tantrums” and provided no definition for the behavior. In the revised CDER, the behavior was narrowed to severe and intense displays of negative emotion related to fear, frustration, or anger.

Reproduction of Calculated Variables

One goal of the revision was to maintain continuity with the original CDER so that DDS could maintain the calculated variables integral to its internal systems. The two calculated variables designated as most important were the Frankland Factor, a measure of severe behavior problems, and Developmental Level, a measure that reflects the relative independence of consumers.

The revised CDER can reproduce the Frankland Factor with reasonable accuracy using a linear combination of the seven items listed in Table 4. Applying differential weights to these items, the new calculated variable correlates strongly with, and produces scores in the same range as, the Frankland Factor ($r = .66$), allowing consistent interpretation across the original and revised forms of the CDER. An even higher correlation could presumably be obtained by incorporating additional items from the revised CDER or by combining the items in a nonlinear manner, as is the case for the calculation of the Frankland Factor. However, these options were not explored, because the revised CDER yields subscale scores that render the Frankland Factor obsolete. Because the subscale scores from the revised CDER are not derived using arcane formulas, as is the case with the Frankland Factor, they are easier to interpret and provide better indicators of a consumer's challenging behaviors. Even so, the .66 correlation demonstrates that the potential exists to compare measures of challenging behaviors across the original and revised versions of the CDER.

Table 4: Items Used To Calculate the Frankland Factor

Item Number & Description	
10	Safety Awareness
11	Focusing on Tasks and Activities
15	Disruptive Social Behavior
16	Aggressive Social Behavior
18	Destruction of Property
19	Running or Wandering Away
20	Emotional Outbursts

The revised CDER can reproduce Developmental Level with high accuracy. Using the eight items listed in Table 5, and giving differential weights to each, the new calculated variable correlates with the original, $r = .90$. The revised CDER can reproduce 81.0% of the variance in the Developmental Level. The algorithm produces scores in the same range as the original CDER.

Table 5: Items Used To Calculate Developmental Level

Item Number & Description	
4	Taking Prescription Medication
5	Eating
6	Toileting
8	Personal Care
10	Safety Awareness
11	Focusing on Tasks and Activities
12	Verbal Communication
14	Social Interaction

Subscales

Combining items that are conceptually and statistically similar yields subscales for the new Evaluation Element. Principal Components factor analysis with Varimax rotation identified three sets of items within the Evaluation Element, one of which included all of the Challenging Behaviors items. The other two groupings represent somewhat different foci within the Daily Living Skills items: Practical Independence, and Personal/Social Skills. The content of the subscales is shown in Table 6, accompanied by the internal consistency (Cronbach's alpha) and test-retest reliability (Pearson correlation) of each. The items are listed in the order of their centrality to the dimension in question.

Table 6: Subscales of the Evaluation Element

Item Number & Description		Dimension
2	Walking	PRACTICAL INDEPENDENCE Internal consistency (α) = .88 Test-retest reliability (r) = .93
5	Eating	
1	Using Hands	
6	Toileting	
7	Bladder and Bowel Control	
11	Focusing on Tasks and Activities	PERSONAL/SOCIAL SKILLS Internal consistency (α) = .92 Test-retest reliability (r) = .97
10	Safety Awareness	
14	Social Interaction	
4	Taking Prescription Medication	
8	Personal Care	
9	Dressing	
12	Verbal Communication	CHALLENGING BEHAVIORS
15	Disruptive Social Behavior	
20	Emotional Outbursts	

Item Number & Description		Dimension
16	Aggressive Social Behavior	Internal consistency (α) = .83 Test-retest reliability (r) = .83
17	Self-Injurious Behavior	
19	Running or Wandering Away	
18	Destruction of Property	

Table 7 shows the correlations between the subscales and the calculated variables. The subscales are scored so that a high level of competence is given a high score, as is true for the calculated variable labeled Developmental Level. In contrast, the Frankland Factor is scored so that a high score indicates less competence.

Table 7: Correlations Between Subscales and Calculated Variables

Subscales	Original CDER		Revised CDER	
	Frankland Factor	Developmental Level	Frankland Factor	Developmental Level
PRACTICAL INDEPENDENCE	-.11	.73	-.02	.59
PERSONAL/SOCIAL SKILLS	-.37	.91	-.46	.99
CHALLENGING BEHAVIORS	-.67	.19	-.93	.18

In both the original and the final revised forms of the CDER, Developmental Level correlated most strongly in a positive direction with Personal/Social Skills items, while the Frankland Factor correlated most strongly in a negative direction with Challenging Behaviors items. These correlations are stronger for the revised CDER than for the original form, and are sufficiently close to 1.00 for the revised CDER that the subscales may substitute for the calculated variables. Subscale scores are readily understood; unlike the calculated variables, they are summed in a straightforward manner directly from the CDER responses. Furthermore, subscale scores are easily interpreted because they can range from a low of 1 to a high of 5, just like the Evaluation Element ratings from which they are derived.

Personal Outcomes Element

The Personal Outcomes Element (POE) is designed to assess life experiences of consumers in order to measure the degree to which DDS is meeting consumers' needs. The Lanterman Act requires DDS to determine the degree to which the services it provides empower consumers to make choices and lead more independent, productive, and normal lives. The POE questions were designed

to assess well-being in different areas of the consumer's life, thereby conforming with Senate Bill 1383 (which modified the Lanterman Act) and reflecting an increased emphasis within DDS on individualized services and supports.

An early version of the POE was pretested by DDS in a 1997 pilot study of 148 consumers in the San Gabriel/Pomona service delivery area.³ The results of the pilot study highlighted several issues that were central to the final revision of the POE. First, a system for obtaining quality of life information directly from consumers was developed because the use of informants for those questions posed a threat to both reliability and validity. Second, the revised POE incorporated questions with simple, direct wording that asked for specific information regarding observable events or situations; questions that used this format yielded the highest reliability in the pilot study.

A November 16, 1999 report of the Service Delivery Reform Committee on the measurement of personal outcomes also provided guidance in developing questions. This report identified 30 possible outcomes of services and supports, clustered under the headings Choice, Relationships, Lifestyle, Health and Well-Being, Development, Rights, and Satisfaction. The revised CDER includes questions pertaining to all of the major areas detailed in the 1999 report.

The final version of the Personal Outcomes Element includes descriptive questions about consumers' school and work experiences, community and social life, out-of-home living experiences, health, and safety. It also contains a 10-item consumer survey that assesses consumers' feelings about their lives, ability to speak up for themselves, satisfaction with living arrangements and caregivers (for consumers who do not live at home), and satisfaction with the school or work environment and staff.

Reliability and Validity Test of the Personal Outcomes Element

The Personal Outcome Element, including the Consumer Survey, was completed for 808 consumers to test its reliability and validity. The sample was the same as that used to test the Evaluation Element, described above. A subset of 368 consumers was randomly chosen for a second administration two to four weeks later.

Internal Consistency

Table 8 summarizes the internal consistency (Cronbach's alpha) for the descriptive questions of the Personal Outcomes Element. The number of responses for each scale differs because some

³ The results of this study are summarized in Pilot Study of The Personal Outcomes Element Part 2: Reliability, a report submitted to DDS by Jamie McCreary, Ph.D. and Eric Cole, California State University, Stanislaus on October 29, 1997.

questions did not pertain to all consumers, and because some consumers chose not to answer the Consumer Survey. The entries in Table 8 demonstrate low to moderate levels of internal consistency. This is not problematic, as the scales with low levels of internal consistency were intended to collect discrete pieces of information; they were not meant to comprise internally consistent subscales. By contrast, the questions for the Consumer Survey were all intended to measure a consumer's quality of life. As expected, these items yielded an acceptable level of internal consistency ($\alpha = .71$), indicating they can be used as a subscale.

Table 8: Internal Consistency of Personal Outcomes Items

Item Number & Description	Number of Consumers	Internal Consistency (α)
School Environment	352	.61
Work Environment	155	.62
Community and Social Life	718	.45
Out of Home Living	258	-.09
Health and Safety	608	.39
Consumer Survey	129	.71

Test-Retest Reliability

Data collected in the original administration of the Personal Outcomes Element correlated well with data collected several weeks later. Most correlations were very high, but there were a few exceptions (see Table 9). Some correlations were low, but these were accompanied by high levels of concordance, suggesting that all items have strong test-retest reliability; low correlations simply indicate a lack of variability in responses across consumers.

Table 9: Test-Retest Reliability of Personal Outcomes Items

Item Number & Description	Test-Retest Correlation (Pearson r)	Concordance
School and Work		
1 Type of school	.83	86.6%
2 Non-disabled contact at school	.91	85.9%
3 Primary language at school	.86	87.4%
4 Type of work or day program	.89	89.5%
5 Non-disabled contact at work or day program	.65	79.6%
6 Primary language at work or day program	.73	85.2%
7 Hours of paid work	.83	80.8%
8 Hourly wages	.84	88.3%

Item Number & Description		Test-Retest Correlation (Pearson r)	Concordance
Community and Social Life			
9	Frequency of community outings	.80	78.9%
10	Number of friends	.78	79.4%
Out of Home Living			
11	Number of disabled people in household	.90	92.7%
12	Number of times moved in past 2 years	.87	90.5%
13	Primary language at home	.80	96.0%
Health and Safety			
14	Physician access	.53	94.4%
15	Dentist access	.75	90.0%
16	No untreated medical or dental condition	.66	94.5%
Consumer Survey			
17	Do you like where you're living?	.69	88.0%
18	Do you like the people who help you at home?	.33	89.5%
19	Do you want to stay where you are living?	.68	87.4%
20	Do you like your school, job, or day program?	.68	95.8%
21	Do you like the people at your school, job, or day program?	.36	89.9%
22	Do you want to keep going to your school, job, or day program?	.46	90.3%
23	Who do you talk to when sad or unhappy?	.56	72.5 %
24	Do you feel safe or afraid most of the time?	.45	80.2%
25	Are you happy or sad most of the time?	.59	83.4%
26	Do you tell people what you want?	.64	81.1%

Content Validity

The Personal Outcomes Element was designed to measure Quality of Life, a construct that generally refers to personal well being (Borthwick-Duffy, 1990). Quality of life is a multidimensional variable that includes both objective and subjective components (Bigelow, Gareau, & Young, 1990; Schalock, 1993). Objective criteria can be measured through observation and are relatively easy to verify. Subjective criteria typically assess attitudes, evaluations, and perceptions of “life in general or

... specific life circumstances” (Heal & Sigelman, 1990, p. 162). The Personal Outcomes Element includes 16 objective and 10 subjective items.

Content validity refers to the extent to which a scale accurately reflects a specific domain or content area. To obtain a valid assessment of quality of life in a developmentally disabled population, the questions must address the most important domains of life for this group. The content validity of the Personal Outcomes Element was tested by comparing the content of the questions with existing standards for measuring quality of life in developmentally disabled persons.

According to Bigelow et al. (1990), assessing a consumer's housing, finances, employment, physical health, psychological health, meaningful use of time, and interpersonal functioning all are important. Bigelow and colleagues also discussed perceived well-being, life satisfaction, and happiness as the subjective criteria that contribute to quality of life. In another comprehensive report, Schalock (1993) grouped quality of life indicators into four areas: independence/decisions, productivity, community integration, and satisfaction.⁴

A comparison of the POE questions with the Bigelow and Schalock dimensions shows that nearly all the topics established by these scholars are included in the Personal Outcomes Element (see Table 10). The one exception is Meaningful Use Of Time as defined by Bigelow.

Table 10: Comparison of POE Questions and Quality of Life Dimensions

Item Number & Description		Bigelow	Schalock
School and Work			
1	Type of school		Community Integration
2	Non-disabled contact at school		Community Integration
3	Primary language at school	Interpersonal Functioning	Satisfaction
4	Type of work or day program		Community Integration
5	Non-disabled contact at work or day program		Community Integration
6	Primary language at work or day program	Interpersonal Functioning	Satisfaction
7	Hours of paid work	Employment	Productivity
8	Hourly wages	Finances	Productivity
Community and Social Life			
9	Frequency of community outings	Interpersonal Functioning	Community Integration
10	Number of friends	Interpersonal Functioning	Satisfaction

⁴ More detailed description of Schalock’s dimensions can be found in Pilot Study of The Personal Outcomes Element Part 1: Content Validity, a report submitted by Troianne Grayson, Eric Cole, and Jamie McCreary, Ph.D., California State University on Stanislaus, September 22, 1997.

Item Number & Description		Bigelow	Schallock
Out of Home Living			
11	Number of disabled people in household	Housing	Community Integration
12	Number of times moved in past 2 years	Housing	Satisfaction
13	Primary language at home	Housing	Satisfaction
Health and Safety			
14	Physician access	Physical Health	Satisfaction
15	Dentist access	Physical Health	Satisfaction
16	No untreated medical or dental condition	Physical Health	Satisfaction
Consumer Survey			
17	Do you like where you're living?	Life Satisfaction	Satisfaction
18	Do you like the people who help you at home?	Interpersonal Functioning	Satisfaction
19	Do you want to stay where you are living?	Life Satisfaction	Satisfaction
20	Do you like your school, job, or day program?	Happiness	Satisfaction
21	Do you like the people at your school, job, or day program?	Interpersonal Functioning	Satisfaction
22	Do you want to keep going to your school, job, or day program?	Life Satisfaction	Satisfaction
23	Who do you talk to when sad or unhappy?	Interpersonal Functioning	Satisfaction
24	Do you feel safe or afraid most of the time?	Psychological Health	Satisfaction
25	Are you happy or sad most of the time?	Psychological Health	Satisfaction
26	Do you tell people what you want?	Interpersonal Functioning	Decision Making

Convergent Validity Tests

Questions from the Personal Outcomes Element were correlated with several previously published measures of Quality of Life to further establish the validity of the POE. Because most of these previously published measures are not suitable for a developmentally disabled population, the validity test was conducted with two non-disabled groups. POE questions relevant to the lives of each group were presented to 120 adults and 81 children, and their responses to the POE questions were compared to their answers to the previously published scales.

Child Study

The non-disabled sample of 81 children was drawn from the Central Valley and matched the DDS child population in ethnicity and age. The validity of the POE for children ages 10-17 years was established by correlating it with scores obtained from two established instruments. The first instrument, the Students' Life Satisfaction Scale (SLSS; Huebner, 1991a, 1991b), provides a reliable and valid measure of global well being in children from 3rd through 12th grade. The second

instrument, the Multidimensional Life Satisfaction Scale (MLSS; Huebner, 1994), assesses life satisfaction in five domains in children’s lives: family, friends, living environment, school, and self.

The revised CDER questions completed by the 81 non-disabled children provided information on eight quality of life dimensions. One of these dimensions was also assessed by the SLSS, and four were also assessed by the MLSS. Correlations between the scores yielded by the revised CDER and the scores yielded by the SLSS and MLSS are listed in Table 11.

Table 11: Validity of the Personal Outcomes Element for Children

Item and Description		Correlation with SLSS or MLSS (Pearson r)
Global Well-Being/Satisfaction with Self		
24	Do you feel safe or afraid most of the time?	.31 (SLSS)
25	Are you happy or sad most of the time?	.33 (MLSS)
Residential Environment		
12	Number of times moved in past 2 years	.14 (MLSS)
Social Acceptance and Social Relationships		
10	Number of friends	.38 (MLSS)
23	Who do you talk to when sad or unhappy?	
School Satisfaction		
20	Do you like your school?	.37 (MLSS)
21	Do you like the people at your school?	
22	Do you want to keep going to your school?	

A low correlation exists between the revised CDER and the MLSS for the residential environment dimension. This is not surprising, as the revised CDER requests objective data pertaining to the past (the number of times the respondent has moved in the two previous years), while the MLSS asks about subjective feelings and future intentions (the degree of satisfaction with the current living environment and whether or not a future move is desired).

The other correlations listed in Table 11 are all moderate and statistically reliable (two-tailed $p < .01$). Higher correlations would provide better evidence of convergent validity for the revised CDER items. However, the revised CDER is designed for use by a population with limited cognitive abilities, and is therefore capable of making only gross assessments of quality of life. Several design features exemplify this, such as the 3-point response scale for items that consumers answer themselves. Accordingly, on most items in the revised CDER, at least 70% of the non-disabled children selected the response that corresponded to the highest quality of life. The SLSS and MLSS, by contrast, are

designed to be sensitive to finer distinctions in quality of life; on these instruments, the response that corresponded to the highest quality of life was rarely selected by more than 50% of the children.

Despite this limitation, the revised CDER functions well. This is best illustrated by noting that the global well-being score generated by the SLSS has a correlation of only $r = .44$ with the corresponding measure generated by the MLSS (satisfaction with self). This suggests that the correlation of $r = .31$ between the revised CDER and the SLSS, and the correlation of $r = .33$ between the revised CDER and the MLSS, is fairly close to the maximum possible value that could be expected for a measure with perfect convergent validity.

Adult Study

The non-disabled sample of 120 adults was drawn from the Central Valley and matched the DDS adult population in ethnicity and age. The validity of the POE for adults was established by correlating it with scores obtained from two established life satisfaction scales for adults. The first scale was based upon the WHOQOL, which is a 100-item instrument developed by the World Health Organization to measure quality of life among adults in diverse cultures (The WHOQOL Group, 1994). The items included in study were drawn from the WHOQOL-BREF, which is a 26-item short form version of the WHOQOL. The second established life satisfaction scale for adults was the Quality of Life Questionnaire (QoLQ) developed by Schalock and Keith (1993). This questionnaire measured four quality of life domains: life satisfaction, competence and productivity, empowerment and independence, and social belonging and community integration.

The revised CDER items completed by the 120 non-disabled adults provided information on eight quality of life dimensions. Five of these dimensions were also assessed by the WHOQOL, and four were also assessed by the QoLQ. Correlations between the scores yielded by the revised CDER and the scores yielded by the WHOQOL and QoLQ are listed in Table 12.

Table 12: Validity of the Personal Outcomes Element for Adults

Item and Description		Correlation with WHOQOL (Pearson r)	Correlation with QoLQ (Pearson r)	WHOQOL/QoLQ Correlation (Pearson r)
Global Well-Being/Satisfaction with Self				
24	Do you feel safe or afraid most of the time?	.63	-.52	-.66
25	Are you happy or sad most of the time?			
Residential Environment				
12	Number of times moved in past 2 years	.31	Not measured by QoLQ	Not measured by QoLQ

Item and Description		Correlation with WHOQOL (Pearson r)	Correlation with QoLQ (Pearson r)	WHOQOL/QoLQ Correlation (Pearson r)
Social Acceptance and Social Relationships				
10	Number of friends	.32	-.21	-.60
23	Who do you talk to when sad or unhappy?			
Work Satisfaction				
20	Do you like your job?	Not measured by WHOQOL	-.44	Not measured by WHOQOL
21	Do you like the people at your job?			
22	Do you want to keep going to your job?			
Recreation and Leisure				
9	Frequency of community outings	.37	-.43	-.37
Physical Well-Being				
14	Physician access	.50	Not measured by QoLQ	Not measured by QoLQ
15	Dentist access			
16	No untreated medical or dental condition			

All of the correlations listed in Table 12 are statistically reliable (two-tailed $p < .05$), and range from moderate to high. Thus, the revised CDER appears to have reasonable convergent validity. Correlations with the QoLQ are negative because a high quality of life corresponds to a numerically high score on the revised CDER and the WHOQOL, but a numerically low score on the QoLQ.

Subscales

Subscales for the new Personal Outcomes Element were created by examining content validity indicators and using these to combine items that shared conceptual and statistical similarities. This led to the creation of two POE subscales. One subscale includes all the questions from the Consumer Survey. This subscale, Personal Well-Being, measures the extent to which the consumer is happy and satisfied with living, school, or work. The other subscale, Integration and Inclusion, assesses the extent to which the consumer spends time in integrated settings and is included in social and community activities.

Few consumers can complete all the questions in a given subscale; for example, consumers who attend school may not work or participate in day programs. Thus, subscale scores are calculated by finding the mean of the items answered within each subscale. The items in each subscale are listed in Table 13, together with the internal consistency (Cronbach's alpha) and test-retest reliability (Pearson correlation) of each subscale.

Table 13: Subscales of the Personal Outcomes Element

Item Number & Description		Dimension
17	Do you like where you're living?	<p>PERSONAL WELL-BEING</p> <p>LIVING AT HOME</p> <p>Internal consistency (α) = .64</p> <p>Test-retest reliability (r) = .56</p> <p>OUT OF HOME LIVING</p> <p>Internal consistency (α) = .64</p> <p>Test-retest reliability (r) = .65</p>
18	Do you like the people who help you at home?	
19	Do you want to stay where you are living?	
20	Do you like your school, job, or day program?	
21	Do you like the people at your school, job, or day program?	
22	Do you want to keep going to your school, job, or day program?	
23	Who do you talk to when sad or happy?	
24	Do you feel safe or afraid most of the time?	
25	Are you happy or sad most of the time?	
26	Do you tell people what you want?	
1	Type of school	<p>INTEGRATION & INCLUSION</p> <p>SCHOOL SAMPLE</p> <p>Internal consistency (α) = .62</p> <p>Test-retest reliability (r) = .86</p> <p>WORK/DAY PROGRAM SAMPLE</p> <p>Internal consistency (α) = .52</p> <p>Test-retest reliability (r) = .73</p>
2	Non-disabled contact at school	
3	Primary language at school	
4	Type of work or day program	
5	Non-disabled contact at work or day program	
6	Primary language at work or day program	
7	Hours of paid work per week	
8	Level of pay at work	
9	Frequency of community outings	
10	Number of friends	

Internal consistency for the POE subscales is difficult to measure because many items are not applicable to large numbers of consumers. This is especially problematic for the Integration and Inclusion subscale. To accommodate this problem, separate statistics were calculated for the Integration and Inclusion subscale for consumers who attended school (using Items 1-3 and 9-10), and for consumers who worked or participated in a day program (using Items 4-6 and 9-10). Items 7 and 8 were excluded from all calculations, even though they pertain to consumers who work, because consumers who participate in day programs only are rarely paid. Similarly, for the Personal Well-Being subscale, separate statistics were calculated for consumers who live at home (ignoring Items 17-19) and for consumers who do not live at home (including Items 17-19).

Both subscales demonstrate reasonable levels of internal consistency. However, the alphas are not particularly close to their maximum possible value of 1.00, suggesting that the individual items

within each subscale provide unique pieces of information. Test-retest reliability is high for the Integration and Inclusion subscale but lower for the Personal Well-Being subscale. The latter result is not surprising because the Personal Well-Being subscale includes questions about transient emotional states, such as being “happy” or “afraid.”

Table 14 shows the correlations between the three Evaluation Element subscales and the two POE subscales. Scores for Personal Well-Being correlated to some extent with those for Challenging Behaviors, in which a high score indicates low levels of challenge. Integration and Inclusion correlated with all three Evaluation Element subscales, and its strongest relationship was with Personal/Social Skills, as would be expected.

Table 14: Correlations Between Subscales in the Revised CDER

	Personal & Social Skills	Challenging Behaviors [‡]	Personal Well-Being	Integration & Inclusion
PRACTICAL INDEPENDENCE	.54*	-.15*	-.03	.26*
PERSONAL/SOCIAL SKILLS		.20*	.07	.50*
CHALLENGING BEHAVIORS [‡]			.16*	.20*
PERSONAL WELL-BEING				.10*
INTEGRATION & INCLUSION				

* Correlation is statistically reliable; two-tailed $p < .05$ ($n = 496$ to 798).

Appropriate Use of the Revised CDER

Limitations: Developmental Centers

The revised CDER was developed for and tested with consumers served by Regional Centers. Given the distinct needs of consumers with more severe disabilities, it is unlikely that the revised CDER will fully meet the requirements of Developmental Centers. Evaluation Element questions can be added to the revised CDER to meet the special needs of consumers who reside in Developmental Centers. However, to assure reliability and validity, testing of these questions within Developmental Centers will be required.

Presentation Order

The service coordinator is expected to answer all items from the Evaluation Element and descriptive questions from the Personal Outcomes Element based on informal interviews with people who have reliable information about different aspects of the consumer's behavior and lifestyle. These items can be completed in any order.

The Consumer Survey is administered through a face-to-face interview. In the pilot test of the revised CDER, questions about personal well-being (23-26) were asked before questions dealing with satisfaction with out-of-home living and school, work, or day programs (17-22). Service coordinators who participated in the pilot recommended that, in future administrations, satisfaction questions be asked before questions about personal well-being. This order would allow consumers to become comfortable with the format before being asked sensitive questions.

Calculated Variables

The calculated variables derived from the original form of the CDER can be reproduced with reasonable accuracy using the revised CDER. However, arcane formulas are used to derive the original CDER's calculated variables, and the resulting scores are difficult to interpret because they bear no obvious relationship to the ratings used in their derivation. By contrast, the five subscale scores generated by the revised CDER are inherently meaningful and share the same range of possible values as the responses used in their derivation. Thus, it is recommended that the subscale scores be adopted in place of the calculated variables. The Personal/Social Skills subscale is highly correlated with Developmental Level, while the Challenging Behaviors subscale is highly correlated with the Frankland Factor. The remaining subscales (Practical Independence, Personal Well-Being, and Integration and Inclusion) provide insight into important consumer characteristics that are captured poorly, if at all, by the calculated variables generated by the original form of the CDER.

CDER Profile

Feedback from Regional Center service coordinators indicated that the existing CDER Profile has little utility. Accordingly, a new CDER Profile should be developed so that a one-page summary can be generated for each consumer from the responses to the revised CDER. The new CDER Profile should be concise, user-friendly, and complete, thereby facilitating the process of making decisions about the level of supports and services required by the consumer.

It is recommended that the new CDER Profile contain the following information:

- A summary of critical needs or issues, provided by the individual responses to Item 3 (use of wheelchair) and Item 13 (use of nonverbal cues for communication) in the Evaluation

Element, and the individual responses to Question 8 (work below minimum wage), and Question 16 (unmet medical or dental needs) in the Personal Outcomes Element.

- The Practical Independence subscale score, calculated by finding the mean of Items 1, 2, and 5-7 in the Evaluation Element.
- The Personal and Social Skills subscale score, calculated by finding the mean of Items 4, 8-12, and 14 in the Evaluation Element.
- The Challenging Behaviors subscale score, calculated by finding the mean of Items 15-20 in the Evaluation Element.
- The Personal Well-Being subscale score, calculated by finding the mean of Questions 17-26 in the Personal Outcomes Element.
- The Integration and Inclusion subscale score, calculated by finding the mean of Questions 1-6 and 9-10 in the Personal Outcomes Element.

These scores can be presented visually to make best use of the new features provided by the revised CDER Evaluation Element⁵. A sample visual presentation of consumer information is shown in Appendix D.

⁵ Information from the Client Master File (CMF) and Diagnostic Element are also required.

Appendix A: Original Evaluation Element Items

THE COER EVALUATION ELEMENT

MOTOR DOMAIN

- 1 O Rolling and Sitting**
t= Does not lift head when lying on stomach
2= Lifts head when lying on stomach
3= Lifts head and chest using arm support when lying on stomach
4= Rolls from side to side
5= Rolls from front to back only
6= Rolls from front to back and back to front
7= Maintains sitting position with minimal support for at least five (5) minutes
8= Sits without support for at least five (5) minutes
9= Assumes and maintains sitting position independently
- 2 D Hand Use**
1= No functional use of hand
2= Uses raking motion or grasps with hand
3= Uses thumb and fingers of hand in opposition
4= Uses fingers independently of each other
- 3 D Arm Use**
t= No functional use of arm
2= Moves arm from shoulder but does not extend or flex arm (i.e., does not have control of elbow joint)
3= Partially extends arm
4= Fully extends arm
- 4 O Crawling and Standing**
1= Does not crawl, creep or scoot
2= Crawls, creeps, or scoots
3= Pulls to a standing position
4= Stands with support for at least one (1) minute
5= Stands unsteadily alone for at least one (1) minute
6= Stands well alone, balances well for at least five (5) minutes
- 5 O Ambulation**
1= Does not walk
2= Walks with support
3= Walks unsteadily alone at least ten (10) feet
4= Walks well alone at least twenty (20) feet, balances well
- 6 D Climbing Stairs**
(rate use of ramps for persons using wheelchairs)
N= No opportunity to use stairs (or ramps)
1= Does not move up or down stairs (or ramps)
2= Moves up and down stairs (or ramps) with help
3= Moves up and down stairs (or ramps) with hand rail independently
4= Moves up and down stairs (or ramps) without need for handrail

7 D Wheelchair Mobility

- N= Does not use wheelchair
t= Sits in wheelchair, does not move wheelchair by self
2= Assists in moving wheelchair
3= Moves self with some bumping and/or difficulty in steering
4= Moves or guides chair independently and smoothly

INDEPENDENT LIVING DOMAIN

8 O Food Preparation

- N= Client is in a service setting in which he/she is prevented from preparing food
1= Does not prepare food
2= Prepares simple foods without cooking (sandwich, cold cereal, etc.)
3= Cooks simple foods (eggs, soup, frozen dinners, etc.)
4= Prepares complete meal

Bedmaking

- N= Client is in a service setting in which he/she is prevented from bedmaking
t= Does not make bed
2= Attempts bedmaking but does not complete
3= Makes bed completely but not neatly. (sheets and blankets appear wrinkled, bedspread is on crooked, etc.)
4= Complete, bedmaking neatly and independently

10 O Washing Dishes

- N= Client is in a service setting which he/she is prevented from dishwashing
t= Does not wash dishes
2= Attempts dishwashing but does not complete
3= Completes dishwashing but with unacceptable results (water left on counter, or floor, dishes chipped, etc.)
4= Completes dishwashing neatly and independently

- 11 **D** Household Chores
(other than food preparation, bedmaking, washing dishes)
N= Client is in a service setting in which he/she is prevented from doing household chores
- 1= Does not do household chores
 - 2= Attempts household chores but does not complete
 - 3= Does household chores, but not neatly (leaves dirt on floor, spills garbage, etc.)
 - 4= Completes household chores neatly and independently

Basic Medical Self-Help

(first aid, nonprescription medication)

N= Client is in a service setting in which he/she is prevented from performing basic medical self-help skills

- 1= Does not display any medical self-help skills
- 2= Seeks aid in treatment of minor injuries
- 3= Performs simple first aid tasks (applies band-aids, ice to a burn)
- 4= Has basic medical self-help skills and uses nonprescription medications (aspirin, cough drops, etc.) appropriately

13 **D** Self-Medication

N= Does not require any routine prescription medication or is in a service setting in which he/she is prevented from self-medication

- 1= Does not take any medication by self
- 2= Takes own medication with supervision and/or assistance
- 3= Takes own medication if reminded of time and/or dosage
- 4= Independently takes own medication as prescribed

14 **O** Eating

- 1= Does not feed self, must be fed completely
- 2= Attempts to linger feed but needs assistance
- 3= Finger feeds self without assistance
- 4= Feeds self using spoon, with spillage
- 5= Feeds self using fork and spoon, with spillage
- 6= Uses eating utensils with no spillage

15 **O** Toileting

- 1= Not toilet trained or habit trained
- 2= Is habit trained
- 3= Indicates need to toilet self and/or must be placed on toilet or bedpan
- 4= Goes to toilet by self, needs assistance to complete toileting
- 5= Goes to toilet by self, completes by self

16 **O** Level of Bladder Control

- 1= No control
- 2= Some bladder control accidents during waking hours (once a week or more)
- 3= Control during day, wets at night
- 4= Complete control

17 **D** Level of Bowel Control

- 1= No control
- 2= Some bowel control, accidents during waking hours (once a week or more)
- 3= Control during day, soils at night
- 4= Complete control

18 **D** Personal Hygiene

(brushing teeth, washing, and behaviors specifically related to gender and age, e.g., shaving, hair care, menses, use of deodorant)

- 1= Does not tend to own personal hygiene
- 2= Tends to some personal hygiene needs but does not complete
- 3= Tends to and completes some but not all personal hygiene tasks
- 4= Tends to own personal hygiene independently

Bathing

- 1= Does not bathe or shower self
- 2= Performs some bathing or showering tasks, but not all
- 3= Bathes or showers self independently

20 **D** Dressing

- 1= Does not put on any clothing by self
- 2= Cooperates in putting on clothes (raises arms, etc.)
- 3= Puts on some clothes by self
- 4= Puts on all clothes but does not tie shoes, close all fasteners or attend to other details
- 5= Dresses self completely including all fasteners and other details (buttons, zippers, shoes)

21 **O** Movement in Familiar Setting

- 1= Does not move about in a familiar setting
- 2= Moves about in a familiar setting but does not successfully move around obstructions or from room to room
- 3= Moves about in a familiar setting and successfully moves around objects but has difficulty going from room to room
- 4= Knows way around and moves about successfully in a familiar setting

22 **O** Movement in Unfamiliar Setting

- 1= Does not move about in unfamiliar settings
- 2= Moves about in unfamiliar setting but does not successfully move around obstructions or from place to place
- 3= Moves about in unfamiliar setting and successfully moves around objects but has difficulty going from place to place
- 4= Finds way around and moves about successfully in an unfamiliar setting

Transportation About Community

- N= No public transportation available
- 1= Does not use public transportation
 - 2= Uses public transportation with physical assistance and/or accompaniment
 - 3= Uses public transportation independently for a simple direct trip
 - 4= Uses public transportation independently for a complex route

- 24 **D** Money Handling
 1= Does not use money
 2= Uses money, but is unable to provide appropriate amount (gives too little to purchase any item in store, etc.)
 3= Uses money, but does not usually make and/or count change correctly
 4= Adds coins of various denominations, makes and/or counts change to \$1
 5= Makes and/or counts change, any amount

- 25 **O** Making Purchases
 1= Does not make purchases
 2= Identifies items desired to purchase, but does not make purchase
 3= Manages purchases with some difficulty
 4= Manages purchases independently

Ordering Food in Public

- 1= Does not order food at public eating places
 2= Orders snacks (ice cream, hot dogs, tacos, etc.)
 3= Orders simple meals (hamburgers and fries, tacos and beans, etc.), may require assistance
 4= Orders complete meals independently

SOCIAL DOMAIN

- 27 **O** One-to-One Interaction with Peers
 (friends, classmates, co-workers, etc.)
 1= Does not enter into interaction
 2= Enters into interaction only when others initiate
 3= Initiates interaction in familiar or previously successful situations or settings
 4= Initiates interaction in both familiar and unfamiliar situations or settings

- 28 **D** One-to-One Interaction with Persons Other than Peers
 (store clerks, foster parents, teachers, bus drivers, etc.)
 1= Does not enter into interaction
 2= Enters into interaction only when others initiate
 3= Initiates interaction in familiar or previously successful situations or settings
 4= Initiates interaction in both familiar and unfamiliar situations or settings

Friendship Formation

- (close social relationships)
 1= Does not form friendships
 2= Potential friends must initiate friendships
 3= Initiates and establishes friendships

- 30 **D** Friendship Maintenance
 (for at least three months)
 1= Does not maintain friendships
 2= Maintains friendships only in stable or familiar settings (classroom, residence, etc.)
 3= Maintains friendships in many different settings

- 31 **O** Participation in Social Activities
 1= Does not participate in social activities
 2= Participates in social activities only with considerable encouragement
 3= Participates in social activities with some encouragement
 4= Does not need encouragement to participate in social activities

Participation in Group Projects

- 1= Does not participate in group projects
 2= Participates in Group projects but efforts do not contribute to group effort
 3= Participates in group projects but efforts only partially contribute to group effort
 4= Participates in group projects and efforts contribute to the completion of the project

- 33 **D** Unacceptable Social Behavior
 (stealing, excessive screaming, teasing, lying, etc.)
 1= Unacceptable social behaviors prevent social participation
 2= Unacceptable social behaviors often disrupt social participation
 3= Unacceptable social behaviors seldom interfere with social participation
 4= Unacceptable social behaviors do not occur or do not interfere with social participation

EMOTIONAL DOMAIN

- 34 **D** Aggression
 1= Has had one or more violent episodes, causing serious physical injury within past year
 2= Has had one or more violent episodes, causing minor physical injury within past year
 3= Resorting to verbal abuse and threats are typical of client's behavior but client has not caused physical injury within past year
 4= Episodes of displaying anger are undetectable or rare and appropriate to the situation

Frequency of Self-Injurious Behavior

(biting, scratching, putting inappropriate objects into ear, mouth, etc.)

- 1= . bii)plays self-injurious behavior at least once a day and/or may require restraint as a preventive measure
- 2= Displays self-injurious behavior at least once a week
- 3= Displays self-injurious behavior at least once a month
- 4= Displays self-injurious behavior not more than three (3) times a year
- 5= Rarely or never displays self-injurious behavior,

36 Severity of Self-Injurious Behavior

(biting, scratching, putting inappropriate objects into ear, mouth, etc.)

- 1"" Self-injurious behavior causes severe injury at least once per week which requires a physician's attention
- 2"" Self-injurious behavior causes severe injury at least once a month which requires physician's attention and/or minor injury at least once per week which requires first aid
- 3= Self-injurious behavior causes severe injury at least once a year which requires physician's attention and/or minor injury at least once per month which requires first aid
- 4"" Behavior exists but no apparent injury occurs
- 5= Rarely or never displays self-injurious behavior

37 Smear Feces

- 1= Smears feces at every opportunity unless prevented
- 2= Smears feces once per week or more
- 3= Smears feces not so often as once a week
- 4= Smears feces only when agitated or nervous
- 5= Never smears feces

38 Destruction of Property

- 1"" Has caused serious property damage within the past year
- 2"" Has caused minor property damage on six (6) or more occasions within the past year
- 3= Has caused minor property damage on two (2) to five (5) occasions within the past year
- 4= Has caused minor property damage once during the past year
- 5"" Does not damage property

39 Running or Wandering Away

- 1= Running or wandering away occurs daily unless prevented
- 2= Running or wandering away occurs weekly but not daily unless prevented
- 3"" Running or wandering away occurs at least once a month
- 4= Running or wandering away occurs at least once every three months
- 5.; Running or wandering away occurs at least once a year
- 6= Running or wandering away is threatened but not attempted
- 7"" Does not run or wander away

40 Depressive-like Behavior

(listlessness, excessive crying and weeping, suicidal threats, etc.)

- y.: Client is too young to display this type of behavior
- O= Client is too disabled to display this type of behavior
- 1= Depressive-like behavior inhibits all functions (prevents interaction with others, daily activities, etc.)
- 2= Depressive-like behavior substantially affects all functions (limits communication and typical performance in daily activities, etc.)
- 3= Depressive-like behavior has minimal effect on functioning (attends to daily activities with slight decrease in performance, etc.)
- 4= No evidence of depressive-like behavior (maintains typical daily activities, etc.)

41 Reaction to Frustration

- Y= Client is too young to display this type of behavior
- D= Client is too disabled to display this type of behavior
- t= Becomes aggressive or hostile in most daily situations when thwarted, hindered or obstructed
- 2= Becomes aggressive or hostile at least once a week when thwarted, hindered or obstructed
- 3= Becomes aggressive or hostile less often than once a week when thwarted, hindered or obstructed
- 4= Deals effectively with frustrating situations; rarely becomes aggressive or hostile when thwarted, hindered or obstructed

Repetitive Body Movements

(hand flapping, rocking and other stereotypic behaviors)

- y= Client is too young to display this type of behavior
- D= Client is too disabled to display this type of behavior
- t= Repetitive body movements occur continuously (without cessation) during waking hours
- 2= Repetitive body movements occur continuously but client can be distracted from behavior (when attending to task, etc.)
- 3= Some repetitive body movements occur daily regardless of situation
- 4= Repetitive body movements occur only under conditions of excitement and/or stress
- 5= No apparent repetitive body movements

Inappropriate Undressing

- y.: Client is too young to display this type of behavior
- D.: Client is too disabled to display this type of behavior
- 1= Undresses self inappropriately in shopping centers, playgrounds, schoolrooms, etc.
- 2= Undresses self in residence inappropriately more than once per week
- 3= Undresses self in residence inappropriately not more than once per week
- 4= Does not undress self inappropriately

Hyperactivity

(as manifested by over-excitability, restlessness, constant movement: exclude CNS spastic movements)

0= Client is too disabled to display this type of behavior

1= Is hyperactive in all environments even with individual attention (one-to-one supervision)

2= Is hyperactive except when given individual attention (one-to-one supervision)

3= Is hyperactive only in stressful situations (when in groups of unfamiliar people, when being reprimanded, etc.); hyperactivity is otherwise controlled by behavior modification techniques and/or medication

4= Hyperactivity is controlled by behavior modification techniques and/or medication

5= No apparent hyperactivity

45 O Temper Tantrums

(emotional outbursts)

D= Client is too disabled to display this type of behavior

1= Typically displays temper tantrums daily and/or may require restraint as a preventive measure

2= Typically displays temper tantrums at least once a week but not daily

3= Typically displays temper tantrums at least once a month but not weekly

4= Displays temper tantrums not more than three (3) times a year

5= Does not display temper tantrums

46 O Resistiveness

(inappropriately stubborn and uncooperative)

Y= Client is too young to display this type of behavior

0= Client is too disabled to display this type of behavior

1= Is resistive in all situations

2= Is resistive in one or more situations

3= Is resistive *only* in stressful situations (when in groups of unfamiliar people, when being reprimanded, etc.)

4= Is not resistive

Adjustment to Changes in Social Relationships

(change of caretaker, disruption of friendship group)

D= Client is too disabled to display this type of behavior

1= Changes in social relationships cause disruption of typical functioning which extends over at least a 3-month period

2= Changes in social relationships cause disruption of typical functioning but there is improvement within one month

3= Changes in social relationships do not appear to disrupt typical functioning

4= Changes in social relationships appear to lead to improvement and personal growth

48 D Adjustment to Changes in Physical Environment

D= Client is too disabled to display this type of behavior

1= Changes in physical environment cause disruption of typical functioning which extends over at least a 3-month period

2= Changes in physical environment cause disruption of typical functioning but there is improvement within one month

3= Changes in physical environment do not appear to disrupt typical functioning

4= Changes in physical environment appear to lead to improvement and personal growth

COGNITIVE DOMAIN

49 O Auditory Perception

(hearing aid may be worn)

1= Does not react to sounds

2= Demonstrates startle response to loud sounds

3= Turns head or eyes towards sound source

4= Responds differently to voices compared to other sounds (by smiling or paying attention to the voices)

5= Responds to voices of familiar people differently from strangers' voices

6= Recognizes words that sound different ("cat" and "door")

7= Recognizes words that sound the same ("hit" and "sit")

SO D Visual Perception

(glasses may be worn)

1= Does not explore visually (includes continuous staring)

2= Some visual exploration, but does not follow moving objects

3= Eyes follow moving objects

4= Rotates head and inspects surroundings (if no motor limitations)

5= Searches for object which disappears from sight

6= Responds differently to grossly different objects (a ball and a pencil)

7= Responds differently to similar objects (a cat and a dog)

a= Responds differently to objects (based on differences of color, size or shape)

51 O Associating Time with Events and Actions

t= Does not associate events and actions with time

2= Associates regular events with morning, noon, or night

3= Associates regular events with a specific hour (dinner is at six)

4= Associates events with specific time in past, present and future (the ball game is at six tomorrow)

- 52 **O** Number Awareness
- 1= Does not count
 - 2= Counts, but inaccurately or by rote
 - 3= Counts to 10 and associates single-digit numbers with quantities
 - 4= Counts to 10 and understands relative values (8 is larger than 3)
 - 5= Counts, including use of multi-digit numbers, and associates multi-digit numbers with quantities

- 53 **O** Writing Skills
(including Braille and typing)
- 1= Does not copy or trace
 - 2= Copies from model or traces
 - 3= Prints (no model) single letters or name only
 - 4= Prints single words only
 - 5= Prints words and sentences legibly
 - 6= Uses longhand for words and sentences

Reading Skills

(including Braille)

- 1= Does not read
- 2= Recognizes single letters
- 3= Reads simple words but does not comprehend
- 4= Reads and comprehends simple words
- 5= Reads and comprehends simple sentences
- 6= Reads and comprehends complex sentences and stories

- 55 **D** Attention Span
- 1= Does not keep attention focused on a single activity
 - 2= Keeps attention focused on a single activity for less than one minute
 - 3= Keeps attention focused on a single activity between one and five minutes
 - 4= Keeps attention focused on a single activity between five and fifteen minutes
 - 5= Keeps attention focused on a single activity between fifteen and thirty minutes
 - 6= Keeps attention focused on a single activity for more than thirty minutes

Safety Awareness

(following safety rules and avoiding hazardous situations)

- 1= Frequently endangers self, must be supervised at all times
- 2= Occasionally endangers self, requires supervision on a daily basis
- 3= Endangers self only in unfamiliar situations or settings
- 4= Typically does not endanger self

- 57 **O** Remembering Instructions and Demonstrations
- 1= Does not display memory of instructions or demonstrations
 - 2= Displays *memory* of instructions or demonstrations if they are repeated three or more times and the client is prompted in recall
 - 3= Displays *memory* of instructions or demonstrations if they are given once and the client is prompted in recall
 - 4= Displays *memory* of instructions or demonstrations without prompting if they are given once

COMMUNICATION DOMAIN

- 58 **O** Word Usage
- 1= No use of words
 - 2= Uses simple (one-syllable) words and associates words with appropriate objects
 - 3= Uses complex words and associates words with appropriate objects, but has a limited vocabulary
 - 4= Has a broad vocabulary, understands meaning of words and uses them in appropriate contexts

- 59 **D** Expressive Nonverbal Communication
(not including sign language or communication aids)
- 1= No expressive nonverbal communication
 - 2= Expresses needs or reactions by squirming, returning smiles, etc.
 - 3= Communicates by pointing, shaking head, leading by the hand, etc.
 - 4= Gestures with hands, uses facial expressions for communication

Receptive Nonverbal Communication

(not including sign language)

- 1= Does not demonstrate understanding of gestures (tactile or visual) or facial expressions
- 2= Demonstrates understanding of simple gestures ("yes", "no", pointing to an object)
- 3= Demonstrates understanding of complex gestures
- 4= Demonstrates understanding of a series of gestures (tactile or visual)

Receptive Language

- 1= Does not understand speech
- 2= Understands simple words
- 3= Understands simple phrases or instructions
- 4= Understands meaning of simple conversation and combination of verbal instructions
- 5= Understands meaning of story plot and complex conversation

- 62 1= Makes no sound
 Babbles but says no words
 Says words
 Says two-word sentences go," "Give me
- Says sentences of three or more words
 Carries on basic conversation
 Carries on more complex conversation

- 66 O Clarity of Speech
- 1= Makes no sounds
 No intelligible speech
 Speech understood only by those who know the client well
 Speech understood by strangers with some difficulty
 Speech is readily understandable to a stranger

- 63 D Receptive Sign Language
- Skills not needed
 Does not respond to signs or fingerspelling
 Responds to one to nine signed basic survival words (stop, restroom, come, as well as other common signs (simple commands, food, clothing,
- 3:: Responds to signed complex commands made up of two or more parts ("Go to the bathroom and bring me a towel")
 Responds to signed complex commands, directions and explanations with a combination of signs and simple fingerspelling
 Responds to signed questions (3. or more words) with a combination signs and fingerspelling

- 64 O Expressive Sign Language
- N= Skills not needed
 1= Does not sign or imitate signs
 2= Imitates sign language but makes no meaningful signs
 3= Makes one to nine signs independently to indicate a need
 4= Makes ten or more signs independently to indicate needs
 5= Makes twenty or more signs independently to indicate needs **and/or** simple conversation
 Makes or more signs, fingerspells simple words and makes simple sentences
 Signs and fingerspells independently in carrying on conversations as well as expressing needs

Expressive Communication With Aids

(includes all types of specialized devices which allow or facilitate communication)

- Aids not needed
- 1= Does not communicate with aids
 2= Communicates single words or ideas
 3= Forms short sentences: combines subject and verb
 4= Communicates combinations of sentences and groups <f ideas together

Appendix B: Revised Evaluation Element Items

DAILY LIVING SKILLS

1. USING HANDS

- 1 =Does not use either hand
- 2 =Grasps objects with one hand
- 3 =Grasps objects with both hands
- 4 =Uses fingers of one hand to manipulate objects
- 5 =Uses fingers of both hands to manipulate objects

2. WALKING

- 1 =Can not walk
- 2 =Walks with support
- 3 =Walks alone at least ten (10) feet, but is unsteady
- 4 =Walks alone at least twenty (20) feet, but is unsteady
- 5 =Walks alone at least twenty (20) feet with good balance

3. USING A WHEELCHAIR

- 1 =Sits in manual or motorized wheelchair, but can not move it
- 2 =Uses manual or motorized wheelchair, but needs assistance
- 3 =Uses manual or motorized wheelchair independently, but has difficulty steering
- 4 =Uses manual or motorized wheelchair independently and smoothly in some situations
- 5 =Uses manual or motorized wheelchair independently and smoothly in nearly all situations

4. TAKING PRESCRIPTION MEDICATION

- 1 =Requires assistance to take medication.
- 2 =Takes medication with supervision
- 3 =Takes medication when reminded
- 4 =Usually takes medication without reminders
- 5 =Always takes medication without reminders

5. EATING

- 1 = Does not feed self; must be fed completely
- 2 = Eats with fingers with assistance
- 3 = Eats with fingers without assistance
- 4 = Eats with at least one utensil, with spillage
- 5 = Eats with at least one utensil, without spillage

6. TOILETING

- 1 = Not toilet or habit trained
- 2 = Habit trained only (toilets at preset intervals)
- 3 = Toilets when prompted
- 4 = Toilets without prompting, but needs assistance
- 5 = Toilets independently; does not require assistance

7. BLADDER AND BOWEL CONTROL

- 1 = No control of either bladder or bowel
- 2 = Wetting and/or soiling occur at least once a week during waking hours
- 3 = Wetting and/or soiling occur at least once a week at night
- 4 = Wetting and/or soiling occur no more than once a month
- 5 = Complete control of bladder and bowel

8. PERSONAL CARE

(Brushing teeth, washing, bathing/showering, hair care, use of deodorant, and care related to gender and age; e.g., shaving and menses. If the consumer can do some of these tasks, but not all, choose the answer that most accurately reflects how much support the consumer requires.)

- 1 = Does not perform or assist with personal care activities
- 2 = Assists with personal care activities by performing helpful movements
- 3 = Performs personal care activities, but needs assistance
- 4 = Performs personal care activities independently when reminded
- 5 = Performs personal care activities independently without reminders

9. DRESSING

(Putting on and removing clothing and shoes, fastening zippers, velcro tabs, and buttons. If the consumer can do some of these tasks, but not all, choose the answer that most accurately describes how much support the consumer requires.)

- 1 = Does not dress self
- 2 = Assists with dressing by performing helpful movements
- 3 = Dresses self, but needs assistance
- 4 = Dresses self independently, but needs reminders to complete
- 5 = Dresses self independently without reminders

10. SAFETY AWARENESS

(Following safety rules and avoiding hazardous situations. The phrase all settings includes both familiar and unfamiliar situations.)

- 1 = Requires constant supervision during waking hours to prevent injury/harm in all settings
- 2 = Requires someone nearby during waking hours to prevent injury/harm in all settings
- 3 = Requires constant supervision to prevent injury/harm in unfamiliar settings only
- 4 = Requires someone nearby to avoid injury/harm in unfamiliar settings only
- 5 = Does not require supervision to prevent injury/harm

11. FOCUSING ON TASKS AND ACTIVITIES

(Visual or other kind of direct attention to tasks requiring cognitive activity and response; TV watching not included. If the consumer shows different levels of skill in different situations, choose the answer that describes what the consumer does most frequently.)

- 1 = Focuses on a preferred task or activity for less than 1 minute
- 2 = Focuses on a preferred task or activity for between 1 and 5 minutes
- 3 = Focuses on a preferred task or activity for between 5 and 15 minutes
- 4 = Focuses on a preferred task or activity for between 15 and 30 minutes
- 5 = Focuses on a preferred task or activity for more than 30 minutes

12. VERBAL COMMUNICATION

(Use of words to ask for something or to indicate needs.)

- 1 = Does not use words to communicate
- 2 = Uses words to communicate, but speech is not easily understood by strangers
- 3 = Uses simple statements of one or two words (e.g. "I go" or "Give me")
- 4 = Uses sentences of three words or more and has a limited vocabulary (30 words or less)
- 5 = Uses sentences of three words or more and has a vocabulary of more than 30 words

13. NONVERBAL COMMUNICATION

(Communication through means other than words, including the use of specialized devices that allow or facilitate communication.)

- 1 = Does not use signals, gestures, or signs to communicate
- 2 = Communicates through movement, smiling, making eye contact, etc.
- 3 = Communicates through simple gestures such as pointing, shaking head, or leading by the hand
- 4 = Uses signs/gestures and facial expressions to communicate, but does not understand those of other people
- 5 = Uses and understands signs/gestures and facial expressions in communication

14. SOCIAL INTERACTION

(Two-way communication with others using either verbal or nonverbal cues. The interaction may involve either peers, family members, or staff. If the consumer shows different levels of skill in different situations, choose the answer that describes what the consumer does most frequently.)

- 1 = Does not engage in interaction with others
- 2 = Does not initiate interaction with others
- 3 = Initiates interactions with others
- 4 = Initiates and maintains interactions in familiar situations/settings
- 5 = Initiates and maintains interactions in familiar and unfamiliar situations/settings

CHALLENGING BEHAVIORS

15. DISRUPTIVE SOCIAL BEHAVIOR

(Behavior that has a negative impact on social participation in group settings at school, day program, home, or work; the impact should be severe enough to interrupt or prevent participation in activities.)

- 1 = Disruptive behavior interferes with social participation almost every day
- 2 = Disruptive behavior interferes with social participation at least once a week, but not every day
- 3 = Disruptive behavior interferes with social participation at least once a month, but not every week
- 4 = Disruptive behavior interferes with social participation less than once a month
- 5 = Disruptive behavior never occurs

16. AGGRESSIVE SOCIAL BEHAVIOR

(Behavior that harms or has the potential of harming others.)

- 1 = Physical aggression resulting in injury occurred more than one time within the past 12 months
- 2 = Physical aggression resulting in injury occurred one time within the past 12 months
- 3 = The consumer has not caused injury within the past 12 months, but physical aggression occurs once a month or more
- 4 = The consumer has not caused injury within the past 12 months, but physical aggression occurs less than once a month
- 5 = Physical aggression never occurs

17. SELF-INJURIOUS BEHAVIOR
(Biting, scratching, or causing injury by putting inappropriate objects into ear, mouth, etc.)
- 1 = Self-injurious behavior causes injury requiring first aid or medical care almost every day
 - 2 = Self-injurious behavior causes injury requiring first aid or medical care at least once a week, but not every day
 - 3 = Self-injurious behavior causes injury requiring first aid or medical care at least once a month, but not every week
 - 4 = Self-injurious behavior occurs, but no apparent injury occurs
 - 5 = Self-injurious behavior never occurs
18. DESTRUCTION OF PROPERTY
(Intentional damage to physical property belonging to self or other; value of object must be \$25 or more)
- 1 = Has caused major damage (requiring replacement and/or substantial repair of object) more than once within the past 12 months
 - 2 = Has caused major damage (requiring replacement and/or substantial repair of object) once within the past 12 months
 - 3 = Has caused minor damage (requiring little or no repair of object) more than once within the past 12 months
 - 4 = Has caused minor damage (requiring little or no repair of object) once during the past 12 months
 - 5 = Intentional destruction of property never occurs
19. RUNNING OR WANDERING AWAY
(Leaving premises without authorization and/or supervision in such a way that safety is endangered; do not consider intentionality or volition)
- 1 = Running/wandering away occurs or is attempted almost every day
 - 2 = Running/wandering away occurs or is attempted at least once a week, but not every day
 - 3 = Running/wandering away occurs or is attempted at least once a month, but not every week
 - 4 = Running/wandering away occurs or is attempted less than once a month
 - 5 = Running/wandering away never occurs
20. EMOTIONAL OUTBURSTS
(Sustained and intense displays of negativity related to frustration, fear, or anger. Intervention refers to intervention by a staff member.)
- 1 = Outbursts occur at least once a week and usually require intervention
 - 2 = Outbursts occur at least once a week, but do not typically require intervention
 - 3 = Outbursts occur less than once a week and usually require intervention
 - 4 = Outbursts occur less than once a week, but do not typically require intervention
 - 5 = Emotional outbursts never occur

Appendix C: Personal Outcomes Element Questions

SCHOOL & WORK

1. What type of school does the consumer attend?
 - 1 = In-home instruction
 - 2 = School with special education students only
 - 3 = Integrated school with some integrated classes
 - 4 = Integrated school with fully integrated academic classes

2. On a typical day, how much contact does the consumer have at school with students who do not have a disability?
 - 1 = No contact
 - 2 = Contact outside of academic classes only
 - 3 = Some contact in academic classes, but not all day
 - 4 = Contact all day (Fully included)

3. On a typical day, how many people does the consumer interact with at school who speak the consumer's primary language (e.g., Spanish, English, Cambodian)?
 - 1 = None
 - 2 = At least one
 - 3 = More than one but not all
 - 4 = All

4. In what type of work or day program does the consumer participate most often?
 - 1 = Day program
 - 2 = Sheltered workshop/facility based employment
 - 3 = Community based employment with supports by vendor agency
 - 4 = Community based employment without supports by vendor agency

5. On a typical day, how many people does the consumer interact with at the day program and/or work site who do not have a disability? (Include both peers and staff.)
 - 1 = None
 - 2 = A few
 - 3 = Most
 - 4 = All

6. On a typical day, how many people does the consumer interact with at the day program and/or work site who speak the consumer's primary language (e.g., Spanish, English, Cambodian)? (Include both peers and staff.)
 - 1 = None
 - 2 = At least one
 - 3 = More than one but not all
 - 4 = All

7. In a typical week, how many hours is the consumer paid for work? (Please estimate if the consumer is paid for productivity.)
- 1 = Less than 10 hours
 - 2 = 10 to 25 hours
 - 3 = 26 to 39 hours
 - 4 = 40 hours or more
8. In a typical week, how much does the consumer earn per hour of work? (Please estimate if the consumer is paid for productivity.)
- 1 = Consumer is paid less than minimum wage
 - 2 = Consumer is paid minimum wage
 - 3 = Consumer is paid more than minimum wage
 - 4 = Consumer is a salaried employee

COMMUNITY & SOCIAL LIFE

9. During the past 6 months, about how often did the consumer participate in community outings for personal errands, recreation, entertainment, or church?
- 1 = Once a month or less
 - 2 = More than once a month, but not every week
 - 3 = At least once a week, but not every day
 - 4 = Almost every day
10. How many friends does the consumer have?
(Friends include individuals with whom the consumer maintains an ongoing relationship by initiating contact, sharing confidences, and/or engaging in special activities; may include family members, but not paid staff or support persons.)
- 1 = None
 - 2 = One
 - 3 = Two or three
 - 4 = More than three

OUT OF HOME LIVING

11. Including the consumer, how many people with disabilities live in the household? (Include both peers and staff.)
- 1 = Five or more
 - 2 = Three or four
 - 3 = Two
 - 4 = Consumer is the only person with a disability
12. How many times has the consumer moved from one residence to another in the last two years?
- 1 = Three times or more
 - 2 = Twice
 - 3 = Once
 - 4 = Consumer has not moved

13. On a typical day, how many people who live at the consumer's household speak the consumer's primary language (e.g., Spanish, English, Cambodian)? (Include both peers and staff.)
- 1 = None
 - 2 = At least one
 - 3 = More than one but not all
 - 4 = All

HEALTH & SAFETY

14. Did the consumer see a physician, nurse practitioner, or physician's assistant for medical care (including check-ups) during the past 12 months?
- 1 = No, but medical care was needed
 - 2 = Yes, but needs were not met
 - 3 = Yes, but needs were only partially met
 - 4 = Yes, and needs were fully met
15. Did the consumer see a dentist for dental care (including check-ups) during the past 12 months?
- 1 = No, but dental care was needed
 - 2 = Yes, but needs were not met
 - 3 = Yes, but needs were only partially met
 - 4 = Yes, and needs were fully met
16. Does the consumer currently have a medical and/or dental condition for which appropriate care is not being provided, although it should be?
- 1 = Yes, and problems are life threatening
 - 2 = Yes, and problems are serious enough to affect well-being
 - 3 = Yes, but problems are not serious enough to affect well-being
 - 4 = No

CONSUMER SURVEY

17. Some people like where they live and others don't. When you think about how you feel most of the time...
Do you like living at _____?
- 0 = Negative Response
 - 1 = Ambivalent or Mixed Response
 - 2 = Positive Response
18. Some people like the people who help them at home and others don't. When you think about how you feel most of the time...
Do you like the people who help you at _____?
- 0 = Negative Response
 - 1 = Ambivalent or Mixed Response
 - 2 = Positive Response

19. Some people wish they could live some place else. Others want to stay where they are. When you think about how you feel most of the time...
Do you want to keep living at _____?
0 = Negative Response
1 = Ambivalent or Mixed Response
2 = Positive Response
20. Some people like their school (or day program or job) and others don't. When you think about how you feel most of the time...
Do you like going to _____?
0 = Negative Response
1 = Ambivalent or Mixed Response
2 = Positive Response
21. Some people like the people who help them at their school (or day program or job) and others don't. When you think about how you feel most of the time...
Do you like the people who help you at _____?
0 = Negative Response
1 = Ambivalent or Mixed Response
2 = Positive Response
22. Some people wish they could go to another school (or day program or job). Others want to stay where they are. When you think about how you feel most of the time...
Do you want to keep going to _____?
0 = Negative Response
1 = Ambivalent or Mixed Response
2 = Positive Response
23. We all feel sad or unhappy sometimes. Talking to other people about what happened can help us feel better. Who do you talk to when you are sad or unhappy? (Ask Who Else? after the first name is given. Do not repeat.)
0 = Consumer does not name anyone
1 = Consumer names one person
2 = Consumer names more than one person.
24. We all feel afraid or scared sometimes. Some people feel like that a lot of the time. Others feel safe most of the time. Do you feel safe or afraid most of the time?
0 = Afraid
1 = Ambivalent or Mixed Response (e.g., maybe; it depends, sometimes)
2 = Safe
25. We all feel sad or unhappy sometimes. Some people feel like that a lot of the time. Others feel happy most of the time. Are you happy or sad most of the time?
0 = Sad
1 = Ambivalent or Mixed Response (e.g., maybe; it depends, sometimes)
2 = Happy

26. We all have times when we need something or want to do something different. Sometimes we speak up and sometimes we keep quiet about it.

Do you tell people what you want most of the time?

0 = Negative Response

1 = Ambivalent or Mixed Response (e.g., maybe; it depends, sometimes)

2 = Positive Response

Appendix D: Sample Visual Presentation of CDER Profile Information

	Not Relevant	Low Skill 1	2	3	4	High Skill 5
Wheelchair Use						
Nonverbal Communication						

	Low 1	2	3	High 4
Unmet Medical Needs				
Ability to Advocate For Self				

	Low Competence 1	2	3	4	High Competence 5
Practical Independence					
Personal and Social Skills					
Challenging Behavior					

	Low 1	2	3	4	High 5
Personal Well-Being					
Integration and Inclusion					

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