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**Attachments 7e-7f-7g-7h: Second follow-up Survey of SEED 1 Adult Children**

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# SEED Follow-Up Study: Second Follow-up Survey of Young Adults (Self-Report)

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## A. Exit from High School

1. When did you complete your high school education?

Month	Year

I did not attend high school (**Skip to Section B, Living Situation**)

2. When you left high school, did you...

- Receive a regular diploma
- Receive an occupational diploma
- Receive a certificate of completion
- Take a test and receive a GED without completing all classes
- Drop out or stop going
- Get expelled (or suspended but did not return)
- I did not attend high school
- Other, specify: \_\_\_\_\_

3. Since leaving high school, have you... (Check all that apply)

- Attended a 2 year or community college
- Graduated with a diploma, certificate, or license from a 2 year or community college
- Attended a vocational, business, or technical school after high school
- Graduated with a diploma, certificate, or license from a vocational, business, or technical school
- Attended a 4-year college
- Graduated with a degree, certificate, or license from a 4-year college
- Attended a graduate program (e.g., master's or doctoral program)
- Graduated with an advanced degree (e.g., master's or doctoral degree)

4. Are you currently enrolled in college or planning to attend college?

- No
- Yes, Part-time
- Yes, Full-time

## B. Living Situation

1. Where do you currently live or what is your current living situation? (Check only one)

- Independently (alone) with some assistance
- Independently (alone) with no assistance
- Independently (with spouse or roommate)
- With parent(s) or foster parent(s)
- With an adult family member who is not a parent (e.g., sibling, aunt, uncle, cousin, etc.)  
Specify relationship: \_\_\_\_\_
- With a legal guardian who is not a family member
- In a group home within the community
- In a residential facility separated from the community
- Other (Specify, please print): \_\_\_\_\_

## C. Daily Activities and Social Participation

1. Since leaving high school, have you participated in:

	Yes	No	Don't know
A sports team or taken sport lessons?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any clubs or organizations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any other organized activities or lessons, such as music, dance or language?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any type of community service or volunteer work at school, church, or in the community?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any work, including regular jobs as well as babysitting, cutting grass, or other occasional work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. IN THE LAST 6 MONTHS, how often do you usually do the following:

	Never	At least once	Every other month	Monthly	Weekly	Daily
Get together socially with friends or neighbors?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Call or text friends on the phone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Use email, instant messaging, Skype, texting, Facebook/Instagram/Snapchat messaging or taken part in chat rooms?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Gotten together with ANY relatives, not including those who live with you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gone to church, temple, or another place of worship for services or other activities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gone to a show or movie, sports events, club meeting, or another group event?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gone out to eat at a restaurant?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. DURING THE PAST MONTH, on how many days have you done a total of 30 minutes or more of physical activity, which was enough to raise your breathing rate? *This may include sports, exercise, and brisk walking or cycling for recreation or to get to and from places but should not include housework or physical activity that may be part of your job.*

**Number of days of exercise during the past month: \_\_\_\_\_**

4. ON AN AVERAGE WEEKDAY, about how much time do you usually spend in front of a TV watching TV programs or movies, including streaming services such as Netflix, Hulu, Apple+?

- None
- Less than 1 hour
- 1 hour
- 2 hours
- 3 hours
- 4 or more hours
- I don't know

5. ON AN AVERAGE WEEKDAY, about how much time do you usually spend with computers, tablets, cell phones, handheld video games, and other electronic devices, doing things other than schoolwork or watching videos on YouTube/TikTok, TV shows, or movies?

- None
- Less than 1 hour
- 1 hour
- 2 hours
- 3 hours
- 4 or more hours
- I don't know

## D. Vocational Support and Training

The next questions are about services or training you may have received after high school exit to help you find and/or keep a job.

1. After you exited high school, did you receive any of the following services? (Check all the apply)

	Service	Yes	No	Don't know
a.	Testing to find out your work interests or abilities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b.	Training in specific job skills, for example food services, computer skills, or training for another kind of job.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c.	Training in basic skills needed for work, like counting change, telling time, or using transportation to get to work.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d.	Career counseling, like help in figuring out jobs that might best suit you.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e.	Help in learning how to search for available job positions online, write a resume, or prepare for a job interview.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f.	Job shadowing, such as visiting a workplace and watching the way a job is done.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g.	Apprenticeships or internships.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h.	Other services or training? Specify: _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Do you think you are getting enough job or career training?

- Yes
- No
- Don't know

3. How useful do you think job or career training is in helping you get a job?

- Very useful
- Somewhat useful
- Not very useful
- Not at all useful
- Don't know

4. Do you think you need job training or additional training that is not being provided now?

- Yes
- No (**Skip to Section E**)
- Don't know (**Skip to Section E**)

5. What other kinds of job training or help do you think you need? (Check all that apply)

- Testing to find out your work interests or abilities
- Training in specific job skills, for example food services, computer skills, or training for another kind of job
- Training in basic skills needed for work like counting change, telling time, or using transportation to get to work
- Career counseling like help in figuring out jobs you might be suited to
- Help in finding or applying for a job such as learning how to search for available job positions online, write a resume, or prepare for a job interview
- Job shadowing, visiting a workplace and watching the way the job is done
- Apprenticeships or internships
- Other, specify: \_\_\_\_\_
- Don't know

## E. Job and Work Experience

- At any time since leaving high school have you worked for pay other than work around the house?
  - Yes (**Skip to question 3**)
  - No

- You have told us you are not currently working for pay. Please help us understand your situation. *Check all that apply then skip to Section F, Financial Support.*

<input type="checkbox"/>	Want to work but can't find work
<input type="checkbox"/>	Have tried to work but faced discrimination or other difficulties with employers because of a disability
<input type="checkbox"/>	Do not wish to work at present (taking care of family members, a stay-at-home parent, etc.)
<input type="checkbox"/>	Not able to work because it would interfere with federal or state benefits (such as disability payments)
<input type="checkbox"/>	Not able to work because the workplace would be too challenging (because of ASD or other health or mental health issues)
<input type="checkbox"/>	Have an unpaid internship or volunteer position
<input type="checkbox"/>	Full-time or part-time college student
<input type="checkbox"/>	Other (Specify: _____)

### Skip to Section F, Financial Support

- What is the longest time you have worked at a particular job since leaving high school?

Number of Weeks    OR     Number of Months    OR     Number of Years    OR     Don't Know

- For your current or most recent job, how many hours per week do/did you work on average?

- 1 - 9 hours
- 10 - 19 hours
- 20 - 29 hours
- 30 - 39 hours
- 40 or more hours

- If you work(ed) part-time, or less than 40 hours per week at your current or most recent job, do you work part-time because you want to, or would you rather work full-time?

- Does not apply, I work(ed) full time
- I want to work part-time
- I would rather work full-time
- Other, specify \_\_\_\_\_



6. For your current or most recent job, about how much are/were you paid per hour, per month, or per year at this job?

\$  per hour    OR    \$  per month    OR    \$  per year

7. Did you receive benefits from this job? (Check all that apply)

- Health Insurance
- Vacation/Sick leave
- Retirement account
- Other insurance (e.g., disability, life, dental, vision)
- Tuition assistance
- None

8. For your current or most recent job, what was the work situation?

<input type="checkbox"/>	Regular paid employment (with no help or support)
<input type="checkbox"/>	Supported employment (you may have a job coach or other special help at work)
<input type="checkbox"/>	Work in a business with a group of other people with special needs, all under supervision of an agency serving people with disabilities
<input type="checkbox"/>	Day program that includes paid work
<input type="checkbox"/>	Paid internship or work study program
<input type="checkbox"/>	Other, specify: _____

9. How satisfied are you with the work situation at your current or most recent job?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied

10. For your current or most recent job, what is the job title?

Job Title: \_\_\_\_\_

11. Did you find your current or most recent job yourself or did you have help?

- Found the job on my own
- Found the job with help from an agency (e.g., a job coach or vocational rehab)
- Found the job with help from a family member or friend?
- Other, specify: \_\_\_\_\_

12. Have you ever applied for any accommodations or supports to help you keep a job?

- Yes, applied and received job accommodations and/or supports
- Yes, applied but did NOT receive job accommodations and/or supports (**Skip to Section F, Financial Support**)
- No, never applied for job accommodations or supports (**Skip to Section F, Financial Support**)

13. If you have ever received accommodations or supports to help maintain employment, how useful were these services?

- Not useful at all (i.e., did not provide any additional advantage keeping job)
- Slightly useful (i.e., helped a little for keeping job)
- Useful (i.e., helped a good deal for keeping job)
- Very useful (i.e., made the difference between keeping or losing a job)

## F. Financial Support

- How much do you rely on your family (such as parents and siblings) for financial support such as paying your bills, housing, transportation, spending money for entertainment, or other financial?
  - My family **does not provide** any financial support for me at all.
  - My family provides **less than half** of my financial support. They help me financially sometimes.
  - My family provides **about half** of my financial support.
  - My family provides **more than half** (but not all) of my financial support.
  - My family provides **all** my financial support.
  
- What federal or state benefits do you currently receive? (Check all that apply or "none" if none apply)

Social Security Disability Insurance (SSDI)	<input type="checkbox"/>
Supplemental Security Income (SSI)	<input type="checkbox"/>
State disability programs that use only state and/or local funds	<input type="checkbox"/>
Medicaid (for health insurance)	<input type="checkbox"/>
Medicare	<input type="checkbox"/>
Medicaid HCBS (Home and Community Based Services) waiver or Developmental Disability waiver	<input type="checkbox"/>
Employment assistance or job support (sometimes called "Vocational Rehabilitation" or "VR")	<input type="checkbox"/>
Section 8 Housing	<input type="checkbox"/>
Transportation services for people with disabilities	<input type="checkbox"/>
Other, specify: _____	<input type="checkbox"/>
None	<input type="checkbox"/>

## G. Health, Mental Health, & Health Care Service Use and Need

1. Which of the following best describes your general health? Please mark ONE Box.

- Excellent
- Very good
- Good
- Fair
- Poor

2. OVER THE LAST 2 WEEKS, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Feeling anxious, nervous, or on-edge.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not being able to stop or control worrying.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. OVER THE LAST 2 WEEKS, how often have you been bothered by the following problems?

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feeling down, depressed, or hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Have you ever seriously thought about committing suicide?

- Yes
- No

5. Have you ever made a plan for committing suicide?

- Yes
- No

6. Have you ever attempted suicide?

- Yes
- No

7. Since leaving high school, was there any time when you needed health care, but you did not receive it?  
*By health care, we mean medical care as well as other kinds of care like dental care, vision care, and mental health services.*

- Yes
- No **(Skip to question 10)**

8. If yes, which types of care were NOT received? (Check ALL that apply)

- Dental Care
- Hearing Care
- Medical care, routine preventative
- Medical care, sick or urgent care
- Medical care, hospital emergency
- Medical care, specialist
- Medical services for diagnosis or evaluation related to a disability
- Mental Health Services, counseling, or psychological services
- Vision Care
- Other, Specify \_\_\_\_\_

9. Which of the following contributed to you not receiving needed health care services:

	Yes	No
I did not have health insurance that covered the services needed	<input type="checkbox"/>	<input type="checkbox"/>
I was not eligible for the services	<input type="checkbox"/>	<input type="checkbox"/>
The services I needed were not available in my area	<input type="checkbox"/>	<input type="checkbox"/>
There were problems getting an appointment when I needed one	<input type="checkbox"/>	<input type="checkbox"/>
There were problems with getting transportation	<input type="checkbox"/>	<input type="checkbox"/>
The (clinic/doctor's) office wasn't open when I needed care	<input type="checkbox"/>	<input type="checkbox"/>
There were issues related to cost	<input type="checkbox"/>	<input type="checkbox"/>
There were issues related to COVID-19 (e.g., concerned about being around others at doctor's office who may have been exposed to COVID-19)	<input type="checkbox"/>	<input type="checkbox"/>
Other (Specify: _____)	<input type="checkbox"/>	<input type="checkbox"/>

10. DURING THE PAST 12 MONTHS, have you had a chance to visit or speak with a doctor or other health care provider alone or privately, without your parents or another adult in the room?

- Yes
- No

11. During any visit in the past 12 months did a doctor or other health care provider ask you if you were sexually active?

- Yes
- No
- Don't remember

The next two questions are only for participants who were born female. If you were born male, **skip to question 14.**

12. DURING THE PAST 12 MONTHS, did you receive any of the following services from a doctor or health care provider?

- Information or advice about birth control
- A method of birth control or a prescription for birth control
- Information or advice about other sexually transmitted diseases (STDs), such as gonorrhea, chlamydia, syphilis, herpes, HIV, AIDS, or HPV
- Testing for STDs
- Treatment for STDs
- Information or advice about using condoms to prevent STDs
- None of the above

13. Have you ever received:

- A Pap test - where a doctor or nurse put an instrument in the vagina and took a sample to check for abnormal cells that could turn into cervical cancer?
- An HPV test - where a doctor or nurse put an instrument in the vagina and took a sample to test for the HPV virus?
- The cervical cancer vaccine, also known as the HPV shot, Cervarix, or Gardasil?
- None of the above

The next question is for participants who were born male. If you were born female answer questions 12 and 13 then skip to **Section H, Educational & Developmental Services**

14. DURING THE PAST 12 MONTHS, did you receive any of the following services from a doctor or health care provider?

- Information or advice about your partner using methods of birth control
- Information or advice about HIV or AIDS
- Information or advice about other sexually transmitted diseases (STDs), such as gonorrhea, chlamydia, syphilis, herpes or AIDS, HPV
- Testing for STDs
- Treatment for STDs
- Information or advice about using condoms to prevent STDs
- Information or advice about using condoms to prevent pregnancy
- None of the above

## H. Educational & Developmental Services

1. Since leaving high school, have you received any of the services listed in the table below?  
*Do not include services/help received from family or friends.*

	Yes, received after high school	No, did not receive after high school	If no, did you <u>need</u> this service?
Financial aid, like paying for college classes or training.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Educational assistance or tutoring.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Reader or interpreter, such as a sign language interpreter.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Independent living or occupational therapy (like help with doing things such as managing money, cooking, or housekeeping).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Childcare services or parenting skills training.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Social work services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Physical therapy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Devices or assistive technology services (like a special calculator, reading machine, or communication device).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Other services (Please specify):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/> Yes <input type="checkbox"/> No

2. Overall, how satisfied have you been with all services your child has received since leaving high school?

- Very dissatisfied
- Dissatisfied
- Neither satisfied nor dissatisfied
- Satisfied
- Very Satisfied

## I. Romantic Relationships, Sexual Orientation, and Gender Identity

1. Do you consider yourself...
  - Male
  - Female
  - Non-binary
  - Other, please specify: \_\_\_\_\_
  
2. Do you consider yourself transgender?
  - Yes, transgender, male-to-female
  - Yes, transgender, female-to-male
  - Yes, transgender, nonconforming
  - No
  - Don't know
  
3. Which of the following best describes how you think of yourself?
  - Heterosexual or straight (attracted to people of the opposite sex)
  - Gay or lesbian (attracted to people of the same sex)
  - Bisexual (attracted to people of both sexes)
  - Pansexual (attracted to people of any gender identity regardless of their biological sex)
  - Asexual (not sexually attracted to other people)
  - I describe my sexual identity some other way
  - I am not sure about my sexual identity (questioning)
  - I do not know what this question is asking
  
4. Have you ever been in a relationship with a romantic partner?
  - Yes
  - No
  
5. Are you currently dating or in a relationship with a romantic partner?
  - Yes (**Skip to Section J**)
  - No
  
6. How much would you like to have a romantic relationship in the next year?
  - Not at all
  - Very little
  - Somewhat
  - Quite a bit
  - Very much



## J. Sex Education and Behavior

The next few questions are about your sexual education and behavior. Remember that all answers you give are kept private and will not be shared with anyone without your written consent. Also remember that you can skip any questions that make you feel uncomfortable.

7. Please tell me where you received formal sex education or any information on the following topics (check all that apply).

	School	Church	Community Center	Doctor's office	Health Center	Friends	Online, Internet	Never have received instruction or information on this topic
How to say no to sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Methods of birth control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Where to get birth control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexually transmitted diseases (STDs)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How to prevent HIV/AIDS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How to use a condom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Some other type of education or information	Please specify type of education/information and place received:							

8. Have you ever had sex, either with a same or opposite sex partner?

- Yes  
 No (**Skip to question 13**)

9. The **last time** you had sex with a partner, what birth control method or methods did you or your partner use? (Check all that apply)

- No method was used to prevent pregnancy  
 Birth control pills (Do **not** count emergency contraception such as Plan B or the "morning after" pill.)  
 Condoms  
 An IUD (such as Mirena or ParaGard) or implant (such as Implanon or Nexplanon)  
 A shot (such as Depo-Provera), patch (such as Ortho Evra), or birth control ring (such as NuvaRing)  
 Withdrawal  
 Some other method  
 Not sure

10. Did you drink alcohol or use drugs before you had sex the last time with any partner (same or opposite sex)?

- Yes
- No

11. How old were you when you had sex for the first time with any partner (same or opposite sex)?

- Less than 15 years old
- 15 to 17 years old
- 18 years old or older

12. DURING THE LAST 12 MONTHS, with how many people did you have sex (same or opposite sex)?

- I have had sex, but not during the past 12 months
- 1 person
- 2 to 3 people
- 4 or more people

13. Has anyone ever forced you to do sexual things that you did not want to do? *Examples might include unwanted kissing or touching, physical pressure (being hit, slammed into something, or injured with an object or weapon) or non-physical pressure (verbal pressure, threats of harm, or by being given alcohol or drugs)*

- Yes
- No
- Prefer not to say

## K. Substance Use and Behaviors

14. Think about the statement, “**I did too much.**” IN THE LAST 12 MONTHS, how often did this apply to your...

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Never used or N/A
Alcohol use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tobacco or Nicotine use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cannabis use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cocaine use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Opioid use	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gambling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Video gaming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Over-eating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexual activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Over-working	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## L. Beliefs & Interests

15. While some of these questions will use words such as “spirituality” please answer them in terms of your own personal belief system, whether it be religious, spiritual or personal.

	Not at all	A little	A moderate amount	A lot	An extreme amount
To what extent does any connection to a spiritual being or force help you to get through hard times?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To what extent does any connection to a spiritual being or force help you to tolerate stress?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To what extent does any connection to a spiritual being or force help you to understand others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To what extent does any connection to a spiritual being or force provide you with comfort / reassurance?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. What particular abilities or strengths do you have? *Check all that apply or "none of the above" if none apply.*

- An ability to think in unusual, creative ways
- An ability to focus intensely on certain topics
- Honesty
- A sense of justice
- A different way of experiencing the world
- Ability in mathematics, science, or computers
- Ability in art or music
- A very good memory for certain topics
- An ability to focus on small details
- An incredible imagination
- Kindness
- Other, specify: \_\_\_\_\_
- None of the above

17. Do you have an intense area of interest or focus? (Sometimes this is referred to as a “special interest”)

- No (**Skip to end of survey**)
- Yes

18. What type of special interest or topic do you have? *Check all that apply if you have more than one.*

- Modes of transportation (such as trains, automobiles, aircraft)
- History
- Science (such as astronomy, geology)

- Science fiction or fantasy (in books, films, video games)
- Computers
- Mathematics or numbers
- Animals (such as dogs, fish, horses)
- Movies
- Cartoons or anime
- Maps, calendars, or dates
- Timetables or schedules
- Dinosaurs, monsters, or fictional creatures
- Music
- Art
- Sports
- Sewing or crafts
- Other, specify: \_\_\_\_\_

19. How does your special interest affect your life? *Check all that apply or "none of the above" if none apply.*

- My job or career involves my special interest.
- My studies in school or college are (or were) related to my special interest.
- I have relationships based on my special interest. I make friends or join groups focused on the same interest.
- I enjoy activities and hobbies relating to my special interest.
- My special interest sometimes gets in the way of success at work, school, or in relationships.
- The special interest has gotten me in trouble. (For example, it may have led to addictive behavior or breaking the law.)
- Other, specify: \_\_\_\_\_
- None of the above

**You have reached the end of the survey.**

**Thank you for participating!**

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# WHOQOL-BREF

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June 1997

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U.S. Version



University of Washington  
Seattle, Washington  
United States of America

Emblem...Soul Catcher: a Northwest Coast Indian symbol of physical and mental well-being. Artist: Marvin Oliver



## Instructions

This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks. For example, thinking about the last two weeks, a question might ask:

	(Please circle the number)				
For office use	Not at all	A little	Moderately	Mostly	Completely
Do you get the kind of support from others that you need?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others. ○

	(Please circle the number)				
For office use	Not at all	A little	Moderately	Mostly	Completely
Do you get the kind of support from others that you need?	<b>1</b>	<b>2</b>	<b>3</b>	<b>④</b>	<b>5</b>

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks. ○

	(Please circle the number)				
For office use	Not at all	A little	Moderately	Mostly	Completely
Do you get the kind of support from others that you need?	<b>①</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>



Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

		<i>(Please circle the number)</i>						
		Very poor	Poor	Neither poor nor good	Good	Very Good		
<i>For office use</i>	G1 / G1.1	1.	How would you rate your quality of life?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

		<i>(Please circle the number)</i>						
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied		
<i>For office use</i>	G4 / G2.3	2.	How satisfied are you with your health?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		<i>(Please circle the number)</i>						
		Not at all	A little	A moderate amount	Very much	An extreme amount		
<i>For office use</i>	F1.4 / F1.2.5	3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>For office use</i>	F11.3 / F13.1.4	4.	How much do you need any medical treatment to function in your daily life?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>For office use</i>	F4.1 / F6.1.2	5.	How much do you enjoy life?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

		<i>(Please circle the number)</i>				
		Not at all	A little	A moderate amount	Very much	An extreme amount
<i>For office use</i> F24.2 / F29.1.3	6. To what extent do you feel your life to be meaningful?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

		<i>(Please circle the number)</i>				
		Not at all	Slightly	A Moderate amount	Very much	Extremely
<i>For office use</i> F5.2 / F7.1.6	7. How well are you able to concentrate?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F16.1 / F20.1.2	8. How safe do you feel in your daily life?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F22.1 / F27.1.2	9. How healthy is your physical environment?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		<i>(Please circle the number)</i>				
		Not at all	A little	Moderately	Mostly	Completely
<i>For office use</i> F2.1 / F2.1.1	10. Do you have enough energy for everyday life?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F7.1 / F9.1.2	11. Are you able to accept your bodily appearance?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F18.1 / F23.1.1	12. Have you enough money to meet your needs?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

		<i>(Please circle the number)</i>				
		Not at all	A little	Moderately	Mostly	Completely
<i>For office use</i> F20.1 / F25.1.1	13. How available to you is the information that you need in your day-to-day life?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F21.1 / F26.1.2	14. To what extent do you have the opportunity for leisure activities?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

		<i>(Please circle the number)</i>				
		Very poor	Poor	Neither poor nor well	Well	Very well
<i>For office use</i> F9.1 / F11.1.1	15. How well are you able to get around?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

The following questions ask you to say how **good** or **satisfied** you have felt about various aspects of your life over the last two weeks.

		<i>(Please circle the number)</i>				
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
<i>For office use</i> F3.3 / F4.2.2	16. How satisfied are you with your sleep?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F10.3 / F12.2.3	17. How satisfied are you with your ability to perform your daily living activities?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F12.4 / F16.2.1	18. How satisfied are you with your capacity for work?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

		<i>(Please circle the number)</i>				
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
<i>For office use</i>						
F6.4 / F8.2.2	19. How satisfied are you with yourself?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F13.3 / F17.2.3	20. How satisfied are you with your personal relationships?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F15.3 / F3.2.1	21. How satisfied are you with your sex life?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F14.4 / F18.2.5	22. How satisfied are you with the support you get from your friends?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F17.3 / F21.2.2	23. How satisfied are you with the conditions of your living place?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F19.3 / F24.2.1	24. How satisfied are you with your access to health services?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
F.23.3 / F28.2.2	25. How satisfied are you with your mode of transportation?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

The follow question refers to **how often** you have felt or experienced certain things in the last two weeks.

		<i>(Please circle the number)</i>				
<i>For office use</i>		Never	Seldom	Quite often	Very often	Always
F8.1 / F10.1.2	26. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>

Did someone help you to fill out this form? *(Please circle Yes or No)*

Yes

No

How long did it take to fill out this form?

---

**THANK YOU FOR YOUR HELP**

**DOMAIN SCORES**

Domains	WHOQOL-100 Facets	Raw domain score	Raw score range
Domain 1: Physical	Facet 1 + Facet 2 + Facet 3	12 - 60	48
Domain 2: Psychological	Facet 4 + Facet 5 + Facet 6 + Facet 7 + Facet 8	20 – 100	80
Domain 3: Level of Independence	Facet 9 + Facet 10 + Facet 11 + Facet 12	16 – 80	64
Domain 4: Social relationships	Facet 13 + Facet 14 + Facet 15	12 – 60	48
Domain 5: Environment	Facet 16 + Facet 17 + Facet 18 + Facet 19 + Facet 20 + Facet 21+ Facet 22 + Facet 23	32 – 160	128
Domain 6: Spirituality / Religion / Personal beliefs	Facet 24	4 – 20	16

**TRANSFORMATION OF SCALE SCORES**

The next step involves transforming each raw scale score to a 0-100 scale using the formula shown below:

$$\text{Transformed Scale} = \left[ \frac{(\text{Actual raw score} - \text{lowest possible raw score})}{\text{Possible raw score range}} \right] \times 100$$

where “Actual raw score” is the values achieved through summation, “lowest possible raw score” is the lowest possible value that could occur through summation (this value would be 4 for all facets), and “Possible raw score range” is the difference between the maximum possible raw score and the lowest possible raw score (this value would be 16 for all facets: 20 minus 4).

This transformation converts the lowest and highest possible scores to zero and 100, respectively. Scores between these values represent the percentage of the total possible score achieved. The WHOQOL-100 scores from other Centers may not be transformed to the 0-100 scale. The U.S.WHOQOL instruments and scoring programs have used this transformation to provide comparative data for interpretation.

*Example: A Facet 1 “Pain and discomfort” raw score of 15 would be transformed as follows:*

$$\text{Transformed Scale} = \left[ \frac{(15 - 4)}{16} \right] \times 100 = 68.75$$

## WHOQOL-BREF Scoring

The WHOQOL-Bref, still in field trials, is a subset of 26 items taken from the WHOQOL-100. The same steps for the scoring WHOQOL-100 should be followed to achieve scores for the Bref. Although scoring the Bref is identical to scoring the WHOQOL-100, there are some differences that need to be addressed:

- The WHOQOL-Bref does not have facet scores
- Mean substitutions are recommended for Domain 1 *Physical Health* and Domain 4 *Environment* if no more than one item is coded missing
- Only three items need to be reversed before scoring

The WHOQOL-Bref (Field Trial Version) produces a profile with four domain scores and two individually scored items about an individual's overall perception of quality of life and health. The four domain scores are scaled in a positive direction with higher scores indicating a higher quality of life. Three items of the Bref must be reversed before scoring. They can be seen in Table 9, indicated by the “- (reverse)” denotation in the *Direction of scaling* column.

**TABLE 9. Scoring Domains of the WHOQOL-BREF**

Domains and questions 236/BREF	Direction of scaling	Raw domain score	Raw item score
<b>Overall Quality of Life and General Health</b>		....(2-10)	
G1.1/B1      How would you rate your quality of life?	+		....(1-5)
G2.3/B2      How satisfied are you with your health?	+		....(1-5)
<b>Domain 1      Physical Health</b>		....(7-35)	
F1.2.5/B3      To what extent do you feel that physical pain prevents you from doing what you need to do?	-(reverse)		....(1-5)
F13.1.4/B4      How much do you need any medical treatment to function in your daily life?	-(reverse)		....(1-5)
F2.1.1/B10      Do you have enough energy for everyday life?	+		....(1-5)
F11.1.1/B15      How well are you able to get around?	+		....(1-5)
F4.1.1/B16      How satisfied are you with your sleep	+		....(1-5)
F12.2.3/B17      How satisfied are you with your ability to perform your daily living activities?	+		....(1-5)
F16.2.1/B18      How satisfied are you with your capacity for work?	+		....(1-5)
<b>Domain 2      Psychological</b>		....(6-30)	
F6.1.2/B5      How much do you enjoy life?	+		....(1-5)
F29.1.3/B6      To what extent do you feel your life to be meaningful?	+		....(1-5)
F7.1.6/B7      How well are you able to concentrate?	+		....(1-5)
F9.1.2/B11      Are you able to accept your bodily appearance?	+		....(1-5)
F8.2.1/B19      How satisfied are you with yourself?	+		....(1-5)
F10.1.2/B26      How often do you have negative feelings such as blue mood, despair, anxiety, depression?	- (reverse)		....(1-5)
<b>Domain 3      Social relationships</b>		....(3-15)	
F17.1.3/B20      How satisfied are you with your personal relationships?	+		....(1-5)
F3.2.1/B21      How satisfied are you with your sex life?	+		....(1-5)
F18.2.5/B22      How satisfied are with the support you get from your friends?	+		....(1-5)

Domains and questions 236/BREF		Direction of scaling	Raw domain score	Raw item score
<b>Domain 4</b>	<b>Environment</b>		....(8-40)	
F20.1.2/B8	How safe do you feel in your daily life?	+		....(1-5)
F27.1.2/B9	How healthy is your physical environment?	+		....(1-5)
F23.1.1/B12	Have you enough money to meet your needs?	+		....(1-5)
F25.1.1/B13	How available to you is the information that you need in your daily-to-day life?	+		....(1-5)
F26.1.2/B14	To what extent do you have the opportunity for leisure activities?	+		....(1-5)
F21.2.2/B23	How satisfied are you with the condition of your living place?	+		....(1-5)
F24.2.1/B24	How satisfied are you with your access to health services?	+		....(1-5)
F28.2.2/B25	How satisfied are you with your transport?	+		....(1-5)

If no more than one item from the *Physical Health* or *Environment* domains has been coded as missing, we recommend that a domain score be calculated by substituting a person-specific average across the completed items in the same scale. For example, if a respondent does not have a value for item B16 *How satisfied are you with your sleep?* in the Physical Health domain, but has answered all of the other items in that domain, then the value for item B16 would be the average of the remaining 6 items. If two or more items are coded missing in these two domains, the domain score should not be calculated, likewise if any items are coded missing in the *Psychological* and *Social Relationships* domains, a domain score for that respondent would not be calculated.

After item recoding and handling of missing data, a raw score is computed by a simple algebraic sum of each item in each of the four domains. Once complete, check the frequencies of each domain to be sure that the scores are within the correct range indicated in Table 9 *Raw domain score* column. The next step is to transform each raw scale score using the formula on page 32. The possible raw score ranges for each domain are as follows: *Physical Health*=28, *Psychological*=24, *Social Relationships*=12, and *Environment*=32.

### **SCORING EXERCISE AND TEST DATASET FOR THE WHOQOL-BREF INSTRUMENT**

The purpose of this scoring exercise is to help WHOQOL-Bref users to evaluate results from each step in the process of calculating the Domain summary scores of the instrument. This exercise was created for SPSS users, but with minor modifications, can be adapted for other computer programs or can be useful for those scoring the survey manually.

A test dataset and SPSS code for scoring the WHOQOL-Bref a computer disk in this packet. The test dataset, which is called “**WQ\_BREF.TXT**” on the disk, contains data from 64 administrations of the WHOQOL-BREF. The data can be seen in *Appendix F*. The enclosed diskette also provides the user with the SPSS syntax used to:

- import raw data into SPSS format [**WQ\_B\_DL.SPS**]
- derive the WHOQOL-BREF domain summaries [**WQ\_BREF.SPS**]



The SPSS code (called “**WQ\_BREF.SPS**”) on the disk begins by labeling all items and checking for out-of-range values. It then recodes the 3 negatively stated items so that a higher score indicates better health. The 4 domains are then scored, labeled, and transformed to a 0 to 100 scale used to interpret and compare to other validated instrument tools such as the WHOQOL-100. A copy of the SPSS syntax is reproduced in Appendix F.




Table 10 presents statistics for the transformed domains for the WHOQOL-Bref. After scoring the test dataset, the means, standard deviations, and minimum and maximum observed values should agree with those presented in Table 10

**TABLE 10. Test Dataset Descriptive Statistics: WHOQOL-BREF**




<b>Descriptive Statistics</b>					
	N	Minimum	Maximum	Mean	Std. Deviation
Physical (TRANSFORMED)	64	32.14	92.86	66.7969	14.5480
Psychological (TRANSFORMED)	64	37.50	95.83	73.5026	13.7165
Social Relations (TRANSFORMED)	64	25.00	100.00	73.1771	17.0891
Environment (TRANSFORMED)	64	28.13	100.00	72.8027	14.1592
Valid N (listwise)	64				




## DISABILITIES MODULE




The next question asks about your disability overall.

						
		Not at all	A Little	Moderately	Mostly	Totally
27G	Does your disability have a negative (bad) effect on your day-to-day life?	1	2	3	4	5

The following questions ask about how you have felt about certain things, how much certain things have applied to you, and how satisfied you have been about various parts of your life over the last two weeks

						
		Not at all	A Little	Moderately	Mostly	Totally
28	Do you feel that some people treat you unfairly?	1	2	3	4	5
29	Do you need someone to stand up for you when you have problems?	1	2	3	4	5
30	Do you worry about what might happen to you in the future? <i>For example, thinking about not being able to look after yourself, or being a burden to others in the future.</i>	1	2	3	4	5

						
		Not at all	A Little	Moderately	Mostly	Totally
31	Do you feel in control of your life? <i>For example, do you feel in charge of your life?</i>	1	2	3	4	5
32	Do you make your own choices about your day-to-day life? <i>For example, where to go, what to do, what to eat.</i>	1	2	3	4	5
33	Do you get to make the big decisions in your life? <i>For example, like deciding where to live, or who to live with, how to spend your money.</i>	1	2	3	4	5
34	Are you satisfied with your ability to communicate with other people? <i>For example, how you say things or get your point across, the way you understand others, by words or signs.</i>	1	2	3	4	5
35	Do you feel that other people accept you?	1	2	3	4	5
36	Do you feel that other people respect you? <i>For example, do you feel that others value you as a person and listen to what you have to say?</i>	1	2	3	4	5

						
		Not at all	A Little	Moderately	Mostly	Totally
37	<p>Are you satisfied with your chances to be involved in social activities?</p> <p>For example, meeting friends, going out for a meal, going to a party etc.</p>	1	2	3	4	5
38	<p>Are you satisfied with your chances to be involved in local activities?</p> <p><i>For example, being part of what is happening in your local area or neighbourhood.</i></p>	1	2	3	4	5
39	<p>Do you feel that your dreams, hopes and wishes will happen?</p> <p><i>For example, do you feel you will get the chance to do the things you want, or get the things you wish for, in your life?</i></p>	1	2	3	4	5

**Do you have any comments about the questionnaire?**

## Camouflaging Autistic Traits Questionnaire (CAT-Q)

Please read each statement below and choose the answer that best fits your experiences during social interactions.

Strongly Disagree (1)	Disagree (2)	Somewhat Disagree (3)	Neither Agree nor Disagree (4)	Somewhat Agree (5)	Agree (6)	Strongly Agree (7)
-----------------------------	-----------------	-----------------------------	---	--------------------------	--------------	--------------------------

1. When I am interacting with someone, I deliberately copy their body language or facial expressions
2. I monitor my body language or facial expressions so that I appear relaxed
3. I rarely feel the need to put on an act in order to get through a social situation\*
4. I have developed a script to follow in social situations (for example, a list of questions or topics of conversation)
5. I will repeat phrases that I have heard others say in the exact same way that I first heard them
6. I adjust my body language or facial expressions so that I appear interested by the person I am interacting with
7. In social situations, I feel like I'm 'performing' rather than being myself
8. In my own social interactions, I use behaviours that I have learned from watching other people interacting
9. I always think about the impression I make on other people
10. I need the support of other people in order to socialise
11. I practice my facial expressions and body language to make sure they look natural
12. I don't feel the need to make eye contact with other people if I don't want to\*
13. I have to force myself to interact with people when I am in social situations
14. I have tried to improve my understanding of social skills by watching other people
15. I monitor my body language or facial expressions so that I appear interested by the person I am interacting with
16. When in social situations, I try to find ways to avoid interacting with others
17. I have researched the rules of social interactions (for example, by studying psychology or reading books on human behaviour) to improve my own social skills
18. I am always aware of the impression I make on other people

19. I feel free to be myself when I am with other people\*
20. I learn how people use their bodies and faces to interact by watching television or films, or by reading fiction
21. I adjust my body language or facial expressions so that I appear relaxed
22. When talking to other people, I feel like the conversation flows naturally\*
23. I have spent time learning social skills from television shows and films, and try to use these in my interactions
24. In social interactions, I do not pay attention to what my face or body are doing\*
25. In social situations, I feel like I am pretending to be 'normal'

**Scoring:**

All items are scored 1-7, with higher scores reflecting greater camouflaging. Items with an asterisk (\*) should be reverse scored.

**Factors:**

Compensation = 1, 4, 5, 8, 11, 14, 17, 20, 23

Masking = 2, 6, 9, 12, 15, 18, 21, 24

Assimilation = 3, 7, 10, 13, 16, 19, 22, 25