Appendix 1

DSM-IV Diagnostic Criteria for 299.0 Autistic Disorder

(I) A total of six (or more) items from (A), (B), and (C), with at least two from (A), and one each from (B) and (C)

(A) Qualitative impairment in social interaction, as manifested by at least two of the following:

1. Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
2. Failure to develop peer relationships appropriate to developmental level.
3. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).
4. Lack of social or emotional reciprocity (Examples: Not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids).

(B) Qualitative impairments in communication as manifested by at least one of the following:

1. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
2. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
3. Stereotyped and repetitive use of language or idiosyncratic language.
4. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

(C) Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least one of the following:

1. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
2. Apparently inflexible adherence to specific, nonfunctional routines or rituals.
3. Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements).
4. Persistent preoccupation with parts of objects.

(II) Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

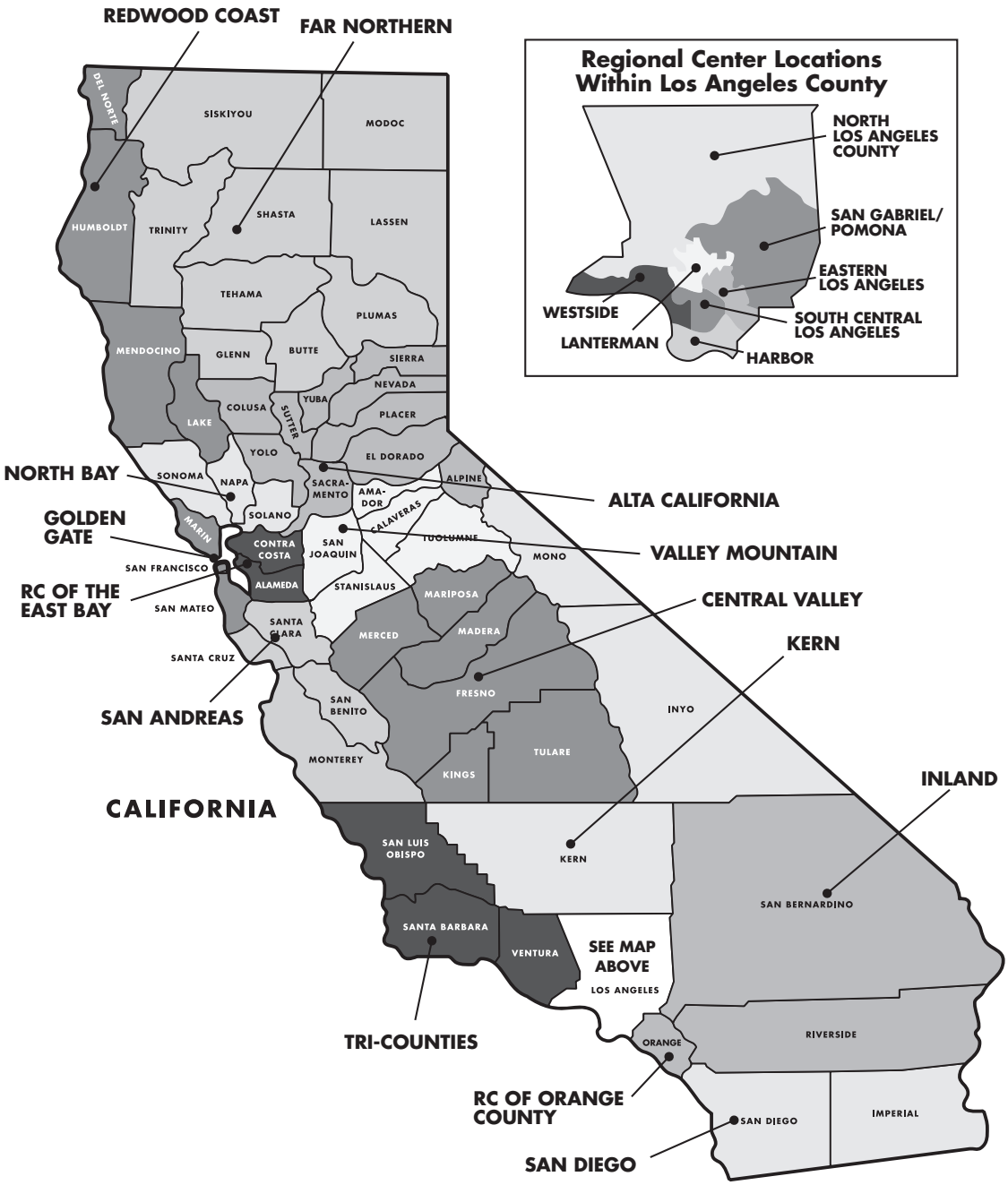
(A) Social interaction
(B) Language as used in social communication
(C) Symbolic or imaginative play

(III) The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

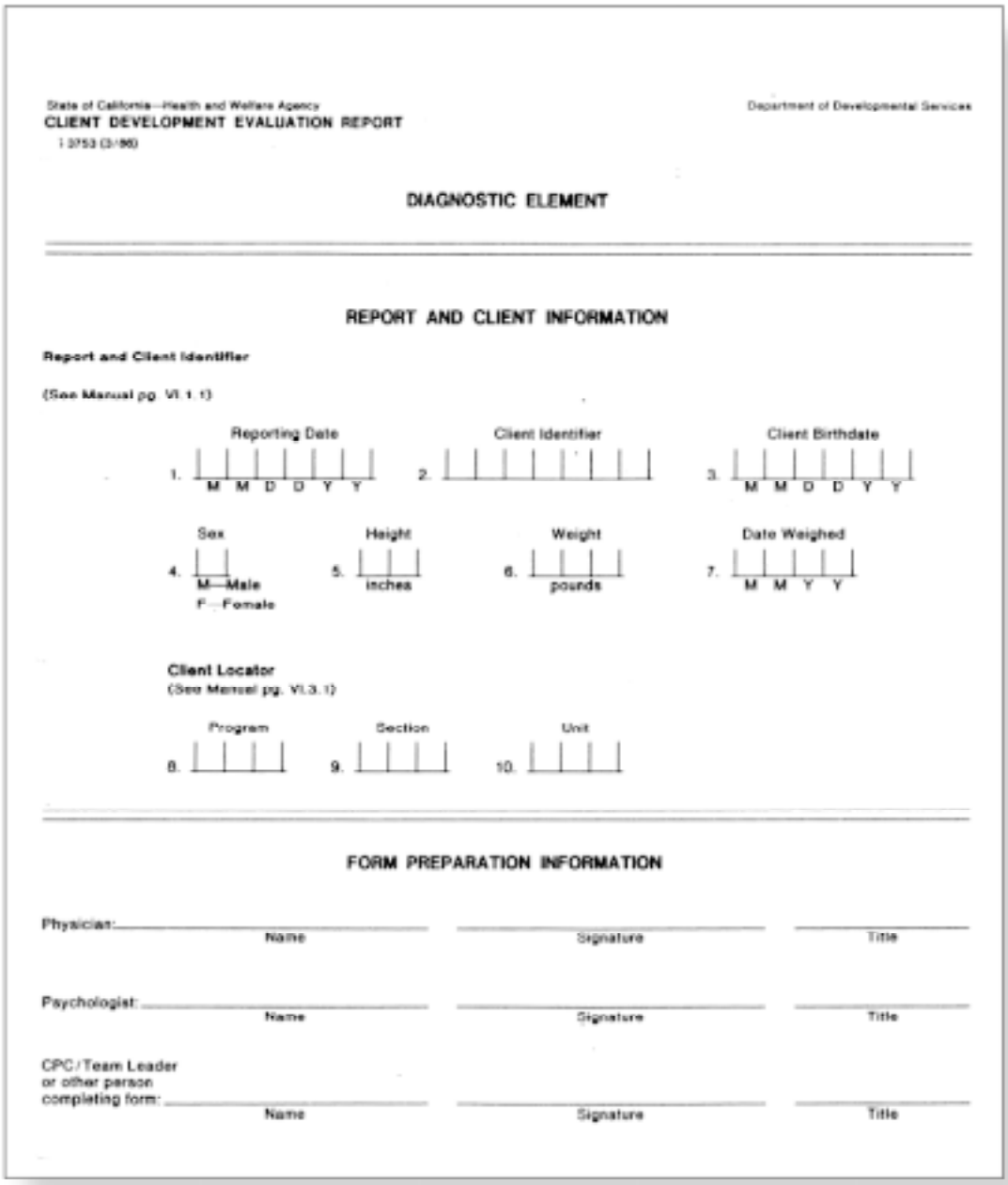
Source: The American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Washington D.C., American Psychiatric Association, 1994.

Appendix 2

Regional Center Locations



Appendix 3



State of California—Health and Welfare Agency
CLIENT DEVELOPMENT EVALUATION REPORT
1 3753 (3/86)

Department of Developmental Services

DIAGNOSTIC ELEMENT

REPORT AND CLIENT INFORMATION

Report and Client Identifier

(See Manual pg. VI.1.1)

1. Reporting Date (M M D D Y Y)
2. Client Identifier
3. Client Birthdate (M M D D Y Y)
4. Sex — M—Male, F—Female
5. Height — inches
6. Weight — pounds
7. Date Weighed (M M Y Y)

Client Locator
(See Manual pg. VI.3.1)

8. Program
9. Section
10. Unit

FORM PREPARATION INFORMATION

Physician: Name / Signature / Title

Psychologist: Name / Signature / Title

CPC / Team Leader or other person completing form: Name / Signature / Title

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DEVELOPMENTAL DIAGNOSTIC INFORMATION

DEVELOPMENTAL DISABILITIES

Record in this section specified diagnosis(es) of the client's disability(ies). Pertinent diagnoses include levels and types, and etiologic factors (ceases) of the disabilities. Code the diagnoses using ICD-9-CM and Risk Factor codes, as applicable, according to manual instructions for each specific item.

MENTAL RETARDATION

Level of Retardation (See Manual pg. VI 5.2)

(ICD-9-CM Code)

11. ___.___

000.0	No Retardation	318.1	Severe
317	Mild	318.2	Profound
318.0	Moderate	319	MR unspecified (level)

Etiology
(ICD-9-CM Code)

12a. ___.___

12b. ___.___

13. ____ **Date of Last Evaluation**
M M Y Y

DEVELOPMENTAL CENTER CLIENTS ONLY

Intelligence Quotient

14. ____

Intelligence Test

15. ____

Adaptive Behavior Rating

16. ____

0	Normal	3	Severe
1	Mild	4	Profound
2	Moderate	5	Unknown

CEREBRAL PALSY (See Manual pg. VI 6.1)

If the client has Cerebral Palsy or other type of motor dysfunction (code "1" in item 17), enter the ICD-9-CM etiology code(s) in items 18a / 18b for either condition (CP or "other motor dysfunction").

17. ____ **Presence of Cerebral Palsy**
0 No CP or other significant motor dysfunction
1 Has CP or other significant motor dysfunction

19. ____ **Level of Motor Dysfunction**
1 Mild, doesn't limit activity
2 Moderate, in between mild and severe
3 Severe, significantly impairs or precludes activity
9 CP suspected, level undetermined

21. ____ **Location of Motor Dysfunction**

1	Monoplegia	5	Paraplegia
2	Hemiplegia	6	Quadriplegia
3	Diplegia	7	Other
4	Triplegia		

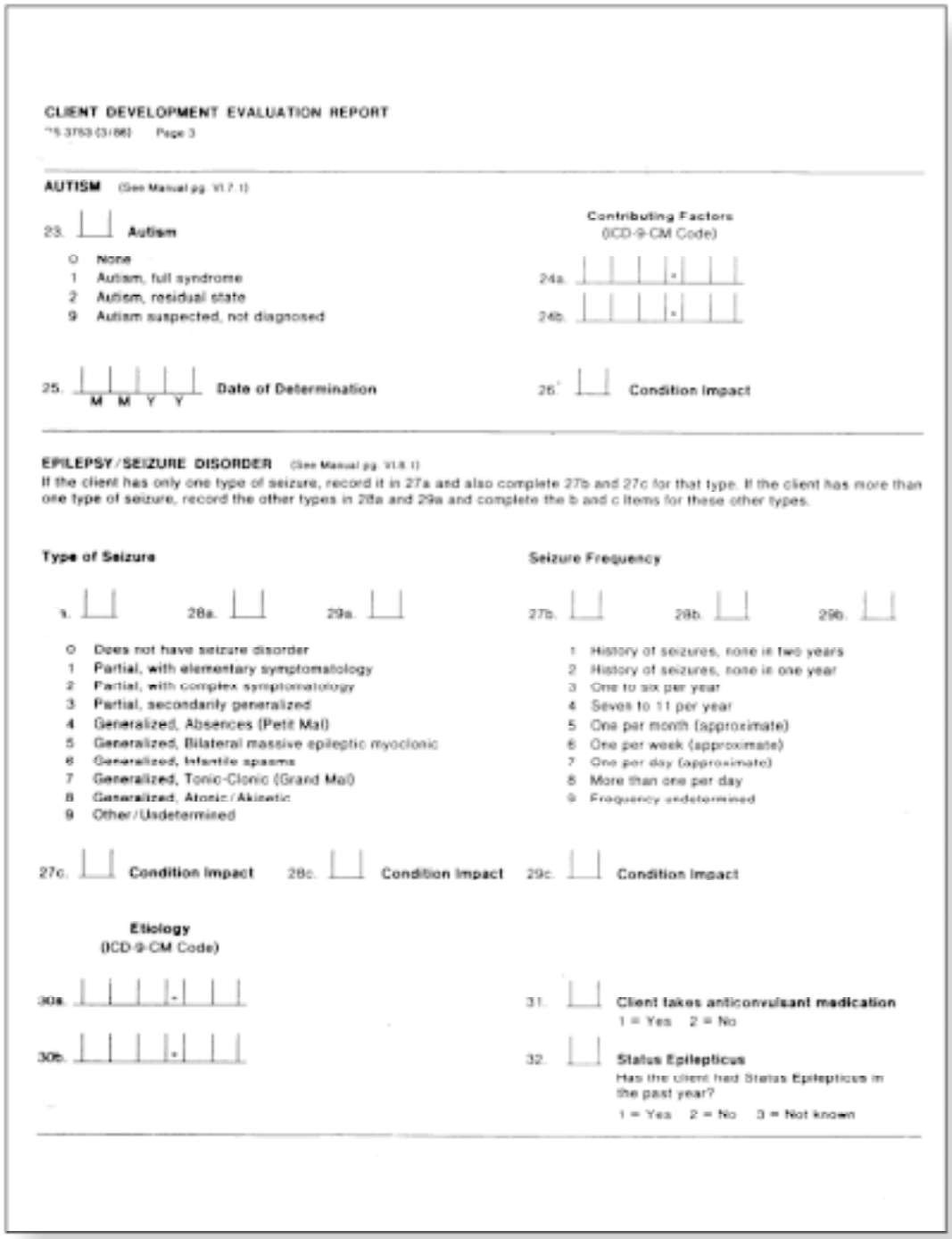
Etiology
(ICD-9-CM Code)

18a. ___.___

18b. ___.___

20. ____ **Type of Motor Dysfunction**
1 Spasticity (includes Hypertonia and Rigidity)
2 Ataxia
3 Dyskinesia (includes Athetosis and Dystonia)
4 Hypotonia
5 Other (includes mixed)

22. ____ **Condition Impact**



CLIENT DEVELOPMENT EVALUATION REPORT

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AUTISM (See Manual pg. VI.7.1)

23. ___ **Autism**

- 0 None
- 1 Autism, full syndrome
- 2 Autism, residual state
- 9 Autism suspected, not diagnosed

Contributing Factors
(ICD-9-CM Code)

24a. ___.___

24b. ___.___

25. ___ ___ ___ ___ **Date of Determination**
M M Y Y

26. ___ **Condition Impact**

EPILEPSY/SEIZURE DISORDER (See Manual pg. VI.8.1)

If the client has only one type of seizure, record it in 27a and also complete 27b and 27c for that type. If the client has more than one type of seizure, record the other types in 28a and 29a and complete the b and c items for these other types.

Type of Seizure

27a. ___ 28a. ___ 29a. ___

- 0 Does not have seizure disorder
- 1 Partial, with elementary symptomatology
- 2 Partial, with complex symptomatology
- 3 Partial, secondarily generalized
- 4 Generalized, Absences (Petit Mal)
- 5 Generalized, Bilateral massive epileptic myoclonic
- 6 Generalized, Infantile spasms
- 7 Generalized, Tonic-Clonic (Grand Mal)
- 8 Generalized, Atonic/Akinetic
- 9 Other/Undetermined

Seizure Frequency

27b. ___ 28b. ___ 29b. ___

- 1 History of seizures, none in two years
- 2 History of seizures, none in one year
- 3 One to six per year
- 4 Seven to 11 per year
- 5 One per month (approximate)
- 6 One per week (approximate)
- 7 One per day (approximate)
- 8 More than one per day
- 9 Frequency undetermined

27c. ___ **Condition Impact** 28c. ___ **Condition Impact** 29c. ___ **Condition Impact**

Etiology
(ICD-9-CM Code)

30a. ___.___

30b. ___.___

31. ___ **Client takes anticonvulsant medication**
1 = Yes 2 = No

32. ___ **Status Epilepticus**
Has the client had Status Epilepticus in the past year?
1 = Yes 2 = No 3 = Not known

CLIENT DEVELOPMENT EVALUATION REPORT

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OTHER TYPE OF DEVELOPMENTAL DISABILITY (See Manual pg. VI.9.1)

Use this section to identify any developmental disability(ies) other than those listed above (mental retardation, cerebral palsy, etc.) "Other" developmental disabilities are conditions which are similar or closely related to mental retardation or which rec treatment similar to that required for mentally retarded individuals.

		Type of Other Disability (ICD-9-CM Code)	Etiology (ICD-9-CM Code)
33a.	_____ (Specify)	___.___	34a. ___.___
33b.	_____ (Specify)	___.___	34b. ___.___

RISK FACTOR (For use in etiology items 12a-b, 18a-b, 24a-b, 30a-b, and 34a-b.) (See Manual pg. VI.10.1)

1 = Yes 2 = No 9 = Unknown

Indicate whether each of the following factors was associated with the client's developmental disability(ies), as specified above. Code "1" for Yes if there are reasonable data to suggest the disability was associated with or significantly impacted by the factor. Code "2" for No if the factor does not pertain to the disability and Code "9" for an unknown association.

35.	Low birth weight or preterm labor with complications	43.	Drug or alcohol abuse
36.	Teenage pregnancy (17 years and younger)	44.	Psychosocial (environmental) deprivation
37.	Maternal age 35 years or older at time of delivery	45.	Family history of mental retardation
38.	Accidents of near drowning	46.	Child abuse or neglect
39.	Accidents involving an automobile	47.	Other causes
40.	Accidents involving other types of vehicles	48.	
41.	Accidents of other types	49.	
42.	Environmental toxins (pesticides, lead, etc.)		

MENTAL DISORDERS (See Manual pg. VI.11.1)

If applicable, enter below the diagnosis(es) that describes the client's mental disorder. If the client does not have a mental disorder, enter 000000 in item 50a and leave 51a–53c blank. Use DSM-III codes for the mental disorders as Axes I and II. Do not enter developmental disability diagnosis(es), including Autism.

Type of Mental Disorder (DSM-III Code)

	Axis I	Date of Last Evaluation	Condition Impact
50a.	___.___	50b. ___ (M M Y Y)	50c. ___
51a.	___.___	51b. ___ (M M Y Y)	51c. ___

	Axis II	Date of Last Evaluation	Condition Impact
52a.	___.___	52b. ___ (M M Y Y)	52c. ___
53a.	___.___	53b. ___ (M M Y Y)	53c. ___

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CHRONIC MAJOR MEDICAL CONDITION(S) (See Manual pg. VI.12.1)

List below major chronic, recurrent medical problems, other than developmental disability, that have significant impact on the client's service provision (i.e., diabetes, heart condition, chronic U.R.I., hepatitis, etc.). If there is no medical condition, enter 000o00 in item 54a and leave items 55a–59b blank.

	Condition Type(s) (Specify)	Condition (ICD-9-CM-Code)	Condition Impact
54a.	_____	___.__	54b. ___
55a.	_____	___.__	55b. ___
56a.	_____	___.__	56b. ___
57a.	_____	___.__	57b. ___
58a.	_____	___.__	58b. ___
59a.	_____	___.__	59b. ___

OTHER DIAGNOSTIC INFORMATION

HEARING (See Manual pg. VI.13.1)

60. ___ **Level of Hearing Loss Uncorrected**

0 Hearing within normal limits
1 Mild to moderate hearing loss (hard of hearing)
2 Severe hearing loss
3 Profound hearing loss
4 Hearing loss, one ear
9 Hearing loss suspected, severity undetermined

61. ___ **Level of Hearing Loss Corrected**

0 Hearing within normal limits
1 Mild to moderate hearing loss
2 Severe hearing loss
3 Profound hearing loss
8 Correction not possible
9 Hearing not corrected

VISION (See Manual pg. VI.14.1)

62. ___ **Level of Vision Loss Uncorrected**

0 Vision within normal limits
1 Mild impairment
2 Moderate impairment
3 Severe impairment (legally blind)
4 Total blindness (no light perception)
5 Vision loss, one eye
9 Vision loss suspected, severity undetermined

63. ___ **Level of Vision Loss Corrected**

0 Vision within normal limits
1 Mild impairment
2 Moderate impairment
3 Severe impairment
8 Correction not possible
9 Vision not corrected

CLIENT DEVELOPMENT EVALUATION REPORT
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BEHAVIOR MODIFYING DRUGS (See Manual pg. VI.15.1)

Types of Prescribed Medication for Maladaptive Behavior

1 = Yes 2 = No

64. ___ Antipsychotic
65. ___ Antidepressant
66. ___ Antianxiety
67. ___ Sedative/Hypnotic
68. ___ Stimulant
69. ___ Other Psychotropic Drug

70. ___ **History of Prescribed Medication for Maladaptive Behavior**

(Do not include medications given only for seizures, sedatives given for examinations or clinics, etc., or medications given on an infrequent PRN basis.)

1 Currently receiving one or more prescribed medication(s)
2 Medication(s) discontinued within six months
3 Medication(s) discontinued more than six months but less than one year
4 Medication(s) discontinued more than one year but less than four years
5 Has not received medication(s) during past four years
6 No known documented history of receiving medication(s)

ABNORMAL INVOLUNTARY MOVEMENTS (See Manual pg. VI.16.1)

(COMPLETE FOR DEVELOPMENTAL CENTER CLIENTS ONLY)

Types of Involuntary Movements

1 = Yes 2 = No

71. ___ Parkinsonism 72. ___ Dystonia 73. ___ Dyskinesia 74. ___ Akathisia 75. ___ Paroxysmal

SPECIAL HEALTH CARE REQUIREMENTS (See Manual pg. VI.17.1)

If the client has special health care requirements, enter the codes for these requirements in items 76–85. Up to 10 special health care requirements can be entered. If the client has no special health care requirements, enter "00" in item 76 and leave items 77–85 blank.

76. ___ 77. ___ 78. ___ 79. ___ 80. ___

81. ___ 82. ___ 83. ___ 84. ___ 85. ___

CLIENT DEVELOPMENT EVALUATION REPORT
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SPECIAL CONDITIONS OR BEHAVIORS (See Manual pg. VI. 18.1)

OPTIONAL: For use in rate justification for out-of-home or day program placement, complete for clients as necessary. Code 1 = Yes ONLY if external documentation of the given condition/behavior exists. If the answer to a particular item is unknown, use code 3.

1 = Yes 2 = No 3 = Unknown

86. ___ Does the client display maladaptive sexual behavior?

87. ___ Has the client engaged in any assaultive behaviors that have or could have resulted in serious bodily injury or death?

88. ___ Has the client attempted suicide in the past five years?

89. ___ Does the client habitually engage in theft?

90. ___ Has the client participated in acts of vandalism or other acts of property destruction?

91. ___ Has the client been convicted of any substance-abuse or alcohol-abuse related offenses?

92. ___ Does the client have a recent history of abusing drugs or alcohol?

93. ___ Does the client have a history of habitual lying?

94. ___ Does the client display behaviors which could result or have resulted in fire setting?

SPECIAL LEGAL CONDITIONS (See Manual pg. VI. 18.4)

Please complete for each client.

1 = Yes 2 = No

95. ___ Is the client currently on probation, county or state parole, or commitment under Penal Code or Welfare and Institutions Code sections relating to a criminal offense?

96. ___ Is the client currently on Diversion pursuant to Penal Code sections 1001.20 et seq.?

97. ___ Is the client currently a person within the provisions of Welfare and Institutions Code section 6500 et seq. (dangerous mentally retarded individual committed by the court)?

98. ___ Is the client currently under a Lanterman-Petris-Short (mental health) conservatorship?

99. ___ Is the client currently a conservatee under the Probate Code (conserved because client is unable to make informed application and consent to treatment)?

___ Is the client currently a dependent child of the Court (Welfare and Institutions Code section 300 et seq.)?

THE CDER EVALUATION ELEMENT

MOTOR DOMAIN

1 ☐ **Rolling and Sitting**
- 1= 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 ☐ **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 ☐ **Arm Use**
- 1= 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 ☐ **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 ☐ **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 ☐ **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 ☐ **Wheelchair Mobility**
- N= Does not use wheelchair
- 1= 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 ☐ **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

9 ☐ **Bedmaking**
- N= Client is in a service setting in which he / she is prevented from bedmaking
- 1= 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= Completes bedmaking neatly and independently

10 ☐ **Washing Dishes**
- N= Client is in a service setting which he / she is prevented from dishwashing
- 1= 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

- 8 -

11 ☐ **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

12 ☐ **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 bandaids, ice to a burn)
4= Has basic medical self-help skills and uses nonprescription medications (aspirin, cough drops, etc.) appropriately

13 ☐ **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 ☐ **Eating**
1= Does not feed self, must be fed completely
2= Attempts to finger 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 ☐ **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 ☐ **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 ☐ **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 ☐ **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

19 ☐ **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 ☐ **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 ☐ **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 ☐ **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

23 ☐ **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

-9-

24 ☐ **Money Handling**
1= Does not use money
2= Uses money, but is unable to provide appropriate amount (gives 10c 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 ☐ **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

26 ☐ **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 ☐ **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 ☐ **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

29 ☐ **Friendship Formation**
(close social relationships)
1= Does not form friendships
2= Potential friends must initiate friendships
3= Initiates and establishes friendships

30 ☐ **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 sett

31 ☐ **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

32 ☐ **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 ☐ **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 ☐ **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 r caused physical injury within past year
4=Episodes of displaying anger are undetected or rare and appropriate to the situation

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35 ☐ **Frequency of Self-Injurious Behavior**
(biting, scratching, putting inappropriate objects into ear, mouth, etc.)

1= Displays 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
D= 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
1= 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

42 ☐ **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
1= 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

43 ☐ **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

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44 ☐ **Hyperactivity**
(as manifested by over-excitability, restlessness, constant movement; exclude CNS spastic movements)
D= 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 ☐ **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 ☐ **Resistiveness**
(inappropriately stubborn and uncooperative)
Y= Client is too young to display this type of behavior
D= 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

47 ☐ **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 is social relationships appear to lead to improvement and personal growth

48 ☐ **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 c[illegible] 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 ☐ **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")

50 ☐ **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)
8= Responds differently to objects (based on differences of color, size or shape)

51 ☐ **Associating Time with Events and Actions**
1= 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 six tomorrow)

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52 ☐ **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 (5 is larger than 3)
- 5= Counts, including use of multi-digit numbers, and associates multi-digit numbers with quantities

53 ☐ **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

54 ☐ **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 ☐ **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

56 ☐ **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 ☐ **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 ☐ **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 ☐ **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

60 ☐ **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)

61 ☐ **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

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62 ☐ **Expressive Language**

1= Makes no sound
2= Babbles but says no words
3= Says simple words
4= Says two-word sentences ("I go," "Give me," etc.)
5= Says sentences of three or more words
6= Carries on basic conversation
7= Carries on more complex conversation

63 ☐ **Receptive Sign Language**

N= Skills not needed
1= Does not respond to signs or fingerspelling
2= Responds to one to nine signed basic survival words (stop, restroom, come, etc.) as well as other common signs (simple commands, food, clothing, etc.)
3= Responds to signed complex commands made up of two or more parts ("Go to the bathroom and bring me a towel")
4= Responds to signed complex commands, directions and explanations with a combination of signs and simple fingerspelling
5= Responds to signed questions (3 or more words) with a combination of signs and fingerspelling

64 ☐ **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
6= Makes fifty or more signs, fingerspells simple words and makes simple sentences
7= Signs and fingerspells independently in carrying on conversations as well as expressing needs

65 ☐ **Expressive Communication With Aids**

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

N= 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 of ideas together

66 ☐ **Clarity of Speech**

1= Makes no sounds
2= No intelligible speech
3= Speech understood only by those who know the client well
4= Speech understood by strangers with some difficulty
5= Speech is readily understandable to a stranger

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Appendix 4

Scientific Advisory Panel

We gratefully acknowledge the members of the Scientific Advisory Panel, and thank them for their valuable contributions to the research design of the Autism Epidemiology Study.

Name/Title	Affiliation
Coleen Boyle, Ph.D. Associate Director for Science and Policy	National Center for Birth Defects and Developmental Disabilities Centers for Disease Control and Prevention Atlanta, Georgia
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Walter O. Spitzer, M.D., M.P.H. Professor of Epidemiology (Emeritus)	McGill University Montreal, Quebec Canada

Appendix 5

List of questions asked on the Autism Epidemiology Study Questionnaire

Families of all children participating in the study were asked to complete a questionnaire (either by self-completing a written questionnaire or by phone interview). The content of the questionnaire included:

- Demographic information
  - Race/ethnicity
  - Place of birth
  - Handedness (right/left/both)
  - Parental education
  - Birth order
- Mobility, including place of birth, movement into or within California up to the age of five
- Diagnostic information
  - Determination of diagnosis of autism
  - Presence or absence of mental retardation, including a question about IQ scores
  - Presence or absence of seizure history
  - Presence or absence of cerebral palsy
  - Presence or absence of other potential co-morbid conditions
- Family history (grouped under first degree, second degree, or greater than second degree relatives):
  - Autism or related disorders
  - Tic disorder, obsessive-compulsive disorder, depressive disorder, bipolar disorder
  - Mental retardation
- Perinatal complications
  - Infertility treatments
  - Viral infections while pregnant
  - Vaccinations while pregnant
  - Augmentation or induction of labor
  - Exposure to alcohol, cigarettes, or street drugs during the pregnancy
- Immunization/vaccination history of the child and younger siblings
- History of significant gastrointestinal symptoms
- History of regression of developmental milestones
- What does the family think caused their child's autism or other developmental problem?
- Interest in participating in future follow-up studies.

Appendix 6

Sample Size Calculations for each Study Aim

Study Aim 1

CDER Data – Identification of Study Subjects

CDER data from all 21 Regional Centers in California were used to identify two groups of children with CDER status 1 autism based on age criteria. The California Department of Developmental Services provided CDER data grouped by Regional Centers for the years 1986 to 1999.

We constructed a sampling frame using all records for children with CDER status 1 autism born in 1983-1985 and 1993-1995. We created an unduplicated list of individual children with autism. The CDER record that first reported the diagnosis of CDER status 1 autism determined the Regional Center and county for that case.

The target study sample was 250 children in each age cohort (year of birth 1983-1985 vs. 1993-1995). With this sample size, we could determine whether or not 20% (or more) of the observed increase in cases of autism was due to changes in diagnostic criteria.

Table A1: *Cases of CDER status 1 autism by Regional Center and the Corresponding Sample for Study Aim 1, Autism Epidemiology Study.*

CDER status 1 autism by Regional Center	CDER Cases, by year of birth			Sample size, by year of birth	
	1983-85	1993-95	Ratio	1983-85	1993-95
Alta California Regional Center	51	90	1.8	13	7
Central Valley Regional Center	16	61	3.8	4	5
Eastern Los Angeles Regional Center	46	263	5.7	12	21
Far Northern Regional Center	15	37	2.5	4	3
Golden Gate Regional Center	41	86	2.1	11	7
Harbor Regional Center	51	298	5.8	13	24
Inland Regional Center	40	199	5.0	11	16
Kern Regional Center	16	37	2.3	4	3
Lanterman Regional Center	45	206	4.6	12	17
North Bay Regional Center	26	70	2.7	7	6
North Los Angeles County Regional Center	99	283	2.9	25	23
Redwood Coast Regional Center	12	18	1.5	3	2
Regional Center of Orange County	75	267	3.6	19	21
Regional Center of the East Bay	64	191	3.0	17	15
San Andreas Regional Center	26	101	3.9	7	8
San Diego Regional Center	81	256	3.2	21	20
San Gabriel/Pomona Regional Center	74	169	2.3	19	14
South Central Los Angeles Regional Center	96	142	1.5	25	12
Tri-Counties Regional Center	28	163	5.8	8	13
Valley Mountain Regional Center	13	63	4.8	4	5
Westside Regional Center	75	208	2.8	19	17
TOTALS	991	3,209		258	259

Two-stage sampling was done to obtain a study sample that was representative of the entire State. Table A1 shows these stratifications by Regional Center. The target number of children sampled from each Regional Center was proportional to the number of children with CDER status 1 autism in each Regional Center for each age cohort. A randomly ordered list was created for each Regional Center. Recruitment packets were mailed based on these randomly order lists. Bad addresses and refusals were replaced by the next child on the randomized list from the same center as the non-participating family. Similarly, non-responders were replaced if they failed to respond to the second mailing.

Sample size considerations:

- Number of cases of CDER status 1 autism in the 1983-85 cohort = 991
- Number of cases of CDER status 1 autism in the 1993-95 cohort = 3209
- Observed increase in number of cases between the cohorts = 2218

Assumptions

We made several assumptions to estimate the sample size needed for this study. We did not have data a priori on changes in the threshold for meeting a diagnosis of CDER status 1 autism. We chose to use DSM-IV criteria as the standard for full syndrome autism across both age cohorts, and to assess how closely the diagnosis of CDER status 1 autism matched this criteria. We assumed that 85% of cases of CDER Status 1 would meet DSM-IV criteria for autism for Cohort 1. With this assumption, the 991 CDER status 1 cases would represent 842 "true cases" and 149 cases of something other than full syndrome autism. If there is no difference between the two cohorts then 85% of Cohort 2 would meet DSM-IV criteria, representing 2728 "true cases" and 481 cases that are not full syndrome autism (out of 3,209 CDER status 1 cases).

Estimation of cohort size necessary to detect a change in the diagnostic criteria used for CDER status 1 autism

A change in the diagnostic threshold for the cases of CDER status 1 autism could account for some of the observed increase between the two cohorts. There are 2,218 more cases of CDER status 1 autism in Cohort 2 than Cohort 1. For a change in diagnostic threshold to account for all of the observed increase in autism cases, only 842 of the 3,209 CDER status 1 autism cases would meet DSM-IV criteria for autism. At this extreme, only 18 study subjects (9 from each cohort) would be necessary to show a change in the diagnostic threshold of this magnitude (assuming power = 80% and $p \leq 0.05$).

While hypothetically possible, it was highly unlikely that only 1 out of 4 CDER status 1 autism cases would meet DSM-IV criteria. If loosening of the diagnostic criteria were to contribute to an artificial increase in the reported cases of autism, it was more likely that it would only be responsible for a portion of the increase. A total sample of 500 (250 from each cohort) would be large enough to detect the difference in correspondence rates of 85% and 75%. If diagnostic criteria changed by this amount, then it would account for 20% of the observed increase in cases.

Study Aim 2

CDER Data – Identification of Study Subjects

CDER data from all 21 Regional Centers in California were used to identify two groups of children with mental retardation without CDER status 1 autism. The California Department of Developmental Services provided CDER data grouped by Regional Centers for the years 1986 to 1999. To be comparable with other aspects of this study, we limited the study population to two birth cohorts of children, year of birth 1983-85 and 1993-95. Sampling was based on an unduplicated list of children with mental retardation without CDER status 1 autism.

The target study sample was 250 in each age group. This would permit determination of whether or not 50% (or more) of the observed increase in cases of autism is due to a change in the rate of misclassification of autism among children listed as having mental retardation.

Table A2. *Cases of Mental Retardation without status 1 autism by regional center and the corresponding sample for Study Aim 2.*

Mental Retardation (without status 1 autism) by Regional Center	CDER Cases, by year of birth			Sample size, by year of birth	
	1983-85	1993-95	Ratio	1983-85	1993-95
Alta California Regional Center	736	265	0.36	16	8
Central Valley Regional Center	795	512	0.64	17	14
Eastern Los Angeles Regional Center	461	335	0.73	10	9
Far Northern Regional Center	315	229	0.73	7	7
Golden Gate Regional Center	407	235	0.58	9	7
Harbor Regional Center	612	478	0.78	13	13
Inland Regional Center	1,146	961	0.84	24	26
Kern Regional Center	358	232	0.65	8	7
Lanterman Regional Center	526	306	0.58	11	9
North Bay Regional Center	318	286	0.90	7	8
North Los Angeles County Regional Center	653	517	0.79	14	14
Redwood Coast Regional Center	201	97	0.48	5	3
Regional Center of Orange County	780	705	0.90	17	19
Regional Center of the East Bay	668	387	0.58	14	11
San Andreas Regional Center	542	478	0.88	12	13
San Diego Regional Center	1,078	1,036	0.96	23	28
San Gabriel/Pomona Regional Center	572	489	0.85	12	14
South Central Los Angeles Regional Center	616	510	0.83	13	14
Tri-Counties Regional Center	452	340	0.75	10	10
Valley Mountain Regional Center	558	554	0.99	12	15
Westside Regional Center	345	323	0.94	8	9
Total	12,139	9,275	0.76	262	258

Assumptions

The rate of misclassification (cases of MR without CDER status 1 autism that meet DSM-IV criteria) was unknown at the outset of this study. For the purposes of sample size calculation, the rate of misclassification was assumed to decrease from 1983 to

1995. Assuming a 5% misclassification rate among 1993-1995 cohort, then all of the observed increase in autism cases could be explained if the misclassification rate among children with MR in 1983-1985 is 22% (22% * 12139 – 5% * 9275 = 3209-991). The sample size necessary to detect a difference between 5% and 22% is 124 (62 in each group). Such an extreme change in misclassification was unlikely. Misclassification, if it were a factor, would more likely contribute to a portion of the observed increase in autism cases.

A sample size of 500 (250 in each age group) would provide 80% power to detect a difference between 5% and 12% with a p-value of 0.05. Misclassification among children determined to have mental retardation without CDER status 1 autism has the potential to account for a large number of "missing" cases of autism. A 5% misclassification rate among the 12,139 children in the 1983-1985 cohort could account for 607 missing cases of autism compared to the 991 children identified with CDER status 1 autism in this same age cohort. If as many as 12% of children classified as having mental retardation were found to meet DSM-IV criteria for autism, then 1,457 such children would have been missed in the older cohort, representing 147% more than the 991 children identified.

Study Aim 3

The sample size considerations for this study aim were similar to that for Study Aim 1. The target study sample was 250 for each birth cohort.

Sample size considerations

To estimate sample size the following assumptions and considerations were made: The sample size would be sufficient to detect whether or not an increase in in-migration accounts for 20% of the increased number of children with autism. The assumptions for this study aim were based on verbal reports by Dr. Croen in advance of her recently published study[35] that showed 85% of CDER status 1 autism cases match to a California birth certificate. Sample size estimates were based on a power of 80% and a p-value of 0.05.

If 20% of the increased number of cases were due to increases in in-migration among children with autism, then 25% of the younger age cohort with CDER status 1 autism would need to have been born out-of-state, as compared to 15% of the older cohort. A comparison of two proportions, 15% and 25%, requires 249 children with CDER status 1 autism in each age group, or approximately 500 study participants.

Study Aim 4

Study Aims 1 and 2 determined the sample size for this study aim. A target sample of 500 children with CDER status 1 autism and 500 children with mental retardation was attempted. If the full sample were enrolled then comparisons between age cohorts would allow for detection of a 12% difference between groups.

Study Aim 5

Study Aim 1 determines the sample size for this study aim. Families of 500 children with CDER status 1 autism will be queried. Comparisons will be made between age cohorts, allowing detection of differences of 12% or more.

Study Aim 6

The sample size requirements for this study aim are as follows: with the assumption of an approximate 5% autism or PDD recurrence risk within families with at least one affected child, using an alpha of 0.05, with 474 families in each study arm (exposed/unexposed) we would have 90% power to find a two-fold increased risk for autism/PDD secondary to vaccination. With 159 families in each study arm, we would have 90% power to find a three-fold increased risk secondary to vaccination. It was unknown how many children with autism selected for the study would have younger siblings who are at least 18 months of age. We aimed to have 159 families in each study arm but realized that we might need to expand the number of families to include additional eligible families. Based on the proportion of study children with younger siblings and the proportion of families choosing to refuse or avoid vaccinations for younger siblings, sample size calculations would be done to determine the number of additional families that would need to be recruited to accomplish this study aim. If feasible, it would be attempted.

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