

Community Medical and Welfare Service System on Early Support for Children with Neurodevelopmental Disorders and Their Families

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Support Needs for Children with Neurodevelopmental Disorders

- In USA, 17% of children aged 3–17 years were diagnosed with a developmental disability, as reported by parents (CDC, 2000).
- In Japan, more than 10% of elementary school children have some characteristics of neurodevelopmental disorders (Honda et al, 2019).

Number of Children Occurring per Year in Need of Developmental Support in the Community

Birth per year	Potential needs	Apparent needs
10	>1	>0.6
100	>10	>6
1,000	>100	>60
2,000	>200	>120
5,000	>500	>300

Three Axes in Support for Children with Neurodevelopmental Disorders

For children

Promote social participation and prevent secondary problems

For families

Promote understanding the child and support rearing

For community

Provide community support system

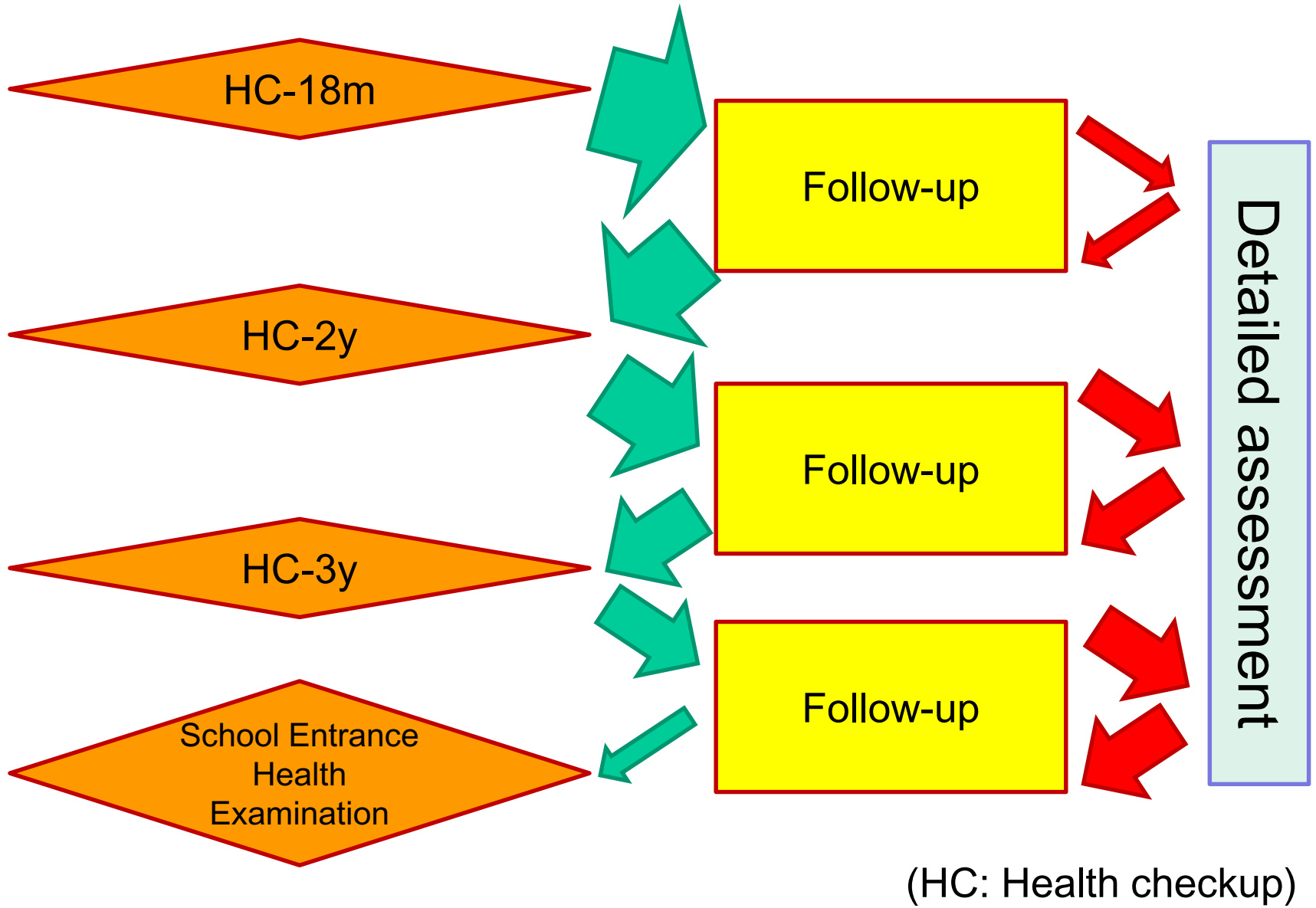
The 'uncertainty principle' in early detection and early intervention

- In diagnosis
- In parental recognition of the disorder
- In boundaries of responsibility among facilities

Parental Support Activities



**An Application of 'Extraction & Refinement'
Strategy in the Community** (Honda et al, 2009)



Checkups, Follow-ups, and Assessment

Sensitivity and Specificity of the Screening for Neurodevelopmental Disorders among 18-month-olds in the early 1990's in Yokohama

Sensitivity for autistic disorder

81% (Honda et al, 2005)

Cumulative incidence of childhood autism: a total population study of better accuracy and precision

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Frequency is one of the most controversial research topics in the field of autism (Gillberg and Wing 1999, Charman 2002, Wing and Potter 2002, Fombonne 2003). In research published since 1996, problems of diagnostic criteria have been greatly reduced because criteria for childhood autism in the *International Statistical Classification of Diseases and Related Health Problems, 10th revision, Diagnostic Criteria for Research* (ICD-10 DCR; World Health Organization 1993) and autistic disorder, as defined in the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* (DSM-IV; American Psychiatric Association 1994), are conceptually identical (Wolkmar et al. 1994). However, problems of methodology linger, even in recent research reports using ICD-10 and DSM-IV.

In previous research, frequency of childhood autism was low in studies with large target populations and high in studies of small populations (Honda et al. 1996, Wing and Potter 2002). This may be explained partly as a problem in the accuracy and precision of case identification. Accuracy is defined as the exactness of a measurement to the true value, and is influenced by systematic error. In epidemiological measurements of frequency, accuracy is difficult to measure quantitatively. A study can achieve a high degree of accuracy only by clearly indicating and implementing improved methods to reduce the inevitable undetected cases in the initial screening.

Specificity for neurodevelopmental disorders

100% (Honda et al, 2009)

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Extraction and Refinement Strategy for detection of autism in 18-month-olds: a guarantee of higher sensitivity and specificity in the process of mass screening

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Proportions of 'No' Answers in the Questionnaire at HC-18m in Okaya City

Question	Category	ASD ^a	Without ASD	Fisher's exact test	PPV ^b
1. Can your child walk without falling much?	Gross motor skills	18.2%	4.4%	p=0.004**	0.12
2. Can your child climb up stairs by holding your hand?		15.2%	3.8%	p=0.010*	0.11
3. Does your child scribble?	Fine motor skills	15.2%	1.2%	p<0.001***	0.29
4. Does your child drink from a cup?		15.2%	6.7%	p=0.072	0.07
5. Can your child build a tower with two or three blocks?		29.0%	4.7%	p<0.001***	0.16
6. Does your child pick up small items?		3.0%	0.5%	p=0.177	0.17
7. Does your child feed himself/herself with a spoon or fork?		18.8%	5.6%	p=0.010**	0.10
8. Does your child say three or more words?	Social and com-	27.3%	7.8%	p=0.001***	0.10
9. Does your child understand what you say?	munication skills	12.9%	0.4%	p<0.001***	0.50 [†]
10. Does your child follow simple instructions?		12.1%	0.3%	p<0.001***	0.57 [†]
11. Does your child respond to his/her name when you call?		0.0%	0.7%	p=0.798	0.00
12. Does your child take an interest in other adults and children?		6.1%	1.2%	p=0.069	0.14
13. Has your child ever had stranger anxiety?		12.1%	8.7%	p=0.332	0.04
14. Does your child point to pictures in a book that he/she recognizes?		30.3%	8.3%	p<0.001***	0.11
15. If you point a toy across the room, does your child look at it?		6.1%	1.1%	p=0.062	0.15
16. Does your child imitate you?		9.1%	1.0%	p=0.007**	0.23
17. Does your child play with toys (e.g. cars, bricks, or dolls)?		3.0%	1.1%	p=0.322	0.08
18. Does your child point to indicate interest in something?		24.2%	2.0%	p<0.001***	0.29

ASD autism spectrum disorder, PPV positive predictive value

*p<0.05, **p<0.01, ***p<0.001

[†]PPV≥0.5

^aSensitivity of identifying ASD in those who answered "No"

^bPPV of identifying ASD in those who answered "No"

(Sasayama D et al, 2020)

Parental Satisfaction and Age When Diagnosis Confirmed: Before Early Detection Was Activated

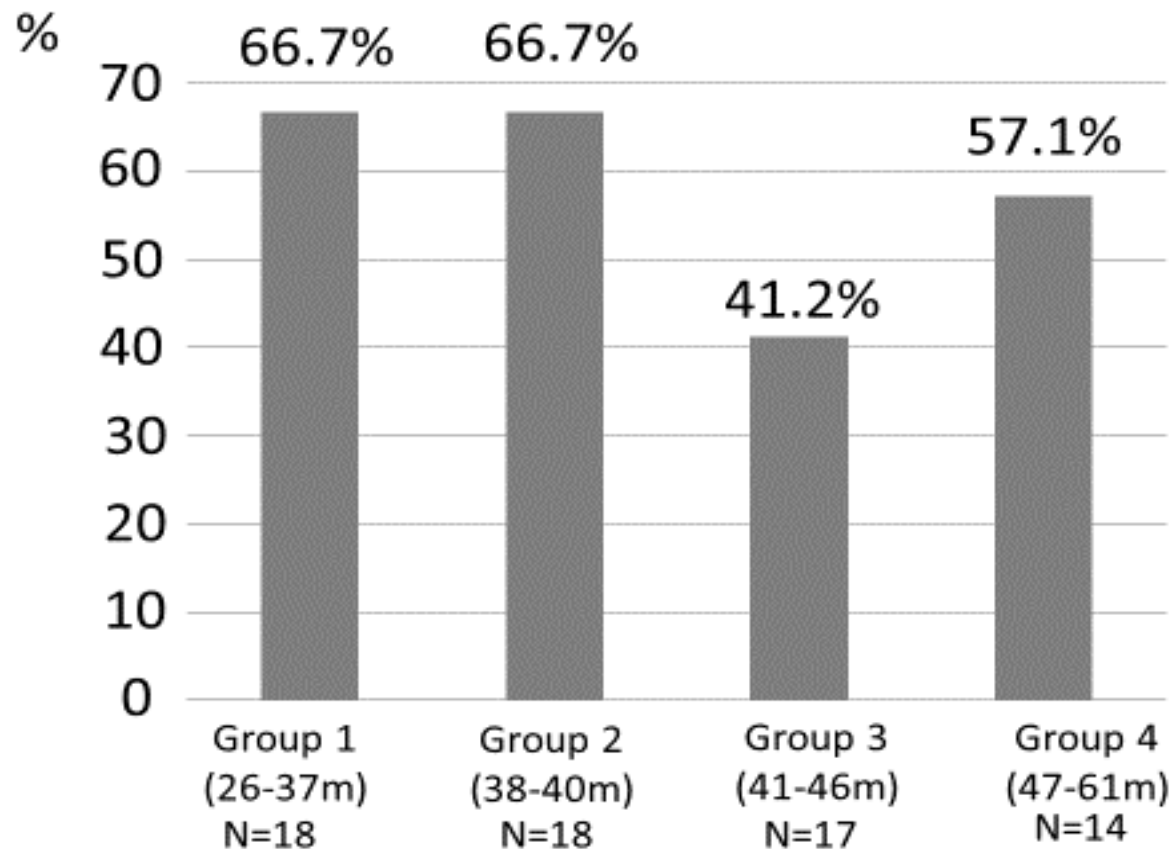
Table 12 Parental satisfaction and age when diagnosis confirmed (N = 1251^a)

Age at diagnosis ^b	Diagnostic process		Help received		Total
	% very/quite satisfied	% not satisfied	% very/quite satisfied	% not satisfied	N
Up to 2	52.9	29.4	52.9	11.8	17
2+ to 5	46.7	37.5	53.5	29.7	664
5+ to 10	25.3	58.7	46.8	39.9	363
10+ to 15	19.3	73.1	31.9	47.0	119
15+ to 20	10.2	73.4	38.7	48.9	49
20+ to 40+	17.9	61.5	38.5	38.5	39

^a Data missing on 44 cases.

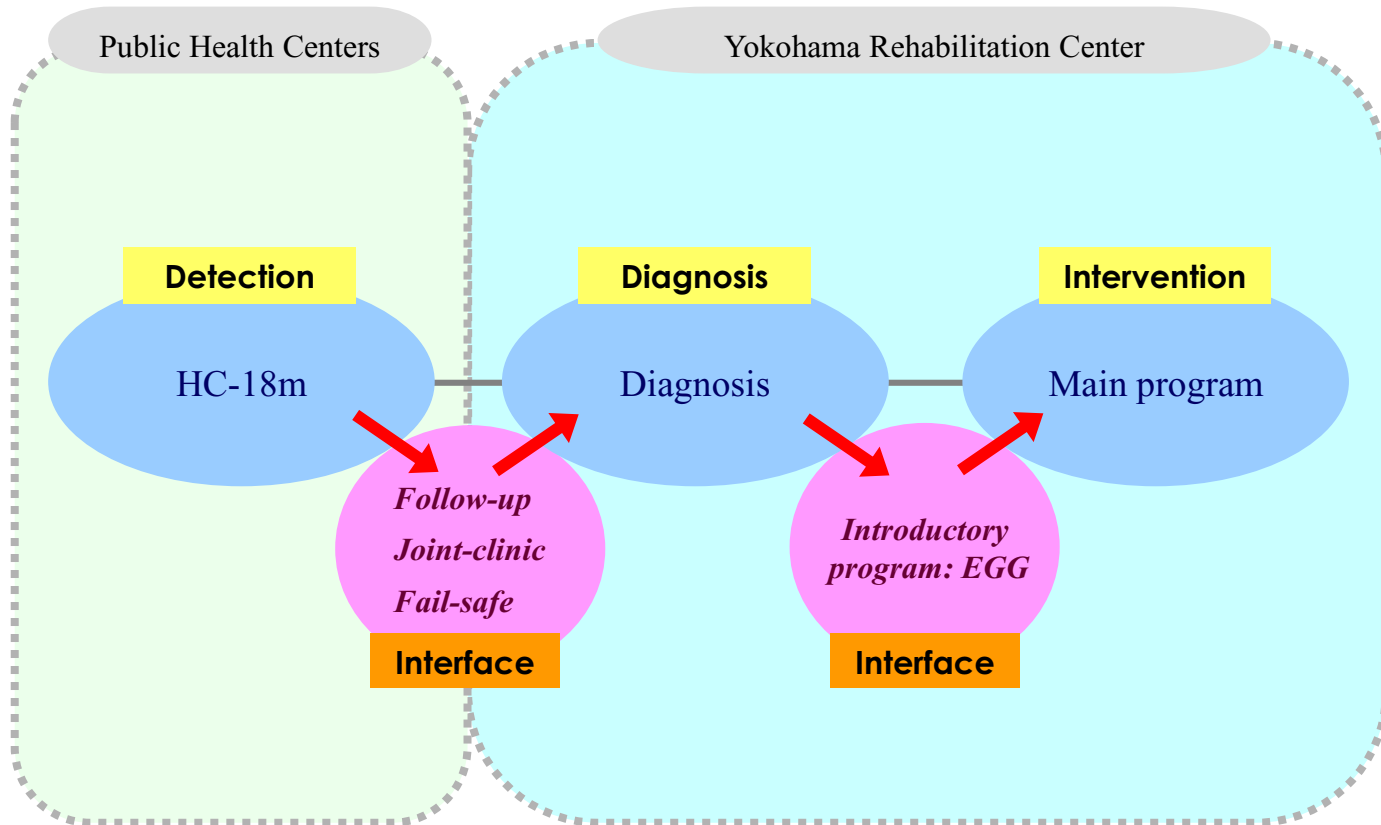
^b Correlations between satisfaction ratings and age at diagnosis were made taking mean age in each age band.

(Howlin & Moore, 1997)



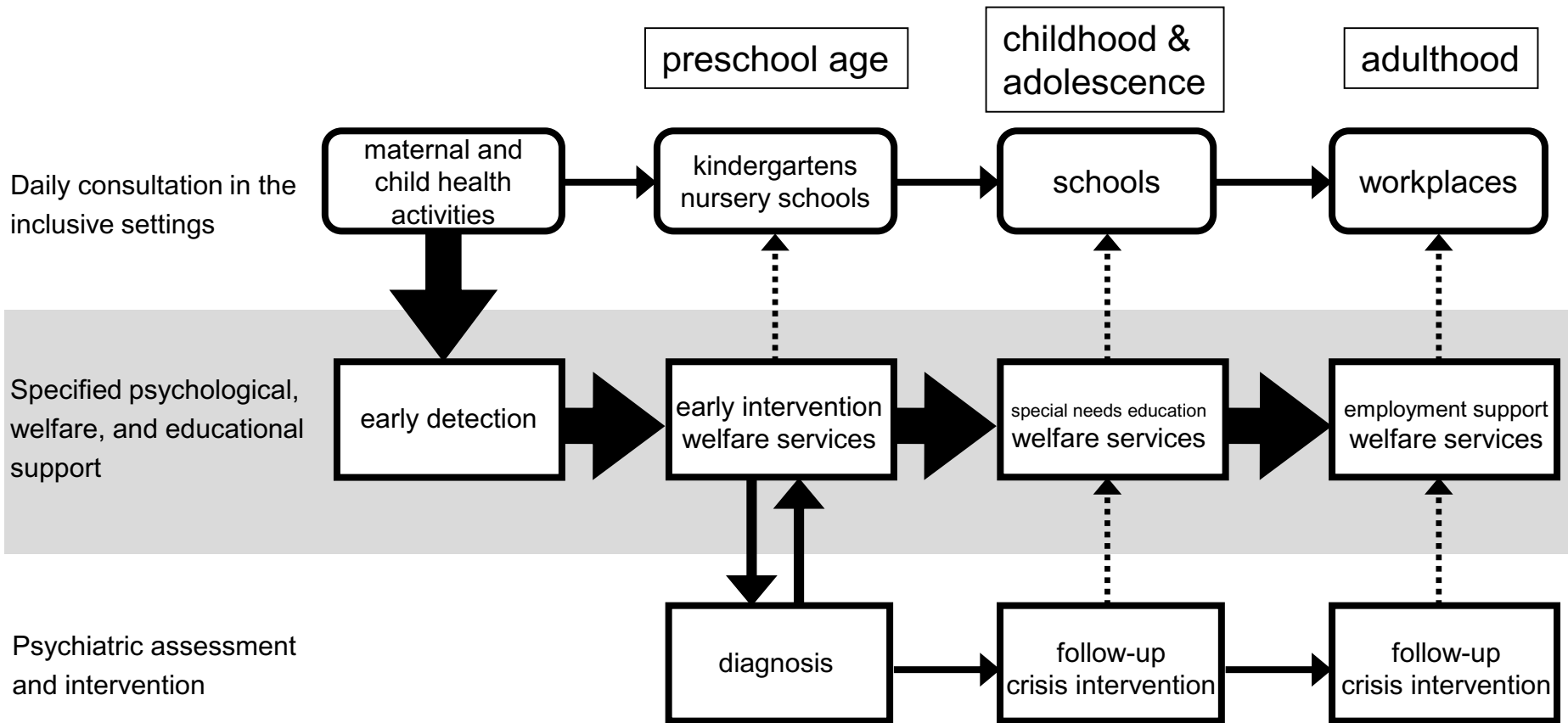
(Iwasa M et al, 2019)

Parental Satisfaction and Age When Diagnosis Confirmed: After Early Detection Was Activated



(Honda & Shimizu, 2002)

DISCOVERY Model



Stratified Community Care for Children and Adults with Neurodevelopmental Disorders

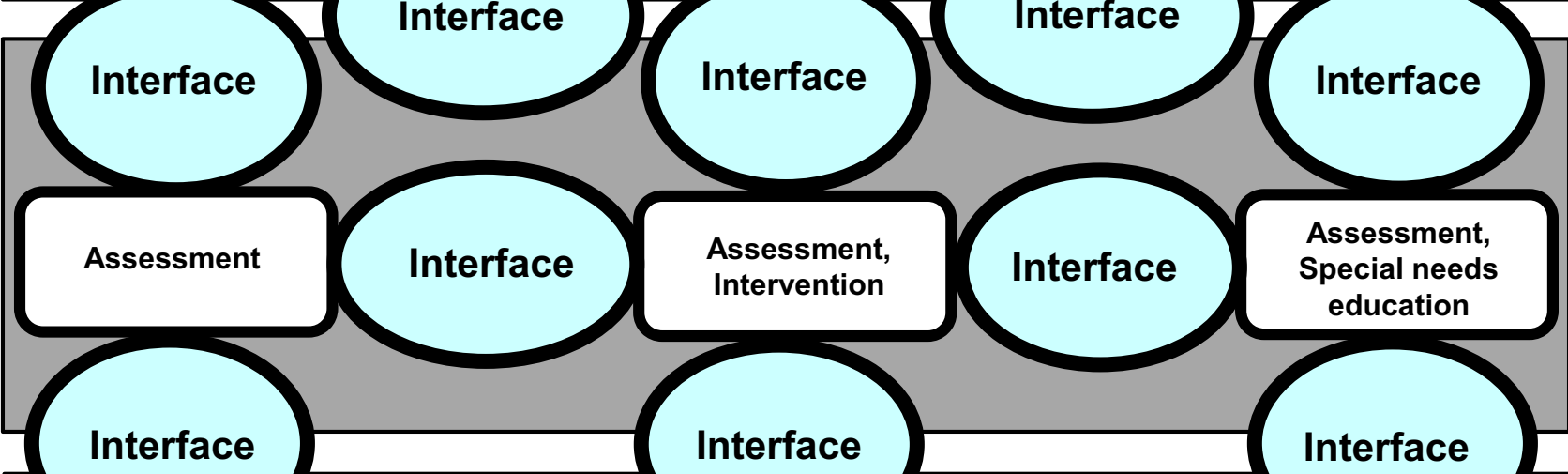
Level I:

Daily consultation in the inclusive settings



Level II:

Specified psychological, welfare, and educational support



Level III:

Psychiatric assessment and intervention



Basic Model for Community Support System for Children with Neurodevelopmental Disorders and Their Families

Recommendations for Local Governments in Japan

Cities larger than 200,000 population

- All levels of support including interfaces should be prepared.

Cities smaller than 200,000 population

- **Level I** support should be prepared.
- **Level II & III** supports may be offered by prefectures.

The Role of Local Governments

Hardware

- Facilities on medicine, welfare, and special needs education

Software

- Programs for early detection, assessment, diagnosis, intervention, and social inclusion

Humanware

- Training programs for staff members