

Childhood Disintegrative Disorder Surveillance Study (CDD-SS)

The second page of the case notification form will be stored separately from the rest of the questionnaire and personal identifying information for the case will be used only for linkage of records.

Reporting Instructions:

- Report any child younger than 16 years of age presenting to you for the first time and seen in the last month, who has had a significant regression in language, play, adaptive behaviour, or functional skills, resulting in impairments similar to Autism Spectrum Disorder. Please report children even if currently undergoing medical investigation for exclusion purposes. Please report a child whose regression may have occurred earlier, but is presenting to you for assessment for the first time.
- Please report only children who have shown apparently normal development for at least the first 2 years of life.
- Do not report children with classic autistic stasis/regression of language and social skills occurring before the age of 1 year 11 months.
- Do not report children with a static brain lesion such as acquired brain injury or those meeting criteria for the BPSU PIND study (<http://www.rcpch.ac.uk/pind>).

Case Definition (case must meet criteria A-E):

A. Apparently normal development for at least the first 2 years of life after birth in children younger than 16 years of age;
and

B. A definite and persistent loss of previously acquired skills in at least two out of the following areas:

- 1)** Expressive or receptive language;
- 2)** Play skills;
- 3)** Adaptive behaviour and functional skills; which can include previously acquired bladder or bowel control, academic, self-care, social, and practical skills;

and

C. Qualitatively abnormal social functioning, manifest by:

- 1)** Qualitative abnormalities in social communication (of the type defined for Autism Spectrum Disorders) manifest by:
 - i. Impairment in social-emotional reciprocity;
 - ii. Impairment in non-verbal communicative behaviours used for social interaction;
 - iii. Impairment in developing and maintaining relationships, to age appropriate level;

and

- 2)** Restricted, repetitive and stereotyped patterns of behaviour, interests and activities, including motor stereotypies and mannerisms.

D. The disorder is not attributable to: acquired aphasia with epilepsy; selective mutism; schizophrenia; Rett Syndrome; neurodegenerative diagnosis; acquired brain injury.

E. Absence of new abnormal neurological signs on examination (hence not meeting criteria for the BPSU-PIND study).

Section A: Reporter Details

1.1 Date of completion of questionnaire:

1.2 Consultant responsible for case: _____

1.3 Hospital name: _____


1.4 Telephone number: _____ Email: _____

1.5 Has the patient been referred to/from another centre? Yes No Not known


If yes: 1) please name centre: _____

2) please name consultant: _____


Section B: Case Details

 **2.1** NHS/CHI No:

2.2 Hospital No:

 **2.3** Postcode: Town of Birth (if ROI) _____

2.4 Sex: M F Date of birth: / /

 **2.5** Ethnicity*: Specify if any "Other" background _____

*Please choose the correct ethnicity code from Appendix A overleaf

Appendix A

Appendix A: Coding for Ethnic Group (ONS 2001 for UK wide data collection)

	Ethnicity Code	
A White	1	Any White background
B Mixed	2	White and Black Caribbean
	3	White and Black African
	4	White and Asian
	5	Any Other Mixed background, <i>please write in section B</i>
	6	Indian
C Asian or Asian British	7	Pakistani
	8	Bangladeshi
	9	Any Other Asian background, <i>please write in section B</i>
D Black or British Black	10	Caribbean
	11	African
	12	Any Other African background, <i>please write in section B</i>
E Chinese or other ethnic group	13	Chinese
	14	Any Other, <i>please write in section B</i>
F Unknown	15	Ethnicity not known

Section C: Presentation/Clinical features

3.1 Reported date of onset
(month/year): _____

Date of diagnosis (if applicable): __/__/____

3.2 Which of the following
symptoms/signs did the
patient demonstrate?

(Please tick Yes/No/NK-not known)

	Yes	No	NK	Details (If Yes):
Loss of expressive language skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Loss of fluent speech <input type="checkbox"/> Loss of phrased speech <input type="checkbox"/> Loss of single words <input type="checkbox"/>
Loss of receptive language skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Loss of play skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Loss of self-care skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Loss of bladder or bowel control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Loss of academic or other practical skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Impairment in social-emotional reciprocity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	- Abnormal social approach <input type="checkbox"/>
				- Failure of normal back and forth conversation <input type="checkbox"/>
				- Reduced sharing of interest, emotions, affect and response <input type="checkbox"/>
				- Lack of initiation of social interaction <input type="checkbox"/>
				- Poor social imitation <input type="checkbox"/>
Impairment in non-verbal communicative behaviours used for social interaction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	- Poorly integrated verbal/nonverbal communication <input type="checkbox"/>
				- Abnormal eye contact and body-language <input type="checkbox"/>
				- Deficit in use of non-verbal communication <input type="checkbox"/>
				- Lack of facial expression or use of gestures <input type="checkbox"/>
Impairment in developing and maintaining relationships, to age appropriate level	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	- Difficulties adjusting behaviour to social context <input type="checkbox"/>
				- Difficulties in sharing imaginative play <input type="checkbox"/>
				- Lack of interest in people <input type="checkbox"/>
Restricted, repetitive and stereotyped patterns of behaviour, interests and activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	- Stereotyped or repetitive speech <input type="checkbox"/>
				- Stereotyped or repetitive movements <input type="checkbox"/>
				- Excessive adherence to routines <input type="checkbox"/>
				- Ritualized patterns of behaviour <input type="checkbox"/>
				- Excessive resistance to change <input type="checkbox"/>
				- Restricted, fixated interests that are abnormal in intensity or focus <input type="checkbox"/>
				- Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment <input type="checkbox"/>

3.3 Other symptoms:

	Yes	No	NK	Details (If Yes):
Needs lots of prompts for everyday life activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Anxiety or fearfulness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Fearfulness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Odd, bizarre behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Talks to self loudly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Self-injurious behaviour	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Disobedient, uncooperative, difficult to control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Aggressive to others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Excessively active	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Depressed/withdrawn/flat affect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Unresponsive to structured activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Variability in functioning and mood from day to day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Appetite reduction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Sleep disturbance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Seizures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Tics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Focal neurological signs (motor or cranial nerves)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Unusual experiences of hearing or seeing things that are not there	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Unusual beliefs that are not true	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
Loss of motor skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
General loss of interest in objects and environment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____

3.4 Clinical Global Impression scale- a global assessment of current autistic symptomatology, behaviour, impact of illness on function (please tick one box):

1	<input type="checkbox"/>	Normal	No evidence of ASD symptoms or functional impairment.
2	<input type="checkbox"/>	Borderline	Subtle or very minimal symptoms
3	<input type="checkbox"/>	Mild	Clearly established symptoms with minimal, if any difficulty in social and educational function
4	<input type="checkbox"/>	Moderate	Overt symptomatology causing noticeable, but modest, functional impairment. Unable to function in some unfamiliar situations without support
5	<input type="checkbox"/>	Marked	Intrusive symptomatology that distinctly impairs social/educational function; needs some support in many situations; symptoms restrict activity (e.g. experiences considerable difficulty with transitions which interferes with daily activities)
6	<input type="checkbox"/>	Severe	Disruptive disorder; behaviour and function are frequently influenced by symptomatology and often requires supervision and 1:1 support
7	<input type="checkbox"/>	Amongst the most severe	Disorder drastically interferes in many life functions; may need continual supervision or residential care; associated symptoms may be extremely intrusive to others or detrimental to self

3.5 Regression:

Details

Please confirm the child's approximate developmental age *just prior* to onset of CDD symptoms:

months

What is the child's *current* approximate developmental age:

months

Please confirm the child's language level *prior* to onset of symptoms:

Fluent speech

Phrased speech

Single words

Did the child have any neurodevelopmental or neurological diagnosis prior to presentation?

No Yes *specify:*

Over what length of time did the regression take place?

weeks

Was there any suspected/reported trigger in the month before regression?

No Yes *specify:*

Section D: Family History

4.1 Please give details of any of the following in the 1st degree family history:

Yes No Unknown In whom

Autism

Schizophrenia

Other neurodevelopmental diagnosis

Specify:

Other psychiatric diagnosis

Other diagnoses

Section E: Diagnosis and Investigations

4.1

Normal Ab-normal Not done Unknown Detail/ Result

MRI Brain

EEG

NMDA receptor Antibodies

Other neuronal surface antibodies

Array-CGH

Other genetic (e.g. genome sequencing)

Other investigations

Formal assessment of cognitive level

Formal assessment of language level

Formal assessment of adaptive behaviour functioning

Autism Diagnostic Observation Schedule

Section F: Management

7.1 Duration of paediatric inpatient stays: days

Duration of psychiatric inpatient stays: days

Psychotropic medications commenced (eg risperidone, stimulants, melatonin etc.): No Yes 1. _____
2. _____

Immunotherapy used (steroids, IVIG) No Yes 1. _____
2. _____

Educational interventions: No Yes 1. Extra support at nursery/school
2. Plan for Education Health Care Plan

Other medical interventions (including nutritional supplements) No Yes _____

Psychological/Mental Health intervention or support for family: No Yes 1. CAMHS
2. Child Development Centre
3. Community/ School

Speech and language therapist-intervention: No Yes 1. Communication 2. ASD
3. Feeding

Ongoing referral to other medical speciality: No Yes _____

Thank you for taking the time to complete the Questionnaire

Please print and return the completed form in the SAE to:

Dr Jessica Turnbull, Children's Neurosciences, 1st Floor, Staircase D, South Wing, St Thomas' Hospital,
Westminster Bridge Road, London, SE1 7EH

If you have any questions about the study please do not hesitate to contact the investigators by email or telephone:

Telephone: 020 3049 8051 Email: jessica.turnbull@gstt.nhs.uk