# BPSU surveillance of Childhood Disintegrative Disorder commences in November 2016

Childhood Disintegrative Disorder (CDD) is a rare condition in which a previously typically-developing child very rapidly, sometimes even over a few days, loses intellectual and developmental skills. Children then stop communicating and playing with other children, and cannot look after themselves, often resembling a severe form of Autism. At present, we do not know what causes this devastating condition.

To begin to unravel such rare conditions, we first require knowledge on the incidence of CDD, the true spectrum of children with such presentation, how they are investigated and cared for, and crucially, their outcome.

We would like to:

- What is the incidence of CDD in the UK and Ireland?
- What is the variability in presenting features diagnostic of CDD?
- What is the distribution by age, sex and broad ethnic groupings?
- What is the rate of first-degree family history of Autism Spectrum Disorder and other psychiatric disease in CDD?
- What are the current investigative approaches to CDD?
- What are the current management approaches to CDD?
- What is the outcome of CDD at one year and two years?
- Can prognostic features for poor outcome in CDD be identified?

**Duration:** BPSU surveillance will be undertaken for 13 months, starting in November 2016 and concluding in November 2017. Follow-up until November 2019 (at 12 months and 24 months).

**Case definition:** Please report any child seen in the last month who meets the case definition in the UK or the RoI.

Child must meet criteria A to E:

**A.** Apparently normal development for at least the first 2 years of life after birth in children up to 10 years of age
**B.** A definite and persistent loss of previously acquired skills in: expressive or receptive language; play skills; adaptive behaviour and functional skills
**C.** Qualitatively abnormal social functioning, manifest by: qualitative abnormalities in social communication (of the type defined for Autism Spectrum Disorders) and 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).

**Website:** www.rcpch.ac.uk/bpsu/CDD

**Funding:** Funding for this study has been granted by The Shirley Foundation (http://www.steveshirley.com/shirley-foundation/).

**Ethical approval:** This study has been approved by the London Bloomsbury REC (Ref: 16/LO/0799) and has been granted Section 251 CAG permission (Ref: 16/CAG/0061).

**Further information:** If you would like any advice regarding the eligibility of a particular case for inclusion in the study please contact:

Dr Michael Absoud, Newcomen Centre at St Thomas', Staircase D South Wing,
St Thomas' Hospital, London SE1 7EH
**Tel:** 0207 188 3995 **Email:** michael.absoud@gstt.nhs.uk

Dr Jessica Turnbull
Sunshine House Children and Young People's Development Centre, 27 Peckham Road, London, SE5 8UH
**Email:** jessica.turnbull@gstt.nhs.uk