

CHILDHOOD DISINTEGRATIVE DISORDER

Abstract	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. The present study will seek to identify the incidence of CDD, presenting features, investigative and management approaches, and short-term outcome.
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Website	www.rcpch.ac.uk/bpsu/CDD
Coverage	United Kingdom and the Republic of Ireland
Duration	November 2016 to November 2017 (13 months of surveillance). Follow-up until November 2019 (at 12 months and 24 months).
Research Questions	▪ 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?

Case definition	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).
Reporting instructions	Please report any child seen in the last month who meets the case definition in the UK or the Republic of Ireland.
Methods	Questionnaire completed by reporting clinicians at baseline, and 12- and 24-month follow-up.
Funding	Funding for this study has been granted by The Shirley Foundation (http://www.steveshirley.com/shirley-foundation/)
Ethics 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).
Support group	Austica UK (https://www.autistica.org.uk/)

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