Accommodating complexity: The need for evidence-informed mental health assessments for children in out-of-home care

Rachel M Hiller, PhD[1,2*], Stine Lehmann, PsyD, PhD[3,4], Stephanie J Lewis, MBBS, PhD[5,6], Helen Minnis, MBChB, PhD[7], Katherine H Shelton, PhD[8], Michael Tarren-Sweeney, PhD[9], Heather Taussig, PhD[10,11]

[1] Division of Psychology and Language Sciences, University College London, United Kingdom

[2] Anna Freud National Centre for Children and Families, United Kingdom

[3] Department of Health Promotion and Development, Faculty of Psychology, University of Bergen, Norway

[4] Regional Centre for Child and Youth Mental Health and Child Welfare – West, NORCE Norwegian Research Centre, Bergen, Norway

[5] Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, United Kingdom

[6] South London and Maudsley NHS Foundation Trust, United Kingdom

[7] Department of Mental Health and Wellbeing, University of Glasgow, Glasgow, United Kingdom

[8] School of Psychology, Cardiff University, Cardiff, United Kingdom

[9] School of Health Sciences, University of Canterbury, Christchurch, New Zealand

[10] Graduate School of Social Work, University of Denver, Colorado, USA

[11] Kempe Center, Department of Pediatrics, University of Colorado School of Medicine

* Corresponding Author
Dr Rachel Hiller
E. r.hiller@ucl.ac.uk

Funding: No funding was directly related to this work.

Conflicts of interest: Co-authors HM and SL were involved in the development of the RADA measure, mentioned in this paper. Co-author MT-S was involved in the development of the ACC and ACA measures mentioned in this paper. None receive any financial benefits from these measures. No other authors have any conflicts to disclose.

Financial disclosures: Authors receive funding from the sources listed below. None of this funding is directly related to this article, and no funder has been involved in any stage of the development of this article.
RH: UK Research and Innovation [UKRI]; National Institute for Health and Social Care Research [NIHR]; Applied Research Collaboration (ARC) network.
SL: Norwegian Research Council.
SJL: UK Medical Research Council [MRC]; South London and Maudsley NHS Foundation Trust.
HM: National Institute for Health and Social Care Research (NIHR); What Works in Children's Social Care.
KS: UK Research and Innovation [UKRI].
HT: US/UK Fulbright Scholar Award; Office of Juvenile Justice and Delinquency Prevention; Arnold Ventures.

Author contributions: RH led the work. All authors contributed to the conceptualisation of the piece and edits and revisions of the manuscript. All approve the final version of the manuscript.

ORCID IDs:
RH: 0000-0002-4180-8941
SL: 0000-0002-3660-0601
SJL: 0000-0002-4153-5728
HM: 0000-0002-2377-8945
KS: 0000-0002-1311-5291
MT-S: 0000-0002-9853-1090
HT: 0000-0001-7909-2988

Word count – 1,502

Children in out-of-home care have all experienced adversity and most have been exposed to maltreatment. Research across many decades has shown that these experiences are important risk factors for mental health problems. However, there is a lack of consensus about how best to formulate and manage the mental health needs of these children. Our own experience, supported by the empirical literature and clinical commentaries,[1-5] suggests that there can be considerable reluctance to use standard assessment protocols and diagnostic frameworks when formulating the needs of this group of young people. Whilst some children in the welfare system may experience significant emotional distress and functional impairment yet not meet current diagnostic thresholds, multiple reviews have shown that almost half of children in the welfare system do meet criteria for a diagnosable mental health disorder[6,7]. More still may be subsyndromal but still benefit from assessment and formulation based on current diagnostic frameworks. Thus, we contend that standard diagnostic frameworks should be central to the formulation and management of mental health difficulties for this group of children, as for any child. Of note, both our opinions here and the empirical literature are near exclusively derived from work in high-income Western countries.[6,7] Further research across a range of cultures and particularly in lower- and middle-income countries is vital.

Deliberations about the appropriateness of diagnostic classification systems are crucial for advancement in science and healthcare, but while these deliberations take place, services should be modelled on current evidence. Indecisive and inconsistent practice has potential to cause confusion and delays for service providers and families. It can limit understanding of the child's difficulties, the ability to advocate for their needs, and reduce referrals and access to the treatment approaches most likely to be effective. We can only know if a child has a treatable psychiatric condition, or needs support with impairing subsyndromal symptoms, if we offer them a full and evidence-informed diagnostic assessment.

We are calling on service-providers to challenge assumptions that can cloud decision-making around assessments, diagnoses, and support/management. Assumptions might include that recognized diagnostic categories do not suit these children (despite significant evidence to the contrary), or that because they are in out-of-home care they must have an attachment disorder (which might or might not be the case). Such assumptions may lead to clinicians failing to assess disorders that commonly occur in the context of trauma, such as major depression.[8]. Ironically, diagnoses classified as trauma- and stressor-related, including posttraumatic stress disorder (PTSD), reactive attachment disorder (RAD), and disinhibited social engagement disorder (DSED), are also often missed or misdiagnosed.[3]

When children in out-of-home care do access services, practitioners often describe mental health problems using general terms such as 'developmental trauma'. These terms do not have established definitions or evidence-based treatments. They are used to describe both the exposure to severe adversity, including maltreatment, and the presumed mental health effects that follow such exposure. This ignores the substantial variation in outcomes between individuals exposed to maltreatment. Not all individuals who have experienced developmental or complex trauma, including children in out-of-home care, will go on to develop mental health difficulties. Conflating the experience with the mental health outcome can be confusing and problematic.

What needs to be considered in an assessment?

A holistic assessment should ideally include assessment of internalizing and externalizing symptom profiles, trauma- and stressor-related symptoms, neurodevelopmental conditions (including learning disabilities), as well as assessments of risk (eg, self-harm and suicidality, substance use, risk of harm from others). All of these areas are more common in youth who have experienced maltreatment.[6-8] While there is no measurement pack universally recommended for assessing child mental health, there are many options available depending

on the resources of the service and the purpose of the assessment (see Table 1 for examples). Using standardized diagnostic assessment tools, like the DAWBA, K-SADS, or RADA, helps to ensure thorough, efficient, and full assessments of a broad range of needs. Where services are too stretched to conduct full diagnostic assessments (although we argue that these can improve efficiency), there are many readily-available validated screening tools for common mental health difficulties, which are time- and cost-efficient to deliver and do not require training (see Table 1). These can then also be used to track progress (e.g., during an intervention). While the original validation of these measures has predominantly been with non-care-experienced youth, many have since been widely and effectively used in research with those in out-of-home care. The strengths and difficulties questionnaire (SDQ) has been shown to identify children in out-of-home care who would benefit from a more comprehensive assessment[9]. England has opted for government-mandated yearly screening of children in out-of-home care using the SDQ. However, unless screening triggers more detailed needs assessments and specialist referrals, this becomes a simple data gathering exercise with little impact on access to healthcare.

Even though children in out-of-home care often have complex symptoms and needs, the underlying symptoms requiring treatment may provide a usefully focused path forward. For example, a child could have PTSD and ADHD, and – following treatment guidelines – might benefit from psycho-education, a trauma-focussed CBT (for PTSD), and stimulant treatment (for ADHD). For those whose symptoms are under the threshold for diagnosis, or clearly over threshold yet not quite meeting typical criteria, a structured and consistent evidence-informed assessment and formulation will ultimately be beneficial if communicated in a way that allows children, their carers, teachers, and service providers to better understand their needs and to develop support and treatment strategies. Many children in out-of-home care presenting to mental health services will have competing complex needs, such as placement instability,

school refusal, or serious risky behaviour. These needs should not preclude the use of a thorough mental health assessment (as they would not in a physical health assessment). If anything, a thorough mental health assessment is even more crucial when the child's life circumstances are challenging.

When should we be conducting assessments?

There is no clear empirically grounded guidance for when to assess, but the timing should balance the burden on services, young people, and caregivers with the importance of understanding their needs. Ideally, mental health would be assessed as soon as appropriate when entering the out-of-home care system, given evidence for chronicity in their difficulties. Assessments should not be delayed because of placement instability. At the very least, a thorough assessment should be conducted when children first have contact with mental health services. Assessments should not be seen as one-offs, but rather as part of an ongoing careful monitoring of needs and progress.

Who should be the source of reporting?

Empirical evidence shows general poor agreement between young people and caregivers (as it does in the general population). Thus, a triangulated approach is best practice, where possible[9]. If not possible, the young person's self-report should be prioritized, as well as the caregiver's report, if they are a caregiver who is familiar with the child and their current mental health. The views of a professional may also be useful (e.g., social worker, teacher). Given that both caregivers and social workers can change regularly, it is crucial that assessment information is accurately recorded and appropriately shared (with the child's knowledge, when age appropriate). This ensures continuity of care and minimises the burden on young people to have to continuously report the same information to different sources. Ultimately, the voice of young people should be central to discussions on their mental health. Like all children, children

in out-of-home care are a heterogeneous group. They will have differing views on topics like the language used around mental health, which should be explored and respected.

Where to from here?

Mental health and social services remain chronically under-funded. Poorly resourced services are hugely problematic for young people, families, and the people who work in them, especially if poor resources mean long waiting lists or absent services except in crisis situations. While capacity and resourcing are potential barriers to conducting thorough assessments, if a child in out-of-home care does access mental health services, ensuring that their needs are thoroughly assessed so that appropriate support can be offered is very likely to be cost-saving in the long run. Fully understanding the type and extent of needs in these young people also provides crucial information that enables advocacy for greater resources, workforce capacity- and competency-building, and more targeted research. The field needs to test existing best evidenced treatments in this population, as well as develop new, culturally- and contextually-relevant treatments. Understanding holistic mental health support for complex needs also remains crucial, including support outside of professional services. Although far more research is needed, services cannot wait for this research to be done. We must draw on existing evidence in child mental health and provide this group of children with excellent assessments, to ensure we are providing the best possible care now.

References

[1] DeJong,M. Some reflections on the use of psychiatric diagnosis in the looked after or "in care" child population. Clinical Child Psychology and Psychiatry. 2010;15:589–599. doi: 10.1177/1359104510377705

[2] McGuire, R., Halligan, S.L., Meiser-Stedman, R., Hiller, R.M. (2022). Differences in the diagnosis and treatment decisions of children in care compared to their peers: An experimental study on post-traumatic stress. British Journal of Clinical Psychology. In Press. doi: 10.1111/bjc.12379.

[3] Grasso D, Boonsiri J, Lipschitz D, Guyer A, Houshyar S, Douglas-Palumberi H, Massey J, Kaufman J. Posttraumatic stress disorder: the missed diagnosis. Child Welfare. 2009;88:157.

[4] Frogley C, John M, Denton R, Querstret D. 'They don't meet the stereotypes in the boxes…': Foster carers' and clinicians' views on the utility of psychometric tools in the mental health assessment of looked after children. Adoption & Fostering. 2019;43:119-36. doi: 10.1177/0308575919841752

[5] Jee SH, Conn AM, Szilagyi PG, Blumkin A, Baldwin CD, Szilagyi MA. Identification of social-emotional problems among young children in foster care. Journal of Child Psychology and Psychiatry. 2010;51:1351-8. doi: 10.1111/j.1469-7610.2010.02315.x

[6] Bronsard G, Alessandrini M, Fond G, Loundou A, Auquier P, Tordjman S, Boyer L. The prevalence of mental disorders among children and adolescents in the child welfare system: a systematic review and meta-analysis. Medicine. 2016;95(7). doi: 10.1097/MD.0000000000002622

[7] Engler AD, Sarpong KO, Van Horne BS, Greeley CS, Keefe RJ. A systematic review of mental health disorders of children in foster care. Trauma, Violence, & Abuse. 2020; 20:1524838020941197. doi: 10.1177/1524838020941197

[8] Lewis SJ, Koenen KC, Ambler A, Arseneault L, Caspi A, Fisher HL, Moffitt TE, Danese A. Unravelling the contribution of complex trauma to psychopathology and cognitive deficits: a cohort study. The British Journal of Psychiatry, 2021, 219:448-455. doi: 10.1192/bjp.2021.57

[9] Goodman R, Ford T, Corbin T, Meltzer H. Using the Strengths and Difficulties Questionnaire (SDQ) multi-informant algorithm to screen looked-after children for psychiatric disorders. European Child & Adolescent Psychiatry. 2004;13:ii25-31. doi: 10.1007/s00787-004-2005-3

Table 1. Overview of Examples of Diagnostic and Symptom Severity/Screening Measures

Measure name	Purpose	Versions	Example non-English translations	Time burden	Further information
Example Diagnostic Interviews					
DAWBA	Interview and questionnaire format to identify DSM and ICD psychiatric diagnoses for 2-17 year olds	Parent/carer interview Interview with 11-17yos Questionnaire for teachers	Approx. 20 official translations available. Translated versions all available at website.	Parent/carer interview ~1hr Young person interview ~30 min Teacher questionnaire ~10 min Skip rule means whole sections are skipped where screening questions shows issue/diagnosis is highly unlikely, reducing unnecessary time burden.	The creators now recommend using the online version where possible, which costs £10 (~US$13). While the online version requires a small cost, it reduces time burden to save money and resources for services. Does not require psychologist or psychiatrist to administer. Designed so it can be administered by people with limited prior experience of child mental health. Time burden is primarily on the carer and young person. However, as this is a diagnostic tool interpretation of responses should be by experienced mental health professional. dawba.info For information about the online version of this tool email support@youthinmind.com
K-SADS	Semi-structured diagnostic interview for	Interview with caregiver and young person, with capacity to	Translated into multiple languages, including	~60-90 minutes	Freely available for non-commercial purposes (e.g., clinical usage) Should be administered by a trained clinician.

	the identification of DSM affective disorders, such as depression and anxiety disorders, in 6-18 year olds	incorporate information from school or elsewhere. There are various potential supplementary components to the interview, depending on the focus and outcome of screening phase.	Farsi, Icelandic, Korean, Japanese, Mandarin, Portuguese.		https://www.pediatricbipolar.pitt.edu/resources/instruments
RADA	Carer report instrument for identification of symptoms of Reactive Attachment Disorder and Disinhibited Social Engagement Disorder; 6-17 year olds.	Can be used as a parent/carer interview or parent/carer can complete online and clinician can rate or use to support face to face clinical assessment.	Norwegian French	~30 -60 minutes for parent/carer and 5 mins for clinician to review.	Available at low cost for clinical or research purposes. Does not require psychologist or psychiatrist to administer. Designed so it can be administered by people with limited prior experience of child mental health. Time burden is primarily on the parent or carer. When used as a diagnostic aid interpretation of responses should be by experienced mental health professional. https://rada.medicalquestionnaires.com/
Example of symptom/ screening tools					
SDQ	Screening tool for	25 items	Translated into >50	~10 minutes	Freely available.

	internalizing (emotional difficulties and peer problems) and externalizing (conduct problems and hyperactivity) difficulties, in 2-17 year olds. Note, there is a general lack of normative and validation data on 2 year olds.	Parent/carer report; 2-4 year olds and 4-17 year olds Young person self report, 11-17 year olds Teacher/educator report; 2-4 year olds and 4-17year olds Newer versions for 18+ year olds (self report and informant report)	languages, spanning every continent. Translated versions available at website.		Not diagnosis specific but potentially useful as routine screener to identify young people who would benefit from further assessment of their mental health needs [see Ref9]. sdqinfo.org
CRIES-8	Screening tool for PTSD symptoms; 8+ year olds.	8-item young person report. The items cover re-experiencing and avoidance symptoms. Note, a 13 item version is also available (CRIES-13),	Translated into >20 languages Translated versions available on website.	<5 minutes	Used extensively with different trauma-exposed populations. Very brief validated screening tool, that can be completed by the young person in 2 minutes, and may form a useful part of an assessment for trauma-exposed children, such as those in out-of-home care. Available at: childrenandwar.org

		which includes items for altered arousal symptoms. The CRIES-8 performs as well as the CRIES-13. There is no carer-report version.			Note – if a clinician wanted a more detailed tool that covers all PTSD symptom clusters, there are many validated PTSD symptom checklists available in young person and carer-report formats, such as the Child & Adolescent Trauma Screen and Child PTSD Symptom Scale for DSM-5. These take longer to complete but cover all symptom clusters.
RCADS	Measures anxiety and depression symptom severity; 8-18 year olds Covers symptoms of social phobia, panic disorder, separation anxiety, generalized anxiety, obsessive compulsive disorder.	Available in young person self-report and parent/carer report. 25-items (original version is 47-items, provides scoring breakdown that is disorder specific)	Translations include Arabic, Danish, Hindi, and Spanish. See childfirst.ucla.edu for all versions	~10 minutes	Freely available. 47-item and 25-item versions available at corc.uk.net and childfirst.ucla.edu

ACC ACA	Measures maltreatment-related symptoms, across empirically-defined clinical scales, including attachment difficulties, mental health, and risky behaviours (e.g., self-harm); 4-17 year olds.	Carer report. ACC, 120-items ACA, 108 items Validated with out-of-home care populations	German, Spanish	~30 minutes	Freely available for clinical purposes. Clinicians must register with the test developer at childpsych.org.uk
BITSEA	Screening tool to assess emotional and behavioural difficulties, and social-emotional development; 12-36 month olds.	Carer report 42 items	Dutch, Japanese, Spanish, Turkish	~10 minutes	Free for individual clinicians, but 'fees may apply' for clinical organisations eprovide.mapi-trust.org

Note. This table provides an overview of some potential diagnostic and symptom/screening checklists, which have evidence of good psychometric properties and have been used in research with care-experienced young people. It is not designed to be an exhaustive list of

available measures. Websites like corc.uk.net provide information on a large range of measures suitable for young people. ACA = Assessment Checklist for Adolescents, 12-17yrs; ACC = Assessment Checklist for Children, 4-11yrs; BITSEA = Brief Infant-Toddler Social and Emotional Assessment; CRIES-8 = Child Revised Impact of Events Scale; DAWBA = Development and Wellbeing Assessment; K-SADS = Kiddie Schedule for Affective Disorders and Schizophrenia; RADA = Reactive Attachment Disorder and Disinhibited Social Engagement Disorder Assessment; RCADS = Revised Child Anxiety and Depression Scale; SDQ = Strengths and Difficulties Questionnaire.