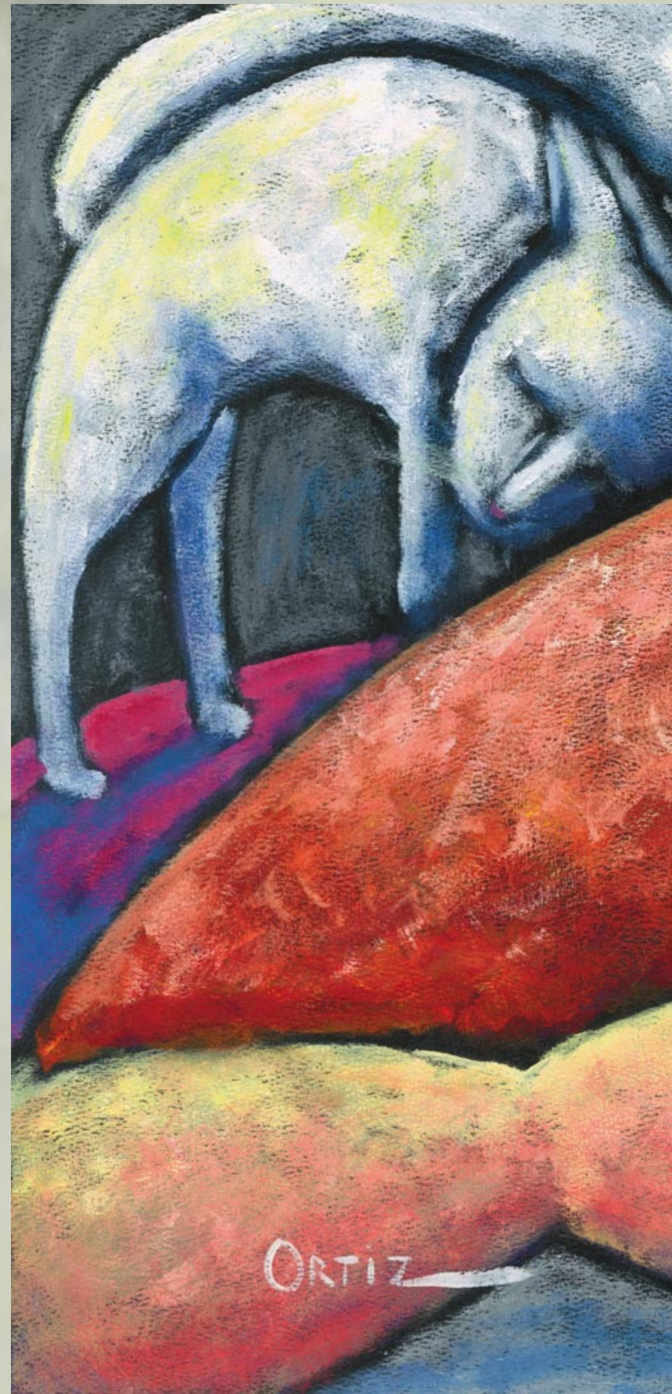
Misunderstood and misdiagnosed

Many abused and neglected children are squeezed into diagnostic categories that show misunderstanding of their true needs. Others with developmental difficulties originating in such trauma fail to meet the threshold for accessing appropriate therapeutic support. Graham Music discusses what must be understood to prevent this



Society is failing a huge number of children who are, or who have been, looked after. For example, a disproportionate number of these children end up in the prison or psychiatric systems, or get excluded from school[1]. Here, I argue that our child mental health services might also be failing them in a similar way, albeit inadvertently.

My clinical work in CAMHS is primarily within the Tavistock Clinic's fostering and adoption and kinship care team, and I know that my colleagues and I never become inured to the shocking states of mind we come across in the children we work with. Often, their inner worlds are filled with horrific fantasies; they show extremes of violence and aggression; and they have little capacity to understand or be interested in minds and emotions, whether their own or others'. There is now plentiful evidence that such high levels of early stress, abuse and trauma are extremely predictive of many poor outcomes in adulthood[2], including high levels of illness and early death[3].

Yet despite the extraordinarily high level of emotional need seen in so many of these children, too many of them do not gain access to mental health services, and when they do, they do not receive the kinds of help they need. Paradoxically, the increasing influence of evidence-based practice agendas, NICE and accompanying developments such as IAPT for children is quite likely to decrease rather than increase the chances of these children gaining appropriate access to therapeutic support.

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An important reason for this is that service provision is increasingly organised with the expectation that clinics must only treat diagnosable mental health disorders, and do so with NICE-approved treatments. The catch for this client group is that being looked after or maltreated is not a disorder, and that the issues with which such children present often simply do not fit into the main diagnostic categories as defined by DSM-IV or ICD10, although it can look at first glance as if their behaviours might fit such categories. For example, many children have presentations that seem just like autistic spectrum disorders, ADHD, or conduct disorders, and sometimes the children are given these diagnoses. But very often, the children fall just under the thresholds to receive the diagnosis[4]. For want of better understanding of them, many children are squeezed into categories that are a very poor fit, much like Cinderella's fabled stepsisters trying desperately to squeeze wrong-sized feet into a slipper meant for someone else.

Developmental difficulties and co-morbidity

What we do know is that many traumatised and maltreated children show a range of developmental difficulties and 'co-morbidity'[5]. This has led researchers such as Tarren-Sweeney to develop alternative profiles and ways of conceptualising the range of issues such children have[6] – arguing

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that these children do not access the correct services sufficiently because they are not well-enough understood[7]. A diagnostic category that is little used by psychiatry but often overused and misused by therapists is that of Reactive Attachment Disorder, a category whose psychiatric diagnostic meanings have often not been properly grasped but which is nonetheless used very loosely by a host of therapists, sometimes to justify therapies of dubious helpfulness[8].

I will now briefly describe a couple of case examples to illustrate these points, one case of a primarily *abused* child and another case of a *neglected* child. After this I will explain how I have come to understand such children from a developmental perspective.

Mick: abused and traumatised

Mick was the older of two siblings, adopted at age four from a drug-using and neglectful mother almost definitely involved in prostitution, and a violent father. There were suspicions that the children were used in a paedophile ring. His younger sister, adopted at nearly two, was doing much better. She had been in care from the age of 11 months, and had escaped the worst treatment. Mick was another story. He was nearly excluded in his first week at school, seemed to have a tough, steely side to him, and seemed to take pleasure in seeing others hurt and in pain. In his play, dolls were cut up, mutilated and tortured to his evident enjoyment, in such a way that made me feel like my blood was running cold. While he was hypervigilant enough to be able to monitor me and

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others for signs of danger, he seemed to have no interest in other people's minds and was almost incapable of understanding that another person had feelings. Maybe this was not surprising, as from the reports we had, it seemed unlikely that in his life before adoption anyone would have offered him anything like kindness or caring or attunement, or shown interest in his thoughts or feelings.

Mick had been given a diagnosis of ADHD, and it is true he was a very active boy, but, I think, hypervigilant due to trauma and the inability to regulate his emotions. He was also given a diagnosis of conduct disorder and due to his almost complete inability to understand other people's minds and emotions, several people were also clamouring for an autistic spectrum disorder diagnosis. His inner world might have been particularly contorted by the madness-inducing horrors that he had experienced, but many maltreated children I have seen show some similarities with Mick. In particular, they often have very poor peer relationships, which as we now know links with a lack of early attunement and insecure attachment relationships[9]. They can be both rigid, not managing any change, yet easily dysregulated and out of control, both being common features of children with disorganised attachments[10]. Many of these children do not seem to be able to fit in anywhere, get excluded from school, have few friends or relationships that last, and many, especially the boys, find themselves quickly in the criminal justice system.

Stephen: a neglected boy

Where Mick was abused and overtly traumatised and showed more externalising symptoms, other children, like Stephen, can present in a quieter, more internalising way. Stephen was six when I first saw him. He had dull, sunken eyes, seemed expressionless, his skin tone was pale and he looked lifeless. He was reported at school to have few friends, rarely smiled or seemed to enjoy anything much, and kept himself to himself. He liked to spend as much time as possible on computers or watching television, or sometimes playing Lego. Children like Stephen rarely come to our attention, but he was referred when his adoption was at risk of breakdown. He had already had a previous placement breakdown. His adoptive parents reported that he seemed not to need them at all, that he gave nothing back, that he did not seem to care if he was with them, or indeed with anyone, and that he was cold and unemotional. He was extremely unrewarding to parent, and like many such children, it was sometimes hard to put a finger on what was disturbing about being with him. He had also been given a diagnosis of Asperger's syndrome and had some extra help at school.

Stephen's history was one of profound neglect. His learning-disabled mother had had previous children taken into care and she had left her town of origin and settled elsewhere, slipping under the radar of statutory services. When Stephen was three years old, social workers, alerted by neighbours, found a home with almost no furniture, little food, and the mother living with an unknown and extremely learning-disabled man, sleeping on the floor without even a mattress but only blankets. The main feature of the home was a large television. Stephen had few words, and it seemed he had suffered more from a lack of good experiences than overtly traumatising ones.

His arrival in our service heralded a long period of work that I cannot describe in detail here, except to say that this was at first primarily with the adoptive parents, helping them understand the impact of early neglect, and beginning to help them spot and build on small developmental and hopeful signs in Stephen's behaviour that could easily be missed. I have described work with such neglected children elsewhere[2,11,12] and a lot of such work is about keeping hold of hope and not feeling deadened or disheartened in the face of what can seem a relentless grind with few rewards. Children like Stephen can develop and grow, but it is slow, painstaking work, and not work that is sufficiently available in clinics.

Developmental understandings

In my experience, CAMH services often do not have a good enough understanding of children like Mick or Stephen, who have suffered abuse or neglect. Despite the increase in Britain of specialist teams of CAMHS professionals attached to social services departments, as well as the recent NICE guidance suggesting the need for such specialist developments[13], many such children do not meet the thresholds that allow them to receive a service. Often, services manage waiting lists by insisting on a diagnosable mental health disorder as a passport. Unfortunately, such children lack the passport to gain access to a service, or end up with diagnoses that do not really fit them, such as Stephen's autistic spectrum disorder/Asperger's diagnosis, or Mick's ADHD and conduct disorders. It is therefore, I believe, more appropriate to develop in-depth developmental understandings of such children, using complex profiling of the kind Tarren-Sweeney suggests[7].

A typical example of this dilemma was demonstrated by as yet unpublished research undertaken by a colleague[14] with a small number of looked-after children, all of whom had been given an autistic spectrum disorder diagnosis. She gave these children a battery of tests, including the Autistic Spectrum Quotient, Story Stems, the Sally-Anne test, which classically measure theory of mind abilities, the Baron-Cohen 'Reading the Mind in their Eyes' test and several others, and her finding was that on such measures there was no evidence of autism. These children had all been maltreated and were typical in displaying 'sub-threshold' levels of behavioural difficulties, of inattention, poor symbolic and imaginary capacities,

basic levels of language skills, and they also struggled with peer relationships. Such findings fit well with our clinical experience and there are clear developmental explanations for why maltreated children end up with such presentations.

Much of the developmental research has emphasised how trauma and abuse can give rise to a range of typical personality features. For example, one is likely to see hypervigilance with accompanying strong amygdala activation, and high cortisol levels, giving rise to difficulties in concentrating that can seem rather like ADHD[15]. Not having an experience of an attuned adult in touch with one's own mental states will stymie the development of mentalising capacities[16], and stress and anxiety diminish any latent capacities to be reflective and thoughtful about one's own and others' psychological and emotional experiences. None of us is very empathic when someone is threatening us! As Ogden[17] argues, a major task of therapeutic work is helping our clients find a window of safety, a place where they are neither too over- or under-aroused, and in which reflective therapeutic work can take place.

Normal developmental capacities

Not surprisingly a whole host of developmental capacities tend to 'co-emerge' when things go reasonably well and children receive parenting which is somewhere on a continuum that one might describe as what humans have evolved to expect[18]. For example, research shows that the capacities for empathy and altruism are part of a whole swathe of developmental capacities that are related and that tend to come on line together. Humans are adaptive and have evolved to develop in a range of emotional environments, but I think that the extremes of neglect and abuse are not what we have evolved to grow in.

Central to these capacities is the ability to be empathic or helpful, which in turn requires the ability to understand the 'intentions' of others, to make sense of what another is thinking and feeling. To work out the meaning of a word or a gesture, or whether we think an act is right or wrong, one needs to have developed an ability to understand another's intentions. Deliberately hitting someone or just accidentally knocking them over will be judged by most of us differently, as we understand that the intention is different.

A classic example is the way in which even very young children normally recognise another's intentions. Reddy[19] showed that infants as young as about five months can 'tease' their parent, such as by offering something and then taking it back, which requires an ability to make sense of the parent's wishes. We know that the ability to understand another's intentions in a relaxed and interested way develops from the first few months, and is a precursor of having a Theory of Mind later, and this depends on having 'mind-minded' input[20], the lack of which partly explains the misdiagnosis of autistic spectrum disorders in so many of these children.

Linked to these capacities is what is often called 'autobiographical memory' and the ability to conceptualise oneself as part of a story, one's own and other people's, having a past, present and future. Of course, tragically, so many looked-after and traumatised children have never really experienced themselves as in anyone else's mind properly, as central to any narrative. Usually, given the right building blocks, autobiographical memory starts to develop apace after children begin to recognise themselves in mirrors, often between about 18 and 24 months. The classic 'mirror-recognition' test places a blob of 'rouge' on an infant's face, and children 'pass' this test if they recognise that it is their face with rouge on in a mirror. Passing the test is also linked to starting to use more personal pronouns[21], often seen as a sign of a separate 'self' forming. Yet another piece of the 'co-emergence' jigsaw is the fact that the ability to play in an imaginary way and to pretend is a linked capacity and particularly related to achieving understanding of other minds[22]. We know how often children who have been traumatised or neglected seem unable to play symbolically.

It seems that these abilities are also linked with the capacity to defer gratification and to self-regulate, something that, again, so many maltreated children struggle with, and which also tends to be related to good early caregiving and attachment relationships. We know that the inability to self-regulate affects a child's ability to negotiate peer and other relationships. And it seems that the ability to defer gratification depends on being able to understand and regulate one's own thoughts and feelings[23]. Deferred gratification and altruism are linked, in that they both entail thinking about minds and feelings, either one's own or those of others. Thus in most children a range of developmental *capacities* are linked and tend to 'co-emerge'.

Many looked-after and traumatised children have never properly experienced themselves as in anyone else's mind

However, in children who have been abused or neglected, we often see the opposite, a range of developmental *deficits* in such areas as the ability to empathise, understand other minds, autobiographical memory, self-regulation, and symbolic play. It is likely that important, ordinarily expected developmental trajectories simply do not occur in severely maltreated populations, because they have lacked the 'experience expected' inputs that we might variously know as mentalisation, containment, mind-mindedness, attunement and such.

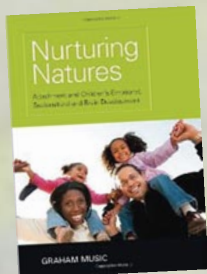
Where now?

In the last few years, the Tavistock, Anna Freud Centre, Great Ormond Street Hospital, BAAF (British Association for Adoption and Fostering), Adoption UK, Coram and the Marlborough Family Centre have formed a consortium to try to think about the particular issues that arise when working with children who have suffered serious maltreatment.

We must move beyond the narrow diagnostic labelling to a clear understanding of developmental trajectories

As part of our work, we received a grant to research what local practitioners, particularly CAMHS therapists and social workers, understood about this client group and the help that was available. Importantly, it was found that many responsible for such children, such as social workers, felt that it was much more difficult than it should be to get these children into services – and there were more CAMHS services than we hoped that did not feel they had the expertise to work with this client group. There are lessons here for policy makers to heed from such findings if the shocking longitudinal outcomes for looked-after children are not to continue or even worsen.

It seems to me that for change to occur we need to really understand the children who have been severely maltreated or neglected. To do this we must move beyond the narrow diagnostic labelling to a clear understanding of the developmental trajectories that are likely to arise following maltreatment and abuse. I believe that, rather than being side-tracked by NICE guidelines and diagnostic categories, we need to ensure that we and our colleagues understand the nature of these issues. Otherwise too many children will not meet the thresholds to gain access to CAMHS, and too many who do make it to clinics will be wrongly diagnosed and not receive the help they so badly need. ■



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References

1 Ford T, Vostanis P, Meltzer H, Goodman R. Psychiatric disorder among British children looked after by local authorities: comparison with children living in private households. The British Journal of Psychiatry. 2007; 190(4):319.

2 Music G. Nurturing natures: attachment and children's emotional, sociocultural and brain development. London: Psychology Press; 2010.

3 Dube SR, Felitti VJ, Dong M, Giles WH, Anda RF. The impact of adverse childhood experiences on health problems: evidence from four birth cohorts dating back to 1900. Preventive Medicine. 2003; 37(3):268-277.

4 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(4):589.

5 Oswald SH, Heil K, Goldbeck L. History of maltreatment and mental health problems in foster children: a review of the literature. Journal of Pediatric Psychology. 2010; 35(5):462-72.

6 Tarren-Sweeney M. The Assessment Checklist for Children – ACC: a behavioral rating scale for children in foster, kinship and residential care. Children and Youth Services Review. 2007; 29(5):672-691.

7 Tarren-Sweeney M. It's time to re-think mental health services for children in care, and those adopted from care. Clinical Child Psychology and Psychiatry. 2010; 15(4):613.

8 Prior V, Glaser D. Understanding attachment and attachment disorders: theory, evidence and practice. London: Jessica Kingsley; 2006.

9 Sroufe LA. The development of the person: the Minnesota study of risk and adaptation from birth to adulthood. New York: Guilford Press; 2005.

10 Solomon J, George C, De Jong A. Children classified as controlling at age six: evidence of disorganized representational strategies and aggression at home and at school. Development and Psychopathology. 1995; 7:447-447.

11 Music G. Neglecting neglect: some thoughts about children who have lacked good input, and are 'undrawn' and 'unenjoyed'. Journal of Child Psychotherapy. 2009; 35(2):142-156.

12 Music G. When life has been sucked out. CCYP. March 2010.

13 NICE/SCIE. NICE Guidelines: Looked After children. 2010. Available from: www.nice.org.uk/nicemedia/live/13244/51173/51173.pdf

14 McCullough E. Narrative responses as an aid to understanding the presentation of maltreated children who meet criteria for Autistic Spectrum Disorder and Reactive Attachment Disorder: a case series study (unpublished).

15 Perry BD, Pollard RA, Blakley TL, Baker WL, Vigilante D. Childhood trauma, the neurobiology of adaptation and use-dependent development of the brain: how states become traits. Infant Mental Health Journal. 1995; 16(4):271-291.

16 Fonagy P. (ed) Affect regulation, mentalization, and the development of the self. New York: The Other Press; 2002.

17 Ogden P. Trauma and the body: a sensorimotor approach to psychotherapy. New York: Norton; 2006.

18 Cicchetti D, Valentino K. An ecological-transactional perspective on child maltreatment: failure of the average expectable environment and its influence on child development. In: Cicchetti D, Cohen DJ. (eds) Developmental psychopathology: risk, disorder, and adaptation. New York: Wiley; 2006.

19 Reddy V. How infants know minds. Cambridge, Mass: Harvard University Press; 2008.

20 Meins E, Fernyhough C, Wainwright R, Gupta MD, Fradley E, Tuckey M. Maternal mind-mindedness and attachment security as predictors of theory of mind understanding. Child Development. 2002; 73(6):1715-1726.

21 Lewis M, Ramsay D. Development of self-recognition, personal pronoun use, and pretend play during the 2nd year. Child Development. 2004; 75(6):1821-1831.

22 Harris PL. Hard work for the imagination. In: Goncu A, Gaskins S. (eds) Play and development: evolutionary, sociocultural, and functional perspectives. London: Psychology Press; 2007.

23 Moore C, Macgillivray S. Altruism, prudence, and theory of mind in preschoolers. New Directions for Child and Adolescent Development. 2004; 2004(103):51-62.