Chapter 13

Sally: A 12-Year-Old Who May Have Disinhibited Social Engagement Disorder

Sally is a 12-year-old, biracial (African-American/white), cisgender child. She is tall and lanky with very neat cornrows. Her adoptive parents, in conjunction with her adoption social worker, referred her for services. Sally seems comfortable living in her adoptive home, with her African-American father, her white mother, and her younger biracial biological sibling. Sally has been in the home for just over 2 years, and her adoption was legally finalized 8 months ago. She interacts smoothly with the family, but her parents say that "something's missing." Sally does not turn to her parents for comfort or guidance when upset or hurt. Her parents have offered considerable daily life structure to help her become more connected, but she does not seem to look for their care and support. They fear she will turn to "just anyone," and as a near teenager, this could mean others might take advantage of her. "She doesn't think at all about her safety." From the parent's perspective, it is difficult "to get so little response" from Sally, though they are quite aware they are "in it for the long haul." "We are committed to her." They find it difficult to understand her nonverbal cues, and, even after they encourage her to talk, Sally seems puzzled about her feelings and needs.

Protective services had placed Sally in several different foster homes due to parental neglect between ages 4 and 9. They returned Sally to her mother after each out-of-home placement, some lasting of up to a year. Her single-parent biological mother worked long hours and, at times, left Sally alone for extended periods. During the foster placements, she was described as "a very eager to please child," who "treated everyone as a friend," was "very open," and "had lots of friends." There was no evidence of physical or sexual abuse during the placements, though other children would sometimes verbally tease Sally. Her first child protective worker noted she was "attractive and pleasant" but also noted she "did not seem to discriminate among people, seeking what contact she could get from just about anyone." She has limited self-care skills and would "get lost" in TV shows if given the chance. She loved "Disney movies" which it seemed had been used as surrogate babysitters. Sally was 2 years behind academically in school at age 9 and had a

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limited vocabulary and limited math and reading skills. None of these learning issues had any apparent organic basis based on physical and neurological exams. She behaved well in school and "was never a behavior problem." "People like her."

The local courts terminated parental rights after the mother's boyfriend got into several fights with Sally. The final straw was that he hit Sally in the back of the head with a frying pan, which seemed to be a one-time occurrence. Sally was unconscious for several minutes and had a very small laceration where she was hit. She was treated for swelling around her brain over the next few days. She was diagnosed with a closed head trauma from the incident. The organic effects of the incident are unclear, both in terms of any learning-related challenges or changes in self-regulatory functions. Still, her neurological and learning testing did not indicate any significant issues beyond lagging beyond grade level. Her biological mother said she seemed "different" after the trauma but was never able to pin point just how Sally had changed.

Sally's adoptive parents have a biological child and wanted to adopt. They were "taken" with Sally immediately upon seeing her: she had the skin tone and hair color of their biological daughter. "She seemed to fit right in" her father said. Early visits and her moving in seemed to go well. Sally showed no hesitancy in engaging with the family, which was a pleasant surprise. "We knew she should be more careful, but we were glad she seemed to accept us." "There was no honeymoon; she was just part of the family."

The problems emerged when Sally got involved in school and in activities beyond the core family. "She treated everyone like family!" In consultation with the adoption worker, the family increased their daily structure and actively kept Sally within defined limits. "This wasn't hard, and we only seldom got upset, but it took vigilance." The limits seemed to provide some order for Sally but did not decrease the indiscriminate reaching out to others, including passersby, the delivery man, and dog walkers. "We weren't sure she'd always be safe, you know, and she's almost a teenager." Her parents also noted they did not understand how Sally got care when she seemed down or hurt. They would have to seek her out and actively question Sally about her emotional state, which seemed to confuse Sally. "At first, we thought we were too pushy, but then we realized she didn't really know how she felt or at least wouldn't easily share it."

Sally has lots of acquaintances, but no real friends. She easily connects with people but does not sustain interactions and most are brief. She makes good eye contact. She displays a wide range of emotion. Though physically capable, she has been oddly resistant to organized sports activities or clubs. Her parents thought these activities might be of interest to her. Her concern is that "the kids will tease me." She has never stuck with a sport or club for more than a few weeks, though her parents are now encouraging her to pick one activity to pursue based on her skills and interests.

Sally appears to meet some DSM-5 criteria for a reactive attachment disorder (RAD) diagnosis and also some criteria for disinhibited social engagement disorder (DSED). She displays diffuse attachments, as evident through indiscriminate sociability and a marked lack of selective attachments (to her biological mother or foster caregivers in the past and to her adoptive parents currently). She often does not look back at her parents when moving into new social situations. She does not seek care and support from her parents when hurt or upset and is often not much consoled when care and succor are provided. This pattern apparently began before age 5 and can be reasonably viewed as the cause of her current attachment problems (called "pathogenic care" in DSM-IV-TR terminology or "social neglect" in DSM-5). The attachment issues do not appear to be related to specific trauma as neither physical nor sexual abuse was reported in the past. Neglect predominated. (Given her multiple placements, the possibility of such abuse is real, but it had not been substantiated by her caregivers or by Sally herself at this point.) There is no evidence of autism spectrum disorder or pervasive developmental delay; in fact, Sally has very good motor skills and eye-hand coordination even after her head trauma. The effects of her head trauma are unknown but do not appear to account for the attachment challenges. Alexithymia is also a rule out given Sally's difficulty identifying her feelings.

Attachment is an interpersonal process that occurs between people (Drisko, 2018). It is quite unlike a bacterial infection or depression that may be viewed as "located" within a person. The consequences of a lack of attachment, or a disinhibited attachment, may be observed in social behaviors such as indiscriminately turning to unknown people for care and support and failing to use a known caregiver for support when hurt or emotionally upset. These behaviors require at least two people in interaction, and the quality of their interaction is crucial to identifying attachment problems.

The interactive quality of attachment disorders make evident some of the shortcomings of medical model diagnosis. The lack of attachment opportunities before age 5 is assumed to have a significant internalized effect on a child's development, but for attachment to develop, other people must offer "good enough" sources of care on a consistent basis. Diagnosing reactive attachment disorder and/or disinhibited social engagement disorder is a difficult endeavor. Clinicians use different diagnostic standards and protocols for children of different ages (Zilberstein, 2006). Children who have received poor care from adults are expected to respond appropriately to any unknown adult, across a variety of contexts, as if such interactions should not be expected to be untrustworthy and stressful.

Due to the interpersonal nature of attachment problems, it is difficult to develop valid standardized measures for them (Drisko, 2018). For nonclinical populations of preschoolers, the Ainsworth Strange Situation Test (1978) is often used to identify different types of attachment. However, the Strange Situation Test is not a scaled measure and is not intended to be used as an outcome measure. It is used to define categorical attachment styles. For school-age children and teenagers, there is no widely used measure of attachment. The Randolph Attachment Disorder Questionnaire [RADQ] is often used as an outcome measure, though it was intended as a general screening tool for broad attachment problems. The Randolph Attachment Disorder Questionnaire has only face validity and emphasizes problems with conduct more than attachment quality per se. Smyke and Zeanah's (1999) Disturbances of Attachment Interview also generates a typology and is rarely used in outcome research. Other measures, particularly the Achenbach Child Behavior Checklist [CBCL] (1991, 1992), are widely used as proxy outcome measures in studies of treatments for RAD, but do not include any direct measures of attachment. Instead, the CBCL's conduct and learning disorder subscales are used as proxies for attachment quality. The problem with this use of proxy measures is that conduct or learning problems may, or may not, be related to attachment quality. These conduct and learning issues may represent distinct but comorbid disorders rather than representing a core aspect of attachment.

These key problems with conceptualizing and measuring RAD have not stopped researchers from preliminary outcome studies. They do seriously limit the confidence that clinicians and researchers can put in their results. What is measured may not fairly and comprehensively reflect the dimension of RAD nor measure it effectively. The conceptual, diagnostic, and measurement problems become crucial in identifying and applying high-quality research to Sally's needs.

Applying the Six Steps of EBP to the Case

Step 1: Drawing on Client Needs and Circumstances Learned in a Thorough Assessment, Identify Answerable Practice Questions and Related Research Information Needs

Sally does not herself identify any problems with her behavior or her interactions with her parents. She says her parents and teachers are "overreacting" (a word she also says is used by her parents about her sister's behavior). Sally's parents are concerned about her disinhibited social interactions that could increasingly be unsafe and risky. They are also concerned that Sally does not turn to them for support when she is hurt or anxious, though this vulnerability is clearly a lesser concern. It does not seem to be the driving force behind their referral of Sally for assessment and possible treatment. The family's adoption worker has been a steady support since Sally's adoption and agrees that Sally's indiscriminate or disinhibited interaction has been consistent and views the parents' concerns as reasonable. Both the parents and the adoption worker believe there may be some subtle medical issue related to her head trauma, but both view her prior workup as thorough. Her parents do not report concern about possible sexual abuse, though both the adaption worker and the clinical social worker doing the assessment think it should remain an open question.

In the **PICO** model, the **P**opulation is school-age children with disinhibited social engagement disorder and/or reactive attachment disorder. The **I**nterventions under consideration are psychotherapies and similar psychosocial interventions or programs. Medication is not under consideration. **C**omparisons would be between different therapies or psychosocial interventions or programs. The **O**utcomes would be increasing Sally's attachment to her parents as most clearly demonstrated through turning to them for support when she is worried or fearful—to be her parental attachment figures. Reduced indiscriminate social interactions are another important outcome.

Step 2: Efficiently Locate Relevant Research Knowledge

A search of the Cochrane Library revealed six trials (or published individual reports) on assessment of disinhibited social engagement disorder. There were no systematic reviews and no publications specifically addressing treatment outcomes for DSED. For reactive attachment disorder, 50 publications were found on the Cochrane Library, but again none were systematic reviews of treatment outcome. Many studies on RAD focused on attachment styles but were not specific to reactive attachment disorder. Those studies most specific to RAD were studies of infants (e.g., Klein Velderman, Bakermans-Kranenburg, Juffer, & van IJzendoorn, 2006) and of efforts to improve empathic maternal care (Raby et al., 2017). The closest match was a study by Bernard et al. (2012) on enhancing attachment security, but it proved to be a study of a successful intervention program for 1–3-year-old children. A similar search for programs at the Campbell Collaboration Library returned zero results for either DESD or RAD as search terms.

RAD and DSED are relatively low incidence disorders that child clinicians may not understand in depth. Limited research is available on treatment outcomes for RAD and DSED. According to O'Connor and Zeanah (2003, p. 233), "no treatment method has been shown to be effective for children with attachment disorders." Further searches of individual research studies are the next approach to locating relevant research literature.

A search on PubMed revealed a report by Zeanah, Chesher, Boris, et al. (2016) that drawing on research available through 2012 finds that RAD and DSED appear to be distinct disorders but that they are also frequently co-occurring or comorbid: "it is likely that comorbidity is the rule rather than the exception" (p. 992). They note that children with DSED "are usually affectively brighter and more social than children with RAD" (p. 993). This appears consistent with Sally's presentation and parental reports. Placement at younger age into good enough care environments is linked to a greater likelihood of functional improvement. The authors state, "Still little is known about individual differences in prognosis, as risk and protective factors have not been well delineated among children with this disorder. In fact, the available data suggest that there are significant individual differences in the course of DSED" (p. 994).

In terms of treatment, Zeanah et al. (2016) state that "The most important intervention for young children diagnosed with RAD or DSED is ensuring that they are provided with an emotionally available attachment figure" (p. 999). They call this a "Clinical Standard"—one based on strong research support and/or "overwhelming clinical consensus" (p. 996). They also state as a Clinical Standard that "clinicians should recommend adjunctive interventions for children who display aggressive and/or oppositional behavior that is comorbid with DSED" (p. 999). They state as a Clinical Opinion—a recommendation lacking strong experimental research support but having some suggestive research support—that "limiting contact with noncaregiving adults may reduce signs of the disorder in the first year of placement (p. 999). Use of medications for DSED is not recommended; and use of physical restraints or holding therapies "should not be administered because they have no empirical support and have been associated with serious harm, including death" (p. 1000).

Myeroff (1997) and Myeroff, Mertlich, and Gross (1999) report that Levy and Orlans' (n.d.) holding therapy produced significant reduction in aggression and delinquency as measured by subscales of the CBCL for 11 adolescents receiving therapy (Aggression subscale, paired $t = 4.26$, $df = 10$, $p = 0.001$; effect size by Cohen's $d = 1.33$. Delinquency subscale, paired $t = 2.37$, $df = 10$, $p = 0.04$; $d = 0.77$), while a comparison group of 9 adolescents showed no change. No significant change in RADQ scores was reported (and this information was simply missing from the 1999 article). No evidence that the adolescents met criteria for a DSM-IV-TR RAD diagnosis was offered. It is unclear if the authors or other provided the treatment. In another study, Wimmer, Vonk, and Bordnick (2009) report a single group pre-post study using a combined 10 hour therapy including family counseling, behavioral management training, and holding therapy as taught by Children Unlimited of South Carolina (2004). All the children had received diagnoses of RAD. They report significant gains on RADQ scores ($t = -3.65$, $df = 21$, $p = 001$; effect size by Cohen's $d = 0.71$) and on the Child and Adolescent Functional Assessment Scale (Hodges, Xue, & Wotring, 2004) for general behavior ($t = -2.61$, $df = 22$, $p = 0.02$; Cohen's $d = 0.65$). It is important to note that holding therapy has been explicitly condemned and prohibited on safety and ethical grounds due to deaths of several children treated with it or variants of it (American Academy of Child and Adolescent Psychiatry, 2005; Zeanah et al., 2016).

While these findings might appear promising, holding therapy (also called rebirthing therapy) has been deemed inappropriate and potentially dangerous by the American Professional Society on the Abuse of Children and the American Psychological Association, Division 37 (2006), and the American Academy of Child and Adolescent Psychiatry (2005; Zeanah et al., 2016). It should not be used due to risk of severe harm or death. Note carefully that finding significant research results does not automatically mean that the treatment is appropriate or without substantial risk of harm. Such harms are unlikely to be noted in the original articles, or necessarily, in later research reviews.

Becker-Weidman (2006a, 2006b) reports a quasi-experimental comparison of Hughes' (2004) Dyadic Developmental Therapy [DDT] versus treatment as usual. All the children included in the study met criteria for DSM-IV-TR RAD diagnosis. Pre-post comparison demonstrated significant improvement for the DDT group ($n = 34$) on five CBCL subscales for aggression, withdrawn, social problems, rule-breaking, and thought problems (t values ranged from 4.38 to 12.81, $df = 33$, all p values were $p < 0.001$; d values ranged from 1.01 to 2.78). In addition, significant improvement on the RADQ was reported ($t = 12.82$, $df = 33$, $p. = 0.001$; $d = 2.70$). Only results on the CBCL subscale anxious-depressed were not significant. The treatment as usual group ($n = 30$) showed no significant pre-post improvement. It is also notable that Becker-Weidman (2006a) was the only provider of DDT in this study and is also the author of this study. Based on a quasi-experiment and with strong potential for attribution bias (favoring one's own work), these results must be considered moderate to low in quality despite their large effect sizes.

Step 3: Critically Appraise the Quality and Applicability of This Knowledge to the Client's Needs and Situation

Research on the effectiveness of treatments for RAD is very limited, especially for school-age children and early adolescents. Further, the measures used to assess attachment are also very limited and of questionable validity. That is, measures of overall conduct may be used as a proxy measure of attachment, failing to specifically measure if the child turns to and uses adults for support and nurture. Some research findings support a therapy that has been essentially banned due to several deaths associated with its use and very high potential for harm. Overall, the best available evidence points to Hughes' (2004) Dyadic Developmental Therapy [DDT]. The evidence is not an RCT but is Level 2 quality. However, the researcher was also the provider of the therapy, which may be a source of attribution bias. Note that the effect sizes are extremely large, near their practical limits. Yet even taking into consideration that Cohen's *d* effects sizes may be inflated when applied to small samples sizes, the effect sizes are very large. In context, this treatment model includes many components also endorsed by observational studies and practice wisdom. Attribution bias may be at play in the DDT outcome studies; replication by others in other settings is needed.

A summary of a wide range of nonexperimental studies completed by Drisko (2009) documents that many studies of RAD address single treatment components or issues that might better be viewed in combination to generate a much more comprehensive treatment package. For example, one excellent clinical report stated that parents underestimate the levels of anxiety of children with RAD and might do better to take a more active and preventive or preemptive approach to caring for their children (Lieberman, 2003). On the other hand, this detailed article did not mention that without a safe, enduring, and consistent family placement, a child with RAD might have a great deal of difficulty making continued progress. It is as if the many components of RAD treatment are stated one by one, with few comprehensive models. This may reflect the interest or expertise of the many researchers. They may be knowledgeable enough to focus on specific treatment components and assume that other conditions are already in place. One comprehensive approach is Hughes' (1988) PLACE model. This model was used in the Becker-Weidman study reported above.

In the diagnosis and treatment of RAD, the clinical social work person-in-environment perspective proves very useful. Clinical social workers should consider the child's placement situation, its safety, empathy, potential longevity, and appropriateness as a foundation to child and family psychotherapy per se. Treatment is best understood as a package of many interventions. These interventions may have different purposes and even different auspices. Drisko and Zilberstein (2008) report that parents attribute improvement by their children with RAD to a combination of factors. These include the (1) constant parental presence and supervision; (2) parental bonding and strong commitment; (3) providing clear and consistent daily life structure; (4) steady behavioral management; (5) acute empathic attunement to interpret the child's often odd or confusing messages; (6) responding to an intuitive or empathic grasp of the child's needs; (7) using social supports, for the parents and for the child; (8) therapy for the child often related to managing the effects of trauma and loss; (9) promoting the child's active involvement in community life; and (10) intervening to support their social activities. Finally, parents and children both had long-term access to prolonged relationships with child welfare/adoptive workers, clinical social workers, and networks of parents of children with similar needs. Treatment of RAD might best be understood as taking an entire childhood and required extensive efforts by parents and professionals together. Yet no RCTs are available to compare such a package of interventions to alternatives. The best available evidence is still quite limited for RAD.

Sally is a biracial child with mixed race adoptive parents and a biracial biological sibling. The research literature on attachment rarely specifies the races of children and parents included in outcome studies. It is not clear that race is a major influence in Sally's situation. It was not raised as a concern by her parents, though it will surely impact her development. Still, the limited detail on sample characteristics provided in the research results offers no information on this topic.

Step 4: Actively and Collaboratively Discuss the Research Results with the Client to Determine How Likely Effective Options Fit with the Client's Values, Preferences, and Culture

It is difficult to provide clients with a summary of the best available research related to their needs when research results are few and perhaps of low quality. There is no specific evidence base for treatment outcomes on either RAD or DSED. Outcome studies for RAD, based on children with clear DSM-III or DSM-IV-TR diagnoses, are very few. Studies using DSM-5 criteria for RAD or DSED are not yet available though some may be underway. However, Sally's parents must be informed that holding therapy, which is widely discussed in the media and on internet sites, presents a great potential for harm and should not be undertaken. Several professional groups prohibit its use for safety reasons.

The best available evidence suggests treatment using the Hughes' (2004) Dyadic Developmental Therapy. It is important to point out to the family that these results are based on only two studies done by the same person. There is no mention in these studies that participating clients and families were biracial, or of co-occurring head trauma. The evidence base for this therapy is quite limited, but it appears to yield good results on several attachment and behavioral issues. Another important practical concern is if any professional trained in the DDT model is available in the geographic location of the family or if the clinician can be trained in this model.

Sally's limited motivation for treatment might also be an obstacle to her participation. Ironically, her lack of motivation is offset by her disinhibited attachment. Sally, like many children, may be brought for treatment "against their will" with a very strong chance that her investment will build over time. Her parents are open to being involved in treatment.

Step 5: Synthesizing the Client's Clinical Needs and Circumstances with the Relevant Research, Finalize a Shared Plan of Intervention Collaboratively with the Client

After discussion with the parents and Sally, a plan centering on Hughes' DDT model was selected. Both Hughes publications, and many reports of the effective components of treatment for children with RAD and their families, indicate this will be a long-term effort. The DDT model emphasizes work with parents to provide safety and security with attention to the parent's own attachment strategies. In parent work and in conjoint work with the child, parents work to increase attunement to the child, to help understand the child's subjective experiences, and to address inevitable misattunements and interpersonal conflicts. Attachment facilitation and cognitive-behavioral interventions are also used in day-to-day interaction. Sally's parents were pleased with this plan, though they were not happy or encouraged by the limited research on effective treatments. They found the lack of strong research support for any treatment to suggest that their therapeutic work might prove ineffective. Sally was willing to be involved but her understanding of the treatment was uncertain.

No therapist trained in Hughes' DDT was found in the family's local region. However, a therapist with expertise in treating RAD, who had attended training workshops by Hughes and others, was available nearby. The family was open to a referral and understood that they might be making a long-term contract to work with a clinical social worker.

Step 6: Implement the Intervention

After 18 months of treatment, Sally's parents reported she had made some progress in reducing her indiscriminate social interactions that they viewed as important. They continued to be concerned that as she entered adolescence, her lack of discrimination and social judgment might increasingly put her safety at risk.

On the other hand, their therapeutic work had helped them better interpret Sally's signs of stress and anxiety. This allowed them to intervene preventively, as well as to help from a relationship in which Sally felt them as supportive, tuned in, and nurturing. They understood this as reflecting changes in Sally's attachment to them, as well as in their own behavior toward Sally.

In individual therapy, Sally had begun to explore and mourn the loss of her biological mother. Sally's repertoire of affect remained limited, but sadness was more apparent and connected to appropriate content. No indications of sexual abuse were evident, though alexithymia remained a relevant rule out.

Sally's treating social worker asked her parents to rate her behavior using the CBCL on an annual basis. Over the course of 1 year, Sally's scores on the CBCL subscales for withdrawal increased, reflecting less disinhibited behavior. At the same time, her CBCL subscale scores on social problems decreased. Visual inspection of the scores was another source of documentation of Sally's improvement.

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