THE ASSESSMENT AND TREATMENT OF CHILD PSYCHOPATHOLOGY AND DEVELOPMENTAL DISABILITIES

Self-Injurious Behavior in Intellectual Disabilities

Johannes Rojahn, Stephen R. Schroeder and Theodore A. Hoch

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Dedications

Dieses Buch ist meinen verehrten, lieben Eltern gewidmet - meiner Mutter Johanna Rojahn, die ihren Glauben an mich nie verloren hat und im Andenken an meinen Vater Rudolf Rojahn, der sich davon überzeugen ließ.

This volume is also dedicated to all families of individuals with self-injurious behavior who persevere in supporting their loved ones in spite of their difficulties.

J.R.

"They came to the other side of the sea, to the territory of the Gerasenes. When he [Jesus] got out of the boat, at once a man from the tombs who had an unclean spirit met him. The man had been dwelling among the tombs, and no one could restrain him any longer, even with a chain. In fact he had frequently been bound with shackles and chains but the chains had been pulled apart by him and the shackles smashed, and no one was strong enough to subdue him. Night and day among the tombs and on the hillsides he was always crying out and bruising himself with stones" (Mark 5:1–5).

Preface

The focus of this book is on the pathological, malignant, and socially unacceptable form of self-destructive behavior among individuals with intellectual disabilities. That means that the subject is anchored by two criteria, the first one being a particular group of behaviors, and the second being a subgroup of individuals within the population at large in which those behaviors are observed.

As for the first criterion, at first glance it seems self-evident that self-destructive behavior is pathological and socially unacceptable. The notion of "deliberately" inflicting physical damage to our own bodies seems disturbing at best, if not repugnant and outright frightening. It may sound surprising therefore, to realize that it is not trivial trying to define self-injurious behavior and to distinguish forms that are aberrant and those that are not. The designation of what behavior is deemed normative and acceptable on the one hand and what is undesirable and pathological is not rooted in a priori, objective, and mutually exclusive categorical criteria. Nor can we hope that science will help us determine such criteria (e.g., Maddux, Gosselin, & Winstead, 2004). The designation is based on our prevailing values and sensibilities that are formed by our socio-cultural context. Whether behavior is seen as acceptable or as pathological depends on morals and traditions that are fluid within and variable across cultures. This is also true for self-injurious behavior.

Taking a very broad definition of self-injurious behavior, we find that we all engage regularly in behavior that causes destruction to our own body tissue, without raising alarms that some deviant behavior is being performed. In fact, not to engage in some of those tissue-damaging behaviors would have negative societal repercussions in many cultures. For instance, in our Western postindustrial societies we are normally expected to keep our fingernails in proper length and shape and we regularly cut and shave our hair. Of course these types of behavior are not considered harmful, probably because they do not cause pain. But many of us also condone or engage in behaviors that actually break the skin and even draw blood. For example, many people pick at sores, exacerbating wounds; or we scratch our itching skin after a mosquito bite. More drastic, but still socially sanctioned forms of self-inflicted tissue damage (or damage we freely permit others to inflict on us) include rather invasive procedures such as tattooing, piercing, and cosmetic surgery for face lifts, breast enlargements, or hair implants. The consensus on acceptability begins to crumble with self-harming practices for religious or spiritual purposes, with traditions such as male and particularly female genital circumcision, or the more radical practices of body-modification practiced by cultural fringe groups such as the Modern Primitives (Musafar, 1996; Vale & Juno,

1989). Few people would argue, we trust, that the removal of ones own eyeball or self-castration as it has been observed by people with schizophrenia are examples of healthy behavior. The same, we believe, is true for the various forms of self-injurious behavior seen in some individuals with intellectual disabilities.

The second boundary we set on the topic of this book is the population. Individuals with intellectual disabilities are biologically and behaviorally vulnerable and many of them run the risk of developing self-injurious behavior at one point or another during the course of their lives. Pathological forms of self-injurious behavior are of course also observed in persons without intellectual or developmental disabilities, and are typically so alarming to warrant the attention of mental health professionals. Unfortunately, there are only very few scientists or clinicians who focus on self-injurious behavior in both the general, intellectually typical, and the intellectually disabled population. The psychiatric literature, for instance, has traditionally not reflected much interest in self-injurious behavior in individuals with intellectual disabilities. Self-injurious behavior in that group has mostly been studied by behaviorally and later by biologically oriented psychologists. This schism within the scientific community into those who studied self-injurious behavior in the intellectually typical or superior population (essentially psychiatry, psychiatric nursing, etc.) and those who specialized in intellectual disabilities (psychologists and special educators) drove a wedge between those two camps that discouraged attempts to inform each other of their respective issues, concerns, and achievements. Theoretical papers, conceptual models and empirical research approaches on self-injurious behavior rarely bridged the gap between the two groups. The upshot is that we have no clear, integrated sense at this point in which aspects and to what extent self-injurious behavior across the intellectual spectrum is conceptually similar or different. Therefore, we will briefly discuss some selected theoretical models of self-injurious behavior as it occurs in the general public and in clinical groups without intellectual disabilities, especially those that seemed relevant, either due to their historical significance or due to their potential significance in expanding our thinking about self-injurious behavior among people with intellectual disabilities. We will also present empirical data on the epidemiology and the behavioral function of self-mutilation in those populations.

Our book is intended to give a broad overview of the literature in the area of self-injurious behavior in people with intellectual disabilities, but most of the text is dedicated to the review of the behavioral and biological research in this field. In fact, it is our view that the most promising heuristic approach for the advancement of our understanding of this phenomenon and for its management and treatment is likely the bio-behavioral perspective in which behavior can be studied at the intersect of learning and the biological bases of behavior. We will propose an overarching heuristic model, which we will call the Gene–Brain-Behavior Model of Self-Injurious Behavior that presents a platform to integrate disparate, and previously isolated scientific approaches.

A word about the terminology of intellectual disabilities: Although not unanimously and universally agreed upon, the term *intellectual disabilities* has been gradually adopted world wide to replace the term *mental retardation*, which, through its derogatory meaning in the vernacular, is seen by many to have become pejorative and

insulting. In keeping with the prevailing sentiments among people with intellectual disabilities and their advocates, and with some of the decisions made by major national and international organizations (e.g., the former *American Association on Mental Retardation* has been renamed in 2006 to *American Association on Intellectual and Developmental Disabilities*), we are using the term "intellectual disabilities" throughout the book.

According to all major diagnostic classification systems, such as the *Diagnostic and Statistical Manual* (DSM-IV-TR) (American Psychiatric Association, 2000), the *International Classification of Diseases, 10th revision* (ICD-10) (World Health Organization, 1993), and the *Definition, Classification, and Supports* of the American Association on Mental Retardation (AAMR, 2002) intellectual disability (now referred to as intellectual disabilities) is a chronic, typically lifelong, and etiologically heterogeneous condition that is defined by three criteria:

1. Significant limitations in intellectual functioning,
2. Significant limitations in adaptive behavior, and
3. Manifestation of these limitations before the age of 18 years.

Largely overlapping but not identical with intellectual disabilities are developmental disabilities. Developmental disabilities are also severe, chronic, usually lifelong conditions due to diverse mental and/or physical impairments. People with developmental disabilities typically have limitations with major life activities such as language, mobility, learning, self-help, and independent living that must appear before 22 years of age. Typical diagnostic categories that can lead to a developmental disability are intellectual disabilities, autism, cerebral palsy, epilepsy, etc.

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Chapter 1

Definition, Classification, and Epidemiology

1.1. Terms and Definitions

Someone interested in the topic of self-injurious behavior (SIB) who approaches the existing literature will encounter a whole host of terms for this puzzling and sometimes terrifying phenomenon. This diversity in the terminology hints at the state of our knowledge but also reflects a fragmentation of different scholarly disciplines, all of which have brought their own terms and approaches to the arena.

Perhaps it is useful to distinguish between two main groups of terms and definitions: Definitions developed by scholars with a primary interest in self-injurious behavior in the general population and psychiatric patients, and those focused on people with intellectual disabilities. The first group has traditionally come from a psychodynamic orientation and tends to use interpretative terms that imply intent or seemingly explain the causes of the behavior. Examples of such charged terms are *auto-aggressive behavior* (Freud, 1949), *self-aggressive behavior* (Cain, 1961), *partial and focal suicide* (Menninger, 1938), *localized self-destruction* (Menninger, 1938), *parasuicide* (Kreitman, Philip, Greer, & Bagley, 1969; Shneidman, 1985), *antisuicide* (Simpson, 1980), *aggressive behavior turned inward* (Cain, 1961), *deliberate self-harm syndrome* (Pattison & Kahan, 1983; Kahan & Pattison, 1984), *self-assault* (Cohen, 1969), *indirect self-destructive behavior* (Simpson, 1980), and *self-mutilation* (e.g., Favazza, 1996; Simpson, 1976; Walsh & Rosen, 1988). A more comprehensive discussion of such terms can be found in Walsh and Rosen (1988). Winchel and Stanley (1991) defined self-injurious behavior as "… the commission of deliberate self harm to one's own body. The injury is done to oneself, without the aid of another person, and the injury is severe enough for tissue damage (such as scarring) to result. Acts that are committed with the conscious suicidal intent or are associated with sexual arousal are excluded. Common forms of self-injurious behavior include cutting and burning, banging the hands and limbs, picking at wounds, and chewing fingers" (p. 306).

Behaviorally oriented scientists tend to use definitions based on observable characteristics of behavior. Tate and Baroff (1966) proposed a non-theoretical, descriptive definition of self-injurious behavior as a general term with inter-individual applicability that intends to capture all forms and types of *pathological* forms of self-injurious behaviors that ought to be included without veiled references to presumed causation or motivational explanation: "Repetitive acts by individuals directed

toward their own body, which result in physical harm or tissue damage.'' A critical advantage of this term is that it avoids subterfuge of preconceived and unproven attributions (e.g., auto-aggressive behavior implies that self-injurious behavior is in fact aggressive behavior turned against oneself), *explanatory fictions*, and circular reasoning.[1] Its main disadvantage as a working definition is over inclusion.

Schroeder, Mulick, and Rojahn (1980) pointed out that even this definition fails to rely only on observable behavioral characteristics because it explicitly refers to socially undesirable and pathological behavior implied in the terms ''harm'' and ''tissue damage,'' offsetting it from other forms of self-directed behavior that causes tissue alterations. Causing *damage* to ones own body is pathological and justifies, and even calls for intervention.

Others have developed variations of Tate and Baroff's definition. Grossman (1973, p. 195) for instance, defined self-injurious behavior as behavior exhibited ''to damage or disfigure a body part by one's own action (e.g., biting or hitting self).'' Matson described self-injurious behavior as a class of often highly repetitive and rhythmic behaviors that result in physical harm to the individual displaying the behavior (Matson, 1989). Many definitions used in epidemiological or survey research can be found in the Appendix. For instance, Oliver, Murphy, and Corbett (1987) defined self-injurious behavior as ''Repeated, self-inflicted, non-accidental injury, producing bruising, bleeding, or other temporary or permanent tissue damage. Also, any such behavior which would produce bruising, bleeding or tissue damage were it not for protective devices, restraints, specific medical or psychological interventions in use.'' The *Behavior Problems Inventory-01* (Rojahn, Matson, Lott, Esbensen, & Smalls, 2001) uses an umbrella definition that applies to self-injurious behavior in general (''Behavior that causes, or at least has the potential to cause, manifest damage to the person's own body'') and then lists specific topographies.

In this book we are using the term ''self-injurious behavior,'' except when reporting the work of other researchers who explicitly adopted different parlance. This term has become common in the literature on individuals with developmental disabilities and beyond (e.g., Yates, 2004).

For the purpose of this book we define self-injurious behavior in persons with intellectual disabilities as self-directed behaviors that

(a) Are pathological in the sense that they are – according to the prevailing sensibilities of our society – clinically significant and require intervention;
(b) Involve relatively stable, idiosyncratic response pattern (i.e., they occur repeatedly and by large uniformly);
(c) Cause or have the potential to cause direct or indirect (cumulative) physical damage to the person's own body (i.e., observable damage has either already occurred,

[1] Skinner (1974) pointed out a common fallacy when explaining human behavior of turning an adjective (e.g., self-injurious) into a noun (self-injury), which then used as a pseudo explanation. A circular statement answers the question ''Why does Rob bang his head?'' ''*because* he has self-injury,'' which later may become ''*because* he has Borderline Personality Syndrome.''

or is likely to occur if the behavior remains untreated or not prevented by physical or pharmacological means); and

(d) Topographies that are typically included as self-injurious behavior if they meet criterion are self-biting, head hitting or banging own body parts or with other objects, body hitting (excluding areas of the head), self-scratching, self-induced vomiting, self-pinching, stuffing or inserting dangerous objects into body orifices, pulling out finger or toe nails, poking or digging in orifices such as eye sockets or rectum, hair pulling, drinking excessive amounts of liquid, teeth grinding, pica (the swallowing of non-edible objects) and aerophagia (air swallowing).

The illegal literature in intellectual disabilities typically does not address, drug use abuse of nicotine and alcohol, or paraphiliac behaviors under the umbrella of self-injurious behavior.

1.2. Classification

One important question is whether all those different types of behaviors that cause self-harm do in fact constitute a meaningful entity or construct where all constituting exemplars show some common characteristics, above and beyond the fact that they cause physical damage to one's own body. For instance, do they have common etiological bases or behavioral functions, collective treatment indications, or similar relationships to other clinical constructs?

In order to get a better handle on the variety of behaviors, it might be useful to review some of the categorization attempts that have been proposed. We can distinguish two basic types of taxonomies or classification systems, structural and functional taxonomies. Structural taxonomies group behaviors on the basis of their similarities in observable dimensions (similar topography, outcome, etc.). Functional taxonomies, on the other hand, are independent of topography. Instead, they seek to group behavior on the basis of their functional similarities.

Before discussing ways of classifying self-injurious behavior in persons with intellectual disabilities, we will turn to taxonomies that were developed primarily with the intellectually typical population in mind.

1.2.1. Classification in Intellectually Typical Populations

1.2.1.1. Structural Classifications

Self-mutilation as a psychopathological phenomenon was probably first addressed comprehensively by Menninger (1935). Based on Sigmund Freud's Eros–Thanatos theory of the human psyche, Menninger postulated the existence of a death instinct, which represents an "adverse tendency within the personality," and which, under certain circumstances, can foment the development of self-harm. To organize the variety of different self-destructive manifestations Menninger proposed a classification system