# A Method for Tracking Severely Emotionally Disturbed Children and Adolescents Through a State Mental Health System

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### Introduction

Cross-cultural issues affecting children and adolescents are gaining increased mention within the United States, in part because of tragic incidents such as those at Columbine High School in 1999. These issues also are raising concerns in part because of demands being placed on the human services system as mental health, social service, and youth corrections agencies vie for scarce state resources.

Intersecting these issues, which often are tracked "in the aggregate," are those which involve individual youngsters, many of whom "don't fit" within readily definable service categories. Social anthropologists, sociologists, and practitioners have been concerned with ways to better track what happens to these youngsters as they move - seemingly in fits, starts, waits, and stops - through the maze of public and private service providers. The case of "Hannah's Dark Journey" (Imse 2000:7), in Colorado, certainly exemplifies this for us. Through no fault of her own, her parents divorced, her favorite grandfather died, she and her mother became homeless, she was sexually assaulted, and a judge took Hannah away from her mother. For the next ten years, Hannah was placed in 21 different foster homes, treatment centers, mental hospitals, and juvenile jails at a cost to the taxpayers of almost \$300,000. While Hannah has finally received intensive mental health care, her odyssey is far from unusual. In fact, it is because of cases very similar to Hannah's that prompted the authors of the present study to devise a method of graphical tracking of children as they move through the child service system. We believe that this method will be of interest to field researchers working in other institutional settings as well.

#### Design

The overall study design was to develop a pilot study as a pre- post longitudinal study with repeated measures. Starting April 15, 1994, the authors assigned the first three children admitted to the five respective child and adolescent treatment teams at Colorado Mental Health Institute at Fort Logan to the pilot study after the children and their parents agreed to participate and signed informed consent forms. Fort Logan is one of two public mental health hospitals in Colorado and during the last three years it has averaged approximately 1000 inpatient admissions annually. The pilot study did not involve the random assignment of children to treatment conditions, except in the sense that the first three children assigned to the five treatment teams during the study period became part of the study. Since the overall number of subjects was small and their outcome data cannot be used to determine that one treatment is better than another, the main purposes of the pilot study were:

- to test the usefulness of the various research instruments;
- to observe possible trends in client tracking and outcomes, including financial cost analyses, suggestive for further study and;
- to provide working time frames for project staff prior to engaging in a proposed larger, more comprehensive study involving 100 to 200 children.

Moreover, by developing a pre-Fort Logan archival profile of each child's psycho/social history, the authors were able to use the analytic framework presented in the Vermont System for Tracking Client Progress (Buchard, Gendebien, and Hinden, et al. 1992), as well as a related technique recently discussed by Van Arsdale (1996). This provides both retrospective and prospective analysis of certain elements of the child's treatment outcomes – analyses that will be useful in the larger study of children following psychiatric hospitalization.

## Method

As noted above, the overall goal of this research project was to develop a method to track the movement of children throughout the mental health system. The authors assumed this could be done in a linear, point-topoint manner. However, collecting historical data on mental health treatment and placements of the children proved to be very difficult. Indeed, when children arrived at Fort Logan for psychiatric treatment, their case files/histories were usually incomplete or non-Some children's case histories were existent. incomplete six weeks after they had arrived. Even with all appropriate medical and legal clearances and signed consent forms, researchers often met resistance from previous mental health providers regarding whether they would release a given child's case files. Not only did this resistance hamper the data collection process, more importantly, it also limited useful information necessary for the child's treatment. While we were able to complete the retrospective profiles of each of the fifteen children we studied, many of the other children's case histories we looked at had gaps ranging from minor to major.

Despite these difficulties, one factor allowed us to develop a linear time frame to track the children through the mental health system. The method is simple in concept and design, but difficult in implementation and analyses. In essence, the method is Follow the Money. The method does not require judgement whether the mental health monies should have been spent, if too much or too little was spent, or who made the payments. Our focus was to simply follow the money trail. Even with this fairly straightforward system, some difficulties were encountered. Different systems and accountability within systems often obscured the trail. Also, during the course of the study, a major shift in Medicaid funding occurred in Colorado.

## **Data Collection**

Prior to designing any of the data collection instruments, the authors of the present study analyzed the Fort Logan Medical Record forms (approximately 200 pages of admission records, assessments, treatment plans, consultations, progress notes, physicians' orders, prior history, therapies, legal status, correspondence, financial status, etc.) for content. From this, we developed a data collection guide to aid researchers in finding information in the Medical Record forms. Following the Vermont system for Tracking Client Progress (Bruchard, Gendebien, and Hinden, et al. 1992) and expanding the content areas to include more detail, the authors completed a demographic worksheet on each child. In addition to basic demographics, this residential and service worksheet includes: prior residential services and restrictiveness of living scale

(Hawkins, Almeida, and Fabry, et al. 1991); the child's age at time of service; the number of times the service was rendered; length of stay in any of the residential services; the cost per day for the specific service; major life events; prior child/family services; educational services; referral source; and psychiatric and/or delinquent characteristics. To establish baseline comparisons, the authors collected and charted these data from the Medical Records for one year prior to each child's admission to Fort Logan.

The expansion of the Vermont System for Tracking Client Progress complement, the methods of event history analysis. For example, Barton, Pillai, and Dietz (1992) note that in the field of program evaluation as applied to human services, researchers must distinguish among "events," "spells," and "states." That is, an event is a dramatic, qualitative occurrence that results in a change of circumstance (e.g., admission to a hospital). A spell is the duration of time between events (e.g., post-admission to discharge). A state is one's condition (e.g., being hospitalized). Events predominate (including referrals) in the present study's research design in large part because of the data available and the investigative methods used. Following Barton et al. (1996), the authors of the present study are able to infer a "risk set;" the group of youngsters who are at risk of experiencing the types of events in question.

Upon admission to Fort Logan, the Child Behavior Checklist (CBCL), Caretaker version (Achenbach 1991) was administered for each of the 15 children from the child's most recent residential setting. Other psychological and educational test results were collected from referral sources, which included "Level of Functioning Scales," then known within Colorado as PES 7A & B and PES 10. Data were also collected on medications at admission, medications at discharge, prior treatment history, treatment plans, discharge data, and diagnosis at discharge. Additionally, the authors designed a pilot study measurement schedule to detail when specific instruments (e.g., PES-7, Child Behavior Checklist, Piers-Harris Self-Concept Scale [Piers 1984], demographic profile, Alliance Test, and the PES-10) were to be administered and by whom, while the child was in Fort Logan, at discharge, and at three-month intervals following discharge.

The authors developed a post-discharge outcome indicator checklist to measure the impact of treatment and the child's ability to reintegrate into the community. The researchers were to complete the checklist at three, six, nine, and twelve months following discharge, a task not fully completed owing to subsequent resource constraints. This checklist included such items as the number of out-of-home placements, length of stay in a variety of inpatient and outpatient settings, psychological test scores, police contacts, and other treatment outcomes treatment staff determined to be important for the specific child.

To work as field researchers, student interns were recruited from the University of Colorado at Boulder and, later, from Denver University. These students collected the majority of information from the Medical Records files, worked with the treatment staff at Fort Logan, and, when appropriate to the measurement schedule, interviewed and tested the children on the various psychological instruments. Treatment staff at Fort Logan were responsible for conducting some of the psychological tests. In addition to signing agreements of confidentiality each student researcher completed detailed time analyses of data collection and data analysis on a child-by-child basis. Initially, three student researchers from the University of Colorado worked with four children each and one worked with three children to complete the final data collection phase. During the time period of the study (April 15, 1994 to May 15,1996), the four student researchers from the University of Colorado logged 310 hours in data collection and analysis, and the five student researchers from Denver University logged 195 hours in data collection and analysis. In all, the student researchers spent 505 hours collecting data, with an average of 34 hours per child.

Financial cost analysis came to play a central role in the pilot study. For the most part, the analyses utilized audited unit cost data rather than data on "expenses per person." An economic analysis was not conducted due to the large number of estimates and assumptions that would be required. For medications and certain other cost categories, expense data were utilized (i.e., that which was actually paid out) rather than expenditure data (i.e., that which refers to obligations incurred, whether paid or not). Charge-based data were used in some instances since it approximates costs. Government benefit data were not collected, and thus only factors in indirectly, as with the hospitalization costs covered by Medicaid. Virtually all unit cost data were current as of fiscal year 1995-96; thus cost adjustments in accordance with Consumer Price Index (CPI) were not necessary.

## Population

Relatively precise numbers regarding those children and adolescents in need of mental health services in Colorado are unknown. As of 1990, the last year for which complete state-wide census data are available, Colorado Mental Health Services estimated 5 percent of those children aged 11 years or younger, or approximately 35,000 children in the state, had the most serious mental health problems and were in need of mental health intervention (Heller and Coen 1996:2). Only about 21 percent of these - some 7,300 children (including repeat admissions) – are served by the public mental health system during the course of any year (Heller and Coen 1996). From vital statistics available to our research team, the authors estimate in Colorado that approximately 30,000 to 40,000 adolescents aged 12 through 17 are in need of mental health services. About 10,000 to 12,500 of these adolescents are served by the public mental health system during the course of any year. Through age 17, most of these children come from families living below the poverty level.

## System of Services

Colorado has four major service systems for at-risk, troubled youngsters: the mental health system, the child welfare system, the youth corrections system, and the private system. Discussion here focuses on the three public systems. Prior to their admission into Fort Logan, each of the 15 children involved in this pilot study were processed through a mental health center. The mental health centers are responsible for following their respective children while they are in the hospital, as well as being responsible for the children's mental health services after hospitalization. The social services system has the financial responsibility for the children's out-of-home placements. The youth corrections system has the responsibility for the child if he or she has been adjudicated of an offense, temporarily placed in a detention center, or committed for a long-term period in a youth corrections institution.

With the advent of managed care in August 1, 1995, Medicaid (the federal government's health-care program for the poor) became capitated and mental health centers could set limits on mental health services to children and adolescents. At this time, fifty-one of Colorado's sixty-three counties were included in a Medicaid capitation pilot program, which included approximately 69 percent of the Medicaid population. Areas initially not included in this pilot program were Denver and Larimer Counties, and ten counties in northeast Colorado. Before the system became capitated, the placement of children outside of the home was the responsibility of the child welfare/social services system, including paying for the out-of-home placement costs. After the system became capitated, children who were placed out of the home continued to be the major responsibility of the social service system, but the capitated mental health centers could use their Medicaid funds for supplemental services after the child was hospitalized. All 15 children included in this pilot study were admitted prior to capitation. By August 1, 1995, the mental health centers included in the Medicaid capitation pilot program that referred children to Fort Logan came under the capitated system, and thus, they became responsible for paying for their children's hospitalization at Fort Logan. Many of the capitated mental health centers, when notified that they had received their managed care awards, began taking their children out of Fort Logan's treatment programs as early as June 1995.

#### Literature Review and Research Rationale

Intensive inpatient psychiatric care for children and adolescents has been utilized in the United States since the 1920s. However, few rigorous follow-up studies were attempted prior to 1958 (Gossett, Lewis, and Barnhart 1983). The first such comprehensive study was published by Masterson (Gossett, Lewis, and Barnhart 1983) in that year. As Gossett, Lewis, and Barnhart (1983:15) note, Masterson found that "neuropathic" traits (like tantrums) in the early lives of schizophrenic patients were not predictive of eventual outcome. During the next few years, other studies followed such as the Timberlawn Adolescent Treatment Assessment Project (Grossett, Lewis, and Barnhart 1983:15) where post-discharge indicators were charted. In this study, favorable outcomes were found in the "Level of Functioning" analysis for over two-thirds of those studied.

In 1986 the National Mental Health Association (NMHA) clarified the need for coordination of services, early identification and assessment of at-risk children, delivery of appropriate community-based services, and comprehensive research and evaluation. As of 1988, some 20,000 children were being served in in-state psychiatric hospitals (Gendebien, Hinden, and Pandina, et al. 1992). Moreover, also during the 1980s, researchers associated with the Colorado Division of Mental Health expanded their investigation of treatment outcome assessment (Ellis, Wilson, and Foster 1985). By the mid-1990s, synthetic studies summarizing what has been learned were appearing regularly (Kutash and Rivera 1996).

## Rationale

No longitudinal studies have been conducted at either of Colorado's two public hospitals – and few anywhere – which have systematically tracked and evaluated children and adolescents from pre-admission, through the duration of hospitalization, and through the first several months or more post-discharge. The 1998-2000 Residential Treatment Study at Fort Logan is now doing this. Useful anecdotal information has been collected, as has some information comparing different groups pre- and post-, but in Colorado no study systematically evaluating a single large group has been completed.

It is essential to understand predictive behaviors of those studied. This ideally can lead to the development and identification of indicators. Both "adjustive" and "predictive" indicators are important. Since several forms of therapy (i.e., interventions) are used at Fort Logan and in other related Colorado programs, it is important to understand the extent to which interventions correlate with post-discharge outcomes. This also would enable a systematic understanding of failures (e.g., re-admission, suicide). At the broadest level this also would allow the identification of typical flow patterns from intake to eventual referral and posthospitalization placement (Forward, Moynihan, and Wilson 1990).

Throughout this pilot study, one of the greatest challenges was comparative. Curry (Goodrich 1994:280-281) writes that in studies of this sort, "...because of the lack of a [formal] comparison group, within-program and between-subject designs are inherently incapable of addressing the question of the effectiveness of a specific program treatment." Furthermore, Curry (1991) notes that, in adolescent inpatient settings, the adjustment of the patient within the program does not predict adjustment during followup, but the degree of support and continuity of key relationships following hospitalization does. According to Grob and Singer (1974), another major challenge is the validity of ratings of patient adjustment and Objective, operationalized research and progress. terminological definitions must be used to aid the rating process. The targeted, tested, and diverse types of instrumentation that would have allowed full-scale comparisons and ratings originally proposed for this pilot study were not utilized here.

#### Key Intervention and Outcome Studies

While there is no clear-cut correlation between type of intervention and type of post-discharge outcome, the recent study of adults by Chandler, Meisel, and Hu, et al. (1995 and 1996) is of special importance. In a threeyear controlled study in California, these researchers gathered data which compared two integrated service agency demonstration programs, one urban and one rural. Capitation was instituted and its goal was to determine if the two integrated programs compared to the programs that provided the usual services produced improved outcomes for clients with severe and persistent mental illness. In contrast to those clients (randomly assigned) who received the usual services, those served by the integrated programs were found to have less hospital care, greater workforce participation, fewer group and institutional housing arrangements, and greater client and family satisfaction, among other factors. Of particular interest in the present context, the average mental health service cost per client was substantially higher for demonstration clients than for the comparison clients.

By contrast, an early research study by Grob and Singer (1974) involved patients admitted to the McLean Hospital near Boston in the early 1960s. The 36 males and 31 females in this study were aged 13 to 19 and had been in residence a minimum of three months. Among the most important findings were that relatively few pre-admission variables and in-hospital variables – taken singularly – were related to outcome. That is, they had little predictive value. However, improvement at discharge (as defined by mental status ratings) turned out to be highly predictive of outcome at follow-up. Improvement begun during hospitalization was inferred to be adaptive after discharge.

Of special interest was the fact that a follow-up study at McLean, although involving different adolescents, was conducted almost a decade later. As of discharge, most characteristics were the same for the two samples. From this sample of 65 patients it was found, for example, that more patients went home after discharge than in the earlier sample.

## **Outcome Ecology**

Because of its singular importance to the Fort Logan Pilot study, the current work of Hernandez and Hodges (1996) is reviewed separately here. The goal of their System Accountability Project for Children's Mental Health at the University of South Florida is "...to better understand the impact that utilizing measurable outcomes such as school attendance, juvenile justice

recidivism, and out-of-home placements [emphasis added] has on the planning and delivery of children's (Hernandez and Hodges mental health services" 1996:iii). To this end, Hernandez and Hodges (1996) recently began a "best practices" investigation tied to "outcome accountability" in which the service system and accountability system overlap. Serving as a foundation to their approach is the premise that service delivery and outcomes attained are contextual. This approach emphasizes stakeholder involvement in the identification of outcomes to be measured, the context (including cultural) within which information is developed and delivered, and the transformation of information – by managers – into appropriate clinical decisions.

## Key Costing Studies

In addition to the study by Chandler et al. (1995) cited earlier, within the context of community mental health care, the study by Wolff, Helminiak and Diamond (1995) in Wisconsin expands upon the concept of "societal costs of care." As these costs are translated into dollars and cents, the authors warn of errors that might arise in calculating - and inferring from - categories variously labeled as "charges," "payments," and "accounting costs." Similarly, the authors of the present study also found it difficult to gather cross-system data that would provide cost analyses of mental health clients within the law enforcement and correctional systems. In Colorado, of the approximately 800 adults in a major treatment outcome study begun during the late 1980s, Shern, Coen, and Bradley, et al. (1990:75) and Coen, Shockly, and Bradley (1996) selected 198 for inclusion in a special costing study. For slightly over half the participants, schizophrenia was the primary diagnoses and for the rest of the individuals, affective disorders were the primary diagnoses. The authors (Shern, Coen, and Bradley et al. (1990) and Coen, Shockly, and Bradley (1996) derived cost estimates for seven broad areas: Mental health, drug and alcohol, law enforcement, courts, casework services, physical health, and government benefits. (By comparison, only the first five are included in the present study). The authors found that mental health costs comprised about twothirds of the total costs and, in turn, inpatient costs comprised about two-thirds of the mental health costs.

While not identical methodologically, the present study's cost analyses were similar to those employed in the studies by Shern et al. (1990) and Coen et al. (1996). Like them, and tied to the use of audited unit cost data, the authors of the present study used units of service that were "inherently logical and specifically tied to costs or charges" (Coen, Shockly, and Bradley 1996). Services within hospital or residential settings were counted as "days" or "months" and those that were encounter-based were counted as "contacts," while others were counted as "cases" or (in the case of non-hospital prescribed medications) "items." While not identical conceptually, the present study's costanalytic "frame" is similar to that of Wolff et al. (1995). Financial costs are emphasized, while social costs are implied. To this end, maintenance, institutional, and "other" cost categories (e.g. law enforcement and correctional) are featured. Unlike Wolff et al. (1995), the authors of the present study did not calculate burden or burden-sharing factors.

# Children's Mental Health Graphical Tracking Charts

The two mental health graphical tracking charts, which follow, are examples of how the data complied by the authors of the present study can be compacted into single charts. In the upper left corner, some major life events, presenting problems at Fort Logan, medications, and costs (pre-and post-Fort Logan only), and other interventions and costs of the child are listed. In the upper right corner, the child's basic demographics and his or her total cost to the childservice system are listed. In the actual chart, the vertical axis displays the incremental cost expenditures (monthly service costs), while the horizontal axis shows the time frame of the expenditures, including the cost of various residential placements, treatments, and related services the child encountered during the course of this study.

## Conclusion

While this study was somewhat limited in size, it does demonstrate that data from existing sources can be compiled and used to calculate system costs for a special population. The method is applicable crossculturally when the focus is on system-wide cost analysis for any population. That is, by employing a financial cost analysis, any government's expenses to institutions can be measured and a given population can be tracked through the system.

Tracking as conducted in the current study has enormous cost. Including outcome tracking in an integrated mental health system database may decrease the cost. State mental health data systems are already conducting outcome tracking in a limited sense, since discharge data is routinely collected. However, after discharge from the state hospital, for example, the client may have other placements that will not be included in the state mental health data base, until the next admission to the hospital. Accurate outcome tracking data, i.e., where the client has been treated since discharge from the hospital, and outcomes from the treatment, can inform this process. The outcome tracking system would likely function as a type of "registry," in which all mental health client services and outcomes would be recorded.

While overall system costs may be described using this method, alternative placements and costs can be analyzed as well. In some cases, the costs for specific services or products, for example, medications are very difficult to measure since those costs may be subsumed within other costs such as residential placement. Moreover, both Graphing Tracking Charts 7 and 12 demonstrate the relatively high cost of private psychiatric hospitalization, which reflects the degree of treatment and security compared to other alternative forms of residential and non-residential treatment. Generally, costs tended to increase prior to hospitalization to Fort Logan stabilized, then tailed off as the individual reintegrated into the larger community.

The advantages of the graphical tracking charts are that they provide a historical context and can be read quickly and they provide a good overview of the child's encounters with the child-service system. Moreover, this method could provide analyses of system-wide accountability of child placements, child-service system best practices analyses, and of course money expenditures.

## Notes

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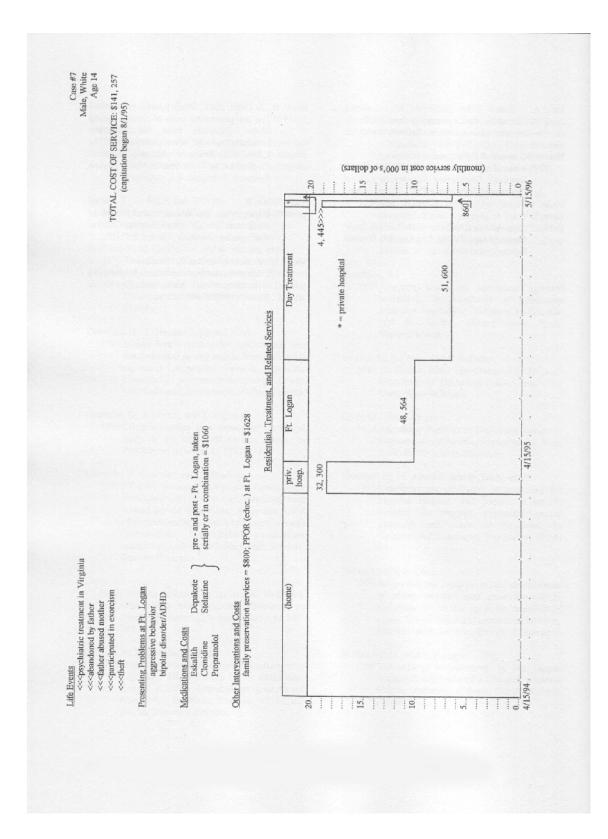
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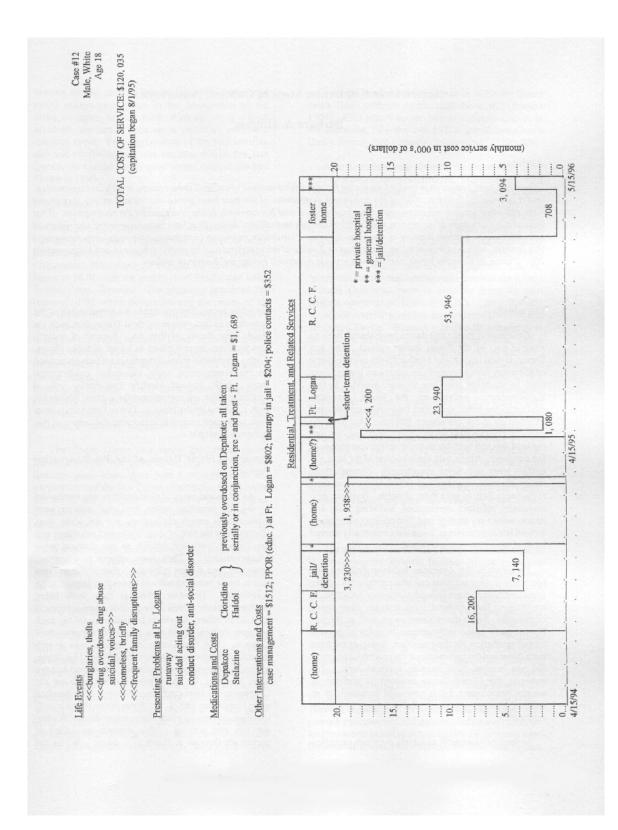
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