*Editorial, Schizophrenia Bulletin 36, 437-439, 2010*

# Deep Concern

**by Luc Ciompi (Switzerland), Courtenay M. Harding (USA) and Klaus Lehtinen (Finland)**

We are three senior clinicians and investigators in the field of schizophrenia research from different parts of the world. We want to emphasize our common deep concern for the often devastating consequences of neglecting, particularly in legal issues, the fact that favorable long term outcomes occur in schizophrenia in a considerable number of cases. Convergent findings from the 11 world studies of 20-30+ years from first admission have consistently shown that persons labeled with prolonged and episodic forms of schizophrenia have a strong possibility of favorable long-term outcomes if given half a chance.[1-11] However, many such persons become adjudicated by the criminal justice system for small legal infractions, known as misdemeanors, and then languish there indefinitely for years on the assumptions that schizophrenia is nothing but a chronic debilitating disease with little hope of reclaiming a life and full citizenship.

Our cry of alarm has been provoked by yet another case of inappropriate long-term imprisonment of a person with schizophrenia in Switzerland on the basis of an inadequate prognosis. This young man had years of obsessive and delusional ideas, hallucinations, and inappropriate social behaviors. He has, however, never lost his capacity for intense emotional feelings and his ability for communication. Under the influence of the “inner voices” which told him that he is a homosexual, he eventually started to hit out compulsively but ineffectively at male nurses in psychiatric institutions. He repeatedly explained that this behavior was to “prove his virility.” In spite of the fact that these symbolic aggressions were objectively harmless and *no one was ever hurt,* one such institution became irritated enough and took him to court over the matter. An expert from a Swiss psychiatric university hospital eventually diagnosed him as suffering from “chronic schizophrenia” with a prognosis of “an incurable life-long illness with danger of violence.” As a consequence, he was sent to a high security ward of a local prison. He now vegetates, mostly in comple-

te isolation and often handcuffed, because, even there, he sporadically tried to hit out at male guards. In spite of extremely high dosages of neuroleptics, antidepressants, and intensive behavioral therapies, he became deeply depressed and tried several severe suicide attempts.  All legal remedies to get the original decisions reversed and to move the patient into one of the existing special settings which provide alternatives to incarceration have failed, so far, for “legal and administrative reasons.

Unfortunately, similar situations have been occurring as well in the United States, Finland, and many other countries across the world. According to a recent report of the U.S. Department of Justice, more than half of all prison and jail inmates have mental health problems of one kind or another, including 705,600 in state prisons, 70,200 in federal prisons, and 479,900 in local jails.[12] It is even more alarming that such inappropriate prognoses and incarcerations now also occur in Switzerland, given that Switzerland is the very country of origin for the dynamic view of “a group of schizophrenias” which Eugen Bleuler [13] proposed in opposition to the more static Kraepelinian concept of “dementia praecox”. Switzerland is also the home to two of the earliest major long-term studies which revealed a substantial proportion of positive outcomes.[1, 2]

How is it possible that unjustified and destructive predictions of the long-term evolution of schizophrenia continue to be applied in spite of the consistent findings across the 11 world studies and thousands of recovered people who talk about their experiences? These well-regarded studies have found that 46 to 68% of persons suffering from schizophrenia can achieve significant improvement and often even full recovery across time.[1-11] Full recoveries, either in the sense of a fully normal professional and social life situation and/or the absence of any psychopathologic symptoms can occur even after decades of illness.[1-11,14-16] Many short term studies have also found improvements as early as 2 to 5 years. [e.g. 17] Furthermore, it must be emphasized that the long-term course and outcome is not predictable in the individual case, given that there are neither individually valid predictors nor biological markers. The value of the “classical” predictors (e.g. type and length of onset, sex, and much of the symptom picture including negative symptoms) is only statistical, mostly for short-term and much less for the long term outcome. [15,16-19]

In fact, late improvements or recoveries in some individual cases have been observed even after long periods of severe illness and insidious onsets with prevailing negative symptoms.[e.g.1,2,4,18,19] On the other hand, it is empirically well established that environmental factors, such as repeated opportunities for rehabilitation, positive expectations and relationships, family psychoeducation, and other evidence-based and promising practices, can have a significant influence on relapse rates and outcome.[3,20-24] In one such study, convergent positive expectations of maintaining hope by the clinical team, the family and the patients themselves was even found to be the most important predictor for a positive short-term outcome among more than 30 relevant biological, psychopathological, social and situational variables.[20]

The prevailing pessimism appears to be primarily related to the “Ideological” prejudice acquired by a century of training a pessimistic outlook. It deeply established the conviction that schizophrenia is “incurable” and that recovered cases are not “real schizophrenia.” Other reasons include the exclusive biologically-oriented short-term views, the related lack of consideration for biographical and environmental factors, the overloaded case loads with limited resources, and the fact that clinicians see the most serious cases much more frequently than the favorable cases.[22] Research reports, too, are generally focused on unfavorable outcome aspects, while favorable ones are neglected. Clinicians seem also to forget that even Kraepelin, known for his strong “downward course” observations, had already reported 8-13% cases of long-term recovery and 17% of marked long-term improvement in spite of his strongly biased hospital samples.[25] Even in Kraepelin’s era, some clinicians argued that these cases were not “real dementia praecox.” [26] The absurd consequence of such a view would be, however, that a sound diagnosis could only be fixed several decades after the onset, given that some cases improve or recover even after very long periods of serious illness.

Use of the long-term data is, however, being applied in different situations with increasing frequency. Such efforts include improving medical education and expanding rehabilitation opportunities in the community. In the U.S., the findings from the long-term studies from across the world have also been used in court cases and class action suits. There exists a process called “the amicus curiae” or “fri-

end of the court" legal briefs. This strategy is particularly appropriate for people with serious illness about to be inappropriately incarcerated or being denied other human rights. Such use has been in the form of filing briefs "to offer information on a point of law or some other case-relevant aspect to assist the court before deciding a matter. The decision whether to admit the information lies with the discretion of the court." [27,28] A decade ago, an amicus brief was submitted using the long-term data to the U.S. Supreme Court in a state of Georgia case (Olmstead v. L.C. and E.W.). The outcome of this landmark case is slowly changing care across the U.S. One of the findings specifically states that "unjustified isolation of individuals with disabilities is properly regarded as discrimination based on disability.[29]

The next target should be increased use of these data on behalf of persons who are found to be mentally ill and have committed offenses. Small steps have been taken sporadically across the U.S., which include establishment of a few mental health courts, as well as the training of some policemen, judges and interventions at every critical clinical/legal interface. There are alternatives to incarceration which include diversion programs within law enforcement, jails/prisons, and courts as well as programs for re-entry back into society.[30] Further, a recent "Call to Action" was issued in 2009 at a meeting of a National Leadership Forum in Behavioral Health and Criminal Justice Services. This earnest report outlines implementation of several phases for actions by federal and local entities to end what they called "An American Tragedy." [31] The case reported earlier might be called "A Swiss Tragedy", and similar tragedies caused by inappropriate prognoses which neglect possible long term recovery are occurring daily all over the world. We suggest that more professional societies become involved in correcting these inequities, and that alternatives to incarceration are systematically used and further developed.

**References**


1. Bleuler, M.: Die schizophrenen Geistesstörungen im Lichte langjähriger Kranken und Familiengeschichten. Stuttgart: Georg Thieme. Translated (1978) by S.M. Clemens as The Schizophrenic Disorders: Long-term Patient and Family Studies New Haven, CT: Yale University Press, 1972.
2. Ciompi, L. & Müller, C.: Lebensweg und Alter der Schizophrenen: Eine katamnestische Longzeitstudie bis ins Senium [Life Course and Old Age of Schizophrenics. A Catamnestic Long-Term Study until the Old Age]. Berlin: Springer-Verlag, 1976
3. DeSisto, M., Harding, C.M., Ashikaga, T., McCormick, R., & Brooks, G.W.: The Maine and Vermont three-decade studies of serious mental illness: Matched comparison of cross-sectional outcome. Brit J Psychiatry, 167: 338-342, 1985
4. Harding, C.M., Brooks, G.W., Ashikaga, T., Strauss, J.S., & Breier, A.: The Vermont longitudinal study of persons with severe mental illness: I. Methodology, study, sample, and overall status 32 years later. AJP, 144(6), 718-726, 1987
5. Hinterhuber, H.: Zur Katamnese der Schizophrenien [On the catamnesis of schizophrenics]. Fortschritte der Neurologie-Psychiatrie, 41:527-588, 1973
6. Huber, G., Gross, G., & Schüttler, R.: Schizophrenie: Verlaufs und sozialpsychiatrische Langzeituntersuchungen an den 1945 bis 1959 in Bonn hospitalisierten schizophrenen Kranken (Schizophrenia. Long-Term Investigations on the Course and Social Situation of Schizophrenics Recovered in Bonn 1945-1959). Monographien aus dem Gesamtgebiete der Psychiatrie. Bd. 21. Berlin: Springer-Verlag, 1979
7. Kreditor, D. Kh.: Late catamnesis of recurrent schizophrenia with prolonged remissions (according to an unselected study). Zh Nevropatol Psikiatr Im S.S. Korsakova, 77:110-113, 1977
8. Marinow, A.: Klinisch-statische und katamnestische Untersuchungen an chronisch Schizophrenen 1951-1960 und 1961-1970 [Clinical-statistical and catamnestic investigations on chronic schizophrenics 1959-1960 and 1961-1970]. Archiv für Psychiatrie und Nervenkrankheiten, 218:115-124, 1974

9. Ogawa, K., Miya, M., Watarai, A., Nakazawa, Yuasa, S., & Utena, H.: A long-term follow-up study of schizophrenia in Japan – with special reference to the course of social adjustment. Brit J Psychiatry, 151: 758-765, 1987
10. Tsuang, M.T., Woolson, R.F., & Fleming, J.A.: Long-term outcome of major psychoses. 1. Schizophrenia and affective disorders compared with psychiatrically symptom-free surgical conditions. Arch Gen Psych. 36, 1295-131, 1979.
11. Harrow, M., Jobe, TH. How frequent is chronic multiyear delusional activity and recovery in schizophrenia: A 20-year Multi-follow-up. Schiz Bull. 36: 192-204, 2010.
12. Jamies, DJ, Glaze, LE. Mental Health Problems of Prison and Jail Inmates. Bureau of Justice Statistics. US Department of Justice, Office of Justice Programs, Report # NCJ 213600, pg. 1, September, 2006.
13. Bleuler, E. (1911) Dementia Praecox or The Group Of Schizophrenias. Joseph Zinkin, trans-ed, New York, NY, International University Press, 1950.
14. Ciompi, L. Catamnestic long-term studies on the course of life of schizophrenics. Schiz Bull. 6:606-618, 1980.
15. Ciompi, L.: Learning from outcome studies. Toward a comprehensive biological-psychological understanding of schizophrenia. Schizophrenia Research 1:373-384, 1988
16. Harding, C.M. Changes in schizophrenia across time: paradoxes, patterns, and predictors. In: Carl Cohen (ED) Schizophrenia into later life. Treatment, Research and Policy, Washington, D.C., APPI Press, pp. 19-42, 2003.
17. Strauss, JS, Carpenter, WT. Prediction of outcome in schizophrenia: II Relationship between predictors and outcome variables. Arch Gen Psych, 31:37-42, 1974.
18. Huber, G, Gross, G, Schüttler, R, Linz, M. Longitudinal studies of schizophrenic patients. Schiz Bull. 6: 592-605. 1980.
19. Strauss, GP., Harrow, M., Grossman, LS., Rosen, C. Periods of recovery in deficit syndrome schizophrenia: A 20 year multi-follow-up longitudinal study. Schizophrenia Bulletin advance access published online on Decenber 18, 2008. Schiz Bull, doi:10,109/schbul/sbn167.

20. Ciompi, L, Dauwalder, H.P, Agué,C. Ein Forschungsprogramm zur Rehabilitation psychisch Kranker. III. Längsschnittuntersuchungen zum Rehabilitationserfolg und zur Prognostik [A research program on the rehabilitation of patients with mental illness. III. Longitudinal studies on the success of rehabilitation and on prognostic factors]. Nervenarzt. 50:366-378, 1979.
21. Anthony, WA, Cohen, MR, Farkas, M, Gagne, C. Psychiatric Rehabilitation (2nd Ed.). Boston, MA: Boston University Center for Psychiatric Rehabilitation, 2002.
22. Harding, CM; Zubin, J; Strauss, JS. Chronicity in schizophrenia revisited. In Supplement: "Transactional Processes in Onset and Course of Schizophrenic Disorders". Bri J. of Psychiatry. 161: 27-37, 1992.
23. Dixon, LB., Dickerson, F., Bellack, AS., et al. The 2009 Schizophrenia PORT psychosocial treatment recommendations and summary statements. Schiz Bull., 36: 48-70, 2010.
24. Kreyenbuhl, J., Buchanan, WR., Dickerson,FB. Dixon, LB. The Schizophrenia Patient Outcomes Research Team (PORT): Updated Treatment Recommendations 2009. Schiz Bull 36: 94-103, 2010
25. Kraepelin, E.: Psychiatrie. Ein Lehrbuch für Studierende und Ärzte [Psychiatry. A Manual for Students and Physicians] (7th edition). Leipzig , Germany, Barth. 207-208, 235, 237, 261, 1904.
26. Kraepelin, E. : Zur Diagnose und Prognose der Dementia praecox [On the diagnosis and prognosis of dementia praecox]. Allgemeine Zeitschrift für Psychiatrie und psychisch- gerichtliche. Medizin .; 56:254-63, 1899.
27. http://en.wikipedia.org/wiki/Amicus_curiae
28. http://www.techlawjournal.com/glossary/legal/amicus.htm
29. http://www.bazelon.org/issues/disabilityrights/incourt/olmstead/index.htm
30. Judge David L. Bazelon Center for Mental Health Law. People with Serious Mental Illnesses in the Criminal Justice System, Washington, D.C., 2002.
31. National Leadership Forum on Behavioral Health/Criminal Justice Services: Ending an American Tragedy: Addressing the Needs of Justice-Involved People with Mental Illnesses and Co-Occurring Disorders. Washington, D.C., September, 2009.