Outcome research is both biographical and statistical. The longitudinal data of biographical studies are multivariate and sequential. They provide the opportunity to tease out the conflation of factors that may be responsible for a given outcome. These factors may then be tested cross-sectionally, one or a few variables at a time, on a group of individuals statistically homogeneous for diagnosis, and for as many other variables as can be held constant. Biographical data should be collected and tabulated systematically, according to a planned schedule of inquiry, and not haphazardly. These data should include wide-ranging information, including some (e.g., handedness, color blindness, or natal sequence) that may not have self-evident significance. The computer program for processing statistical data should be planned ahead of time so as to ensure that no variable will be fortuitously overlooked and that there will be no overload of surplus data (e.g., on a questionnaire). Today, the logistics, continuity, and funding of longitudinal outcome research are more likely to be haphazard than predictably guaranteed.

Since 1951, three of the categories of outcome research for which I have been responsible have pertained to IQ and specific cognitional functioning, incidence of major psychopathology, and sexological issues. The syndromes studied have included congenital hypothyroidism, Turner syndrome, congenital adrenal hyperplasia (CAH) female hermaphroditism, androgen insensitivity syndrome, micropenis, and male hermaphroditism. Sexological issues are particularly difficult to manage because of the cultural taboos against speaking of sexual problems and the attached social stigma associated with it. The management of cases is made more difficult through faulty prescientific ideology and folk sexology that resists and limits sex education. To be fully literate in the sexological outcome of the syndromes treated by medical professionals, a formalized discipline needs to be created. Although needed, there is no specialty of pediatric sexology.
It goes without saying that long-term follow-up and outcome studies in pediatric endocrinology require long-term logistical planning and stability of personnel, both of which require a guarantee of long-term funding amounting cumulatively to very large sums of money. Meticulous attention must be given to statistical design to ensure diagnostic homogeneity and to avoid skewing so that patients with chronic or recurrent symptoms are overrepresented, and patients who become symptom free are underrepresented. Satisfying all of these criteria, especially in today's climate of research funding, is more likely to be haphazard than systematically guaranteed.

In my own case, for example, I have lived hand to mouth, from one grant renewal to the next, since I began working in pediatric psychoendocrinology under Lawson Wilkins in 1951. I became a grantee of the National Institute of Child Health and Human Development when it was chartered in 1962 (1). Even though my renewal applications have been approved continuously since then, with only one short hiatus, I have had no way of predicting that they would be, nor that the amount would progressively shrink. In recent years, in fact, I have been too underfunded and too short-staffed to do the full range of outcome studies that deserve to be done. In addition, I have encountered restrictions on the publication of sensitive sexological case history data.

Since 1951, I have published follow-up psychohormonal data on several pediatric syndromes, in some instances before and after treatment. These publications are subdivisible into three categories. Category I pertains to IQ and specific cognitional functions. In the case of hypothyroidism, for example, the data showed that in extreme cases the deficiency at birth was so severe as not to benefit from very early onset of replacement therapy. At the other extreme, there were, unexpectedly, a very few cases in which the IQ, after remaining low for several years, despite treatment, would unpredictably increase into the normal range, or in one case from below normal (IQ, 84) at age 5 to IQ 127 at age 27 (2–4).

Another Category I example is that of alleged mental retardation in Turner syndrome. Follow-up in my unit showed that the IQ deficit is not across the board, but rather that it affects nonverbal or praxic IQ only, and represents a specific cognitional defect (i.e., space-form blindness and impaired directional sense) (5–7).

Category II pertains to the incidence of major psychopathology. A history of the traumatizing sequelae of Turner syndrome was found not to be associated with major psychosis (8,9). A parallel lack of incidence of major psychosis was also found in CAH female hermaphroditism with a history of either female or male rearing, either before or after the discovery of cortisol treatment in 1950 (10,11). By contrast, an association might exist between psychosis and a subtype of those with a history of male hermaphroditism that has as yet no identifiable etiology.

Category III pertains to sexological issues (e.g., precocious and delayed puberty) and in various syndromes of birth defect of the sex organs. Here, I