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פרופ' הראל שאול, ד"ר רחל יפעת, ד"ר יעל לייטנר,
ד"ר רונית מסטרמן, ד"ר גבי גילטז, גב' עופרה לוי-הכיני,
גב' אורה ביטאונסקי



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A Long-term, Epidemiological Survey of Outcome and Adjustment of Children with Developmental Disabilities

MD Yael Leitner, PhD Rachel Yifat, MD Ronit Mesterman,

MA Gabi Gilutz, MSW Ofra Levi-Hakeini, Ora Bitchonsky,

MD Shaul Harel



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ABSTRACT

The medical, educational and psychosocial outcome of 3,224 children (age range 7-33, mean age 20.06, SD 5.74) diagnosed and treated in the Institute for Child Development in Tel Aviv between the years 1975 and 1994 was assessed by a telephone interview.

Results indicate that only 9% of the subjects are seriously disabled and 8% are mentally retarded. Over the years, children were referred to the CDC at a younger age, probably reflecting greater professional and parental awareness of the importance of early intervention. The nature of interventions changed, so that physiotherapy, occupational therapy, and psychological guidance were more often provided. While more children were referred to special education at kindergarten, the percentage of those graduating from regular schools has increased. Most completed 12 years of schooling, and successfully acquired full or partial matriculation certificates. As adults, most function independently; fulfill civic obligations, such as their army service, are fully employed and express satisfaction with their life. These results suggest that children with early developmental disabilities are likely to be functionally independent and to be satisfied with their lives, although they continue to need medical services and require some national support. Further studies are essential to examine the correlation of specific risk factors and early interventions with outcome.

INTRODUCTION

As many of the infectious diseases that effected children in the past have been overcome, or ameliorated, an increasing portion of pediatric practice involves developmental delays, learning difficulties, emotional and behavioral problems. These conditions (and others, such as allergies, asthma, and eating disorders) have been labeled the “new morbidity of childhood”.^{1,2} Despite improved prenatal diagnosis and neonatal intensive care unit practices, the prevalence of childhood developmental disabilities has remained at a steady rate of 3-5% in children up to 5 years of age.³

Data from the USA National Health Interview Survey (1994) showed that 17% of children between 0-14 years of age were reported to have had a developmental disability. In this survey, learning disorders were regarded as a developmental disability, with a prevalence of 6.5%.⁴

The nature of these disabilities varies in severity from global impairments, such as cerebral palsy (CP), autism, or mental retardation, to more specific difficulties, e.g. developmental language disorders, learning and attention disabilities, motor and developmental coordination disorders. These combined afflictions have a substantial impact on the health and educational performance of affected children, with 2- to 3-fold more medical visits and hospitalization days, and a 2.5-fold rise in the likelihood of repeating a grade in school.⁴

Other studies also showed increased healthcare use by these children⁵ and higher mortality.⁶ Children born after an abnormal pregnancy or delivery, those with low birth weight, or prematurity, and those growing up in deprived

environments, are at increased risk for developmental disabilities, and need early diagnosis and intervention in order to fulfill their maximum potential.

To better understand the natural history of neurodevelopmental disorders, and to judge the impact of early intervention and rehabilitation, long-term studies of these children are essential. This is particularly true for young children, as the full impact of a disability cannot be appreciated until physical, cognitive and psychological maturation is achieved.⁷

Numerous studies have described the short-term outcome of specific disabilities,⁸⁻¹⁶ or specific risk groups,¹⁷⁻³⁷ whereas only a few studies have taken the “wide angle” view of developmental disabilities as a category. One of these is the Dunedin Multidisciplinary Health and Development Study in New Zealand, a well-designed, 15-year, longitudinal cohort study of 1,037 children born between 1972 and 1973. The children were studied at birth and followed-up and assessed at 3 years of age, and every 2 years thereafter, to the most recent assessment at age 15 years. Multiple outcome measures, including medical, developmental, psychological, psychiatric and social aspects were investigated, and were found to change according to the age of the children . The outcome measures reported by 124 different authors appeared in over 328 separate publications.³⁸ One study³⁹ using the a cohort of 476 girls and 510 boys looked at the correlation between four indices of adversity, namely perinatal complications, family background, child- rearing practices and the child's physical health to see if they could predict cognitive and motor abilities at age 5 years. Family background and child rearing practices were highly related to developmental outcomes. The index of health problems was related to motor

ability, while perinatal complications were related only to specific cognitive ability for boys.

Another study⁴⁰ used the ICDH (International Classification of Impairments Disabilities and Handicaps) to develop a self-administered questionnaire completed by 831 parents of thirteen year old children participating in the Dunedin cohort study. The most common reported disabilities were: writing/spelling (26%), coping with dust/pollens or chemicals (15%), and coping with school work (15%). Eighty one (9.7%) parents reported their child to have some circumstantial dependency (receiving medication or other support).

Among other existing "wide angle" studies, is the Collaborative Perinatal Project conducted by the National Institutes of Health, USA, between 1959 and 1965. This study comprised more than 50,000 pregnant women and their children. This collaborative study was the baseline for major research projects, leading to an improved understanding of predisposing and causative factors in childhood epilepsy⁴¹ and etiology of CP.⁴²

Whereas the aforementioned studies referred to a general population of children, our study examined a very large population of children and specifically analyzed the outcome of children with developmental disabilities. Thus, the current study provides longer follow-up data than is usually available in the literature concerning developmental disabilities.

The Tel Aviv Child Developmental Center (CDC) established in 1970, was until 1996 the sole provider of services for the Tel Aviv metropolitan area. The CDC provided both diagnostic and rehabilitation services: A neurodevelopmental

assessment and follow-up by pediatric neurologists, physiotherapy, occupational therapy, speech & language therapy, psychological diagnosis, guidance and follow-up, and a social service. A minority of the children with multiple developmental disabilities and/or social risk were treated within three Day-care kindergartens within the CDC manned by special education teachers. The children qualified for the day-care centers were receiving the rehabilitation services from the CDC personnel as required. The service of the CDC was provided to children from birth to 5 years of age, and served a population of 500,000 people, demographically and ubiquitously representative of the Israeli population.

In preparation for the present study, we have previously conducted a *retrospective* study⁴³ reviewing the epidemiologic data of children with developmental disabilities who were diagnosed and treated at the Tel Aviv CDC between 1975 and 1994. The medical files of 4,309 children, from birth to 5 years, were reviewed.

The mean age at first referral was 2 years and seven months (age range: birth to 5 years). The most common complaints at referral were delayed speech and language 38% , global developmental delay-GDD 20% , motor difficulties 16% , and emotional/behavioral difficulties 15% . Medical or environmental risk factors in 9.5% and others 1.5%. The male: female ratio was 2:1 Children were diagnosed as belonging to at least one of three major risk categories: medical, genetic, or social risk. Medical risk was defined as any prenatal or perinatal risk factor

(e.g. maternal toxemia or smoking, asphyxia, SGA, hypoxic ischemic encephalopathy etc.)

Social risk was defined in accordance with the reports of the CDC social workers. Genetic risk was defined when congenital anomalies were found, when a genetic syndrome was diagnosed, when parental consanguinity was reported or if other siblings suffered from a significant developmental problem. Ninety percent of the children were found to belong to at least one risk category. Normal intelligence was found in 87%. Different degrees of mental retardation (IQ <70) were found in 13% of the children. The incidence of mental retardation was associated with a greater number of major risk categories. Only 9% suffered from a severe disability (e.g. motor disability causing total dependence, blindness deafness, or mental retardation (IQ<55)). Twenty six percent of the children received only one category of treatment (e.g. only speech therapy), while 37 % needed more than one type of treatment, hinting at a broader type of developmental difficulty. At age 5 years, upon termination of treatment, 51% of the CDC "graduates" were referred to regular schools, while the rest were recommended special education schools or special programs within the regular school system.

This retrospective survey provided the solid basis for planning the present long-term outcome study.

The infrastructure of pediatric primary care in the Tel Aviv municipal area, and the fact that in Israel most youngsters, upon reaching the age of 18, are recruited into the army, provided us with an additional criteria of health status

and adjustment, and led to the unique opportunity of locating the majority of the children and young adults previously diagnosed and treated at our CDC. The goals of the present long-term follow-up study were to locate and interview the patients or care-givers of patients diagnosed and treated in our CDC between 1975- 1994, as they reached maturity, and to assess both the *natural history* of their developmental disabilities, and the *broader aspects of outcome*: medical, academic and psychosocial.

The long time span covered by this study also enabled us to study the changing attitudes in the diagnosis and treatment of developmental disabilities over the years.

Future studies will thus use this database in order to investigate specific disabilities and to judge the correlations of specific risk factors and early interventions with outcome.

METHODS

A detailed telephone questionnaire was designed to ascertain the clinical, educational and psychosocial outcomes of subjects who, during the years 1975-1994, had been diagnosed and treated in early childhood for developmental difficulties, at the Tel Aviv CDC. The total number was 4,280 subjects.

A telephone questionnaire approach was chosen as it was impractical to obtain a personal interview and evaluation of such a large number of subjects living in various towns.

The questionnaire was constructed in the form of a checklist to aid subjects in recalling events. One section asked subjects to describe factual events, whereas another section explored their feelings and attitudes. A number of pilot tests were run. The first version of the questionnaire was administered to 55 subjects; it was then revised, and administered repeatedly to a smaller number of subjects until the final and satisfactory version was achieved.

The final version of the questionnaire contained **151** items regarding the child's development from infancy through adulthood. Each item was designated as belonging to one of the following areas: **health status, academic achievements, social and family status, family employment status, respondent's employment status, social activity, and feelings of satisfaction and personal fulfillment.**

The specific items selected for this study were regarded by the authors as being among the most important outcome indicators (Table 1). As some items were relevant only to a specific age group (e.g. high school graduation, employment status, satisfaction) the subjects were divided into two age groups,

with age 18 as a cutoff point. Where necessary, Pearson Chi-square tests were used in order to test differences in proportions between the two age groups.

The final version of the questionnaire was approved by the research team of JDC-Brookdale Institute of Gerontology and Human Development, Jerusalem, Israel.

The interviewers (social workers, psychologists, and education specialists with good conversational skills) established contact with the subjects and initially explained the nature and purpose of the interview, ensuring confidentiality. Only after receiving informed consent were the answers of the subjects (adult patients, or parents of patients) entered on a questionnaire form designed to facilitate quick and easy recording of information.

Reliability

To assess the reliability of the questionnaire, 60 subjects representing both age groups, completed the questionnaires twice and the repeatability (internal consistency) of the items on both questionnaires was tested using the Cronbach α model. Results showed a high extent of repeatability ($\alpha=0.98$), indicating a high consistency of the data items being examined.

In addition, each completed questionnaire (from the total number 3,224) was checked by a senior member of the research team to avoid omission of information. The data was then computer-processed in a program especially designed for this current study. Wherever possible, results were compared to epidemiological data obtained from other studies conducted in the general population in Israel and published by the Central Bureau of Statistics; National

Insurance Institute of Research and Planning Authority; Department of Information and Assessment at the Ministry of Health; and National Road Safety Authority, among others.

RESULTS

Of the total number of children (4,280), follow-up data were obtained from 3,224 subjects (75%), while 1,056 (25%) were lost to follow-up (Table 2). The demographic characteristics of the lost- to follow-up children and families were found to be identical to the study group.

In the younger group (<18 years), 87.6% of the respondents were the parents, while in the older group 50.4% of the respondents were the CDC graduates themselves. The age range of the whole study population was 7-33 years (mean age 20.06, SD 5.74). The demographic characteristics of each of the two study groups are presented in Table 3.

The types of interventions provided to the subjects in the CDC as children are described in Table 4.

General Health Status

Thirty-three percent of all subjects reported to suffer from a health problem.

Neurological follow-up was reported by 15% of those younger than 18 years,

and in 7.4% of those older than 18 years. The reasons for neurological follow-up are described in Figure 1.

Approximately 20% of the subjects are under medical supervision other than neurological. The comparison between the two age groups regarding types of outpatient clinics attended (n=618) showed that more adults (28%) attend psychiatric clinics than youngsters (20%) whereas youngsters visit orthopedic clinics more (29%) than adults (21%). ($p=0.05$)

A *disability* was defined by the telephone questionnaire as any handicap, motor, sensory or mental that is interfering with the activities of daily living- ADL, and when the respondent reported that the disability was verified by a medical professional: e.g. when a visual impairment was reported- the respondent was asked to specify how the impairment was diagnosed. "Subjective" reports of a handicap were not included. In the two age groups 28% of subjects reported that they suffer from some form of a disability (motor disability 13.4%; cognitive dysfunction 11%; hearing problems 4.7%, visual problems 9.5%; emotional disability 7.8%).

Subjects were asked if they were officially rated by the Israeli Social Security Service and/or by the Services for the Mentally Retarded (IQ<70) as suffering from a handicap. This official rating is granted after a thorough medical and psychosocial evaluation, and is therefore regarded as a reliable criterion of medical or cognitive handicaps. A significant increase with age for eligibility was noted for both services (9.4% vs. 7.1% for social security allowance, and 9.1 vs. 6.7 for recognition by the services for the mentally retarded $p=0.05$).

Twelve percent of subjects reported they require some assistance for activities of daily living, such as dressing, eating and personal hygiene. From a motor point of view, 94% are completely ambulant. Assistance in walking is required by 6% of subjects, including 2.7% wheelchair bound.

Academic Achievements

Academic achievements are described in detail in Table 5. More than 70% of subjects in both age groups attended regular classes at primary school and more than 75% of subjects in both age groups attended regular classes at junior high and high schools.

According to the retrospective epidemiological study, in 49% of cases placement in the special education stream was recommended at age 5.

Apparently these early recommendations were only partly implemented.

Thirty –seven percent of CDC graduates achieved full matriculation certificate.

According with national data, the percentage of full matriculation certificate-holders between the years 1996 and 2001 was 52%.

A report by the Ministry of Health indicated that the percentage of those suffering from learning disabilities in Israel is between 10% and 15%. This percentage is lower than that found in our population for both age groups (Table 6).

Psychosocial adjustment

Sixty six percent of the adult subjects served in either the army or national service (after correcting for those subjects officially recognized as mentally

retarded), of these- 85% completed full service. Over 50% of subjects who were inducted into the army were regarded as eligible for a combat medical profile. National data states that the percentage of inductees who were born between 1973 and 1990 was higher than 75%.

Three percent of adult subjects reported having problems with the law, 2.2% reported alcohol consumption and 1.6% reported drug use. According to the report on mental health services by the Department of Information and Assessment at the Ministry of Health, the average percentage of drug users between the ages of 12 and 40 was 10.5% in the year 2001. These figures are considerably higher than in our population. We assume however that the present data may not reliably reflect reality, as some subjects may have preferred not to discuss these personal issues.

Fifty six of the adult subjects live independently, and over 74% are employed or study.

The percentage of subjects who reported being socially active (having friends), is significantly higher (87%) than those who said they have no friends at all (9%). A high percentage of subjects (72%) go out for entertainment. However, it should be noted that 27% of the younger group and 24% of the adults reported that they never leave their homes for entertainment purposes.

Looking at well-being and self-esteem of the adult group (n=908) the percentage of subjects (68%) who are very satisfied with their lives at follow-up is significantly higher ($p<0.05$) than those who are dissatisfied (4%).

It is of interest that a significant percentage (81%) ($p < 0.05$) of subjects believe that in 5 years' time, they will be even more satisfied than they are today, while at present they regard themselves as better off than they were 5 years ago.

DISCUSSION

Large review studies observing the broad spectrum of developmental disabilities and their outcome are rarely found in the medical literature.¹⁻⁷

Between 2000-2002, the Center for Disease Control and Prevention conducted a telephone survey of some 373,055 parents or guardians of children aged 0-17 years in an effort to compare the needs of children with EBD- emotional, behavioral and developmental problems to those of children with CSHCN- children with special health care needs who had no reported EBD problems.⁴⁴

The results indicated that EBD children were more likely to experience diminished health and quality of life and to have problems accessing and receiving needed care.

While this study describes the short term outcome (17 years) of developmental disabilities, their late outcomes are less well studied.

The infrastructure of the medical system in Israel in general, and in the field of child development in particular, provided us with the unique opportunity of locating and interviewing 3,224 subjects who were diagnosed and treated at our CDC between 1975 and 1994, and to study their outcome as young adults. Although a large population was investigated, it should be borne in mind that the study is inherently retrospective and the information was provided solely by our subjects. Such information is often subject to bias by memory loss,

modification and self interpretation.⁴⁵ In our preliminary study⁴³ we found that the socioeconomic and demographic status of the population of children treated in our CDC during the aforementioned period reflects the general demographic and socioeconomic status of the Israeli population at large, and therefore the outcomes are not biased by these factors. Another important fact elicited from our initial retrospective study is the general profile of developmental disabilities within our population, i.e., most children suffered from speech and language disorders, global developmental delay, motor delay and emotional/behavioral problems. The minority suffered from mental retardation, CP, or major neurological disorders. We believe these milder developmental difficulties are the most prevalent developmental disorders worldwide,⁴ but in contrast to the major neurological disorders, only a few studies have analyzed their late outcome.

Dividing our large study population into those younger and older than 18 years, gave us the opportunity of examining the data from two perspectives, i.e., time and age. The time perspective provided us with a good impression of the changing patterns and attitudes in the field of child developmental disabilities over the years. The age perspective made it possible for us to perceive how individual children with developmental disabilities performed as adults. Both these aspects should be considered when endeavoring to comprehend the implications of the present study.

From the time perspective – we have shown that over the years children were referred to the CDC at a younger age. We have also found that the types of

treatments provided changed over time with physiotherapy, occupational therapy and psychological intervention being utilized relatively more than in the past. This could possibly be explained by motor problems or delays being more prevalent in the younger children, and also by a greater awareness of the parents of more minor developmental difficulties like fine motor coordination and their implications on academic performance.

The type of population using the services of the CDC has also changed over the years, as is demonstrated by the medical, genetic and social risk factors of the subjects, and the parental level of education. Fewer children with social risk factors are lately identified, while no significant change is found in the percentage of medical and genetic risks. This could be explained by the improved national socioeconomic and educational level. It might also hint at the changing attitude towards the CDC from serving the severely handicapped to a service for a wider spectrum of developmental disorders.

We have also found that special education placement in kindergartens has increased over the years. This again, might be explained by the increasing public and professional awareness of the significance of early intervention. The fact that this trend is reversed in primary, junior and high schools, probably reflects the greater opportunities for educational interventions that have lately been established within the regular schools (e.g.: in-class support for special education, withdrawing children for special education support in resource rooms etc).

Attention deficit disorder and learning disabilities were significantly more prevalent in our research population. This is not surprising, as developmental

delays in general are a risk factor for both these problems, while developmental language disorders are particularly related to dyslexia.⁴⁷⁻⁴⁹

In one late study conducted by Webster et al.⁵⁰ 36/43 children (84%) with SLI-specific language impairment at age 3.6 ± 0.7 years showed persistent language impairment at school age (7.4 ± 0.7 years).

From the age perspective we have clearly shown that most children with early developmental disabilities are well adapted and fully integrated in society. They achieve a reasonable level of education, fulfill their civil obligations and most live independently and find employment. Their medical problems seem to become more minor. Perhaps the most overwhelming fact is the satisfaction with life expressed by the large majority, accompanied by a sense of optimism for the future. Using "happiness" as an outcome measure in disabled children is seldom found in the literature, but we strongly believe it is an excellent indicator of outcome⁵¹. This could also be tied to the "disability paradox" suggesting that although individuals may have disabilities they may experience a high quality of life⁵²⁻⁵³.

CONCLUSIONS

Despite well-known multiple risk factors, the medical, educational and psychosocial outcome of our subjects were generally good. The large number of unselected subjects, and their wide age range made it possible to reach the conclusion that most children with developmental difficulties who were diagnosed and treated in early childhood gain full independence as they

mature, acquire a good educational level, function as productive citizens, and express satisfaction with their lives.

The increasing public and professional awareness of the impact of childhood developmental disabilities, and the changing trends towards earlier diagnosis and treatment reflected in this study, clearly contribute to this good outcome.

We believe Child Developmental Centers should no longer be regarded as centers for “doomed”, or “retarded” children, but rather as multidisciplinary clinics dealing with the most prevalent pediatric disorders of the modern era.

Future studies will use the same database to analyze the prognosis of specific disabilities, and to measure the impact of risk factors and specific interventions on outcome.

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**MD Yael Leitner, PhD Rachel Yifat, MD Ronit Mesterman,
MA Gabi Gilutz, MSW Ofra Levi-Hakeini, Ora Bitchonsky,
MD Shaul Harel**



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