Coordinated Care for Crippled Children in New York during the Infantile Paralysis Epidemic of 1916

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In 1935, the federal government established a new program to meet the social and medical needs of crippled children.¹ Unlike other federal child health programs from the 1920s and 1930s, Services for Crippled Children, Part 2 of Title V of the Social Security Act (SSA), provided federal dollars for medical and preventive care for children with crippling and physically disabling conditions.² But organized efforts to treat crippled children in the US began in the late nineteenth century. During the first three decades of the twentieth century, many state and local governments and community agencies developed programs for children with crippling conditions resulting from diseases such as tuberculosis, rickets and polio. Services provided included orthopedic and medical treatments, home services, medical equipment and specialized educational services. Not only would these local and state programs

¹The term crippled children was the common term used during this time period to refer to children with special health care needs.
inform the development of an important federal child health program initiated at the height of the Depression, they also represented the role progressive era reformers took in promoting the expansion of medical and social treatments for crippled children.

The development of After-Care Committees following the 1916 infantile paralysis (poliomyelitis or polio) epidemic in New York offers an important example of an early community-based program for crippled children. The Committees organized treatment and services for children afflicted with polio during the epidemic to prevent or reduce permanent paralysis. In New York City alone, over 2,400 children died from the disease and another 6,600 required specialized, long-term medical care that severely taxed local hospitals, dispensaries and families’ resources. From 1916 to 1920, two After-Care Committees (one for New York City and one for New York State) organized local health and social welfare services and created new services to meet the needs of crippled children and their families. It was the first time in New York that many of these agencies collaborated on such a large scale for crippled children. The work of the After-Care Committees demonstrated an important interdisciplinary effort of public health, medical and social service professions to address a major health care crisis in the early 20th Century. Additionally, the Committees served as a model for other collaborations for crippled children between public and private agencies at local and state levels of organization.

Little has been written about this early public health demonstration project, and my research attempted to uncover how the New York Committee on After Care of Infantile Paralysis Cases (NYCACIPC) and the State Charities Aid Association’s (SCAA) Special Committee on the After-Care of Infantile Paralysis developed and functioned, and how their unique contributions fit within the larger context of a federal health programs for disabled children in early 20th century. The Rockefeller Archive

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Center provided an excellent resource for materials on the Committees and their response to the 1916
polio outbreak. The Rockefeller Foundation provided financial support for both committees from 1916
to 1920, and records from the Foundation provided the major sources for this research. Additional
information was obtained from the records of the Commonwealth Fund and the Foundation for Child
Development (previously known as the Association for Aid to Crippled Children), also held by the
Rockefeller Archives Center.

The Need for Coordinated Care

“Never before has there been so united and energetic a movement to follow up on every child to
see that it has the best treatment that the city can afford,” reported Dr. Thomas Riley, secretary of the
newly established NYCACIPC, in the New York Times on November 12, 1916. The follow-up
treatment was for over 6,000 children in New York City left paralyzed in the wake of the worst polio
epidemic in the US to that point. Nationally, 27,000 cases of infantile paralysis and 6,000 deaths were
recorded in 1916, but New York City and surrounding counties were hit hardest by the epidemic. Over
9,000 cases of infantile paralysis were diagnosed in New York City among children less than 16 years of
age and 2400 deaths were recorded. One-third of all infantile paralysis cases and deaths in the US in
1916 occurred in New York City. Of those children that survived the first weeks of developing the
disease, more than half required lengthy, intensive treatment to prevent permanent disfigurement.

When cases started appearing in late spring of 1916, the New York City Department of Health
issued quarantine orders and forcibly removed afflicted children from their homes. Quarantine consisted
of eight weeks of isolation in a local hospital or dispensary without contact from family or friends. As
the number of children in quarantine grew, the New York City Commissioner of Health, Dr. Haven
Emerson, recognized the inability of the City’s Health Department to meet all the medical and social

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needs of these children upon their release from isolation. Conventional medical treatment of the time included giving electricity to the paralyzed extremity, regular massage and passive motion exercises, the use of rigid braces or body casts, and surgery to lengthen or shorten limbs and tendons. Emerson calculated that 80% of children who contracted infantile paralysis would survive, and at least half of these children would need long-term follow-up care. He recognized that the City’s Health Department could not provide the after-care such as weekly massages of paralyzed limbs and medical supervision following surgery or the long-term use of braces and body casts. To address the problem, Emerson convened a meeting of representatives from local dispensaries, hospitals and relief agencies on July 30, 1916, and proposed the idea for an After-Care Committee to coordinate the needed services and track cases. The City’s health and welfare agencies quickly formed the After-Care Committee, but it lacked the money needed to start operations and fund services.

Prior to the Committee’s creation, the Rockefeller Foundation had received numerous requests from local New York City charity organizations for financial assistance to meet the needs of polio survivors. With so many requests, the Foundation sought advice from the local medical community about how best to respond to the epidemic. As Jerome D. Greene, secretary of the Rockefeller Foundation said, “One of the purposes of the Rockefeller Foundation is to deal with an emergency and an emergency in our own city and our own state makes a peculiarly strong appeal to us, and we are anxious to be of service.” By October 1916, the Foundation followed the advice of its experts and funded two after-care committees, one in New York City and one in upstate New York, to provide after-care services to children affected by polio. In doing so, the Foundation embarked on a novel public health demonstration project that not only provided care and treatment to thousands of children, but also

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7“Conference of Infantile Paralysis,” 1916, p. 10.

8“Conference of Infantile Paralysis,” 1916, p. 3.
served as a model for other communities dealing with polio outbreaks, and other agencies working to improve the lives of crippled children.

Work done by After-Care Committees of New York

On August 17, 1916, just a few weeks after Dr. Emerson’s initial appeal for a coordinated effort to address the polio epidemic, the NYCAIPC drafted by-laws, elected officers and submitted a request to the Rockefeller Foundation for $25,000 for its first year’s budget. The Committee included more than 50 members from local hospitals, dispensaries, local nursing agencies like the Henry Street Settlement Nursing Program and the Brooklyn Bureau of Charities’ District Nursing Committee, and other social service organizations like the New York Children’s Aid Society and the New York Charity Organization Society. The Committee defined its mission as the facilitation of “after-care of children recovering from poliomyelitis in co-operation with physicians and other existing agencies, and to encourage such additional provisions as may be found necessary and advisable.”

To this end, the NYCAIPC established a centralized office staffed with an executive director, secretaries and file clerks whose job was to track the after-care treatment for thousands of crippled children in New York City, coordinate referrals for medical care between the City’s Department of Health and community-based medical services, and promote the best medical practices for treating infantile paralysis. The Committee typically did not provide direct medical care itself, but rather sought to organize local efforts according to the objectives outlined in its first report:

1. Maintain a central registry of all cases of infantile paralysis in New York City and a record of their after-care;
2. Divide the city into appropriate districts and group the cases within the districts so as to secure the best treatment and care without the overlapping of agencies or the neglect of any cases;
3. Encourage or provide special clinics for the attendance of orthopedic surgeons and for the instruction of nurses and masseurs and other attendants;
4. Conduct a bureau of advice and information as to the agencies and methods of after-care; and

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9 “Report of the Executive Committee to the General Committee on After Care of Infantile Paralysis Cases,” August 17, 1916, p. 1, Folder 278, Box 25, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
5. Facilitate this after-care in such other ways as may seem to the committee necessary and advisable.\textsuperscript{10}

The NYCACIPC promoted the use of nurses to follow-up on all cases of infantile paralysis in the City. After eight weeks in quarantine in a local hospital, the City’s Health Department would discharge a child to her or his home. Once notified of the discharge, the Committee referred the case to one of four local nursing services: the Brooklyn Committee on Crippled Children (BCCC), the Association for the Aid of Crippled Children (AACC), the Henry Street Settlement, or the Bureau of Educational Nursing of the New York Association for Improving the Condition of the Poor (AICP). A typical home visit to a child recovering from polio included the nurse observing the child’s status, educating parents about the physician’s medical recommendations, and providing muscle treatments or massages if needed.\textsuperscript{11} After such a home visit, the designated nursing agency reported back to the Committee about the child’s status and treatment plan. The Committee tracked each case to ensure that crippled children received after-care in a timely and appropriate manner and to justify financial reimbursement the nursing agencies.

From the beginning, the NYCACIPC struggled to ensure timely after-care for the children of New York City. By June 1917, the Committee had referred over 7,500 cases to the four different nursing agencies but of these total cases, over 60% of the children had received no treatment or irregular treatment since the initial referral. In a progress report, the Committee noted “this showing is, of course, disappointing, the more so because, accepting the use of the Nursing Associations as the proper method of conducting follow-up work, there seems to be no serious defects in the system.”\textsuperscript{12} The Committee’s medical director, Dr. Donald E. Baxter, offered two reasons for the follow-up problems. First, infantile paralysis was one of many medical needs in the community being addressed by the nursing agencies. Of the four agencies, only the AACC provided nursing services solely for crippled children. Second, Dr.

\textsuperscript{11}Wald to Greene, November 3, 1916, Folder 279, Box 25, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
\textsuperscript{12}“Report of the Work of the New York Committee on After Care of Infantile Paralysis Cases,” June 28, 1917, p. 7, Folder 284, Box 25, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
Baxter thought the nursing agencies were resistant to changing their clerical and administrative activities to accommodate the large number of referrals. He suggested that “such a lack of cooperative spirit seems to me to promise ill for successful development of the work under that management.”

In contrast, the nursing agencies reported insufficient funds to hire the appropriate number of staff to meet the high demand for after-care services. The Henry Street Settlement, the AACC and the BCCC had all requested funding from the Rockefeller Foundation prior to the development of the NYCACIPC for help in hiring and training nurses to provide the necessary orthopedic after-care. Lillian Wald, founder of the Henry Street Settlement, wrote to Jerome Greene, Secretary of the Rockefeller Foundation on October 1, 1916, that “to care for the discharged cases thoroughly necessitates a large staff, and for the present…consists of [only] eight nurses, a supervisor, and a stenographer.” Similarly, the BCCC had only 13 nurses in its employ in 1916. Combined, these two agencies received 89% of all cases referred by the Committee in 1916. Wald later requested more funding from the NCYCACIPC to hire more nurses for the Henry Settlement, but no evidence suggests this ever occurred. As the number of new cases declined over time, the nursing services were better able to meet the demand for after-care services, but no records or reports from the NYCACIPC mentioned the need to increase nursing staff. Rather, the Committee suggested improving standards of nursing care and withholding payments to the nursing agencies as methods of improving follow-up services. A 1920 survey of crippled children in New York suggested that home-work done by nurses

13 Baxter to Greene, November 14, 1916, p. 1, Folder 279, Box 25, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
15 Wald to Greene, October 1, 1916, Folder 279, Box 25, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
16 Wald to Greene, November 3, 1916.
for children crippled in the epidemic required a ratio of one nurse to 40 patients, not the one nurse to 200 patients that the nursing agencies were able to provide following the epidemic.  

Despite initial and continuing difficulties with nursing care, the NYCACIPC was very successful in developing ancillary services that supported the health care needs of crippled children. Early on the Committee began an aggressive campaign to raise money for braces, transportation and other outpatient treatments needed by children to correct weak limbs affected by paralysis. During its first four months (by December 1916), the Committee raised over $147,000 (equivalent to $2.8 million in 2007). The demand for braces was so great in New York City that, in June 1917, the Committee hired a worker specifically to process the physicians’ orders and work with local brace makers to ensure the quality of the braces. Prior to the epidemic, social workers employed by local hospitals had assisted crippled children in obtaining braces, working with local relief agencies to pay for the braces when families could not afford them. From 1916 to 1918, the NYCAIPC provided over 2,300 children with braces, for a total cost around $20,000 (equivalent to $275,000 in 2007). Additionally, the Committee successfully bargained with local brace makers and physicians to accept the Committee’s set payments for different types of braces, significantly reducing the cost and establishing standards of quality among local brace makers in New York City. The Committee also organized transportation services for crippled children. In 1916 the NYCAIPC purchased several ambulances at a cost of $12,000 (equivalent to $165,000 in 2007), and then collaborated with the New York City’s Department of Charities to help transport crippled children to and from needed after-care services. The Department of

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20 “Duties of Brace Fund Worker,” June 15, 1917, Folder 280, Box 25, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.


22 “Report of the Work of the New York Committee on After Care of Infantile Paralysis Cases,” June 28, 1917, p. 12; Riley to Vincent, April 19, 1918, Folder 281, Box 25, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC, p. 2.
Charities provided drivers and maintained the ambulances while the Committee processed the transportation requests from all over the city. At peak operation, approximately 600 children received rides to medical appointments, hospital care and other needed services each month, at a cost of about $5500 per month (equivalent to $97,000 per month in 2007).  

For crippled children outside of New York City, the SCAA Special Committee on After-Care of Infant Paralysis coordinated after-care services in collaboration with the New York State Department of Public Health. The SCAA Committee established a slightly different service delivery pattern than the New York City After-Care Committee. Only 3000 cases of polio occurred outside of New York City in 1916, with the most cases occurring in Westchester just north of New York City.  

Crippled children living in these counties had limited access to specialized medical services. The closest orthopedic hospitals and dispensaries were located in New York City or Boston and most families could not afford travel expenses to these facilities, especially with a disabled child. To address this need, the SCAA Committee arranged for public orthopedic clinics that travelled throughout the state to provide medical care, finding it was more cost effective to bring services to the children. Orthopedic surgeons, nurses and muscle trainers employed by the State Health Department staffed the clinics, and only in extreme cases did the Committee send children to New York City for treatment and convalescent care. In the first year of operation (1916-1917), the SCAA Committee sponsored a total of 146 clinics, providing examination and medical care to over 2500 children.

Another difference was the role of social workers in the SCAA’s after-care program. Instead of nurses, social workers coordinated after-care services for the crippled children referred to the Committee. The SCAA modeled these services after a program that was developed in cooperation with

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25 “Report of the Special Committee on the After-Care of Infantile Paralysis, October 1, 1916 to October 1, 1917,” p. 2, Folder 288, Box 26, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
the State Health Department in 1907. In this model, the State Health Department provided medical and in-home nursing care to patients and the SCAA provided all social services and coordinated relief efforts. The SCAA reassigned some full-time social work staff to crippled children’s work and utilized social workers from existing child welfare programs already established in some New York counties. As a result, each county affected by the polio epidemic had a social worker responsible for after-care. These social workers travelled with public orthopedic clinics to track patients’ progress, assess eligibility for braces and other needed medical equipment, coordinate the relief of other needs, and ensure that children received appropriate after-care.

In a progress report, the SCAA’s secretary, Homer Folks, remarked that the “social deficiencies of the families in which after care work is being done such as intemperance, shiftlessness, incompetency and mental deficiency…brings to light the full extent of the social work required and increases the burden upon the agencies dealing with the social aspects of the undertaking.”

In contrast, the NYCACIPC provided only limited social services through the social work departments of area hospitals, and most children in New York City did not receive follow-up from social workers in the home.

Like its sister-committee in New York City, the SCAA Committee actively raised money to provide transportation services, braces and other medical equipment. These funds also financed care for numerous children who had been crippled by polio prior to the 1916 outbreak. These children were so badly crippled that surgery was the only viable treatment, an expensive option that required children to go to New York City hospitals for treatment. The SCAA and its social work staff did most of the

26 Folks to Greene, October 3, 1916, Folder 285, Box 26, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
27 Folks to Greene, September 13, 1916, Folder 285, Box 26, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
28 “Report of the Special Committee on the After-Care of Poliomyelitis of the State Charities Aid Association,” Jan. 30, 1917, Folder 288, Box 26, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC; Folks to Greene, September 13, 1916.
29 Folks to Embree, Feb 15, 1917, Folder 286, Box 26, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
30 Wright, Survey of Cripples in New York City, p. 17.
31 Folks to Rockefeller Foundation, January 31, 1917, Folder 286, Box 26, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
collection and distribution of funds to needy children because it was considered a conflict of interest for government agencies like the State Health Department to engage in fundraising.\textsuperscript{32}

*Termination of Work*

By the end of 1918, the Rockefeller Foundation had donated almost $100,000 (in 1918 dollars) toward after-care services in New York. From the beginning, the Foundation considered the effort a public health demonstration project; it was not interested in funding after-care services indefinitely. Both After-Care Committees received notification that the Foundation would be phasing out its funding. However, the NYCACIPC still had over 3000 crippled children on its registry in 1918. While the Committee managed to continue services through the end of 1919, it was scheduled to end services on January 30, 1920. Robert Stuart, the Committee’s executive director, expressed concern about who would now care for these children and appealed to the community for money to help with the transition of the Committee into a “federation among the various out-patients and social services agencies, homes for crippled children, etc…to conserve in its entirety the work done since the epidemic.”\textsuperscript{33} Stuart also advocated strongly for the continuation of transportation services. While some of the local nursing services, such as the AACC and the BCCC, were able to assume full responsibility for the crippled children still in need of medical care, there was no other agency equipped or willing to continue transporting the children to medical care. In New York City, the transportation of crippled children was costly because it required large automobiles or ambulances, and attendants to lift children in and out of vehicles.\textsuperscript{34} Although the Rockefeller Foundation declined to contribute more money to the After-Care Committee, the newly-established Commonwealth Fund agreed to provide $30,000 to fund

\begin{itemize}
  \item \textsuperscript{32} Folks to Greene, September 13, 1916.
  \item \textsuperscript{33} Stuart to Rockefeller, March 17, 1919, p. 2, Folder 250, Box 24, Series General Welfare, RG 2, Rockefeller Family Archives, RAC.
  \item \textsuperscript{34} Minutes of the Board of Directors of the Common Wealth Fund, February 17, 1920, Folder 2326, Box 244, Series 18, RG Commonwealth Fund Archives, RAC.
\end{itemize}
transportation services until the end of 1920. The Commonwealth Fund provided additional funds to organize a federation of crippled children services in New York City.

Neither objective was accomplished. Transportation services operated by the City’s Department of Charities were abruptly suspended on September 1, 1920, when funding ran out early.\textsuperscript{35} Further, the creation of a federation of crippled children agencies in New York City never materialized. The participating agencies could not agree on a focus for the proposed federation, such as whether to have a coordinated effort for crippled children or only a broader effort to include all disabled individuals, including disabled soldiers from World War I. Without a united organization to raise funds, agencies like the AACC and the BCCC withdrew their support and began their own fundraising efforts so they could continue providing services for children crippled by the epidemic.

Despite its anti-climatic ending, the NYCACIPC has many notable accomplishments. Over its three years of operation, the Committee received referrals on over 8000 cases of polio.\textsuperscript{36} Of these cases, 2309 children (or 26\%) were classified as cured due to treatment received through the Committee. Additionally, the Committee raised $200,000 (equivalent to $2.8 million in 2007) to provide medical care and transportation, and over 2900 needy children had received leg and body braces.\textsuperscript{37} Further, the committee managed to coordinate the work of 50 local hospitals, dispensaries and nursing services in New York City. One of the nursing services, the Association for Aid to Crippled Children, credited its work with the NYCACIPC as an important factor in improving and expanding its nursing services for crippled children in New York during the 1920s and 1930s.\textsuperscript{38} The Rockefeller Foundation was so impressed with the Committee’s work, it commissioned a study in December 1919 to investigate the after-care services developed and provided in New York City. Dr. Henry Wright, Director of the

\begin{thebibliography}{9}
\bibitem{35} Minutes of the Board of Directors of the Common Wealth Fund, October 5, 1920, Folder 2326, Box 244, Series 18, RG Commonwealth Fund Archives, RAC.
\bibitem{36} Stuart to Rockefeller, March 17, 1919.
\bibitem{37} “Infantile Paralysis Summary,” 1918, Folder 275, Box 24, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC; Stuart to Rockefeller, March 17, 1919.
\bibitem{38} Association for the Aid of Crippled Children, Annual Reports, 1920-1934, Foundation for Child Development, Microfilm Collection, RAC.
\end{thebibliography}
Hospital and Institutional Bureau of Consultation, coordinated the survey, which was one of the first to determine the number of disabled individuals in New York City. The survey was published in 1920 and widely publicized and referenced throughout the country.39

Results from the study showed that about 36,000 individuals in New York City were diagnosed as crippled or disabled, and that most became crippled before the age of sixteen. Fifty percent of these individuals had not received medical treatment nor were they involved with a social service agency. The report also noted that medical and clinical service for crippled children and adults was adequate, however it stated, “in the social work for cripples, there are portions of the field uncovered, and at the same time somewhat vague limits assigned to the work of various agencies.”40

The work of the SCAA’s After-Care Committee ended in March 1919 with even less notice. At that time, a total of 1700 children were still receiving services from the committee, mostly braces and social service assistance. Medical services for these children continued through the nursing services of the State Health Department and local area physicians. Ida Curry, secretary of the Committee, in her final progress report noted that financial costs associated with the care of crippled children would become the responsibility of the county governments and local community services. She wrote, “As the work progressed, we gradually developed local responsibility for the expenses of individual patients.”41

While less was recorded about the outcomes of the SCAA’s after-care efforts, there appeared to be two important benefits from its work. First was the awareness raised in the rural areas of New York about the medical and social care available for crippled children in 1918. Through case finding and education, the SCAA’s Committee reached not only 2900 crippled children affected by polio in 1916, but almost 500 children who were afflicted by disease before 1916.42 Curry concluded that “by bringing selected patients into the orthopedic hospitals and sending them home in greatly improved conditions, we have

40 Wright, Survey of Cripples in New York City, p. 11.
41 Curry to Embree, April 4, 1919, p.2, Folder 287, Box 25, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
42 Curry to Embree, December 3, 1917, p.4, Folder 286, Box 26, Series 200, RG 1.1, Rockefeller Foundation Archives, RAC.
made a material contribution toward informing the people of the State as to the possibility of materially improving the conditions of cripples”.

The second benefit was the expansion of social services into other State Health Department programs. In 1918, two social workers were hired by the State Health Department to work in a venereal disease prevention program. Curry wrote “this is the first time that social workers have been employed by the State Department, and the experiment was deemed worth while because of the help we had given the Department in the infantile paralysis campaign.”

Conclusion

The After-Care Committees on Infantile Paralysis in New York represent an important early public health demonstration effort on behalf of crippled children in the early 20th century. First, it is unique among progressive era reform efforts for crippled children during the 1910s and 1920s. Most treatment programs focused on developing services within institutional and educational settings. In contrast, the New York After-Care Committees specifically worked to coordinate and develop community-based services to reach disabled children in their homes and communities. Second, the Committees worked to mobilize and change systems of care in New York rather than provide direct care to individual children. Important practices that the Committees developed included transportation services; a centralized registry and referral system; and the recognition of social work as an important profession in the work for crippled children. Several of these practices became standard in the care for crippled children and would become required services in the Federal Crippled Children Services program created in 1935, almost two decades later.

43 Curry to Embree, April 4, 1919, p.2.
44 Curry to Embree, April 4, 1919, p.2.