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As an advocate for the Consumer Directed Personal Assistance Program it is my hope that the following information will serve to encourage those who are seeking ways to correct and refocus this important program.

A History of the
Consumer Directed Personal Assistance Program (CDPAP)
in New York City
1977 to 2001

Prior to the creation of the vendor based Home Attendant Program in New York City, the City of New York managed a direct payment system, using the Welfare Department's computer, to issue two party checks which included both the Consumer's and the Home Attendant's names. In the direct payment system, Home Attendants were considered to be independent contractors, were paid the minimum wage, did not pay any taxes and did not receive any benefits. From the perspective of most Consumers (especially the frail elderly and the non-self-directing), many Home Attendants and various governmental entities; including the IRS, the Social Security Administration and the New York State Department of Labor; the program was clearly a disaster. But from the perspective of the self-directing Consumer, it was an opportunity to be empowered. For a Consumer to succeed in this program it was up to the Consumer to hire, train and supervise the Home Attendant of their choice. To remedy the program's problems for the majority, the City began to develop a plan, to move the program to a group of vendor agencies (Vendorization), which would have threatened the self-directing community and their ability to live independently.

In response to the City of New York's effort to move from the direct payment home care system, a group of disabled and non-disabled people, connected to the "new" Roosevelt Island community, created a member organization that was originally called Concepts of Independence for the Disabled. Led by the corporation's founder Victoria Holland with Ira Holland and Ed Litcher, they were joined by Christine Flynn, Rose Pallasino, Judy Scherer, Art Tutman and a pro-bono Attorney Ray Werchen, to have the organization incorporated on December 12, 1977.

As stated in the corporation's original (please forgive the antique language) Certificate of Incorporation, the purposes of this Not-for-Profit Corporation are:

- A. *To enable functionally handicapped persons to live independently, by assisting them to achieve and maintain control over their own lives;*
- B. *To receive on behalf of those members of the corporation (service recipients) who are functionally handicapped persons, funds allocated to them under the Social Security Act and similar Federal, State, local and/or private agencies, and to disburse such funds pursuant to law to home attendants on behalf of such functionally handicapped member of the corporation;*
- C. *To make home attendants available to functionally handicapped persons;*
- D. *To provide information to functionally handicapped persons with respect to Federal, state and local assistance programs which are or may be available to functionally handicapped persons;*
- E. *To provide and make available all incidental information necessary or proper for carrying out the express purposes here in before stated, and*
- F. *To raise funds for carrying out the purposes herein before enumerated.*

According to the Special Report – Evaluation of the Client Maintained Home Attendant Plan dated June 1981 by Robert Trobe Deputy Administrator Family and Adult Services and Gregory M. Kaladjian Assistant Deputy Administrator Office of Home Care Services/FAS.

After a group of severely disabled persons, (many of whom were in motorized wheelchairs with ventilators plugged into corridor outlets) held a protest demonstration outside the chambers of the New York City Board of Estimate, and a meeting of handicapped persons (led by) Sandra Schnur with Carol Rafael the Deputy Administrator of Family and Adult Services, a joint Family and Adult Services / Community Task force was established in August 1978. After much discussion with key members of the disabled communities, representing a variety of organizations, it was concluded that representatives of the handicapped community would meet with selected persons from FAS to attempt to devise an alternative plan for self-directing disabled persons.

Disabled Community: Ann Didio, Daniel Ginsburg, Ira Holland, Anna Kopel, Ed Litcher, Joy McCall, Marilyn Saviola, Gertrude Schleier, Sandra Schnur, Angela Thompson, James Weisman, Muriel Zgardowski and Vincent Zgardowski.

Family and Adult Services: Carol Rafael, Bonnie Stone and Robert Schick.

New York State Department of Social Services: Ann Hallock.

*The Task Force met regularly for a year and a half (from August 1978 to December 1979) and a variety of approaches were explored for developing a program geared to the needs of the client who has a stable medical condition, may have severe physical disabilities, and expressed a strong desire to manage the delivery of his or her services to the maximum degree possible. **Included in these discussions was an attempt to stop Vendorization, an attempt to exempt the self-directing population from this program, and an attempt to create a consumer friendly environment within the conventional vendor model.** The most significant of these was a three-year demonstration project, which would allow clients to act as the legal employers of their own home attendants. A request for a waiver of federal Medicaid regulations for such a project was prepared by New York State DSS and New York City DSS in November 1979. As a result of a reconsideration by the Task Force, this waiver request was never submitted to the federal government; as a federal demonstration project it was considered to be too time limited.*

*On December 4, 1979 the Task Force voted in favor of a second alternative **proposed by Concepts of Independence for the Disabled, Inc.,** known as the Client Maintained Home Attendant Plan. Unlike the demonstration project this alternative only required New York State approval. This plan divides the responsibility for all aspects of service between the participating clients and an agency (selected by the task force and approved by HRA) which handles payment and record keeping functions and services as the attendant's employer of record. The client is responsible for recruiting, selecting, training and orienting the attendant; directing the attendant's daily activities; identifying and assigning the attendant; discharging the attendant when necessary and notifying the agency to formally dismiss him/her; signing the attendant's timesheet and forwarding them to the agency; transmitting any attendant complaints to the agency; arranging for emergency coverage in the absence of the regularly assigned attendant; and maintaining contact with their case manager. The final Client Maintained Home Attendant Plan offers the self-directing disabled the opportunity to maximize their goals of self-direction and participation while maintaining a parallel with the vendor system. On December 15, 1979, the disabled persons in the Task Force selected Concepts of Independence for the Disabled, Inc. as the agency for the Client Maintained Home Attendant Plan and informed Family and Adult Services of its decision. Although Concepts of Independence for the Disabled, Inc. was already in existence as a corporate entity, its Board of Directors was **voluntarily** reconstituted specifically for this plan to include the members of the Task Force, giving the agency maximum consumer input. The program's inception*

was on May 28, 1980 and the second full year contact has been negotiated and approved by the Board of Estimate for Fiscal 81-82.

When the program began, with the enrollment of four clients, the members of the Concepts board were advised, that the program had to exceed 100 clients within a year or risk program termination. As of the writing of the Special Report in June 1981, HRA had approved 187 clients and had transferred 139 active consumers to the program.

Finally, the HRA description of Concepts of Independence for the Disabled, Inc contained in this June 1981 report is that of a *Not-For-Profit Corporation organized for and by disabled individuals. The Board of Directors is comprised of eleven members, all of whom are handicapped.* **Sandra Schnur - President, Ira E. Holland - Vice President, Cynthia Bell, Thomas V. Brown, Rhea Dopico, Daniel Ginsburg, Sandra Olitsky, Joy McCall, Gertrude Schleier, Muriel Zgardowski and Vincent Zgardowski, with Edward Litcher - Program Director and Angela Thompson - Assistant Director.**

From the earliest days of program operation, the Board of Directors and staff recognized the requirement to maximize the program's liability protection by maintaining a clear line of separation between program administration and the Consumer's authority. As a result of this understanding the program developed a Consumer based Home Attendant enrollment system, a Consumer based time sheet, a system that required Consumer participation in the payroll distribution process and a Recruitment Assistance Service to increase the flow of information between Consumers and potential Personal Assistants. In the ensuing years of program operation, HRA made a decision to move the process of completing the periodic nursing assessments from their responsibility to that of the vendor agency nurses. When this change occurred, Concepts used the same principle of separation to develop a system that employed independent contractor nurses, who were hired by the Consumers, to complete this required assessment.

As the program developed, the Board of Directors elected to shorten the name of the corporation from Concepts of Independence for the Disabled to Concepts of Independence on September 04, 1983.

The next major event occurred in 1992 when home care advocates from the Capital District like Michael Peluso and representatives from Concepts of Independence (Concepts) were able to convince New York State Legislator's to modify the Nurse Practice Act - Education Law Article 139: Nursing Section 6908 - Exempt persons. By achieving this landmark legislative change the group was able to garner the support of the NYS Nursing Association because they were able to avoid the problem of Nurse Delegation, empower home care consumers who required routine yet complex nursing services and set the stage for significant home care savings. In addition to achieving the this major legislative modification, 1992 also marked the year that the NYS Department

of Health took control over the Home Care program from the Department of Social Services and proposed the first statewide demonstration project that was called the Patient Managed Home Care Program.

In 1994 Ira Holland became the program's next President and Muriel Zgardowski became the new Vice-President.

In 1995, in an effort to save Home Care dollars, the State of New York, based upon information supplied by home care advocates and Concepts, passed - Social Services Law Title 11: Medical Assistance for Needy Persons Article 5: Section 365f.

When New York mandated the statewide expansion of the renamed Consumer Directed Personal Assistance Program (CDPAP) into each of the "upstate" counties, Concepts and David Whalen an Attorney and the first CDPAP Consumer in the Capital District developed the first Memorandum of Understanding (MOU). As a result of this MOU, the CDPAP became available to the Consumers in the counties of the Capital District, and Constance Laymon was first introduced to the program. As the first coordinator of the program in Albany County, she worked closely with members of the Concepts Board of Directors, Ed Litcher and Carmen Silva to develop a clear understanding of this program and to determine the best way to apply the program to the unique circumstances that Consumers in Albany County would encounter. As Constance became more familiar with the program, the local agency that employed her had a severe economic crisis that could have terminated the CDPAP in Albany. Instead of ending the program, Constance embraced the program and began administering it, without compensation from her own home. Today, Constance is a Consumer, Founder, and CEO of Consumer Directed Choices a Capital District CDPAP provider and is the President of the Consumer Directed Personal Assistance Association of New York State.

In 1999 Concepts entered into a special MOU relationship to manage the Personal Assistant payroll and benefits for Independence Care Systems (ICS) a special New York City based managed care program. When this contract was executed all parties understood that Concepts would, as was the normal practice for all of the MOU programs, provide salary and benefit parity with the NYC-HRA program, an understanding that suffered severely subsequent to 2001.

As indicated above, the purpose of the MOU was to establish a relationship between Concepts and a county or another authorized entity to facilitate the spread of the CDPAP through example and education. In each case, it was

understood that the program would require a local entity to manage the critical consumer centered issues of the program. Given the limited nature of these agreements it was also assumed that the full authority of the program would quickly be shifted to the local program.

Unfortunately, although nearly 15 years have passed since the development of the first MOU, many of these relationships still remain. It is my belief that the corporation should begin the process of actively removing itself from these arrangements. Arrangements that provide no direct benefit to the corporation and are only useful to permit the payment of salaries (that many consider unreasonable), the withholding of excessively large sums from "Related Programs" (possibly HRA), and the withholding of large sums from various Personal Assistant benefit trusts. For additional information on this issue, please examine a copy of the IRS form 990 for Concepts of Independent Choices a public document found on the Guidestar.org web site.

The final major program change also occurred in 1999 when Concepts in consultation with HRA developed a system to permit a non-self directing Consumer with a Surrogate to jointly manage the Consumer's home care services. When this program change was developed, the principle of significant daily presence was established to insure that the Surrogate would provide adequate service supervision. As a result of this change, the number of potential Consumers was dramatically increased and the program census quickly exceeded more than 1,000 consumers.

In 2001 a problem occurred involving the alleged misuse of their Consumer authority by members of the board. Although the problem was beyond the control of the administrative staff, and it did not result in either criminal or civil penalties, Ira Holland and another member of the Board withdrew from their positions, Muriel Zgardowski was named the new President, and members of the, long term, senior staff were forced to resign. Shortly after the events of March 2001, the administration seized power and engineered an arrangement with HRA. As a result of this arrangement that undermined the historic understanding between Consumers and HRA, the administration chose to trample the line that separated agency responsibility from Consumer authority, purged all of the Consumers from the Board of Directors, and ended the Recruitment Assistance Service.

To conclude, it is my belief that the history of the CDPAP from 1977 to 2001 and the program's success during this period, demonstrate that the core principals of this program are worthy of duplication and preservation.

Chief among the core principles that should be re-established is the composition of the Board of Directors. To quote from the original Corporate by Laws, "*No more than two*

seats are available for occupancy by non-disabled individuals.” Given the importance of board membership to the long term success of the CDPAP, it is my belief that board memberships should be time limited, should be independent from any control of the program’s administration, and should directly incorporate consumers in the process of selecting and electing new board members.

Next the program should recognize its obligation to provide a Recruitment Assistance Service. A service that is consistent with the first, third, and fifth corporate purpose. A service that can be successfully and safely (from a liability standpoint) administered provided the corporation reestablishes the clear line of separation between themselves and the Consumers by suspending any activities that offer the impression of direct Personal Assistant or Home Care Service supervision. Activities that include the Personal Assistant orientation program and the current practice of using staff nurses to complete the required nursing assessments.

Finally, the program should learn to afford reasonable attention to the issue of Medicaid Fraud, while recognizing that consumers are the reason the program exists and that consumers should be respected for their vital contribution to this important program.

Thank you for the opportunity to offer this information.

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April 27, 2010

APPENDIX

Individuals Named:

1. Bell, Cynthia - Consumer, Staten Island
2. Brown, Thomas V – Consumer, Roosevelt Island
3. Didio, Ann – Consumer, Disabled In Action
4. Dopico, Rhea – Consumer, Coney Island
5. Flynn, Christine - Roosevelt Island Development Corporation
6. Ginsburg, Daniel – Consumer, Human Resources Administration
7. Hallock, Ann, New York State Department of Social Services

8. Holland, Ira - Consumer, Roosevelt Island Resident, Co-Founder – Concepts of Independence for the Disabled, Vice President 1977 to 1994, President 1994 to 2001
9. Holland, Victoria - Consumer, Roosevelt Island Resident, Founder – Concepts of Independence for the Disabled, President 1977 to 1979
10. Kaladjian, Gregory M. - Assistant Deputy Administrator Office of Home Care Services/FAS.
11. Kopel, Anna – Senior, Coop-City
12. Laymon, Constance - Consumer, Founder, and CEO of Consumer Directed Choices a Capital District CDPAP provider and is the President of the Consumer Directed Personal Assistance Association of New York State
13. Litcher, Edward - Roosevelt Island Resident, Co-Founder – Concepts of Independence for the Disabled, Member of the Board 1977 to 1980 (Acting President 1979 to 1980), Program Director 1980 to 2001, Founder - Consumer Directed Services 2001
14. McCall, Joy – Consumer, Easter Seals
15. Olitsky, Sandra – Consumer, NYS VESID
16. Pallasino, Rose - Consumer, Goldwater Memorial Hospital
17. Peluso, Michael – Consumer, CAP Director NYS Commission on Quality of Care
18. Rafael, Carol - Executive Deputy Commissioner of the Human Resources Administration
19. Saviola, Marilyn – Consumer, Center for the Disabled in New York (CIDNY)
20. Scherer, Judy – Columbia University Anthropologist – studying the disabled community on Roosevelt Island
21. Schick, Robert – Family and Adult Services
22. Schleier, Gertrude – Consumer, Lower East Side
23. Schnur, Schnur – Consumer, Director The New York City Half Fair Program for the Disabled, President Concepts of Independence 1980 - 1994
24. Silva, Carmen – Client Coordinator, Concepts of Independence.
25. Stone, Bonnie – Family and Adult Services

26. Thompson, Angela – Consumer, United Cerebral Palsy of New York City
27. Trobe, Robert - Deputy Administrator Family and Adult Services
28. Tutman, Art - Roosevelt Island Resident
29. Whalen, David – Consumer, Attorney and the first CDPAP Consumer in the Capital District
30. Weisman, James – Attorney, Eastern Paralyzed Veteran’s Association (EPVA)
31. Werchen, Ray – Pro Bono Attorney, Roosevelt Island Resident
32. Zgardowski, Muriel – Consumer, Muscular Dystrophy Association, Vice President 1994 to 2001, President 2001 to 2001
33. Zgardowski, Vincent - Consumer, Muscular Dystrophy Association