Faneblad 6

Klinisk resultat af undersøgelse af genoptræning hos Family Hope Center og en national kontrol gruppe. Foretaget af University of Buffalo[1].

Universitetet har udarbejdet en rapport over resultaterne for Family Hope Center, hvori de sammenligner patienter på FHC's programmer med en national kontrol gruppe indenfor samme diagnoser, jf. bilag 7.

I rapporten bruger universitetet "WeeFIM program", som er blevet et standard evaluerings redskab for pædiater (børnelæger) indenfor genoptræning i mere end 70 genoptrænings institutter i 11 lande og adskillige hospitaler i USA.

I undersøgelsen anser den nationale kontrol gruppe at et barn er mobilt, såfremt barnet kan køre i elektrisk kørestol. FHC's børn er mobile når de kan gå - uden brug af hjælpemidler.

Undersøgelsen er opdelt i 3 grupper af børn, med forskellige diagnoser. En gruppe med Cerebral parese, en anden gruppe med udviklingshæmmede (kognitiv og udviklings forsinkelse) og en tredje gruppe med hjerne dysfunktion.

Aldersmæssigt[2] er (FHC) børnene i den første gruppe med Cerebral parese i gennemsnit 99 måneder. Dem der startede i nationalt regi var i gennemsnit 89 måneder.

Den første gruppe, som er gruppen af børn med Cerebral parese, består undersøgelsen af 137 børn[3].
Undersøgelsesresultatet af den første gruppe er således:

Børn, som er selvhjulpne
FHC	64%
Kontrol gruppe	27%

Børn med mobilitet:
FHC:	63%
Kontrol gruppe	26%

Kognitiv udvikling
FHC	44%
Kontrol gruppe	18%

Total:
FHC	56%
Kontrol gruppe	24%

Resultaterne fra de andre 2 grupper der er blevet sammenlignet, viser at FHC's børn har en bedre udvikling end de børn der genoptræner i nationalt regi, jf. bilag 7.

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[1] University of Buffalo er staten New Yorks største universitet, som rangerer blandt USA's bedste forskningsuniversiteter med primært indsatsområde indenfor medicin. Der er tilknyttet 13 hospitaler til universitet.
[2] Jo ældre et barn er, jo længere vil der gå med genoptræningen, idet det bl.a. tager længere tid at rette fejlstillinger op.
[3] Undersøgelsen er lavet med 3 evalueringer over 2 år fra januar 2002 til december 2004.

CLINICAL OUTCOME SCORES FOR THE FAMILY HOPE CENTER FOR THREE YEARS, COMPARED TO NATIONAL SAMPLE OF OUTPATIENT REHABILITATION FOR SIMILAR DIAGNOSES

This document references data from a Report compiled by Uniform Data System for Medical Rehabilitation titled Custom Report, Functional Progress Comparison, January 1, 2001 to December 31, 2004

Introduction: The "FIM" Programs

The Functional Independence Measure (FIM) programs are the most widely used systems in the world for documenting the severity of patient disabilities and rehabilitation outcomes. They are administered by Uniform Data System for Medical Rehabilitation (UDSMR), which is affiliated with the University of Buffalo in New York, and are used by insurance companies to benchmark patient care needs, assess treatment success, and set reimbursement levels. Detailed information about UDSMR's origin and purposes is available at http://www.emedicine.com/pmr/topic155.htm.

The focus of the FIM programs is on "functional assessment," *i.e.*, measuring how well patients perform basic activities of daily living. These activities include such things as the ability to feed, groom, dress and bathe oneself; memory, problem solving, speech and other cognitive skills; bladder and bowel control; social skills; and basic mobility skills, such as crawling, creeping and walking. The FIM programs also seek to measure levels of resource use and burden of care, including substituted time and energy requirements of caring for the disabled.

The "WeeFIM" Program

The program UDSMR developed specifically for children – WeeFIM – has become the standard assessment tool for pediatric rehabilitation patients. More than 70 rehabilitation facilities in 11 countries participate in the WeeFIM program. Examples of WeeFIM participants in the United States include Children's Specialized Hospital in Mountainside, New Jersey; the Cleveland Clinic Children's Hospital in Cleveland, Ohio; Johnson Rehabilitation Institute in Edison, New Jersey; Alfred I DuPont Institute Hospital for Children in Wilmington, Delaware; The Hospital for Sick Children in Washington, DC; and the Kennedy Krieger Institute in Baltimore, Maryland.

Facilities that participate in the WeeFIM program, including The Family Hope Center, submit data to UDSMR for quality checks after being trained and credentialed to collect and submit the data. The Family Hope Center received this training and credentialing in 2001, its first full year of operation, because participation in WeeFIM:

- Provides an objective, widely-recognized tool for benchmarking and tracking patient progress
- Helps the FHC staff develop individualized treatment programs for our patients
- Guides quality improvement efforts, by providing specific data on the relative effectiveness of treatment modalities
- Gathers patient outcome data for research in the children's rehabilitation arena
- Provides an easily understandable record of each child's progress in therapy, which parents can use in support of insurance reimbursement claims

How WeeFIM Works

On their first admission or visit to a WeeFIM facility, a child is assigned to one or more of 19 "impairment groups." The impairment groups that Family Hope Center children typically fit into include:

- Cerebral palsy
- Development disabilities, cognitive & developmental delay
- Development disabilities, disorders of attention, socialization & behavior
- Development disabilities, speech & language
- Developmental disabilities, disorders of motor control
- Brain dysfunction
- Congenital disorders
- Neurological disorders
- Stroke
- Childhood disorders with high risk

The facility then assesses the child's degree of independence in 18 different functions in three general areas – self-care, mobility, and cognition - as applicable. For each function the child is assigned a number from 1 to 7, with 1 meaning the child cannot perform the function independently at all ("total assistance needed from a helper or device") and 7 meaning the child can fully perform the function without assistance ("complete patient independence"). This creates a baseline for measuring the child's progress, in terms of these functions, over the course of his or her treatment program. Additional assessments are conducted at subsequent appointments (as at The Family Hope Center) or after standard intervals (as at inpatient facilities).

The data from these assessments - original and follow-up - are sent to UDSMR electronically. UDSMR organizes the data from all participating facilities, aggregates it, and prepares quarterly and annual reports for each facility. These reports contain an abundance of data about how well the facility's patients are progressing, by impairment group and, within each impairment group, by specific function. **It is presented in a way that allows the facility to see how well its patients are doing, individually and in statistical averages, and how well its patients are doing compared to other facilities' patients.**

Some Notes About the WeeFIM Program

There are a few things to keep in mind about WeeFIM scores and reports.

First, even "normal," unimpaired three-year olds will require some assistance with a skill like dressing themselves. Such a child might receive a WeeFIM score of 5 (out of 7) for this skill. A three-year old who receives a WeeFIM of 4 for this skill would be only slightly behind his chronological peers, indicating only a small degree of impairment. But a twelve-year old with a WeeFIM score of 4 for this skill would be far behind his chronological peers, indicating a much greater degree of impairment. In short, **a given WeeFIM score indicates a higher degree of impairment for an older child than for a younger one.**

Second, the goals measured by the WeeFIM program are more limited than The Family Hope Center's goals for our children. For example, a child who can maneuver in a motorized wheelchair without assistance is considered almost fully mobile for WeeFIM purposes. The Family Hope Center, by contrast, aims for full normal function, including unassisted walking and running, for all of its children. WeeFIM scores do not capture the progress made by Family Hope Center children that goes beyond the more limited abilities measured by WeeFIM.

Third, WeeFIM facilities reports do not assign numerical ranks to the participating facilities, or provide data from which a numerical rank can be inferred. Thus no WeeFIM facility can say whether it ranks 1st, 15th or in any other position for effectiveness of its treatment for any condition. Rather, the reports indicate average progress by the facility's own patients, by impairment group and function. They also show how the facility's results compare to the average for participating facilities nationwide. But the data do not allow a facility to determine its specific rank, in any category, among participating facilities.

Finally, each WeeFIM facility gets facility-specific information only about its own results. Information about other participants' results is presented in the form of aggregated averages. This means that a facility cannot say, from the reports it receives, how its patients fare compared to the patients of any other specific facility.

WeeFIM and The Family Hope Center

The Family Hope Center, like other WeeFIM facilities, conducts a full WeeFIM assessment of each child at each appointment. Parents receive a record of their child's initial and subsequent levels of function, in the form of a "polar graph" like the sample shown below, at the end of each appointment. These graphs illustrate the level of the child's degree of ability in each of the 18 domains of functioning. The parents, in turn, can provide copies of these graphs to insurance companies when seeking reimbursement.
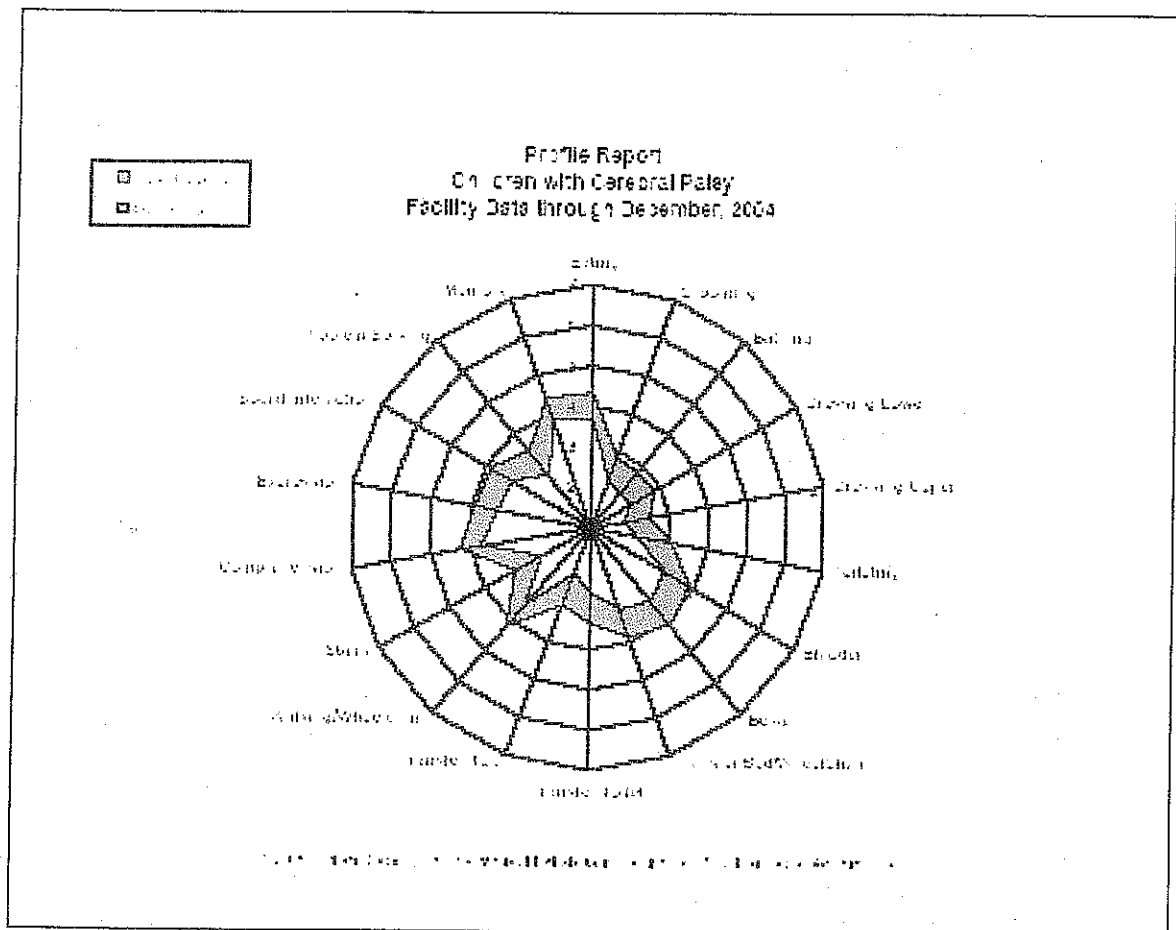
The Family Hope Center has received a report from UDSMR, called *"Functional Progress Comparison January of 2002 to end of December, 2004,"* that incorporates the WeeFIM scores and other data for all children who have been assessed by FHC at least three times in the last three calendar years. The full report can be viewed by clicking here. Generally, children with three or more assessments by The Family Hope Center fall into one of three major diagnostic categories:

- Cerebral Palsy
- Developmental Disabilities, with cognitive and developmental delay
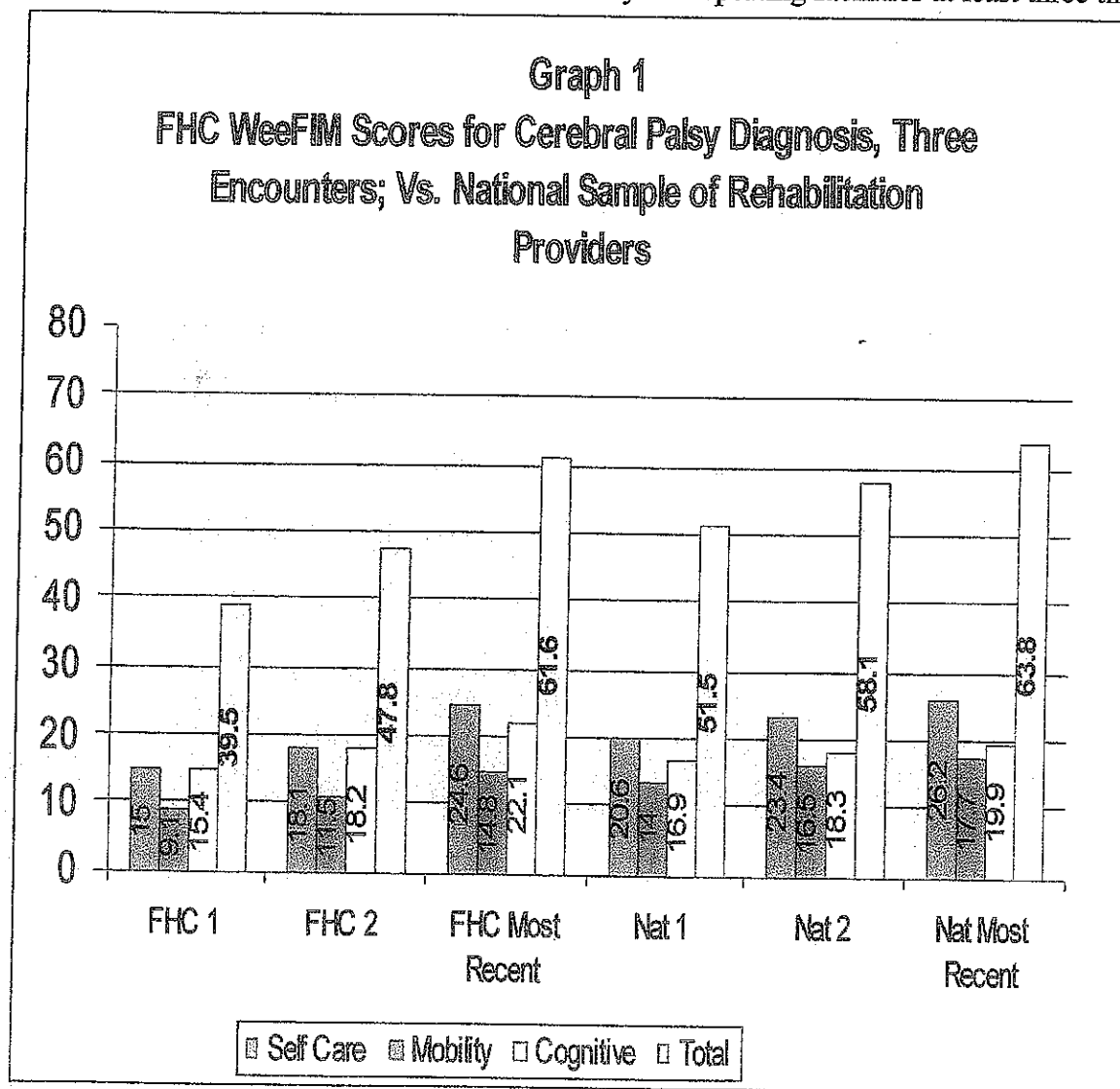- Brain Dysfunction

Data for each of these major categories, and for all children with all impairments as a whole, appears below.

Cerebral Palsy

Children diagnosed with cerebral palsy (CP) generally exhibit signs of neurological impairment at birth, including movement disorders that affect coordination, voluntary movement, postural control, and muscle tone. Involuntary contractions are also common. Approximately 30% of FHC children come to us with this diagnosis.

Graph 1: WeeFIM Scores for CP Children with Three or More Assessments.

Graph 1 shows WeeFIM scores, as provided by UDSMR, for CP children at their first, second and most recent assessments. The three sets of bars on the left-hand side of the Graph show the average scores for 31 FHC children with CP, and the three sets of bars on the right-hand side show the average scores for 106 children with CP at WeeFIM facilities nationwide. Both sets of bars include data only for children who have been assessed by the reporting facilities at least three times.

Graph 1
FHC WeeFIM Scores for Cerebral Palsy Diagnosis, Three Encounters; Vs. National Sample of Rehabilitation Providers

Note that in all three categories of functioning – self-care, mobility and cognitive – FHC's CP children were significantly more impaired at their first assessment, on average, than other facilities' CP children.

The UDSMR data also indicate that CP children are older almost a year older when they start with FHC (99 months on average) than when they start with other facilities (89 months). It is FHC's experience that this is because CP children often come to The Family Hope Center after months or years of treatment, with little or no success, at other facilities.

These two factors – lower scores and higher age when treatment begins – make for "harder cases," with lower expectations for improvement. Nevertheless, children with CP not only improved under their FHC programs, as shown by Graph 1; as shown by Graph 2, they also improved at a greater rate than CP children at other facilities.

Graph 2: Gains by FHC's CP Children Compared to CP Children in National Sample

Graph 2 compares the gains made by Family Hope Center patients with CP compared to the national sample, using data from Graph 1.

Graph 2
Gains of Family Hope Center Children
Diagnosed with Cerebral Palsey
vs. Comparable National Sample
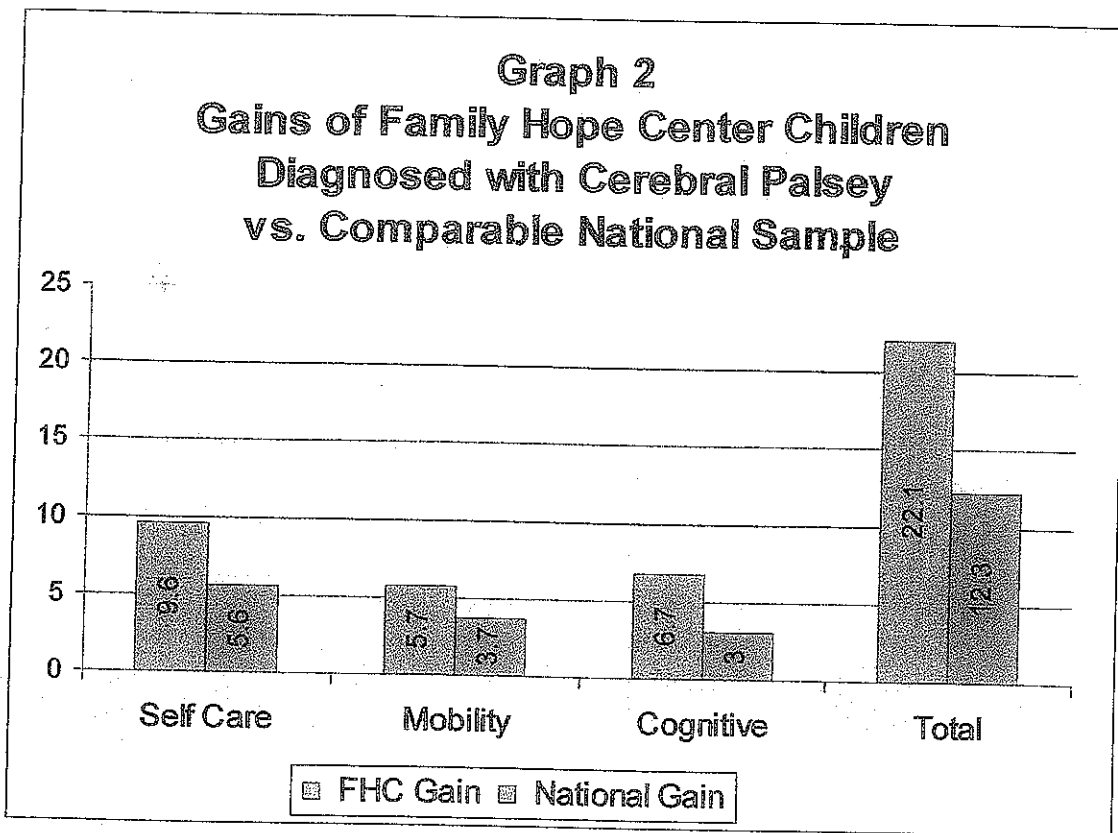
The data from Graphs 1 and 2 may also be presented in table form, as follows:

Self-Care	1st Assessment	Most recent	Points Gained	% Gained
FHC:	15.0	24.6	9.6	64%
National:	20.6	26.2	5.6	27%

Mobility	1st Assessment	Most recent	Points Gained	% Gained
FHC:	9.1	14.8	5.7	63%
National:	14.0	17.7	3.7	26%

Cognitive	1st Assessment	Most recent	Points Gained	% Gained
FHC:	15.4	22.1	6.7	44%
National:	16.9	19.9	3.0	18%

Total	1st Assessment	Most recent	Points Gained	% Gained
FHC:	39.5	61.6	22.1	56%
National:	51.5	63.8	12.3	24%

In short, FHC children with CP improved their WeeFIM scores in all major diagnostic categories, at rates substantially higher – in fact, more than twice as high - as children at other facilities in the national sample.

This is especially noteworthy with regard to the improvements in mobility scores, for two reasons: first, because the level of initial mobility impairment is significantly higher (scores are lower) for FHC children with CP; and, second, because FHC's programs are directed at achieving full mobility, without the use of mobility devices (such as wheelchairs), instead of the assisted mobility that most other facilities aim for and UDSMR considers sufficient. **A child who is self-mobile in an electric wheelchair, for example, will have a higher WeeFIM score than a child who is crawling, but will not make as much neurological progress over time.**

Children with these kinds of diagnoses typically have low IQ scores, with severe speech, language, hearing and memory disorders that impair learning. Approximately 30% of FHC's children come to us with a diagnosis of this general type.

Graph 3:   WeeFIM Scores: Developmental Disabilities, Three or More Assessments

Graph 3 shows WeeFIM scores, as provided by UDSMR, for children diagnosed with these developmental disabilities at their 1st, 2nd and most recent assessments. The three sets of bars on the left-hand side of Graph 3 show the average scores for 31 FHC children with these diagnoses, and the three sets of bars on the right-hand side show the average scores for 567 children at WeeFIM facilities nationwide. Both sets of bars include data only for children who have been assessed by the reporting facilities at least three times.

Graph 3
Comparison Scores for Developmental
Disabilities: Cognitive and Developmental
Delay
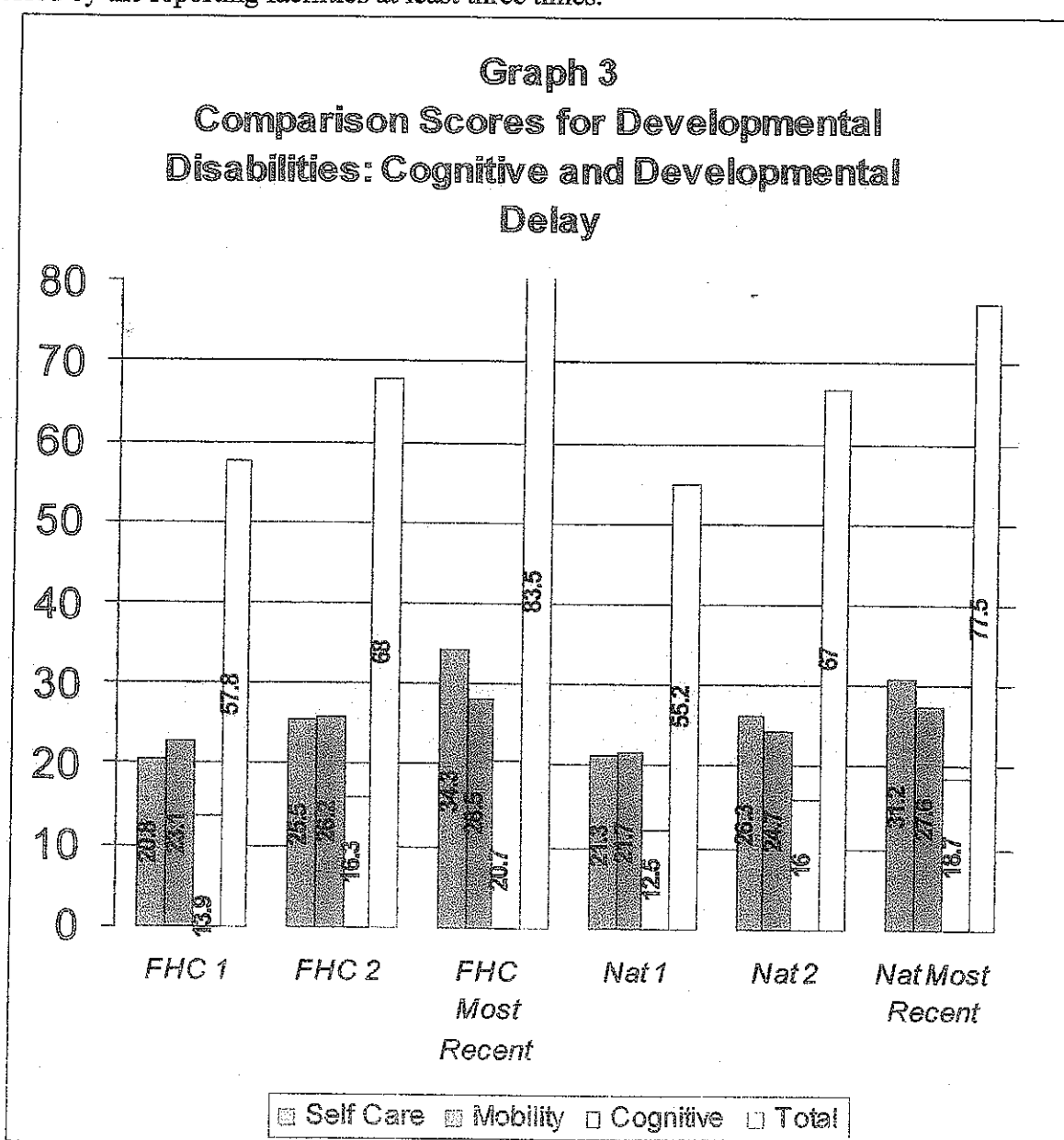
As shown by Graph 3, Family Hope Center children in this group started with total WeeFIM scores (57.8) that were close to the average for all children in the national sample (55.2).

As with cerebral palsy, however, children with these diagnoses were much older when they first presented to FHC (71 months) than when they first presented to pediatric rehabilitation facilities nationwide (40 months).

As described above, a given score indicates a greater degree of impairment for an older child than the same score for a younger child. Nevertheless, the total gains by FHC children were either comparable to or significantly better than the national sample.

Graph 4:   Gains by FHC Children with These Developmental Disabilities
             Compared to Other Facilities' Children with the Same Diagnosis

Graph 4 compares the gains made by Family Hope Center patients with Developmental Disabilities: Cognitive & Developmental Delay vs. the national sample, using data from Graph 3.

Graph 4: Comparison of Gains for Developmental Disabilities, FHC vs. National Sample
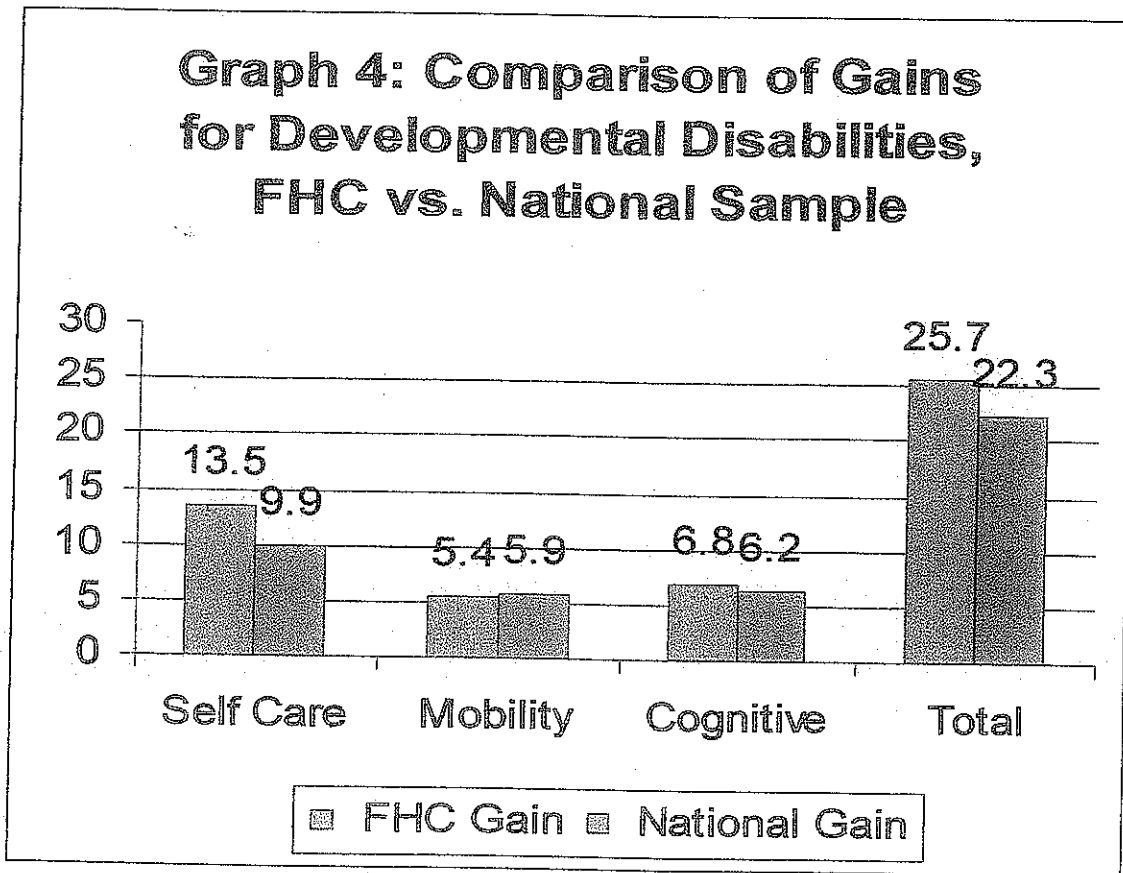
The data from Graphs 3 and 4 may also be presented in table form, as follows:

Self-Care	1st Assessment	Most recent	Points Gained	% Gained
FHC:	20.8	34.3	13.5	65%
Nation:	21.3	31.2	9.9	47%

Mobility	1st Assessment	Most recent	Points Gained	% Gained
FHC:	23.1	28.5	5.4	23%
Nation:	21.7	27.6	5.9	27%

Cognitive	1st Assessment	Most recent	Points Gained	% Gained
FHC:	13.9	20.7	6.8	49%
Nation:	12.5	18.7	6.2	50%

Total	1st Assessment	Most recent	Points Gained	% Gained
FHC:	57.8	83.5	25.7	44%
Nation:	55.2	77.5	22.3	40%

Again, FHC children with these diagnoses were considerably older when they first presented to FHC (71 months) than when they first presented to pediatric rehabilitation facilities nationwide (40 months). Their similar initial WeeFIM scores thus show a greater degree of impairment for the FHC children in this diagnosis group. The FHC children's gains were nonetheless either comparable to or better than the national sample.
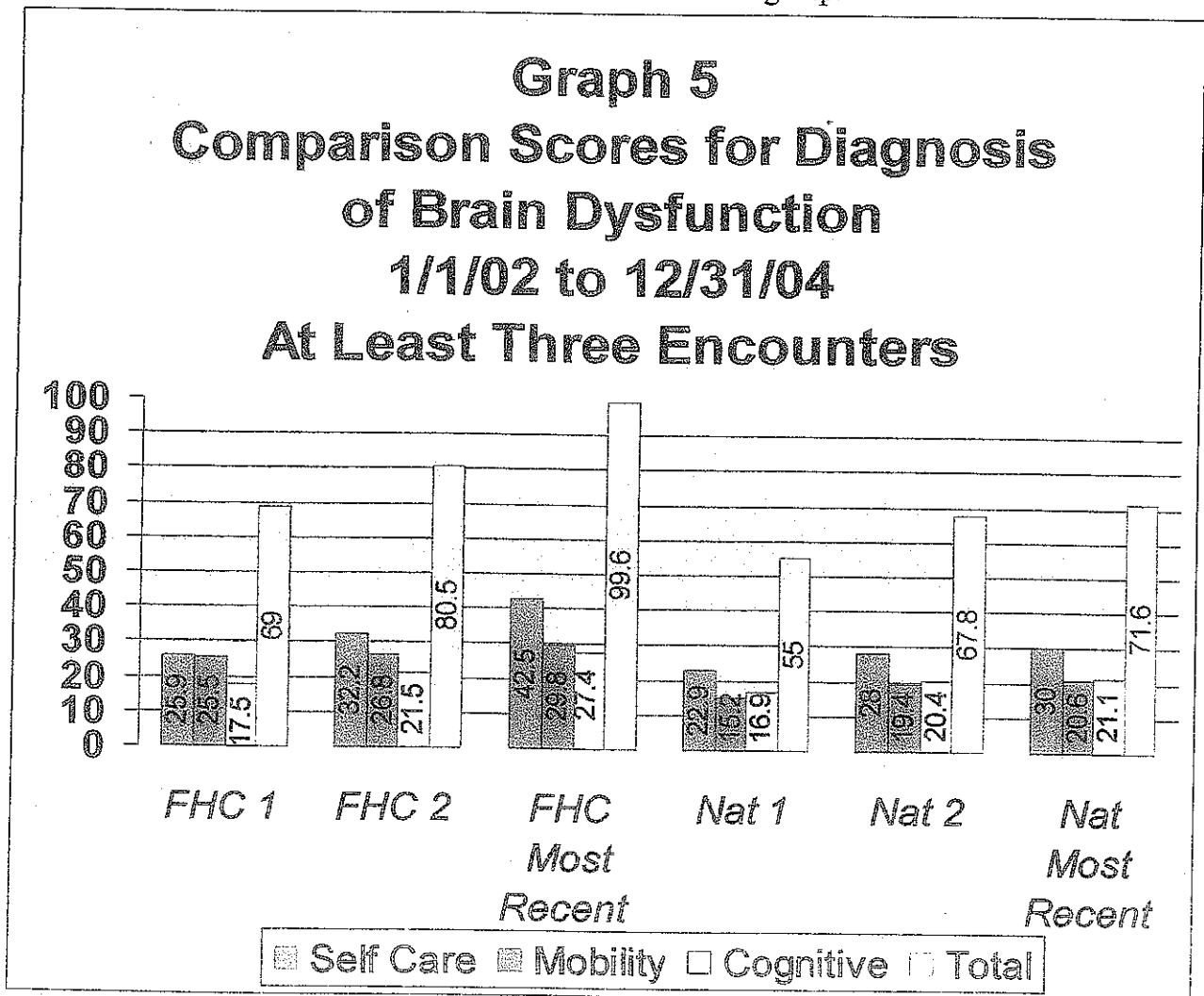
Children with diagnoses of "Brain Dysfunction" typically have conditions that are non-traumatic in origin, with such etiologies as encephalitis, anoxia at birth, inflammation due to infection and metabolic toxicity. Approximately 15% of FHC children come with a diagnosis of this general type.

Since only 11 FHC patients with this diagnosis had three or more appointments at FHC in the three-year period covered by the report, the data for FHC is not yet considered to be statistically valid. With this in mind, however, it shows significant gains for FHC children in this diagnostic group, in some cases substantially greater than the gains made by the comparison national group.

Graph 5:   WeeFIM Scores: Children with Brain Dysfunction, Three or More Assessments

Graph 5 shows the WeeFIM scores, as provided by UDSMR, for children diagnosed with brain dysfunction at their 1st, 2nd and most recent assessments. The three sets of bars on the left-hand side of Graph 5 show the average scores for 11 Family Hope Center children with this diagnosis, and the three sets of bars on the right-hand side show the average scores for 99 children with this diagnosis at WeeFIM facilities nationwide. Both sets of bars include data only for children who have been assessed by the reporting facilities at least three times. The admission age for the FHC group averaged 73 months, versus 91 months for the national group.

Graph 5
Comparison Scores for Diagnosis
of Brain Dysfunction
1/1/02 to 12/31/04
At Least Three Encounters

	FHC 1	FHC 2	FHC Most Recent	Nat 1	Nat 2	Nat Most Recent
Self Care	25.9	32.2	42.5	22.9	28	30
Mobility	25.5	26.8	29.8	15.4	19.4	20.6
Cognitive	17.5	21.5	27.4	16.9	20.4	21.1
Total	69	80.5	99.6	55	67.8	71.6

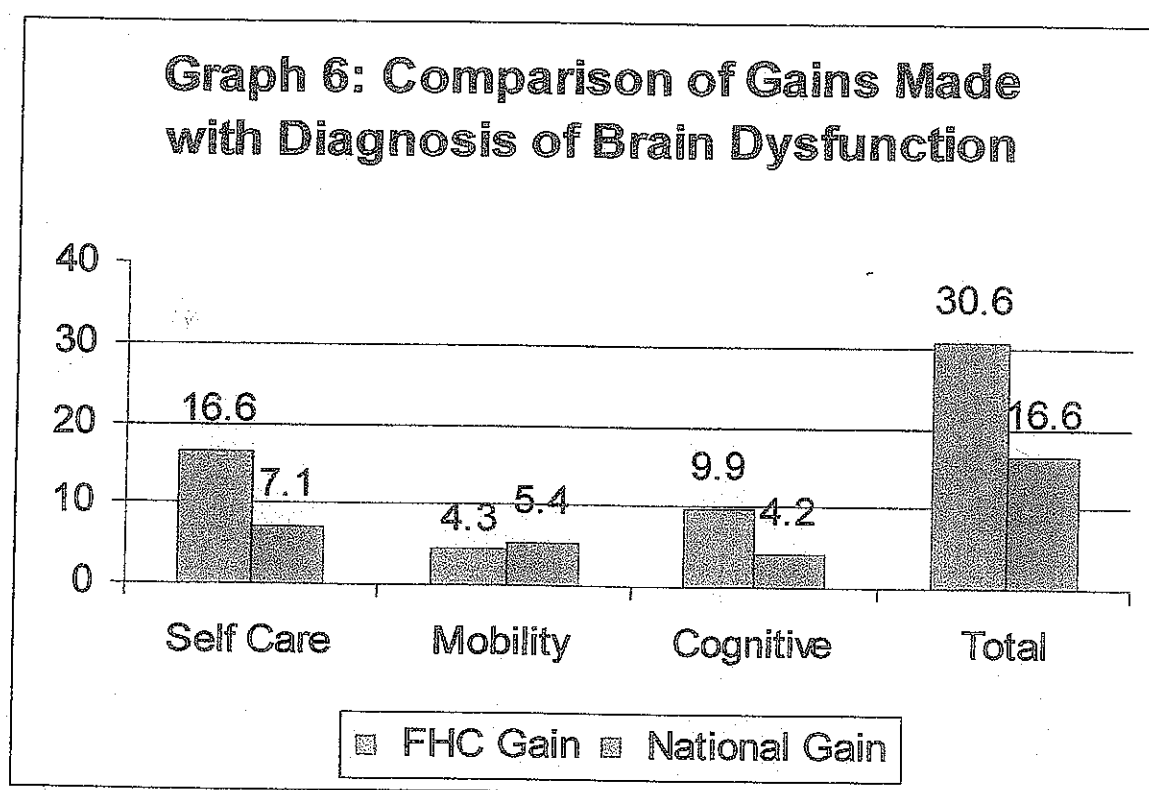Self Care   Mobility   □ Cognitive   Total

As shown by Graph 5, Family Hope Center children in this group started with self-care and mobility scores that were higher than for the national sample. They remained higher at the third assessment, with dramatic growth (16.3 points) in self-care skills.

FHC children were initially close to the national average in cognitive skills. Please note, however, that FHC children gained 9.9 points in cognitive skills, while the national sample gained 4.2 points – less than half the gain for FHC children.

Graph 6:   Gains by FHC Patients with Brain Dysfunction Compared to Other Facilities' Patients with Brain Dysfunction

Graph 6 compares the gains made by Family Hope Center patients with a diagnosis of brain dysfunction compared to the national sample, using data from Graph 5.

Graph 6: Comparison of Gains Made with Diagnosis of Brain Dysfunction

	Self Care	Mobility	Cognitive	Total
FHC Gain	16.6	4.3	9.9	30.6
National Gain	7.1	5.4	4.2	16.6

The data in Graphs 5 and 6 may also be presented in table form, as follows:

Self-Care	1st Assessment	Most recent	Points Gained	% Gained
FHC:	25.9	42.5	16.6	65%
Nation:	22.9	30	7.1	31%

Mobility	1st Assessment	Most recent	Points Gained	% Gained
FHC:	25.5	26.8	1.3	5%
Nation:	15.2	20.6	5.4	36%

Cognitive	1st Assessment	Most recent	Points Gained	% Gained
FHC:	17.5	27.4	9.9	57%
Nation:	16.9	21.1	4.2	25%

Total	1st Assessment	Most recent	Points Gained	% Gained
FHC:	69.0	99.6	30.6	44%
Nation:	55.0	71.6	16.6	30%

In brief, Family Hope Center children showed total gains that were almost twice the national average in terms of points gained, and 50% better than the national average in terms of percent gained over starting baselines. In the areas of self-care and cognition, FHC children improved their skills at rates more than twice those of the national group.

Functional Progress, All Impairments/All Age Groups

UDSMR has also provided data showing average WeeFIM scores for all children assessed by FHC, and corresponding data for children assessed by WeeFIM facilities nationwide, regardless of the nature or extent of their impairments.

Graph 7:   WeeFIM Scores: All Impairments/All Ages, Three or More Assessments

Graph 7 shows WeeFIM scores, as provided by UDSMR, for all children assessed at least three times from January 1, 2001 through December 31, 2004, regardless of the nature of their impairments. The three sets of bars on the left-hand side of Graph 7 show the scores for 83 children assessed by FHC, and the three sets of bars on the right-hand side show the scores for 935 children assessed at WeeFIM facilities nationwide.

The admission age for the FHC group averaged 86 months, versus 60 months for the national group.
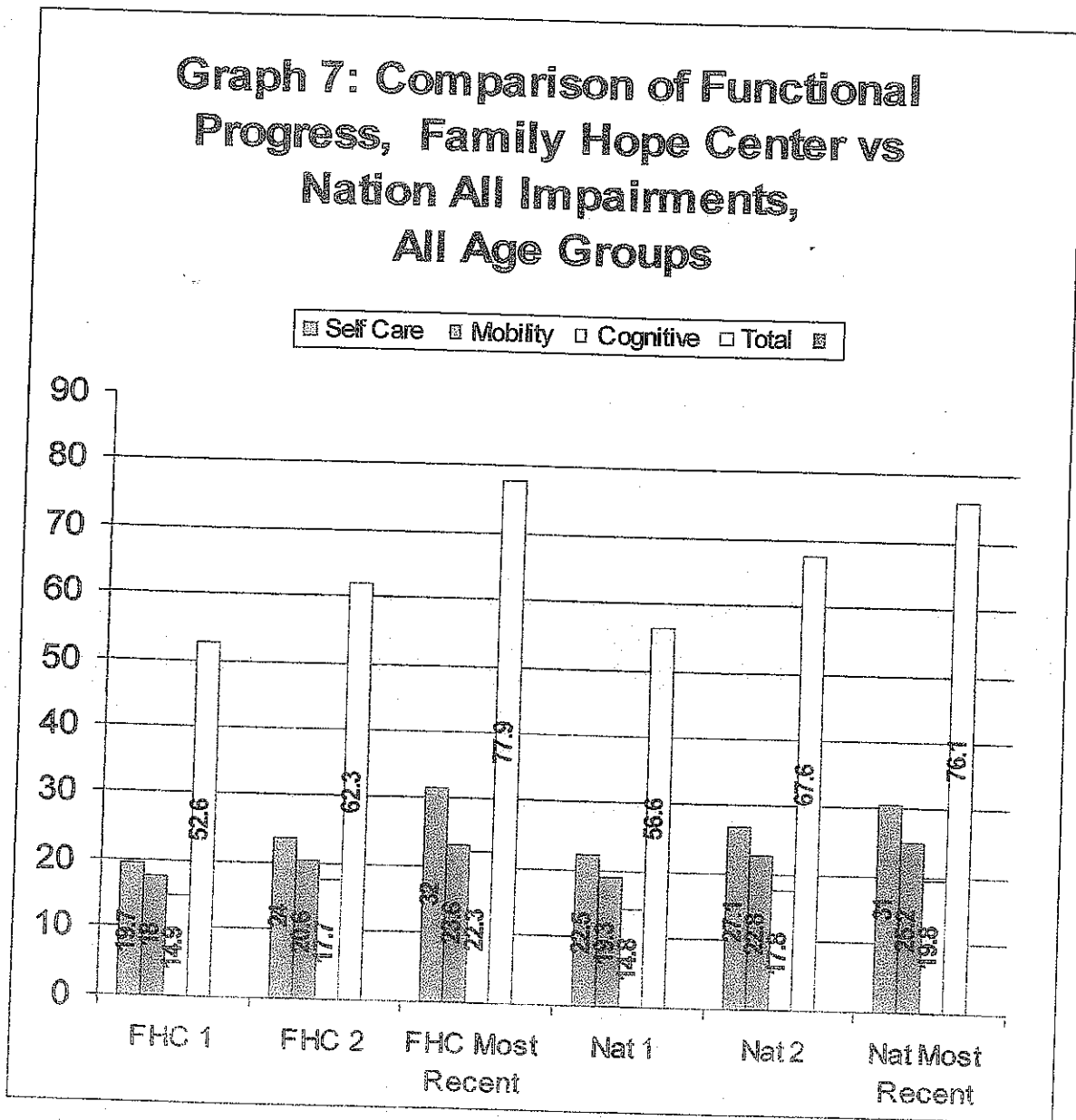
Note that, while a good deal older (86 months at 1st appointment vs. 60 months for the national group), FHC children had initial WeeFIM scores that were either lower (self-care and mobility skills) or virtually identical (cognitive skills) to the children in the national group, indicating more severe initial impairment. Nevertheless, total WeeFIM scores for FHC children as a whole increased by 25.3 points, while total scores for children in the national sample increased by 19.5 points.

Graph 8:   Gains by FHC Patients Compared to National Sample,
            All Impairments/All Age Groups, At Least 3 Assessments

Graph 8 compares the average gains in WeeFIM scores by all children/all diagnosis groups with at least three appointments at FHC, compared to all children/all diagnosis groups with at least three outpatient encounters at WeeFIM facilities nationwide, using data from Graph 7.
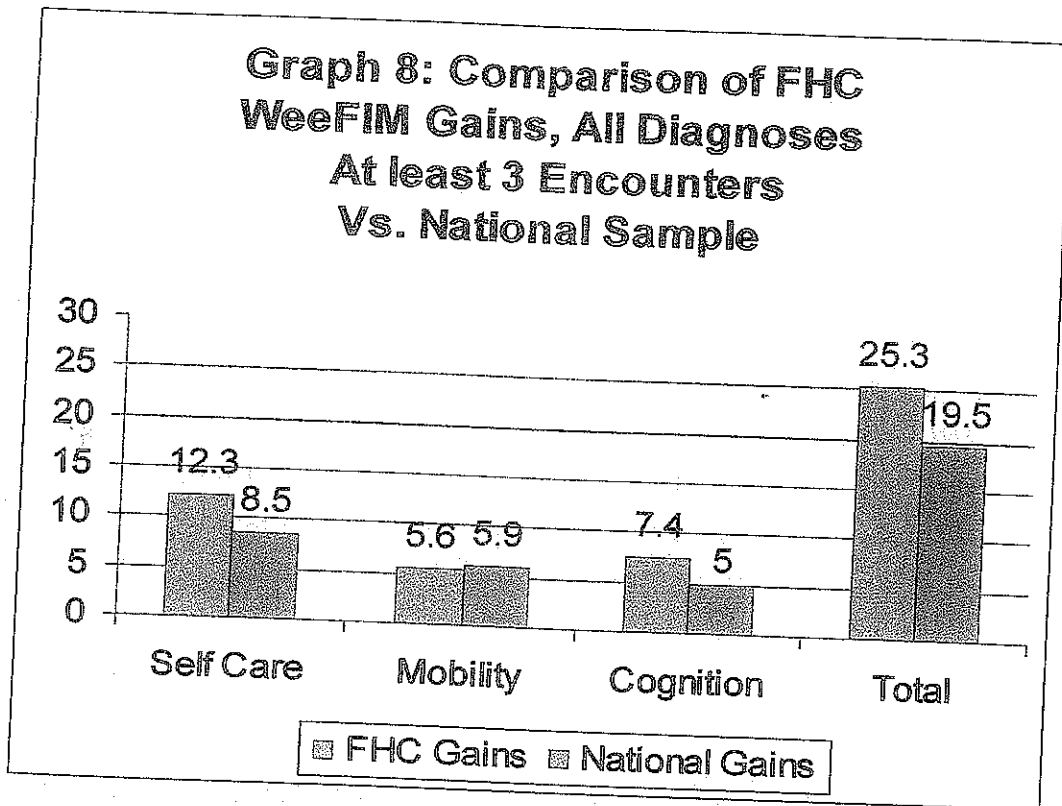
The data in Graphs 7 and 8 may also be presented in table form, as follows:

Self-Care	1st Assessment	Most recent	Points Gained	% Gained
FHC:	19.7	32.0	12.3	62%
Nation:	22.5	31.0	8.5	38%

Mobility	1st Assessment	Most recent	Points Gained	% Gained
FHC:	18.0	23.6	5.6	31%
Nation:	19.3	25.2	5.9	31%

Cognitive	1st Assessment	Most recent	Points Gained	% Gained
FHC:	14.9	22.3	7.4	50%
Nation:	14.8	19.8	5.0	34%

Total	1st Assessment	Most recent	Points Gained	% Gained
FHC:	52.6	77.9	25.3	48%
Nation:	56.6	76.1	19.5	34%

Although the national group has less initial impairment (higher WeeFIM scores at first assessment) than FHC children, after at least three appointments the FHC children performed significantly better overall, particularly in the Self-Care and Cognitive domains. The average FHC child gained 25.3 total WeeFIM points, compared to the national sample that gained 19.5 points - about 30% better gains for the FHC children.