

***CLINICAL OUTCOME SCORES FOR THE FAMILY HOPE CENTER  
FOR 8.0 YEARS, COMPARED TO NATIONAL SAMPLE OF OUTPATIENT  
REHABILITATION FOR SIMILAR DIAGNOSES***

This document references data from a Report compiled and prepared by Uniform Data System for Medical Rehabilitation titled "Custom Report for Facility W1101, Comparison of Functional Progress Report: Cumulative, Report Range January 1, 2002 - December 31, 2009"

### Introduction: The FIM™ Programs

The FIM™ programs are the most widely used systems in the world for documenting the severity of patient disabilities and rehabilitation outcomes. This program was initiated by the U. S. Department of Education's National Institute on Disability and Rehabilitation Research, and is sponsored by the American Congress of Rehabilitation Medicine and the American Academy of Physical Medicine and Rehabilitation. It is administered by Uniform Data System for Medical Rehabilitation (UDSMR), a non-profit organization affiliated with the University of Buffalo in New York. Data from FIM™ programs are used by insurance companies to benchmark patient care needs, assess treatment success, and set reimbursement levels.

The focus of the FIM™ programs is on "functional assessment," that is, measuring how well patients perform basic activities of daily living. 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 80 rehabilitation facilities in 11 countries participate in the WeeFIM® program. Examples of WeeFIM® participants in the United States include Penn State Hershey Medical Center, in Hershey, Pennsylvania; Children's Hospital and Research Center, in Oakland, California; Spaulding Rehabilitation Hospital in Boston, Massachusetts; HSC Pediatric Center in Washington, DC; and the Kennedy Krieger Institute in Baltimore, Maryland.

Facilities that participate in the WeeFIM® program 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 children
- Guides quality improvement efforts, by providing specific data on the relative effectiveness of treatment modalities
- Provides an easily understandable record of each child's progress in therapy, which parents can use in support of insurance reimbursement claims

## How WeeFIM<sup>®</sup> Works

On their first admission or visit to a WeeFIM<sup>®</sup> facility, a child is assigned to one or more of 19 “impairment groups.” The impairment groups that most Family Hope Center children are assigned to include:

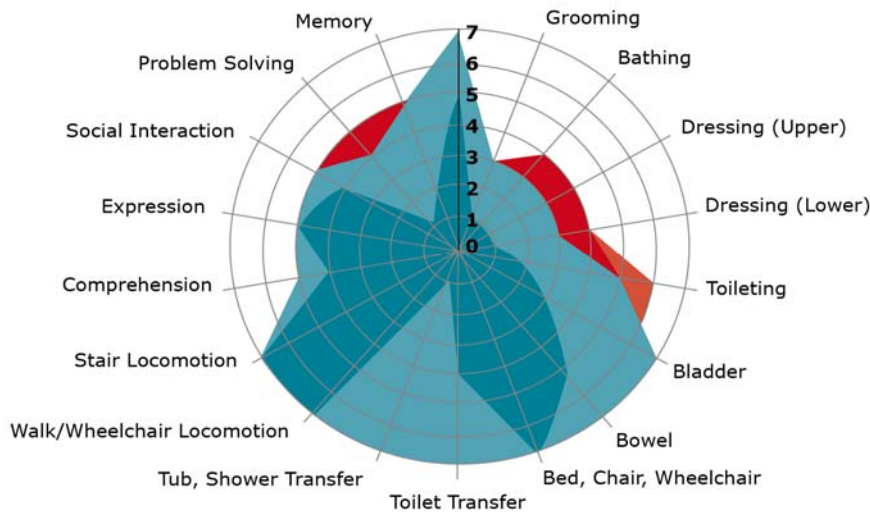
- Autism spectrum disorders
- Cerebral palsy
- Development disabilities, cognitive & developmental delay
- Development disabilities, disorders of attention, socialization & behavior
- Development disabilities, speech & language
- Developmental disabilities, disorders of motor control
- Brain dysfunction
- 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 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 show the facility how well its patients are doing, by themselves and compared to the averages for other facilities’ patients.

## WeeFIM<sup>®</sup> and The Family Hope Center

The Family Hope Center conducts a full WeeFIM<sup>®</sup> assessment of each child at each appointment. Parents receive a record of their child’s levels of function, in the form of a “polar graph” like the sample shown on the next page, 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.



#### PATIENT SUMMARY

Patient Code:  
 Birth Date:  
 Age at Admission:  
 Gender:

#### CASE SUMMARY

Program Type:  
 Admission Date:  
 Admission Class:  
 Discharge Date:  
 Impairment Group:  
 Onset Date:  
 Etiologic Diagnosis:  
 Actual Length of Stay:

### Some Notes About the WeeFIM<sup>®</sup> Program

There are a few things to keep in mind about WeeFIM<sup>®</sup> scores and reports.

First, even “normal,” unimpaired three-year olds will need some help with a skill like dressing themselves. Such a child might receive a WeeFIM<sup>®</sup> score of 5 (out of 7) for this skill. A three-year old who receives a WeeFIM<sup>®</sup> 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<sup>®</sup> score of 4 would be far behind his chronological peers, indicating a much greater degree of impairment. In short, **a given WeeFIM<sup>®</sup> score indicates a higher degree of impairment for an older child than for a younger one.**

Second, the goals measured by the WeeFIM<sup>®</sup> 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<sup>®</sup> purposes. The Family Hope Center, by contrast, aims for full normal function, including unassisted walking and running, for all of its children. WeeFIM<sup>®</sup> scores do not capture the progress made by Family Hope Center children that goes beyond the more limited abilities measured by WeeFIM<sup>®</sup>.

Third, WeeFIM<sup>®</sup> 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<sup>®</sup> facility can say whether it ranks 1st, 15<sup>th</sup> or in any other position for effectiveness of its treatments. Rather, the reports indicate average progress by the facility’s own patients, and how that facility’s results compare to the average for all participating facilities.

Finally, each WeeFIM<sup>®</sup> 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.

## CURRENT ANNUAL UDSMR REPORT on FHC

The Family Hope Center has received the following from UDSMR:

*“Custom Report for Facility W1101, Comparison of Functional Progress Report: Cumulative, Report Range January 1, 2002 - December 31, 2009.”*

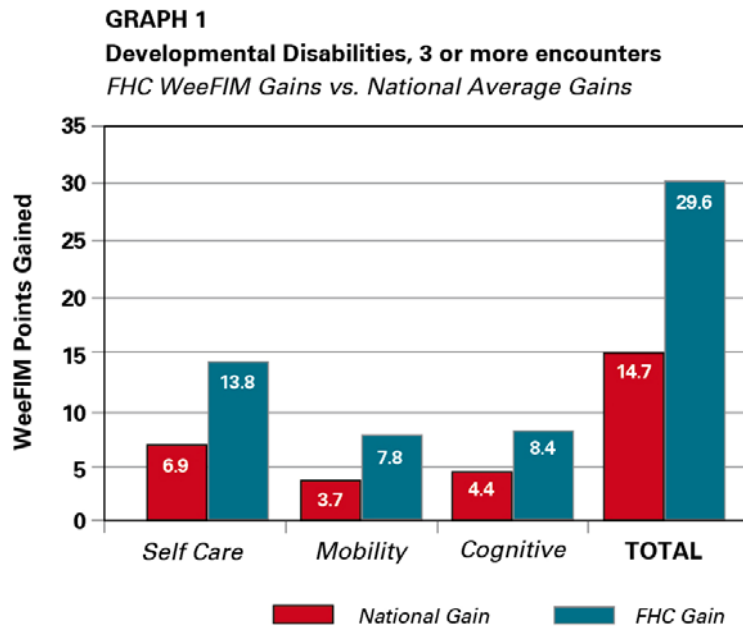
This Report incorporates the WeeFIM<sup>®</sup> scores and other data for all children who have been assessed by FHC at least three times during the eight years beginning January 1, 2002. It shows the results for all FHC children, comparing them to the results for all patients at all WeeFIM<sup>®</sup> facilities in the United States. It then shows and compares the results for children who fall into one of four major diagnostic categories. The presented categories are:

- Developmental Disabilities Summarized on page 5 below
- Autism Spectrum Disorders Summarized on page 6 below
- Cerebral Palsy Summarized on page 7 below
- Brain Dysfunction Summarized on page 8 below
- All Impairments Summarized on page 9 below

## Developmental Disabilities: Cognitive & Developmental Delay

Children with these kinds of diagnoses typically have low IQ scores, with speech, language, hearing and memory disorders that impair learning. Approximately 54% of FHC children reported by WeeFIM<sup>®</sup> come to us with a diagnosis of this general type.

According to the UDSMR data, children with these diagnoses were substantially older when they first came to FHC (66 months) than when they first presented to WeeFIM<sup>®</sup> facilities nationwide (40 months). They also had lower initial scores, which also indicates greater impairment. Nevertheless, the gains by FHC children were much better than the national average in all three areas – self-care, mobility and cognition.



This data may be presented in table form, as follows:

**TABLE 1**  
**Developmental Disabilities, 3 or more encounters**  
*FHC WeeFIM Gains vs. National Average Gains*

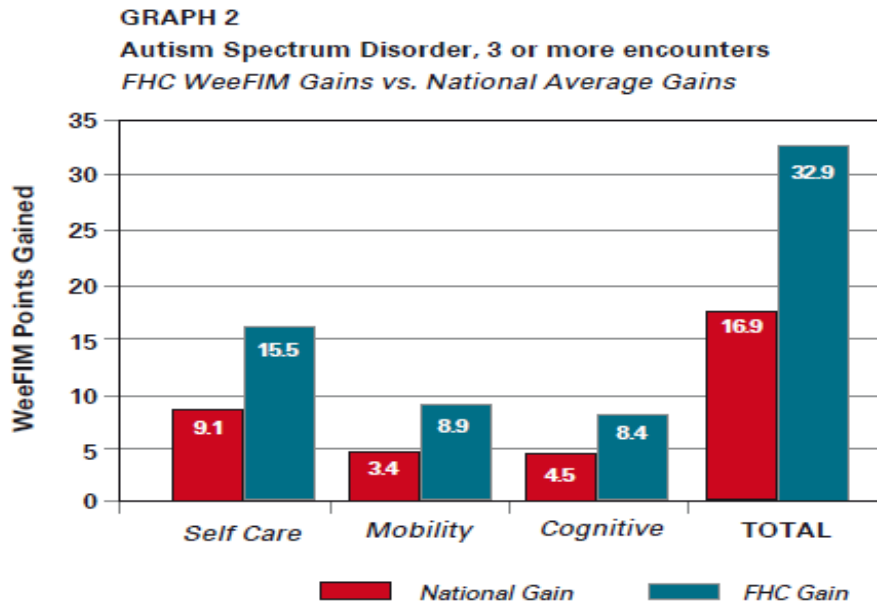
	1 <sup>st</sup> Assessment	Most recent	Points Gained	% Gained
<b>Self-Care</b>				
FHC	18.4	31.7	13.3	72.3
Nation	22.3	29.1	6.8	30.5
<b>Mobility</b>				
FHC	18.7	26.5	7.8	41.7
Nation	21.1	24.7	3.76	17.0
<b>Cognition</b>				
FHC	9.9	18.3	8.4	84.8
Nation	12.9	17.4	4.4	34.1
<b>TOTAL</b>				
FHC	47	76.6	29.6	63
Nation	56.3	71	14.7	26.1

Again, children with these diagnoses were considerably older when they first came to FHC (66 months) than when they first presented to WeeFIM<sup>®</sup> facilities nationwide (40 months). These similar initial scores show a greater degree of initial impairment for these FHC children, who nevertheless showed gains in all areas that were higher, or much higher, than the national average.

## Autism Spectrum Disorders

Autism spectrum disorders encompass a wide continuum of associated cognitive and neurobehavioral disorders, typically including often-debilitating problems with communication, social interaction, language and abnormal act repetition. Approximately 16% of Family Hope Center children tracked by WeeFIM<sup>®</sup> come to us with a diagnosis of this type.

In all three categories, FHC children started with lower scores, but saw much higher gains than the national average for these children. The percentage gain for FHC children was more than twice as great for self-care, more than *three* times as great for mobility, and more than twice as great for cognition.



The data may be presented in table form, as follows:

**TABLE 2**  
**Autism Spectrum Disorder, 3 or more encounters**  
*FHC WeeFIM Gains vs. National Average Gains*

	1 <sup>st</sup> Assessment	Most recent	Points Gained	% Gained
<b>Self-Care</b>				
FHC	19.1	34.6	15.5	81.2
Nation	24.3	33.4	9.1	37.4
<b>Mobility</b>				
FHC	21	29.7	8.9	42.4
Nation	26.9	30.3	3.4	12.6
<b>Cognition</b>				
FHC	10.4	18.8	8.4	80.8
Nation	11.8	16.2	4.5	38.1
<b>TOTAL</b>				
FHC	50.5	83.4	32.9	65.1
Nation	63.1	80	16.9	26.8

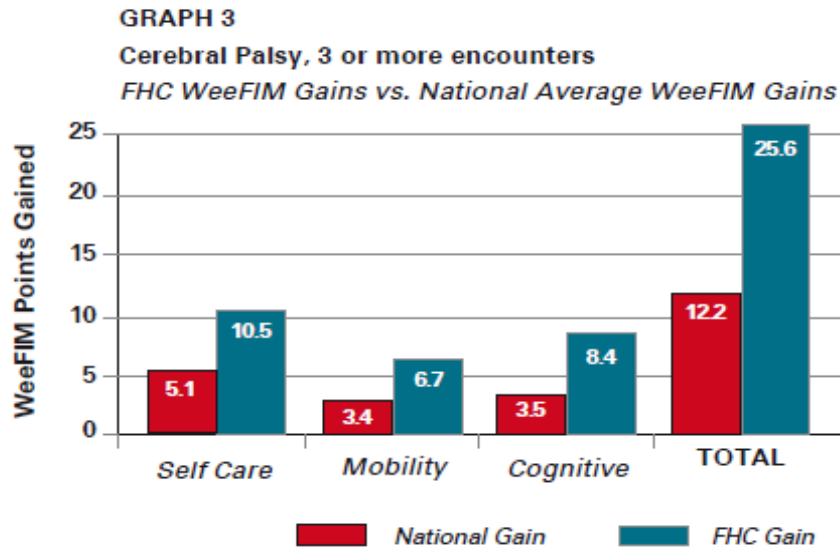
In sum: FHC children with autism spectrum disorders showed gains in all three diagnostic categories that substantially exceeded the gains by children at WeeFIM<sup>®</sup> facilities nationwide.

## 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 25% of FHC children tracked by WeeFIM<sup>®</sup> come to us with this diagnosis.

In all three categories of functioning – self-care, mobility, cognition – the data show that children who come to The Family Hope Center with a diagnosis of CP were significantly more impaired at their first assessment, on average, than other facilities' CP children. This typically makes for “harder cases,” with lower expectations for improvement.

Nevertheless, children diagnosed with CP not only improved under FHC programs; as shown by Graph 3, they improved by much more than similar children at other facilities.



The data may be presented in table form, as follows:

**TABLE 3**  
**Cerebral Palsy, 3 or more encounters**  
*FHC WeeFIM Gains vs. National Average Gains*

	1 <sup>st</sup> Assessment	Most recent	Points Gained	% Gained
<b>Self-Care</b>				
FHC	11.9	22.4	10.5	88.2
Nation	19.6	24.7	5.1	26.0
<b>Mobility</b>				
FHC	8.1	14.8	6.7	82.7
Nation	13.9	17.3	3.4	24.5
<b>Cognition</b>				
FHC	12.9	21.3	8.4	65.1
Nation	16.1	19.6	3.5	21.7
<b>TOTAL</b>				
FHC	32.5	58.5	25.6	77.8
Nation	49.5	61.7	12.2	24.6

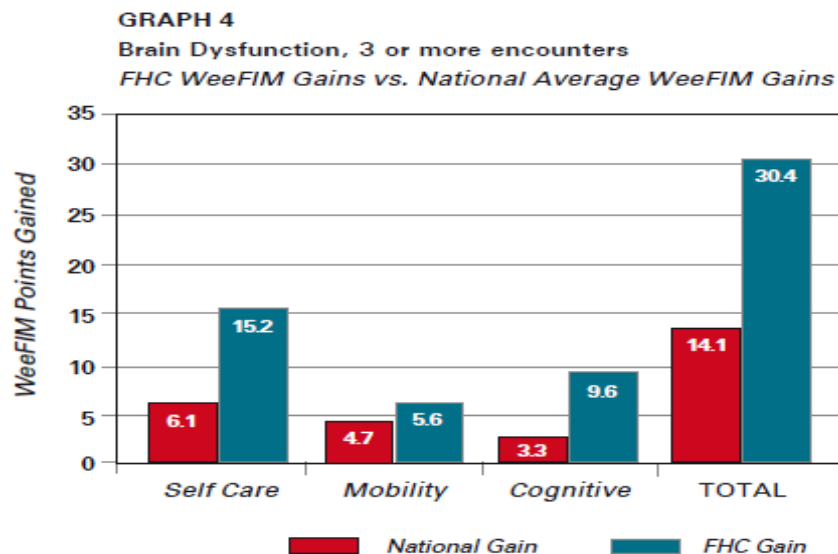
In short, FHC children with CP improved their WeeFIM<sup>®</sup> scores in all major diagnostic categories, by twice as much or more than children at other facilities in the national sample.

## **BRAIN DYSFUNCTION**

Children with diagnoses of “Brain Dysfunction” typically have conditions that have non-traumatic etiologies, such as encephalitis, anoxia at birth, inflammation due to infection and metabolic toxicity. About 5% of FHC children reported by WeeFIM<sup>®</sup> come with a diagnosis of this general type.

Since only 16 FHC patients with this diagnosis had three or more appointments at FHC in the 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.

As shown by the UDSMR data, FHC children in this group started with mobility scores that were higher than the national average. They were higher by a larger margin at later assessments. The UDSMR data also show that FHC children in this group were initially close to the national average over all. Please note, however, that FHC children gained 30.4 points in overall function, while the national sample gained 14.1 points – less than half the gain for FHC children.



The data may also be presented in table form, as follows:

**TABLE 4**  
Brain Dysfunction, 3 or more encounters  
FHC WeeFIM Gains vs. National Average WeeFIM Gains

	1 <sup>st</sup> Assessment	Most recent	Points Gained	% Gained
<b>Self-Care</b>				
FHC	23.4	38.6	15.2	65
Nation	24.9	31	6.1	24.5
<b>Mobility</b>				
FHC	20.4	26	5.6	27.5
Nation	16.3	21	4.7	28.8
<b>Cognitive</b>				
FHC	14.8	24.4	9.6	64.9
Nation	18.2	21.5	3.3	18.1
<b>TOTAL</b>				
FHC	58.6	89	30.4	51.9
Nation	59.4	73.5	14.1	23.7

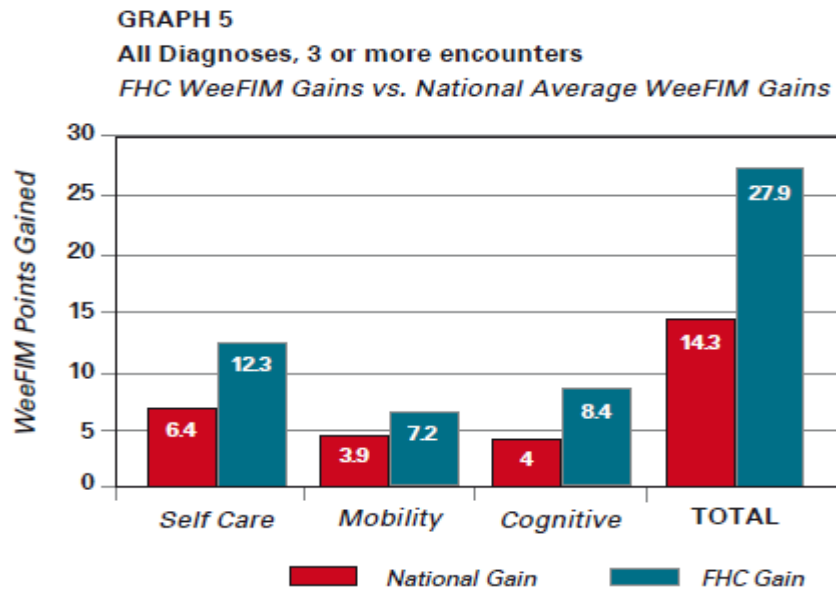
In brief, Family Hope Center children showed total gains that were more than twice the national average both in terms of points gained, and in terms of percent gained over starting baselines.



## Functional Progress, All Impairments/All Age Groups

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

Note that, while fully 1.5 years older at their first appointments (72 months vs. 54 for the national group), FHC children had initial WeeFIM<sup>®</sup> scores that were lower in all three “domains” (self-care, mobility and cognition) than children in the national group. This combination of higher starting age and lower initial scores indicates significantly more severe initial impairment. Nevertheless, total scores for children in the national sample increased 14.3 points, while total scores for FHC children increased 27.9 points - *almost twice as much as the national sample*.



The data may also be presented in table form, as follows:

**TABLE 5**  
**All Diagnoses, 3 or more encounters**  
*FHC WeeFIM Gains vs. National Average WeeFIM Gains*

	1 <sup>st</sup> Assessment	Most recent	Points Gained	% Gained
<b>Self-Care</b>				
FHC	17.0	29.3	12.3	72.4
Nation	23.0	29.4	6.4	27.8
<b>Mobility</b>				
FHC	15.6	22.8	7.2	46.2
Nation	19.6	23.5	3.9	19.9
<b>Cognitive</b>				
FHC	11.3	19.7	8.4	74.3
Nation	14.7	18.7	4.0	27.2
<b>TOTAL</b>				
FHC	43.8	71.7	27.9	63.7
Nation	57.3	71.6	14.3	25

Although the national group has less initial impairment (higher WeeFIM<sup>®</sup> scores at first assessment) than FHC children, after at least three appointments the FHC children performed significantly better overall: The average FHC child gained 27.9 total WeeFIM<sup>®</sup> points, compared to the national sample which gained 14.3 total points – *almost twice as much total gain for Family Hope Center children*.