

Family Management Measure Items and Factor Loadings and Comparative Fit Index
(CFI)

Factor		
(CFI)	Standardized	
	Loading	Item Wording
1. Child		
Daily Life		
	16.18	Our child's friendships are different because of the condition.
	12.73	Our child's everyday life is similar to that of other children his/her
		age.
	12.71	Our child is different from other children his/her age because of the
		condition.
	10.26	Our child enjoys life less because of the condition.
	6.17	Our child takes part in activities he/she wishes to despite the
		condition.
2. Condition		
Management Ability		
(.67)		
	11.77	We often feel unsure about what to do to take care of our child's
		condition.
	11.66	When something unexpected happens with our child's condition, we
		usually know how to handle it.
	9.43	We are looking forward to a happy future for our child
	8.36	In the future we expect our child to take care of the condition.
	-7.96	It is difficult to know when our child's condition must come first in
		our family.
	6.60	We have some definite ideas about how to help our child live with
		the condition.
	6.41	Despite the condition, we expect our child to live away from home

		in the future.
6.17		We have enough money to manage our child's condition.
-5.83		We have not been able to develop a routine for taking care of our
		child's condition.
5.27		We have goals in mind to help us manage our child's condition.
-4.97		It is often difficult to know if we need to be more protective of our
		child.
4.52		We feel we are doing a good job of taking care of our child's
		condition.

3. Condition

Management Effort

(.98)

14.15		Our child's condition doesn't take a great deal of time to manage
13.98		It takes a lot of organization to manage our child's condition
12.15		Our child's condition is like a roller coaster with lots of ups and
		downs.
8.87		Our child's condition requires frequent visits to the clinic.

4. Family Life

Difficulty

(.98)

17.21		A condition like the one our child has makes it very difficult to lead
		a normal life.
17.17		A condition like the one our child has makes family life very
		difficult.
16.55		Dealing with our child's condition makes family life more difficult.
15.34		We are sometimes undecided about how to balance the condition
		and family life.
14.95		It seems as if our child's condition controls our family life.
14.12		It is difficult to fit care of our child's condition into our usual family
		routine.
13.82		It is very hard for us to take care of our child's condition.
13.40		Taking care of our child's condition is sometimes overwhelming.
-13.15		Even though our child has the condition, we have a normal family

	life.
11.59	Our child's condition gets in the way of family relationships/
9.57	Our child would do better in school if she/she didn't have the
	condition.
9.41	It's hard to get anyone else to help us with our child's condition.
-7.09	Our child's condition rarely interferes with other family activities.
-6.09	We know when our child needs to be a child.

5. Parental Mutuality

(.93)

17.67	I am pleased with how my partner and I work together to manage
	our child's condition.
15.90	My partner and I support each other in taking care of our child's
	condition.
15.08	I am unhappy about the way my partner and I share the management
	of our child's condition
10.37	My partner and I have similar ideas about how we should be raising
	our child.
9.20	My partner and I consult with each other before we make a decision
	about our child's care.
-9.04	My partner and I argue about how to manage our child's condition.
-7.97	My partner and I have different ideas about how serious our child's
	condition is.
6.61	We are a closer family because of how we deal with our child's
	condition.

6. View of Condition

Impact

(.82)

10.34	We think about our child's condition all the time.
10.11	Because of the condition, we worry about our child's future.
9.64	Our child's condition will be harder to take care of in the future.
7.34	People with our child's condition have a normal length of life.
7.08	It's hard to know what to expect of our child's condition in the
	future.

-7.05 We expect to be devoting less time to our child's condition in the future.

6.74 Our child's condition requires frequent hospitalizations.

-6.71 We are confident that we can take care of our child's condition.

6.64 Our child's condition is the most important thing in our family.

-4.82 Many conditions are more serious than our child's.

Eliminated Items

We have strong convictions about the best way to raise our child

We understand our child's condition better than doctors and nurses

Sometimes doing what is best for our child means we have to change the treatment plan.

We plan ahead to avoid problems in managing our child's condition.

We check with doctors and nurses before making any changes in how we manage our child's treatment.

We can usually tell when there are going to be problems with our child's condition.

Our child does not want to be treated differently from other children because of the condition.

We have our own "tricks of the trade" for managing our child's condition.

Our child feels unlucky to have the condition.

We expect our child's condition to get better in the future.

My partner and I rarely discuss our child's condition.