

Delivery of Community-Based Services for People with Arthritis:

**A Survey of Disability and Mobility in Children
using the
Childhood Health Assessment Questionnaire (CHAQ)**

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TABLE OF CONTENTS

EXECUTIVE SUMMARY	1
INTRODUCTION	1
METHODS	
1. Procedure	1
2. The Questionnaire	1
3. Analysis	2
RESULTS	
1. Characteristics of Clients	
a. Services received	3
b. Demographic and Disease Characteristics	4
2. Disability: The Childhood Health Assessment Questionnaire (CHAQ)	
a. Disability Index	5
b. Activities of Daily Living	6
c. Pain Scores	8
3. Mobility	9
4. Suitability for Ambulatory Therapy	9
DISCUSSION	10
APPENDIX A: Singh G, Brown B, Athreya B, Goldsmith D, Rettig P, Block D, Fries J. Functional Status in Juvenile Arthritis: Sensitivity to Change of the Childhood Health Assessment Questionnaire. <i>Arth & Rheum</i> 1991; 34 (9 Suppl.):S 81.	
APPENDIX B: Singh G, Athrey B, Fries J, Goldsmith D, Ostroy B. Measurement of Functional Status in Juvenile Rheumatoid Arthritis. <i>Arth & Rheum</i> 1990; 33 (9 Suppl.):S15.	
APPENDIX C: THE ARTHRITIS SOCIETY CONSULTATION AND THERAPY SERVICE CHILDREN'S SURVEY	

LIST OF TABLES AND FIGURES

Table 1.1	Demographic and Disease Characteristics of Clients
Table 2.1	CHAQ Disability Index
Table 2.2	Pain Scores
Figure 1.1	Questionnaires Returned by Service
Figure 2.1	CHAQ Functional Categories: Performance
Figure 2.2	CHAQ Functional Categories: Activities Requiring Assistance From Another Person and/or Use of Assistive Devices
Figure 3.1	Restriction in Independent Mobility

EXECUTIVE SUMMARY

- This survey of children seen by The Arthritis Society's Consultation and Therapy Service (CTS) is a followup to a survey of adults seen in May, 1993. The goal of the survey, was to provide information about the disability and mobility status of CTS clients to enhance service planning and development.
- The survey included a new instrument, the Childhood Health Assessment Questionnaire (CHAQ) . Also included were questions about pain and mobility.
- Questionnaires were collected from 117 clients. Most of the questionnaires returned were from home therapy clients (93%), with physiotherapy clients returning 84% of all questionnaires.
- The average age of children seen was 9.7 years (ranging from approximately 2 to 18 years). Most of the clients reported a diagnosis of juvenile arthritis (88%), with the most common onset type being polyarticular (44%). The mean duration was 2.7 years.
- The mean disability index of all children was .53, and the mean pain score was 2.84. Children with polyarticular and systemic juvenile arthritis scored higher on the CHAQ than those with pauciarticular arthritis, indicating greater disability.
- A large proportion of children reported difficulty with gripping/opening (33%), dressing/grooming (23%), and reach (18%). The ranking of problem areas was approximately the same as for the adults in the larger survey except in the area of dressing/grooming, which was ranked higher for children.
- Generally, few children used assistive devices. The most frequently used pieces of equipment were splints (6%). Children reported using assistance rather than assistive devices for personal care activities.
- The overall mean pain score for all CTS children was 2.84 (s.d. = 1.71). Children reporting systemic juvenile arthritis scored significantly higher on the pain scale ($p = 0.000$) than those with pauciarticular, or polyarticular arthritis.
- Few children reported difficulty with mobility in their environment. Generally, 96% of children reported being independently mobile. Therapists reported that 61% of children could be seen in ambulatory settings such as clinics/groups.
- Survey results indicate that there may be a role for increased use of assistive devices to facilitate independence in children.
- There appears to be room for further development of ambulatory services for children by the CTS. Further research needs to be conducted examining the effectiveness of community-based ambulatory therapy for people with arthritis and other chronic debilitating conditions.

I. Introduction

The Arthritis Society's Consultation and Therapy Service (CTS) provides rehabilitation services to clients with arthritis throughout Ontario. At the time of this survey, there were 62 therapists employed by the CTS. Most clients seen by the CTS are adults, with children under the age of 19 representing only 4% of clients seen over the year 1992-1993.

This survey of children seen by the CTS is a followup to a general survey done in May, 1993 of adults seen by the service.¹ This survey was done by the CTS in conjunction with its research partner, the Arthritis Community Research and Evaluation Unit (ACREU).

The goal of the general survey (both adults and children), was to provide information about the disability and mobility status of CTS clients to enhance service planning and development.

Specific objectives of the survey included:

1. To provide information regarding disability and pain in children seen by CTS.
2. To provide information regarding mobility in children seen by CTS.
3. To determine how many children seen by CTS may be seen in ambulatory settings.

II. Methods

1. Procedure

Therapists were requested to give questionnaires to all CTS clients under the age of 18 (as the adult HAQ was

done in those 18+), seen in the months of May, June and July. The survey was done over three months (as opposed to one month for the adults), as the CTS does not see many children, and it was desirable to survey as many children as possible.

The questionnaires were provided to the children and their parents during therapy sessions. Either the children or the parents could complete the questionnaire. Therapists were requested not to influence how the clients completed the questionnaires. Clients who were seen in more than one service completed a questionnaire for each service.

2. The Questionnaire

The questionnaire consisted of three sections (see Appendix A). The first section contained questions related to client characteristics such as sex, date of birth, diagnosis, and whether the client was a new referral and/or a consultation only. A consultation is defined by the CTS, as a limited intervention for a client of three visits or less.

The second section consisted of the disability and pain subscales of the Childhood Health Assessment Questionnaire (CHAQ).³ The CHAQ is a new instrument which has been adapted from the Stanford HAQ for adults. It has been designed to assess disability in children ages 1-19, with arthritis.

The CHAQ consists of 8 categories; dressing and grooming, arising, eating, walking, hygiene, reach, grip and activities. A total of 20 new questions have been added to the original HAQ, so that in each functional area, there is at least 1 question (activity) that is relevant

to a child of any age group. A new response "not applicable" has been added to indicate those activities where the child has not reached the age that is developmentally appropriate to perform the task. As a result of these modifications, children of all ages can be assessed using this questionnaire.

The parent or child is requested to record the amount of difficulty the child has had over the past week as a result of their arthritis. Each question is scored from 0 to 3, with 0 = no difficulty, 1 = some difficulty, 2 = much difficulty, and 3 = unable to do. The question with the highest score determines the score for that functional area. If aids or devices are used or assistance is required, a minimum score of 2 is recorded for the corresponding functional area. The Disability Index is obtained by averaging the scores for each of the 8 functional areas. The index ranges from 0 to 3, with the level of disability increasing with the score. A supplementary question asks about pain. The amount of pain experienced due to arthritis in the past week was measured on a scale of 1 to 7, with 1 labelled as "none", 4 labelled as "moderate", and 7 labelled as "extreme" pain.

As the CHAQ is a newly developed instrument, there is only one published paper and two abstracts currently available describing its formal properties. Singh et. al. report strong reliability and validity. Validation was done on 72 children, with a diagnosis of JRA according to the American College of Rheumatology criteria. The children were from a large referral centre, and it is assumed that they were outpatients. Preliminary work has found The CHAQ to be sensitive to changes in functional status in children (Appendix A).² Singh

et. al. have also documented that parents can serve as reliable proxy reporters for their children (Appendix B).^{3,4} The sensitivity of the CHAQ to record shifts in functional status as a result of therapeutic interventions, has yet to be determined. References will be made throughout this working report comparing the results of the CTS study to those presented in the Singh paper.

A final question refers to the child's level of mobility in their environment (mobility handicap). This mobility question was originally developed in the context of an earlier population survey.⁵ The question asks about the child's ability to move around in their home, and to leave their home and its immediate surroundings taking into account the assistive devices/equipment that they normally used. The adult questionnaire had several more questions regarding mobility, however these questions were not appropriate for the children.

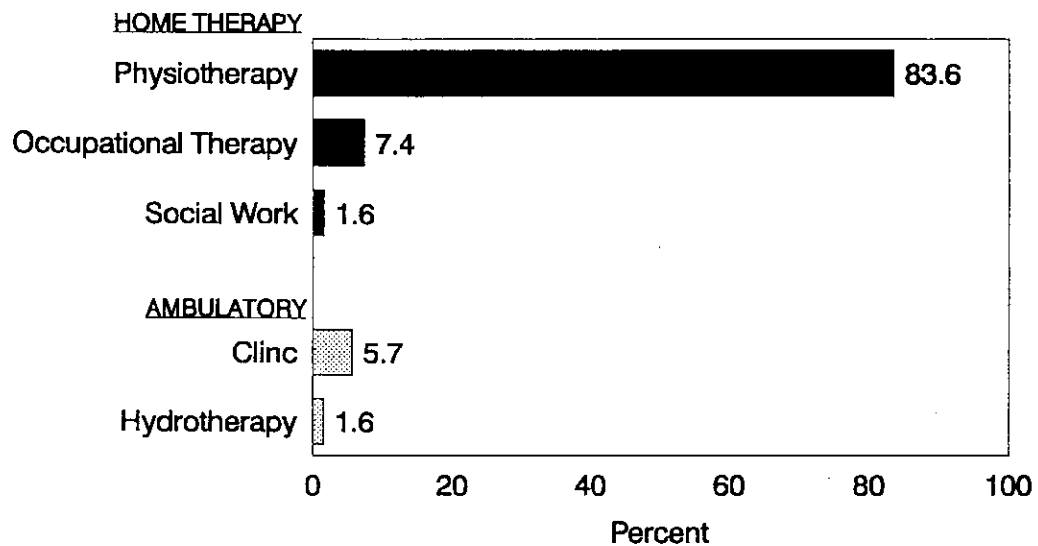
Completed questionnaires were sent in by the CTS therapists together with the children's case data forms to provide additional demographic information.

3. Analysis

Univariate analysis was done for all variables and are presented as frequencies and percentages, and means. Analysis of CHAQ scores also included stratification by sex and diagnosis. Pain scores were stratified by diagnosis. In the presentation of results, percentages have been calculated excluding missing data. The proportion of questionnaires with missing data was generally low.

- III. Results:
 - 1. Characteristics of Clients
 - a. Services Received

Figure 1.1: QUESTIONNAIRES RETURNED BY SERVICE



A total of 122 questionnaires were returned from 117 individual clients, of whom only 4 were seen by more than one service. It was not possible to calculate response rates, as the CTS does not collect data regarding the number of individual clients seen per month. Most

of the questionnaires returned were from home therapy clients (92.5%), with physiotherapy clients returning 83.5% of all questionnaires. Approximately a quarter of the children seen were new referrals, and 12% were being seen on a consultation basis.

b. Demographic and Disease Characteristics

There was no significant difference in age of males versus females. Most clients reported a diagnosis of juvenile arthritis. The most frequently reported type of

juvenile arthritis was polyarticular arthritis. The mean duration of arthritis was 2.7 years.

Table 1.1 Demographic and Disease Characteristics of Clients

Age (years)	mean 9.8 (s.d. 4.62)
Female	81 (70%)
Juvenile Arthritis	103 (88%)
Polyarticular	51 (44%)
Pauciarticular	37 (32%)
Systemic	14 (12%)
Duration	mean 2.6 (s.d. 2.9)

2. **Disability: The Childhood Health Assessment Questionnaire (CHAQ)**

a. Disability Index

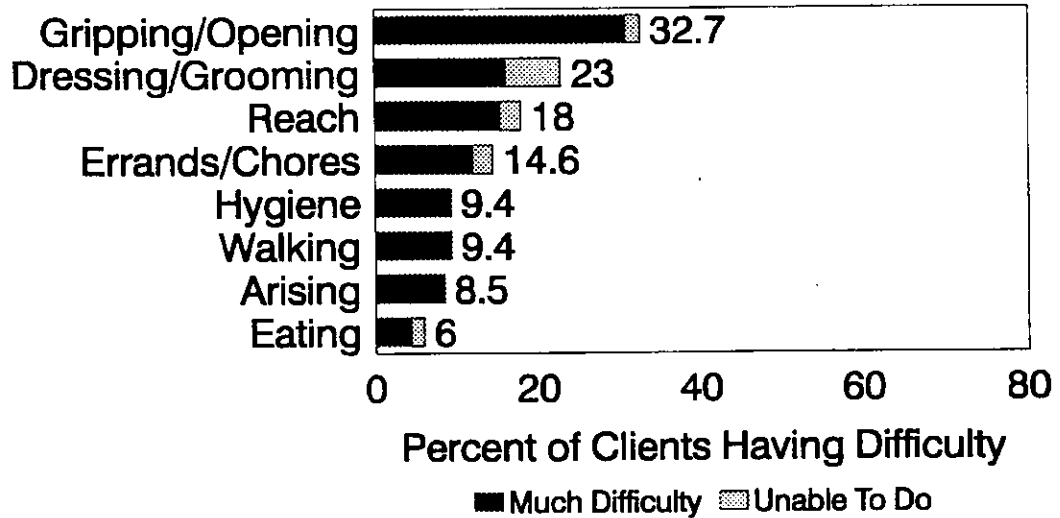
Table 2.1: CHAQ Disability Index

All Children	.53 (.57)
Pauciarticular JA mean (s.d.)	.28 (.41) (n = 37)
Polyarticular JA mean (s.d.)	.70 (.60) (n = 51)
Systemic JA mean (s.d.)	.80 (.59) (n = 14)

The mean disability index of all children was .53. There was no significant difference in the scores of males versus females. In the bivariate analysis, CHAQ scores were not correlated with age. As

might be expected, children with polyarticular and systemic juvenile arthritis scored significantly higher on the CHAQ than those with pauciarticular arthritis, indicating greater disability.

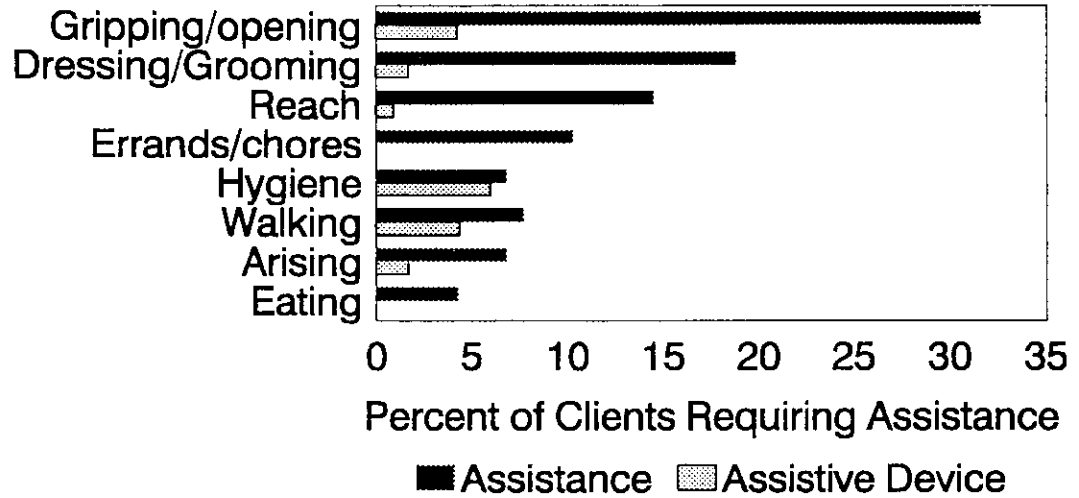
Figure 2.1 CHAQ FUNCTIONAL CATEGORIES - PERFORMANCE



A large proportion of children experienced difficulty with gripping/opening, dressing/grooming, and reach. Although the proportions of children who had difficulty with these tasks was smaller than the adults, the ranking of problem

areas was approximately the same except in the area of dressing/grooming. In the adults, this category was ranked sixth for percentage of those reporting difficulty, whereas in children, it was ranked second.¹

Figure 2.2: USE OF ASSISTIVE DEVICES AND/OR ASSISTANCE FROM ANOTHER PERSON



Generally, few children used assistive devices. The most frequently used pieces of equipment were splints (6%), followed by jar openers (4%). In all functional areas except hygiene and

eating, few assistive devices were reportedly used and more assistance from others was required. More children reported using assistance for personal care problems than adults.

c. Pain Scores

Table 2.2: Pain Scores

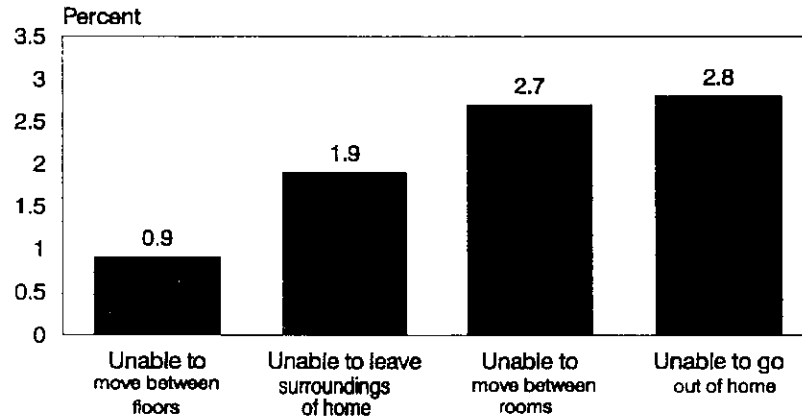
All Children	2.84 (1.71)
Pauciarticular JA (n = 36)	2.25 (1.52)
Polyarticular JA (n = 51)	3.14 (1.51)
Systemic JA (n = 14)	4.00 (2.22)

The mean pain score for all CTS children was 2.84 (s.d. = 1.71), which was significantly lower than the mean pain score for adults (4.6, s.d. = 1.48, $p=0.000$). Children reporting systemic

juvenile arthritis scored significantly higher on the pain scale ($p = 0.000$) than those with pauciarticular, or polyarticular arthritis.

3. MOBILITY

FIGURE 3.1: RESTRICTION IN INDEPENDENT MOBILITY WITH REGULARLY USED ASSISTIVE DEVICES



Few children reported difficulty with mobility in their environment. The most frequently reported difficulty was getting out of the home, with only 2.7% of children reporting restriction. Generally, 96% of children reported being independently mobile, compared to 81% of adults.

A similar proportion of adults seen by the CTS was also identified to be suitable for ambulatory therapy by their therapists (60%).

4. Suitability for Ambulatory Therapy

Therapists reported that 61% of children could be seen in ambulatory settings such as clinics/groups.

Discussion

The primary purpose of the Consultation and Therapy Service (CTS) client survey was to provide information regarding clients' disability and mobility status in order to enhance service planning and development. The survey of children seen by CTS found that these children reported significantly less disability on the Childhood Health Assessment Questionnaire (CHAQ), than children seen in an institution-based setting reported in the literature ($p = 0.000$). When comparing the scores from the two studies by diagnostic groups, it was found that the scores of children seen by CTS were the same as those reported in the literature for those with pauciarticular arthritis, but were significantly lower for those with polyarticular ($p = 0.000$) and systemic juvenile arthritis ($p = 0.000$). Unfortunately, insufficient information was provided in the Singh paper to determine how the pain scores were derived in order to do a comparison with the CTS clients.

It is possible that the difference in disability scores between the CTS clients and those reported in the literature reflect the difference in the types of service setting in which the questionnaire was used. Although the type of patient population the CHAQ was used with was not specified in the Singh paper, there was reference made to the setting being a large referral centre. The difference in the CHAQ scores between the CTS clients and Singh's clients may therefore, be portraying that children with more disability are being seen in institution-based settings as opposed to those that are community-based. It is also possible that differences in scores are reflecting

cultural differences in perception of illness and completion of disability questionnaires in America and Canada, with Canadians for whatever reason, reporting less disability.

When looking at the individual categories of the CHAQ, it was found that generally children received more assistance from another person and used less assistive devices for their activities of daily living. This is different in adults, where larger proportions of adults reported using assistive devices for many of their personal care activities (e.g. hygiene, walking, and eating) than ask for assistance from another person. Adults reported that they received assistance for less personal tasks such as gripping/opening and errands/chores.

It is understandable that children receive more assistance for their daily activities than adults, as it is more acceptable for children to receive assistance. In the CHAQ however, children are only being marked on tasks that are developmentally appropriate for them to be performing independently for their age level. According to the results of this survey, there appears to be a role for increased use of assistive devices to facilitate independence in children.

Finally, the same proportion of children and adults (approximately 60%) were identified by their therapists to be suitable for participation in therapy in an ambulatory setting. In addition, very few children reported mobility restrictions (4%), and they reported minimal levels of disability. These findings may indicate

that similar to adults, there appears to be room for further development of ambulatory services for children by the CTS. It is important to note however, that this survey did not address the effectiveness of home-based or community-based ambulatory care therapy. Although ambulatory care could result in greater efficiency for the agency, it may be that the costs to individuals and the detrimental effects of fatigue and pain associated with getting to sessions, could in fact cancel out the benefits of ambulatory therapy. Further research needs to be conducted examining the effectiveness of community-based ambulatory therapy for people with arthritis and other chronic debilitating conditions.

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A96

FUNCTIONAL STATUS IN JUVENILE RHEUMATOID ARTHRITIS: SENSITIVITY TO CHANGE OF THE CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE. Gurkirpal Singh, Byron Brown, Balu Athreya, Donald Goldsmith, Patricia Rettig, Daniel Bloch, James Fries. Stanford University, Stanford, CA 94304 and Children's Seashore House, Philadelphia, PA.

We recently developed the Childhood Health Assessment Questionnaire (CHAQ) to measure functional status in children with juvenile rheumatoid arthritis (JRA). The CHAQ is a parent- or self-administered questionnaire which measures function in 8 areas of daily living and includes at least one question relevant to children of all ages in each functional area. The CHAQ has strong internal and test-retest reliability and convergent validity (*Arthritis and Rheumatism* 1990; 33:S15). In this report, we describe the sensitivity of the CHAQ Disability Index (DI, average score on all functional areas) to small changes in functional status.

The CHAQ was administered on at least two occasions (range 2-10) to parents of 62 JRA patients (74% girls, mean age 7.9 years (range 1-19 years), mean disease duration 3.5 years, onset type 13 systemic, 18 poly, 31 pauci) during the course of their regular clinical care. A total of 174 observations were available for analysis. The parents' "global arthritis assessment" (measured on a visual analog scale from 0 to 100) was considered to be the "gold standard" for reflecting functional status. During the observation period, global assessment changed in 26 patients (ranging from an improvement of 48 to a deterioration of 77). The DI (0-3 scale) also changed in 26 patients, from an improvement of 1.42 to a deterioration of 1.37. We modeled the change in global assessment to be proportional to change in DI. For each patient, we obtained a proportionality constant by least squares. The average of these proportionality constants (\pm SEM) was 34.6 ± 14.4 , statistically significantly different from zero ($p < 0.02$). On the other hand, the average proportionality constants (\pm SEM) for morning stiffness and joint counts were, respectively, 3.4 ± 11.6 and 2.1 ± 1.9 (neither statistically significant), indicating that these measures do not adequately reflect changes in global assessment.

In conclusion, these data suggest the CHAQ Disability Index reflects changes in functional status of children with JRA and may be a more sensitive measure than either morning stiffness or joint counts.

34

MEASUREMENT OF FUNCTIONAL STATUS IN JUVENILE RHEUMATOID ARTHRITIS.

Gurkirpal Singh, Balu Athreya, James Fries, Donald Goldsmith, Barbara Ostry. Children's Seashore House, Philadelphia, PA 19104 and Stanford University Medical Center, Stanford, CA.

Few well-validated self- or parent-administered instruments are available for measuring functional status in children with juvenile rheumatoid arthritis (JRA). We adapted the Stanford Health Assessment Questionnaire (HAQ) for use in children aged 1-19 years by adding several new questions so that for each functional area, there was at least one question relevant to children of all ages. Further, to eliminate developmental discrepancies, only difficulties caused by arthritis were noted. Discomfort and global health assessment were measured by doubly-anchored visual analogue scales. The face validity of the instrument was evaluated by a group of 20 health professionals and parents of 22 normal children. The questionnaire was then administered to parents of 72 JRA patients (mean age 9.12 years (range 1-19 years), mean disease duration 4.03 years, onset type 16 systemic, 21 poly, 35 pauci). The instrument showed excellent internal reliability (Cronbach's coefficient alpha = 0.94), with a mean inter-item correlation of 0.6. The convergent validity was demonstrated by strong correlations of Disability Index (DI, average of scores on all functional areas) with Steinbrocker functional class (Kendall's tau b = 0.77, p < 0.0001), number of involved joints (Kendall's tau b = 0.67, p < 0.0001) and disease activity status (Kendall's tau b = 0.66, p < 0.0001). Principal component analysis revealed that 82.3% of variability was explained by two factors only: the first component with nearly equal positive weightings on all functional areas explained 71.4% of all variability. The second principal component was negatively weighted on questions involving lower extremities and positively weighted on those involving upper limb joints. The Spearman's correlation coefficient between the parents' and the older (> 10 years) children's DI was 0.84 (n = 29, p < 0.0001), showing that parents can accurately report for their children. The test-retest reliability, studied at a two-week interval revealed virtually identical DI measured at the two occasions (0.96 vs. 0.95, n = 13, paired t-test p > 0.9; Spearman's correlation coefficient = 0.8, p < 0.002). The childhood HAQ, which takes less than 10 minutes to complete is thus a valid, reliable and sensitive instrument for measuring functional status in children with JRA.

In this section, we are interested in learning how your child's illness affects his/her ability to function in daily life. Please feel free to add any comments on the back of this page. In the following questions, please check the one response which best describes your child's usual activities (averaged over an entire day) **OVER THE PAST WEEK. ONLY NOTE THOSE DIFFICULTIES OR LIMITATIONS WHICH ARE DUE TO ILLNESS.** If most children at your child's age are not expected to do a certain activity, please mark it as "Not Applicable". For example, if your child has difficulty in doing a certain activity or is unable to do it because he/she is too young but NOT because he/she is RESTRICTED BY ILLNESS, please mark it as "Not Applicable".

	<u>Without ANY Difficulty</u>	<u>With SOME Difficulty</u>	<u>With MUCH Difficulty</u>	<u>UNABLE To Do</u>	<u>Not Applicable</u>
DRESSING & GROOMING					
Is your child able to:					
-Dress, including tying shoelaces and doing buttons?	_____	_____	_____	_____	_____
-Shampoo his/her hair?	_____	_____	_____	_____	_____
-Remove socks?	_____	_____	_____	_____	_____
-Cut fingernails?	_____	_____	_____	_____	_____
ARISING					
Is your child able to:					
-Stand up from a low chair or floor?	_____	_____	_____	_____	_____
-Get in and out of bed or stand up in crib?	_____	_____	_____	_____	_____
EATING					
Is your child able to:					
-Cut his/her own meat?	_____	_____	_____	_____	_____
-Lift a cup or glass to mouth?	_____	_____	_____	_____	_____
-Open a new cereal box?	_____	_____	_____	_____	_____
WALKING					
Is your child able to:					
-Walk outdoors on flat ground?	_____	_____	_____	_____	_____
-Climb up five steps?	_____	_____	_____	_____	_____

* Please check any AIDS or DEVICES that your child usually uses for any of the above activities:

- | | |
|-------------------------------------|--|
| <input type="checkbox"/> Cane | <input type="checkbox"/> Devices used for dressing (button hook, zipper pull, long-handled shoe horn, etc) |
| <input type="checkbox"/> Walker | <input type="checkbox"/> Built Up pencil or special utensils |
| <input type="checkbox"/> Crutches | <input type="checkbox"/> Special or Built Up chair |
| <input type="checkbox"/> Wheelchair | <input type="checkbox"/> Other (Specify: _____) |

* Please check any categories for which your child usually needs help from another person BECAUSE OF ILLNESS:

- | | |
|--|----------------------------------|
| <input type="checkbox"/> Dressing and Grooming | <input type="checkbox"/> Eating |
| <input type="checkbox"/> Arising | <input type="checkbox"/> Walking |

	<u>Without ANY Difficulty</u>	<u>With SOME Difficulty</u>	<u>With MUCH Difficulty</u>	<u>UNABLE To Do</u>	<u>Not Applicable</u>
HYGIENE					
Is your child able to:					
-Wash and dry entire body?	_____	_____	_____	_____	_____
-Take a tub bath (get in & out of tub)?	_____	_____	_____	_____	_____
-Get on and off the toilet or potty chair?	_____	_____	_____	_____	_____
-Brush teeth?	_____	_____	_____	_____	_____
-Comb/Brush hair?	_____	_____	_____	_____	_____

REACH

Is your child able to:					
-Reach and get down a heavy object such as a large game or books from from just above his/her head?	_____	_____	_____	_____	_____
-Bend down to pick up clothing or a piece of paper from the floor?	_____	_____	_____	_____	_____
-Pull on a sweater over his/her head?	_____	_____	_____	_____	_____
-Turn neck to look back over shoulder?	_____	_____	_____	_____	_____

GRIP

Is your child able to:					
-Write or scribble with pen or pencil?	_____	_____	_____	_____	_____
-Open car doors?	_____	_____	_____	_____	_____
-Open jars which have been previously opened?	_____	_____	_____	_____	_____
-Turn faucets on and off?	_____	_____	_____	_____	_____
-Push open a door when he/she has to turn a door knob?	_____	_____	_____	_____	_____

ACTIVITIES

Is your child able to:					
-Run errands and shop?	_____	_____	_____	_____	_____
-Get in and out of car or toy car or school bus ?	_____	_____	_____	_____	_____
-Ride bike or tricycle?	_____	_____	_____	_____	_____
-Do household chores (eg, wash dishes, take out trash, vacuuming, yardwork, make bed, clean room)?	_____	_____	_____	_____	_____
-Run and play?	_____	_____	_____	_____	_____

* Please check any AIDS or DEVICES that your child usually uses for any of the above activities:

- | | |
|---|---|
| _____ Raised Toilet Seat | _____ Bathtub bar |
| _____ Bathtub Seat | _____ Long-Handled Appliances for Reach |
| _____ Jar Opener (for jars previously opened) | _____ Long-Handled Appliances in Bathroom |

* Please check any categories for which your child usually needs help from another person BECAUSE OF ILLNESS?

- | | |
|---------------|-----------------------------------|
| _____ Hygiene | _____ Gripping and Opening things |
| _____ Reach | _____ Errands and Chores |

We are also interested in learning whether or not your child has been affected by pain because of his or her illness.

* How much pain do you think your child has had because of his or her illness IN THE PAST WEEK?

Place a mark on the line below to indicate the severity of the pain.

No Pain

|
0

Very Severe Pain

|
100

