

A QUESTIONNAIRE SURVEY OF JUVENILE TO YOUNG-ADULT AMPUTEES WHO HAVE HAD PROSTHESES SUPPLIED THEM THROUGH THE UNIVERSITY OF ILLINOIS DIVISION OF SERVICES FOR CRIPPLED CHILDREN

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The purpose of this survey was to obtain information which would be helpful in evaluating various services to juvenile and young-adult amputees. The term juvenile amputee is used by us more broadly than in the usually accepted definition, as the Division gives service to amputees from the time of referral until they are twenty-one years of age. The age groups were evaluated as preschool (under five years old), young school-age, and pre-adolescent (six to twelve years old), adolescent (thirteen to seventeen years old), and young adult (eighteen years old and over). The amputees under discussion were under the medical supervision of clinics throughout the State. The interest of the orthopædists and their training in amputee rehabilitation varied widely. In general, the personnel within the various disciplines (orthopædists, physiatrists, pediatricians, therapists, psychologists, nurses, medical social workers, prosthetists) with whom we got in touch agreed that the most effective approach to the rehabilitation of amputees is an integrated program involving psychological preparation of the juvenile amputee and his parents; surgery as needed, with aftercare of the stump preparatory to the prosthetic fitting; selection of and fitting of the prosthesis most suited to the amputee's needs; training in the use of the prosthesis; and follow-up evaluation of the patient's ability to adjust to daily living function and to undergo eventual vocational rehabilitation. The questions in this study were therefore designed to obtain information regarding these factors. The questionnaire (see appendix) was sent out in April 1955 to parents of juvenile amputees who had been fitted with prostheses by the University of Illinois Division of Services for Crippled Children from July 13, 1945, to March 9, 1955. The latest recipient of a prosthesis had had it for two months and two days at the time of the questionnaire. A total of 363 questionnaires were sent: 197 were returned, but 15 were not used in this report because of meager or incomplete replies. The number not returned was 121; 45 were returned undelivered. In evaluating the results of these questionnaires an attempt was made to determine whether or not we had improved the juvenile amputees' adjustment to life, guided them toward as full independence as possible, and helped them as individuals to find their places in our whole society.

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Statistical Study

This study included 182 amputees with 198 amputations of whom 124 (68.1 per cent) were male and 58 (31.9 per cent) were female. The greater number of male amputees is due to a higher incidence of traumatic and congenital amputations as well as to a higher incidence of amputations caused by disease (infections and arterial insufficiency) among males in this series. Of the amputations, 94 (51.65 per cent) were traumatic; 71 (39.01 per cent) were congenital; 10 (5.5 per cent) were due to malignant growths; and 7 (3.85 per cent) were due to disease. In the group of 124 male amputees, 73 amputations (59 per cent) were traumatic; 41 (33 per cent) were congenital; 5 (4 per cent) were due to disease; and 5 (4 per cent) were due to malignant neoplasms. Of the 58 female amputees, 30 amputations (52 per cent) were congenital; 21 (36 per cent) were traumatic; 5 (9 per cent) were due to malignant growths; and 2 (3 per cent) were due to disease.

Among the patients with amputations caused by trauma, there were 73 (77.7 per cent) male patients; the amputations were: 10 below the elbow, 19 above the elbow, 29 below the knee, 11 above the knee, and 4 were multiple. There were 21 (22.3 per cent) female patients; the amputations were: 1 below the elbow, 3 above the elbow, 9 below the knee, and 8 above the knee.

Among the patients with congenital amputations there were 41 (57.7 per cent) male patients; the amputations were: 10 below the elbow, 3 above the elbow, 16 below the knee, 5 above the knee, and 7 were multiple. There were 30 (42.3 per cent) female patients; the amputations were: 12 below the elbow, 1 above the elbow, 8 below the knee, 7 above the knee, and 2 were multiple.

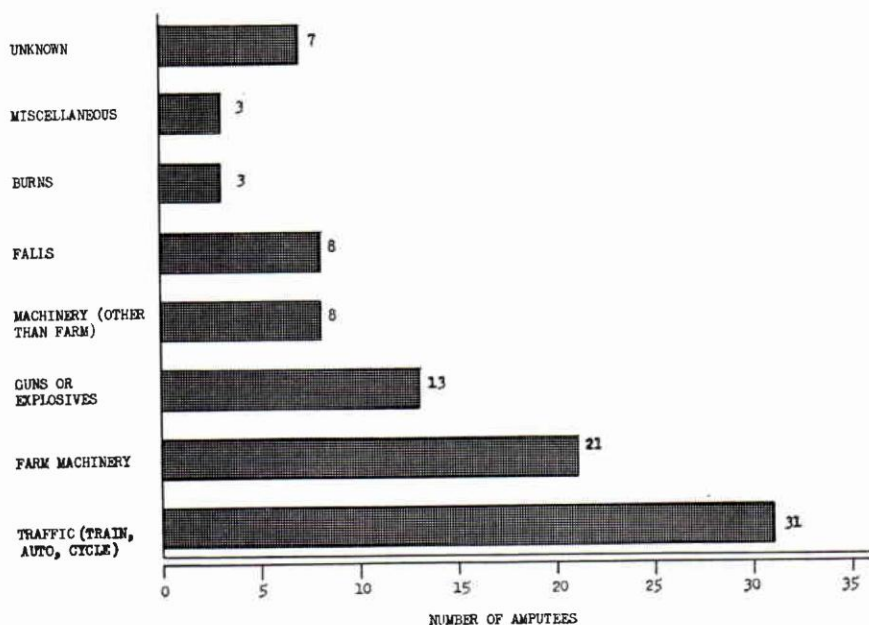


Chart I—Causes of 94 traumatic amputations.

In the group of patients with amputations resulting from disease, there were 5 (71.4 per cent) male patients; the amputations were: 4 below the knee and 1 above the knee. There were 2 (28.6 per cent) female patients; the amputations were: 1 each above and below the knee.

In the group of patients with amputations required because of malignant neoplasms, there were 5 (50 per cent) male patients; the amputations were: 1 below the knee and 4 above the knee. There were also 5 (50 per cent) female patients; the amputations were: 1 below the elbow, 1 below the knee, and 3 above the knee.

When the number of patients having amputations due to both neoplasms and disease were combined, there were 10 (58.8 per cent) male and 7 (41.2 per cent) female patients.

The types of amputations in this series were classified rather simply as being either above or below the elbow in the upper extremity or above or below the knee in the lower extremity. More technical studies indicate the size of the stump in inches or designate the stumps as short, medium, or long, or above or below a joint. Further classification, in regard to the upper extremity, may specify shoulder, elbow, or wrist disarticulation, and partial hands; in regard to the lower extremity it may specify hemipelvectomy, hip, knee, or ankle disarticulation, and partial feet. We did not believe that such distinctions could be made in this type of study, and the questionnaire was incomplete in this respect.

The greatest number of amputations—94—were due to trauma; the causes are listed in Chart I. It is evident that more emphasis is needed on educational measures to prevent accidents caused by automobiles, trains, motorcycles, farming, and firearms. Immediate care of even supposedly minor injuries is also indicated. For example, two amputations in this series were necessary after one youngster crushed his finger in a door and tetanus and gas gangrene developed and after another youngster cut his foot on a can in a fall and a chronic osteomyelitis developed.

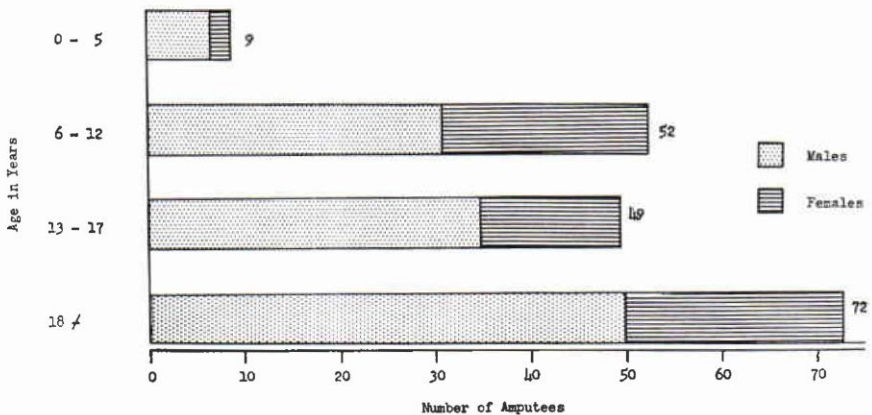


Chart II—Age of the amputee when the questionnaire was sent.

These accidents occurred at ages which ranged from 1½ to 19 years. The group 6 to 12 years of age was the most vulnerable to accidents leading to amputations, since 40 (42.55 per cent of all accidents) occurred in this age group. The preschool group was next with 24 (25.53 per cent). The teen-age group (13 to 17 years) was a close third with 22 (23.41 per cent). This indicates the need for more intensive programs in safety education and

accident prevention, closer supervision by parents or other responsible adults, and the removal of so-called attractive nuisances.

In the group of 71 congenital amputees were included 39 youngsters born with an amputated extremity; 27 who had an anomalous extremity leading to a conversion amputation of whom 2 also had a true amputation; and 5 with a congenital defect of the vascular or lymph system which led to surgical amputation. Of the congenital amputations, those below the knee occurred most frequently, followed in order by those below the elbow, above the knee, multiple, and, lastly, above the elbow. Here it seems that in congenital amputations, the right side is more likely to be involved, since, in 62 patients with unilateral congenital amputations, 40 (64.5 per cent) had right-sided involvement as against 22 (35.4 per cent) with left-sided involvement.

The 10 amputations for malignant growths were because of: liposarcoma, carcinoma, sarcoma, fibrosarcoma, neurofibroma, and Ewing's sarcoma. The 7 amputations due to disease were because of: osteomyelitis, Potts's disease, and emboli.

The greatest number of referrals, which was 112, to this Division were from doctors or ancillary medical services; 53 were from the family physician; 34 were from the public-health nurse; 1 was from the surgeon; 24 were from the hospital staff; 30 were from the limb-manufacturing companies; and 32 were from some other source (school staff, social or welfare agencies, friends, and the like). In 8 instances this question was not answered.

Age Distribution

At the time of this study the age distribution was 18 months to 27 years (Chart II). As stated earlier, this questionnaire was sent to all the juvenile amputees who were fitted with prostheses by the University of Illinois Division of Services for Crippled Children between July 13, 1945, and March 9, 1955. Only about one-fourth of the amputees in this study were under the care of the University of Illinois Amputee Clinic, which was established in 1952. About one-third of the amputees were first fitted with prostheses at 12 or more years of age, which accounts for the high upper-age limit at the time the questionnaire was sent.

The age at which the youngsters were first fitted with prostheses ranged from 9 months to 20 years. Seventy-four patients (40.66 per cent) were fitted with 80 prostheses in the group 6 to 12 years old; in the group 0 to 5 years old, which was next, there were 56 patients (30.77 per cent) fitted with 58 prostheses; in the group 13 to 17 years old, which was third, there were 41 patients (22.53 per cent) fitted with 45 prostheses; in the group 18 years and older, which was last, there were 11 patients (6.04 per cent) fitted with 11 prostheses. In all age groups, the majority of amputees who were fitted with prostheses had acquired amputations except in the group 0 to 5 years old, where the majority had congenital amputations.

In the group with below-the-knee amputations, the greatest number were fitted with prostheses in the age group 0 to 5 years old followed, in order, by the groups 6 to 12, 13 to 17, and 18 and over years old. The youngest below-the-knee amputee was fitted with a prosthesis at 9 months of age. In the group with above-the-knee amputations, the greatest number fitted with prostheses were in the group 6 to 12 years old followed, in order, by the groups 0 to 5, 13 to 17, and 18 and over years old. The youngest above-the-knee amputee was fitted with a prosthesis at 13 months of age. Some lower-extremity amputees were fitted with pylons when they were less than 9 months old.

The 60 patients with unilateral upper-extremity amputations were first fitted with prostheses when they were from 3 to 20 years of age. In the group with amputations above the elbow and in the group with amputations below the elbow, the majority were first fitted with prostheses in the age group 6 to 12 years old followed, in order, by the age groups 13 to 17, 0 to 5, and 18 years and over. The youngest below-the-elbow amputee was fitted with a prosthesis at 3 years of age; the youngest above-the-elbow amputee, at 5 years of age.

Surgical Procedures

With acquired amputations, reconstructive or reparative surgery may be required, either initially or for revision of the stump. It is important for the surgeon to keep in mind the fitting of the prosthesis at the time of surgery, whether it be the initial surgery or revision of the stump^{5,6}. Surgical problems of juvenile amputees differ from those of adults⁷. In this study no definite conclusions could be drawn concerning the results of the surgery. The question concerning this was not only poorly worded but also failed to cover the various aspects of this subject. Some of the patients or their families or both thought that this question related only to surgery being necessary after the child was referred to this Division for a prosthesis. Several interesting factors were noted: the younger the child at the time of the initial amputation, the greater was the likelihood of one or more revisions being necessary; and the below-the-knee amputees, followed by the above-the-elbow amputees, had more revisions than those in other groups. Some youngsters had as many as three revisions. We did not find a single below-the-elbow amputee who had a revision because of over-growth of one or both of the forearm bones at the distal end of the stump.

The surgical procedures on most of the lower-extremity congenital anomalies were performed to convert a deformed extremity to an amputation. Most of these amputees had had other treatment previously, including casts, braces, built-up or extension shoes, and other surgical procedures such as subtrochanteric osteotomy, bone grafts, growth arrest of the normal leg, and surgical correction of a chronic dislocating patella. Three below-the-knee amputees with short femora were treated by arthrodesis of the knee and were then fitted with above-the-knee prostheses. There were fewer stump revisions in this group of amputees than in groups whose amputations were owing to other causes. Rarely, except in congenital lymph hemangiomas and arteriovenous fistulae, is a congenitally deformed upper extremity amputated. Surgery—such as the removal of rudimentary nubbins, the correction of other deformities (such as webbed fingers), and derotation osteotomies—was done in the upper-extremity amputees. Some parents refused to allow the recommended amputation because they lacked understanding of the child's deformity. Other parents preferred to wait until the child could make the decision. One child in this study was 19 years old before he requested surgical treatment.

Systematic stump hygiene is important^{8,9}. The doctor, nurse, and therapist should give definite instructions. The following is suggested: the stump should be cleansed daily with a mild soap (in specific instances a germicidal soap may be recommended), dried thoroughly by patting rather than rubbing, and aired at intervals, especially in cases of excessive perspiration. Stump socks, if they are worn, should be clean (it is important to give instructions as to the care and laundering to keep them soft and to reduce shrinkage). Cleaning the sockets of the prostheses is especially important if stump socks are not worn. Close watch for redness or break in skin or any

other signs of irritation is essential so that prompt treatment may be given as necessary.

According to the replies to the questionnaire, 75 amputees or parents had received some instructions, whereas 26 had had none, and 4 misunderstood the question and gave answers concerning the care of their prostheses. In 77 instances the question was unanswered. Several amputees or parents indicated that their only instructions were given to them by the prosthetists. It is fortunate that skin problems are not common in juvenile amputees. Many of the amputees in this series had amputations prior to their referral to this Division. This does not excuse the failure to give these patients instructions in stump care or to at least review them. It may be that instructions were given but not sufficiently stressed. Perhaps they need to be repeated several times. The answers to this question emphasize the need for the responsible personnel to review the instruction in stump care more completely with the amputees or their parents, or both.

Attitudes of Parents

The education of the family is of the greatest importance since the parents supervise the child's total care, and the child interprets his defect according to what it means to his parents. Once the parents have insight into the total program of habilitation, or rehabilitation, as the case may be—just being reconciled to the defect is not enough—a plan can be worked out for the child^{1,2,3}. Of the 182 replies, 165 persons said that they understood the findings and recommendations of the clinician and the other members of the clinical staff as to plans for their children; 3 said that they needed more interpretation; and 14 did not reply. From these replies, it would seem that most of the families have had no problems from this standpoint, but that this obviously was not so was indicated in replies to other questions. In 29 instances the parents said that they felt the need for more time at the clinic (some of them had previously said that they understood what had been said to them). The parents of above-the-elbow and above-the-knee amputees felt this need more than parents of the other amputees.

Most of the parents replied to the third part of this questionnaire concerning how the staff might be more helpful. Some parents said that the clinicians expected too much from the children. Other parents stated that the clinicians did not expect enough and could get the children to do more. Many wanted to know how to help the child overcome his self-consciousness.

All but 1 parent indicated that their children had accepted the idea of being fitted with a prosthesis. The replies to the two subsections of this question revealed, however, that the children (or perhaps the parents themselves) had not accepted the idea of a prosthesis. For example, although only 1 parent said that his child did not accept the idea of a prosthesis, 52 parents replied to part (a) of question 5, and of these, 33 said that they had discussed this problem with the clinic staff. Many parents explained in part (b) of this same question how they helped their children's attitudes toward prostheses. Some said that they compared prostheses to false teeth. Others said that their youngsters were too young to know and therefore accepted the prosthesis. Some complained that the prostheses were recommended too early (in the cases of upper-extremity amputees only). Many urged amputees to be fitted with prostheses as early as possible. Some asked for pointers on how to explain the usefulness of the prostheses to the child.

Several parents gave information regarding the assistance that they gave their youngsters in dealing with the curiosity of, and teasing by, others. Some parents suggested that other amputees visit their youngsters to see how much could be accomplished. Some parents (of congenital amputees only)

suggested that parents' clubs be formed. It would seem from this that these parents feel a greater need for this type of group therapy. Classes for parents of congenital amputees have been found helpful at the Kessler Institute for Rehabilitation⁴.

The parents of patients with acquired amputations accepted the defect and the use of a prosthesis more readily than the parents of the congenital amputees. Several parents of children with upper-extremity amputations (both congenital and acquired) were more interested in hiding the deformity than in function. Some believed that the prosthesis made the deformity more obvious. Several parents of upper-extremity amputees stated that they had not cooperated in helping their children use their prostheses but would do so in the future. Many parents of children with lower-extremity amputations (congenital and acquired) stated that very few outsiders knew of their child's amputation. Some parents were very hostile toward society. A few suggested issuance of inexpensive, informative pamphlets.

There seemed to be a definite correlation between the parental acceptance and the child's adjustment to not only his amputation and prosthesis, but also to his general adjustment in his daily activities. Some parents encouraged a variety of activities; others suggested how parents might introduce new activities for their youngsters; and still others asked to have their youngsters excused from certain activities in school or other group activities.

Prosthetic Fitting and Adjustment

A prosthesis should not be prescribed unless the child is physically ready and the parents are mentally, emotionally, and socially ready for it. The child's readiness is strongly dependent on the readiness of his parents. Sometimes it is necessary to delay prescribing a prosthesis if the amputation is done for a malignant growth. The child should be checked periodically, both clinically and by roentgenograms, for the presence of metastases. Six months is the usual period allowed to lapse before prosthetic prescription. The periodic check-ups for metastases should continue after the prosthesis is provided.

In this study, the interval between the surgical amputation and the prosthetic fitting varied from 1 month to 11 years after operation, excluding the cases with malignant growths. Most were fitted within a year after operation. Some of the upper-extremity amputees were not fitted for several years, particularly those patients seen prior to 1951, principally because of the types of prostheses available at the time. After 1951, the latest developments in upper-extremity prostheses were made available to us.

A total of 182 amputees were fitted with 194 prostheses. In 65 amputees with 73 amputations (26 above the elbow, 34 below the elbow, and 5 multiple) the patients were fitted with upper-extremity prostheses and the following terminal devices: hooks only, 34; hands and hook, 27; and hand only, 4. In many instances, the hooks and hands were provided at the same time. Prior to 1951, only cosmetic or dress hands were provided. After 1951, APRL hands became available and were supplied to 9 amputees in this study. The current practice at the University of Illinois Hospitals Amputee Clinic is to provide an APRL hand (if the child's natural hand is near the size of the currently available APRL hand) only after he has learned to use his hook well and is wearing his prosthesis regularly. Cosmetic or dress hands are seldom recommended, and therefore an amputee usually is in his teens before he obtains a hand. Some parents bought dress hands for their children.

Of the 65 amputees with 73 amputations, 32, of whom there were 29 with unilateral amputations (14 above the elbow and 15 below the elbow) and 3 with multiple amputations, wore their prostheses all day; 13 amputees (5 with above-the-elbow and 8 with below-the-elbow amputations) wore their prostheses for five to eight hours; 8 amputees, of whom there were 7 with unilateral (1 above the elbow and 6 below the elbow) and 1 with multiple amputations, wore their prostheses for three to four hours; and 12 amputees, of whom there were 11 with unilateral (6 above the elbow and 5 below the elbow) and 1 with multiple amputations, wore their prostheses for less than three hours.

Of the 65 amputees with 73 amputations who were fitted with upper-extremity prostheses, 26 (40 per cent) had complaints: pain in the stump or skin irritation in 12; poor fit of the socket in 1; shortness of the stump, making the limb hard to use, in 1; and dissatisfaction with the appearance or no functional benefit in 12. For these youngsters, the functional value of the prostheses in many instances was not sufficient to overcome the discomfort. Regardless of whether the discomfort was organic or emotional, the youngsters did not wear their prostheses regularly.

The extent of the use of upper-extremity prostheses was graded as good, fair, and poor. Good use, which implies that the amputee uses the prosthesis consistently in a diversity of activities as a hand strongly supportive to the natural hand, was reported in 36 instances. Fair use, which implies moderate but active and consistent use within certain areas of activity, was reported in 8 instances. Poor use, which implies that the prosthesis is seldom worn or worn merely as an added appendage, the amputee performing primarily one-handedly, was reported in 21 instances.

A close correlation was found between the length of time that the prosthesis was worn daily and the extent of use. Of the 32 amputees who wore their prostheses all day, 30 had good use and 2 had poor use. Of the 13 amputees who wore their devices for five to eight hours, 5 had good use; 6 had fair use; and 2 had poor use. Of the 8 amputees who wore their devices for three to four hours, 1 had good use (he had a claw hand and wore a hand terminal device for cosmetic purposes only, as he had his own "hook"); 2 had fair use; and 5 had poor use. All 12 amputees who wore their prostheses for less than three hours had poor use.

To the question, "Could the amputee do things faster with the hook terminal device?" there were 43 replies from 65 amputees: 12 replied "yes"; 14 replied "no"; and 17 replied "sometimes." Thus, 29 (67.4 per cent) of these 43 amputees could do things faster either sometimes or regularly when using their hook terminal devices. It is interesting to note here that not one amputee with poor use of the prosthesis answered "yes," and only 3 with poor use answered "sometimes." All except one of the amputees with good use of their prostheses answered "yes" or "sometimes."

The ratings of the amputees as to the usage of the prosthesis were compared (Chart III). In 27 amputees who were fitted with hook and hand terminal devices there were 13 (48.1 per cent) with good usage; 4 (14.8 per cent) with fair usage; and 10 (37.037 per cent) with poor usage. In 34 amputees who were fitted with hooks only, there were 20 (58.8 per cent) with good usage; 4 (11.764 per cent) had fair usage; and 10 (29.4 per cent) had poor usage. These figures indicate that the providing of hands, as well as of hooks, did not improve the children's adjustment to their prostheses; the more basic psychological needs were not met.

The sex of the child with upper-extremity amputations did not seem to

be a significant factor in his adjustment. The cause of the amputation, the dominance of the hand, and the interval between amputation and fitting with the prosthesis seemed to have no specific effect on the adjustment of the child with amputations above the elbow.

Training seemed to be important among children with amputations above the elbow. Of the 11 who had "use" training (by trained professional per-

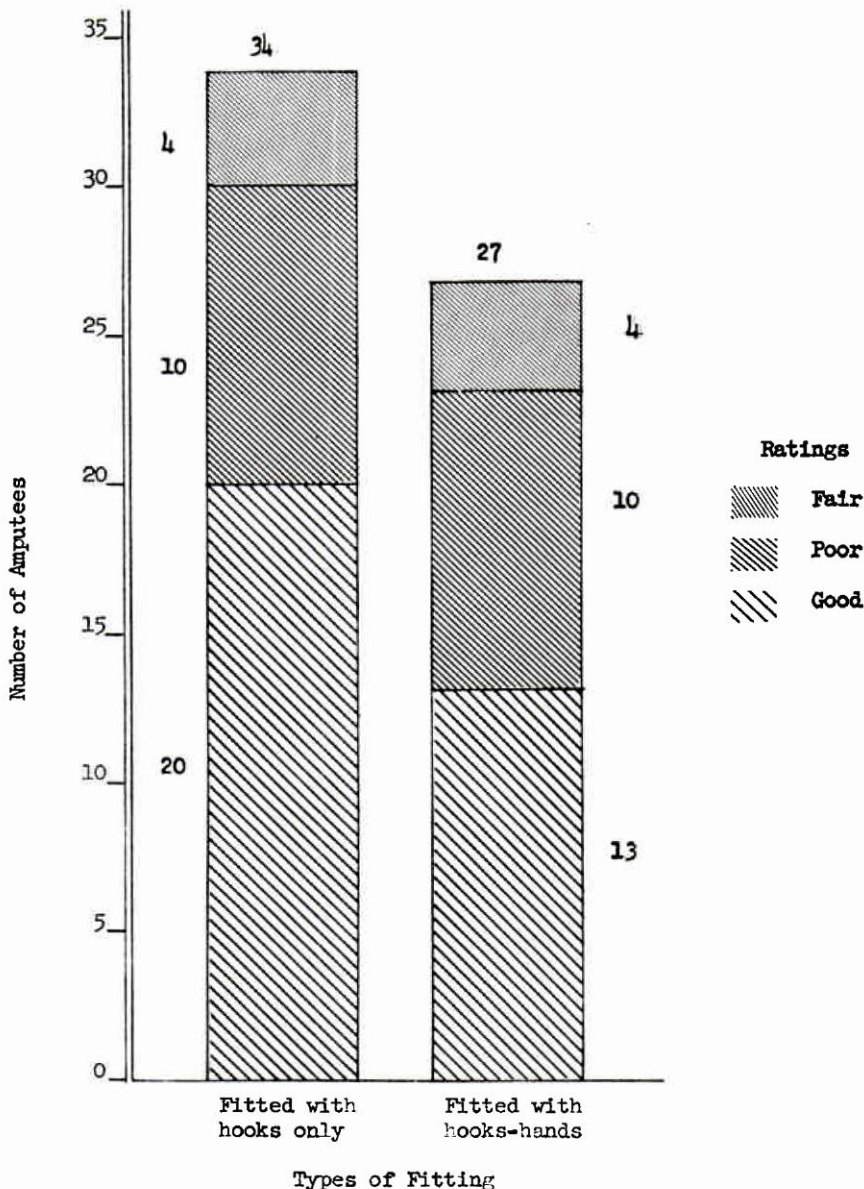


Chart III—Comparison of the ratings of the use of prostheses by 34 upper-extremity amputees fitted with hooks only and 27 fitted with hooks and hands.

sonnel), 7 wore their prostheses all day; 1 wore his for five to eight hours; 1 wore his for three to four hours; and 2 wore theirs seldom or not at all. The 2 children who had "controls" training (by the manufacturer), both wore their prostheses all day. Of the 13 children who had no training, 5 wore their prostheses all day; 4 wore theirs for five to eight hours; and 4 wore theirs seldom.

We found that the child with a congenital amputation below the elbow was not so good about wearing his prosthesis as the child with a traumatic amputation below the elbow.

Of the 22 children with congenital amputations, 7 (31.8 per cent) wore their prostheses all day; 7 (31.8 per cent) wore theirs for five to eight hours; 5 (22.7 per cent) wore theirs for three to four hours; and 3 (13.6 per cent) wore theirs for less than three hours. Of the 11 children with traumatic amputations, 8 (72.7 per cent) wore their prostheses all day; 1 (9 per cent) wore his for five to eight hours; 1 wore his for three to four hours; 1 wore his less than three hours.

Only 9 of the 22 children with congenital amputations below the elbow made good use of their prostheses, whereas 10 of the 11 children with traumatic amputations made good use of theirs. We wonder if this situation could be due to the greater time interval between the congenital amputation and the fitting of the prosthesis. Eight children (the majority) with traumatic amputations were fitted with prostheses 1 year or less after surgery, 2 children were fitted later but less than 2 years after surgery, and 1 child was fitted 11 years after surgery (he had had a partial hand amputation). The youngest of the children with congenital amputations below the elbow was fitted with a prosthesis at 3 years of age; the majority of the children in this group were fitted when they were between 6 and 12 years old. Some parents of the children with congenital amputations below the elbow said that the children did not wear their prostheses because they had learned to do everything with one hand; other parents said that the prostheses were in the way.

The suggestion was made that if the amputees had been fitted prior to 1951 they would have received so little training that they would be reluctant to use their prostheses. It was found, however, that 15 of the 22 children with congenital amputations below the elbow had been fitted after 1951, and from a review of the records it was obvious that the preparation of the parents or amputees, or both, had been inadequate.

The statistics also indicated that the earlier a child with a congenital amputation below the elbow is fitted with a prosthesis, the more likely is he to be a good prosthesis wearer. Children first fitted up to 5 years of age were the best wearers, those from 6 to 12 years old were the next best, and those 13 to 17 years old were the poorest wearers.

The side involved seemed to have some effect on the adjustment of the child with an amputation below the elbow. In this small series it appeared that a child with a congenital amputation below the elbow was a better prosthesis wearer if the left hand, which should have been the supportive hand (as judged from the statistics on handedness in the general population), rather than the right, or dominant, hand was involved. In contrast to this finding, the child with a traumatic amputation below the elbow seemed to be a better prosthesis wearer when the dominant hand was involved.

In this study it was found that children with traumatic amputations below the elbow were good prosthesis wearers whether or not they had had training, whereas children with congenital amputations below the elbow were

not good wearers even though more of them had training. The dexterity of those who had received little or no training could not be evaluated.

All but 1 of 119 children (109 with unilateral and 10 with multiple amputations) who were fitted with lower-extremity prostheses wore their prostheses all day. The one exception was less than 1 year old and wore the prosthesis during all the time he was awake.

Of the 119 children with lower-extremity prostheses, 10 (8.4 percent) complained of either pain in the stump or skin irritation, and 1 complained of poor fit of the socket. Nevertheless, they still wore their prostheses all day.

The extent of use of prostheses by the 109 children with unilateral lower-extremity amputations was graded according to the child's participation in activities.

Above-average use of the prosthesis implies that the child either participates in a wide variety of activities or does not object to the prosthesis or stump being exposed, or both.

Average use of the prosthesis implies that the child participated in a fairly wide variety of activities but preferred not to engage in any in which the prosthesis or stump would be exposed.

Below-average use of the prosthesis implies that the child participated in few activities and would not engage in any in which the prosthesis or stump would be exposed. Either the child or his parents asked for his excusal from the activities.

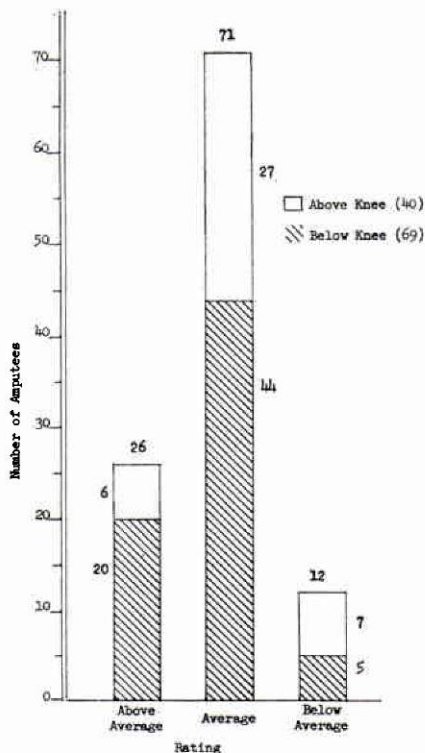


Chart IV—Extent of use of lower-extremity prostheses.

The extent of use of lower-extremity prostheses is shown in Chart IV. It was noted that the child with an amputation above the knee is less likely to participate in activities in which his stump or prosthesis is exposed.

The sex of the child, etiology, the side involved, the training, the age when he was fitted with the prosthesis, and the interval between the amputation and the fitting seemed to have no effect on the way in which the child with a lower-extremity amputation adjusted to the prosthesis. Gait, balance, posture, and the like, however, could not be evaluated.

Training

Training by a qualified therapist in the use of the prosthesis is essential in the rehabilitation of the amputee^{5,6,10,11,12}. The training must be adequate to be effective. The amount of training that is adequate varies according to the type of amputation, the prosthetic fitting, the age of the patient, the attitude of the amputee and of the parents, and the amputee's general muscle tone and coordination. The objective of therapeutic exercises and training in the use of a prosthesis is to get maximum effective function of the prosthesis under normal daily living conditions. When a prosthesis is replaced it is considered good practice to review functions, activities, and care with the patient, but usually additional training is not necessary unless a new type of component has been added. Checkout of a new prosthesis to determine whether or not it meets with certain standards is a part of this training. The occupational therapist or the physical therapist, or both, may be involved in the training program.

Gait training, posture, and balance are the usual goals for a patient with an amputation of the lower extremity. The training of the juvenile patient with an amputation of the upper extremity is more difficult. The guides for activities of daily living for adult-amputee training are helpful. Many therapists use the findings of research on the development of children as guides in the training of the juvenile amputee. In general, training starts with play and self-care, followed by various activities leading up to as full independence as possible and eventual educational or vocational rehabilitation, or both. If the child has a hand terminal device as well as a hook, additional training may be needed.

Some of our teen-age patients with traumatic below-the-elbow amputations have become adept in the use of their prostheses in 3 days of training on an in-patient basis. Patients with other types of amputations and younger amputees take an average of about 10 days of training on an in-patient basis. The youngsters who have multiple needs or have complicated fitting problems require longer periods of hospitalization. During this time, the nurses help to carry on the training suggested by the therapists in the daily care and play activities of the patient. Out-patient therapy extends over a longer period of time. Some amputees are able to come in daily, whereas others come three times a week. Gradually, these visits become less frequent. Here again, the type and duration of therapy depend on the individual needs of the amputees. The amputees are expected to master certain functions before training is discontinued.

In the replies to the question concerning training in the use of the prosthesis there was some confusion, in a few instances, with vocational training. The following data, however, were obtained: of a total of 182 amputees fitted with prostheses, 90 said that they had had training; 83 said that they had had none; and 9 did not reply. Of the 90 who said that they had had training, 61 had had "use" training (training by professional therapists) in hospitals, special schools, or treatment centers; 19 had had "con-

trols" training (training by limb manufacturers); and 10 indicated that they had had training by only answering "yes." Of the 42 parents (or patients) who thought that more training would have been helpful, 35 thought that more training was needed to make the patient more independent and able to take better care of the prosthesis. Some respondents said that more encouragement was needed, and others felt the need of a review.

The parents of several children with upper-extremity amputations who had received no training stated that if the children had had training they would have made better use of the prostheses. Parents of children with lower-extremity amputations also stated that if the children had received training they would have walked better or would have better posture, or both. Thus, the comments of many parents indicated that they realized the importance of training. Several parents, who apparently believed that the therapists who had trained the children were inadequate, stated that all therapists should have training with amputees.

Generally, additional training (called "keep-up training" by several parents) as such is not necessary after the child has received adequate training. Usually, an amputee who has been adequately trained in the basic functions quickly learns to apply this training to other activities.

Most of the amputees who had poor use of their prosthesis (poor wearers) and their parents need considerable help in developing better personal relationships. For instance, the child needs to feel loved and wanted, and the parents should express such emotion toward the child and help him to develop greater independence. Both the parents and the amputees need more interpretation of their own feelings about the defects, the injuries, and the prostheses.

The duration, quality, and adequacy of the training, or whether it was on an in-patient or out-patient basis could not be critically evaluated. However, prior to about 1951, plans for training were not routine, and there were few therapists trained in working with amputees. Often, training was not recommended as some of the clinicians seemed to feel that the instructions available from the manufacturer were adequate.

Now, plans for training are arranged as needed. Wherever resources permit, arrangements are made for out-patient training. It has been our feeling that hospitalization should be reserved for the seriously ill child or one needing surgery. In-patient training is arranged if there are such factors as large families, illness in the family, long distances to travel, if the prosthetic problem is a complicated one, and if intensive training is needed. The amount of time varies with the patient and his specific needs. The parents are included in this training program and are instructed in the care of the prosthesis, in training in its use, and in ways to encourage the youngsters to use their prostheses in additional activities. The very young amputees (less than 12 months) are usually not given formal training as such; their training amounts to functional play therapy and help in the development of balance and the ability to get about at will, as the needs may indicate. Instruction of the parents is especially emphasized during visits for occupational or physical therapy. In-patient therapy may be arranged for the very young amputee if necessary.

Follow-Up

Fitting the child with a prosthesis and teaching him to use it expertly does not necessarily mean that he will make good use of his prosthesis. He needs to be seen periodically not only to check his use of it in every-day activities but to encourage him in additional activities.^{10,12} The length of the time interval between clinic visits varies—it may be as often as once a

month during the period of rapid growth, after the first fitting with the prosthesis, or in the event that a difficult fitting problem is encountered. Parents and patients are advised to feel free to get in touch with the clinic or field staff earlier, if necessary. On these clinic visits: the family may be given further instructions in the care of the stump if skin irritations have arisen, a stump revision may be found necessary, repairs or adjustments of the prosthesis may be made, a new prosthesis may be ordered, bad habits in the use of the prosthesis may be prevented or corrected, and the family may be given further suggestions regarding the use of the prosthesis.

Of the 136 persons who replied to the question about clinic recheck examination, 68 (49.9 per cent) stated that they return to clinic every 6 months; 29 (21.3 per cent) return to clinic every 3 months; 26 (19.1 per cent) return yearly; and 13 (9.5 per cent) return at various intervals. It was also found that the non-wearers and the poor users kept clinic appointments in about the same fashion as the good wearers.

Repairs and adjustments (to which there were 114 replies) were needed at intervals ranging from 3 months to more than 1 year. The cost of upkeep is therefore an important consideration. The repairs most frequently needed were: replacements of straps, leather and rubber parts, and screws and bolts; new joints; new washers; new feet (for the below-the-knee more often than for the above-the-knee amputee); new pelvic belts for above-the-knee amputees; repair of fingers; and new cables and new harnesses. The below-the-knee amputees needed the most repairs; next came the below-the-elbow amputees, then above-the-knee amputees, and, finally, above-the-elbow amputees. The families contribute toward the cost of repairs according to their ability to pay. The need for repairs (unless due to neglect or abuse) is an indication that the amputees are using their prostheses. Because the cables break frequently two cables, or cable units, are now supplied to the upper-extremity amputees. When one breaks, the spare is applied, and parents are advised to replace the broken one as soon as possible so that a spare will always be available.

There were 98 replies to the question as to how long the first limb had remained satisfactory (59 amputees in this study had been fitted with their initial prosthesis only). There were 30 (30.6 per cent) who had used their limbs for 3 years; 30 (30.6 per cent) for 2 years; and 26 (26.5 per cent) for 1 year, and 12 (12.6 per cent) whose limbs lasted for various periods. The problem of a limb that is outgrown before it is outworn is ever present, and every effort is made to cope with it. On an over-all basis, however, the cost per amputee is one of the lowest expenditures, and the results, in most instances, more than justify the outlay of funds.

The questions did not consider other aspects of follow-up care. Clinic follow-up is supplemented by home visits, school visits, and conferences with other persons or agencies concerned with the patient's adjustment. The community nurse is the key person in integrating the total care of the juvenile amputee. State and local agencies for education, public health, and social welfare, both voluntary and government, the amputee's family physician, pastor, school counselors or other school personnel, the local public-health nurse, the caseworker, local therapists, psychologist, or some fraternal group—in fact, almost anyone who is needed to help in the child's and the family's adjustment—may be involved in the rehabilitation of amputees. Acceptance at home alone will not suffice. The child must have happy group experiences.

Social Acceptance

An important factor in the juvenile amputee's adjustment is his acceptance by various individuals and groups outside the home, such as neighbors and church, school, and recreational groups. Problems concerning children with lower-extremity amputations are rare. Considerable prejudice against children with upper-extremity amputations exists, however, and this seems to increase when the child is fitted with a hook prosthesis. A recent survey indicates the need for further study of social influences on amputees.¹³ A close correlation has been found between the degree of acceptance of the child with upper-extremity amputations in these outside relationships and the development of a satisfactory attitude toward the handicap and the prosthesis by the child and the family. Both the parents and the child may need help in their approach to others so that it enhances rather than aggravates the situation when the youngster meets other people.

In many instances, of course, social prejudice is a product of ignorance and superstition. Education of the public is the answer here as it is with other problems of prejudice. This educational process needs to be continuous to be effective.

There is a trend to send these youngsters, unless severely handicapped, to regular school, although this trend has not yet been generally accepted. Schools frequently accept the youngsters, but the parents, however, want the child to attend a special school. Free transportation to and from special schools seems to influence some parents.

Of the 133 amputees who answered the question concerning whether or not they wore their prostheses to school, all but 14 replied in the affirmative. Of these 14, 1 had multiple amputations, 5 had above-the-elbow amputations, and 8 had below-the-elbow amputations. It is interesting that in this study not one parent said the school would not permit the child to wear the prosthesis.

Of the 121 who replied to the question concerning activities permitted in school, 100 said that they were permitted to wear their prostheses in all activities. The activities prohibited by some schools were swimming, gymnastics, baseball, and football. (Swinging was not permitted for some children with upper-extremity amputations.) All activities except sports and all sports except football, basketball, or gym were permitted if the child did not wear his prosthesis. In our questionnaire we failed to consider whether the child attended a hospital school, special school or room, or a regular school. Moreover, even in a regular school, there is a difference in activities, so that saying that a child participates in all activities in one school does not necessarily mean that this school has more understanding than others in which the activities are "limited."

Some youngsters in this study are in the Little League or Pony League; however, we have noticed that many of them do not play bimanually. There has been some question as to whether or not these youngsters are as well adjusted as appears on the surface.

One very important fact which was mentioned several times was that these youngsters would like to participate in games for which sides are chosen. In several instances, mention was made that other children did not like to touch the hook, as, for example, in such games as crack the whip and other hand-holding games.

Information based on how the parents thought that their children were accepted by school personnel, children, and neighbors was tabulated and graded as follows:

Above-average acceptance by the school, community, and children implies that the child is well accepted as one of the group. The child is helped toward greater independence, and his situation is often interpreted to others.

Average acceptance implies that the child participates as one of the group in activities.

Below-average acceptance implies rejection from the group and its activities or acceptance only as a handicapped and dependent person. Of the 129 respondents to the question on the attitudes of the principals and teachers, 51 specified above-average acceptance; 74 specified average acceptance; and 4 specified below-average acceptance. Of the 132 respondents concerning the attitude of the school children, 37 specified above-average acceptance; 91 specified average acceptance; and 4 specified below-average acceptance. Of the 138 respondents to the question of attitudes of neighbors and friends, 35 specified above-average acceptance; 96 specified average acceptance; and 7 specified below-average acceptance. It is interesting to note that of the 15 children who were reported to have below-average acceptance (all types of amputation), 7 had amputations below the elbow; 3 had amputations below the knee; 2 had amputations above the knee; 2 had amputations above the elbow; and 1 had multiple amputations. Apparently, the child with amputation below the elbow seems to have the most difficulty in social acceptance.

Several parents said that their youngsters did not wear their prostheses during play for fear of hurting themselves or others. Instances in which children with prostheses accidentally hurt themselves or others have been rare, and the injuries were no more than minor bruises. Deliberate use of a prosthesis as a weapon has rarely occurred. Nose-pinching with the hook terminal device has caused parents of playmates concern and has definitely impeded the amputee's acceptance. It is wise for children with upper-extremity amputations not to wear their prostheses in body-contact sports or games.

Several parents and amputees brought out the problem of finding jobs. Many told of successful job placement and job accomplishments, household care, and care of babies. It is especially important that prospective employers be reached so that when the patient becomes employable, a job suitable to his training and ability is open to him, since our ultimate goal is a well adjusted, independent individual. The Division of Vocational Rehabilitation is active in this area, and several amputees in this study had had, or were having, job training or higher education through this agency. Besides governmental activities in this field there are many voluntary agencies and fraternal clubs active in this work.

Summary

Although this questionnaire did not cover the various facets of rehabilitation as well as had been hoped for, it revealed some interesting findings.

Greater stress should be placed on prevention, since the largest number of amputations were on a traumatic basis.

Definite conclusions could not be made about surgical treatment. However, the need for further study of growth patterns was definitely indicated. It was noted that although the greatest number of revisions were in the children with amputations below the knee, most of these were done for the acquired amputations due to trauma, malignant growth, and disease; very few revisions were done in the below-the-knee conversion amputations of congenitally anomalous lower extremities.

After the necessary surgery, aftercare of the stump is very important. Physical therapy to maintain, or obtain, full range of motion in the remaining

joints is often started before surgery. Bandaging the stump to reduce induration and edema and to shape the stump is recommended. This study reveals the need to stress and to review instructions in stump hygiene with the patient and parents.

More investigation is needed as to the age when a child should be fitted with a prosthesis and the age when training should begin. Most physicians associated with amputee services recommend that a prosthesis be fitted at the earliest possible age, providing that the child is physically, emotionally, socially, and mentally ready. All agree that when a child with a lower-extremity amputation is ready to walk, he is ready for a prosthesis. If the amputation is acquired, the youngster should be fitted with a prosthesis as soon as the stump is in good condition.

There seems to be no universal agreement as to what is the earliest possible age for an upper-extremity prosthesis to be fitted. Passive prostheses have been put on children at about 4 to 6 months of age to teach them to hold or push an object against the normal hand and gross grasping, such as holding a nursing bottle; to have the child become accustomed to the added length of the stump; to encourage the youngster to tolerate an appliance; and to help in functional activities. Recommendations for fitting with a prosthesis depend on the child's development rather than his age.

Further investigation of the influence of the hand which is dominant seemed to be indicated.

The child with amputation above the elbow is as good a prosthesis wearer and user, within the limits of his increased handicap, as the child with below-the-elbow amputations.

The fitting of children with upper-extremity amputations with a hand terminal device did not improve their adjustment to the prosthesis. It has been our experience, with rare exception, that the anticipation of getting a hand is greater than the realization.

Children with lower-extremity amputations and those with traumatic amputations below the elbow wore their prostheses whether or not they had had training. However, training was very important to the adjustment to the prosthesis of the child with amputations above the elbow. Children with congenital below-the-elbow amputations were the poorest prosthesis wearers. This is not meant to imply that training is not important to all groups. Rather, it points out that some types of amputees find their prosthesis helpful to them whether or not they have had training. The initial preparation did not seem to be adequate for children with congenital below-the-elbow amputations. Perhaps they need a different approach or a different method of training. It may be that earlier fitting with a prosthesis, as is now done, may resolve this problem. It was definitely found that this group of children showed the best results when fitted with a prosthesis before they were 5 years of age.

The child's evaluation of himself, his parents evaluation, and the attitude of the whole population were brought out repeatedly in these questionnaires as being very important factors in his rehabilitation.

The study also revealed the need for greater dissemination of the available information to the many disciplines concerned with the rehabilitation of the child amputee.

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A QUESTIONNAIRE SURVEY OF JUVENILE AMPUTEES

APPENDIX

UNIVERSITY OF ILLINOIS
 DIVISION OF SERVICES FOR CRIPPLED CHILDREN
 1105 South Sixth Street
 Springfield, Illinois
 ARTIFICIAL LIMB STUDY

NAME _____ BIRTHDATE _____ CASE NUMBER _____
 ADDRESS _____

(Street) (City) (County)

1. (a) What part or parts of the body are involved?

Right arm:	Above elbow _____	Below elbow _____
Left arm:	Above elbow _____	Below elbow _____
Right leg:	Above knee _____	Below knee _____
Left leg:	Above knee _____	Below knee _____
- (b) What was the cause of the amputation:

(1) Born that way _____	What kind? _____
(2) Accident _____	What? _____
(3) Disease _____	What? _____
(4) Tumor or growth _____	
- (c) Was an operation necessary before getting the limb(s)? _____
2. (a) At what age was your child fitted with his first limb? _____
- (b) Did you or another agency buy a limb for your child before he was referred to this Division? Yes _____ No _____ Name of agency? _____
- (c) If (b) was answered "yes," who prescribed that limb? _____
- (d) Did he have any training in the use of the limb at that time? Yes _____ No _____ If "Yes," where did he get the training? _____
3. Who referred your child to the Division of Services for Crippled Children? (Circle)
 - (a) Your family physician?
 - (b) Your public health nurse?

- (c) A limb manufacturing company?
 (d) Someone else? Who?-----
4. (a) Did you understand what the doctor and other clinic staff said to you and your child at the clinic? Yes----- No-----
 (b) Did you need more time at the clinic? Yes----- No-----
 (c) How do you think the clinic staff might have been more helpful to you in understanding your child's needs?-----
5. Did your child accept the idea of being fitted with a limb? Yes----- No-----
 If he didn't:
 (a) Did you discuss this with the clinic staff? Yes----- No-----
 (b) What did you do to help your child's attitude toward getting the limb?
6. (a) How old was your child when he was fitted with a limb by this Division?-----
 (b) After your child was fitted with this limb:
 (1) Did he have any training in its use? Yes----- No-----
 (2) If he had training, where did he get it?-----
 (3) Do you feel it would have been helpful if he had more training? Yes----- No----- If yes, why?-----
 (4) What instructions were you given on the care of the stump?-----
7. (a) How many hours a day does your child wear the artificial limb(s)? (Circle)
 (1) 1 hour (2) 2 hours (3) 3-4 hours (4) 5-8 hours (5) All day
 (b) If he attends school, does he wear the limb at school? Yes----- No-----
 (c) Is he permitted to wear it in all school activities? Yes----- No-----
 If no, in what activities is he not permitted to participate?-----
 If no, in what activities does he participate but is not permitted to wear the limb?
 (d) If not worn routinely, why? (Circle those that apply) Because of:
 (1) cosmetic appearance (2) pain in stump (3) poor fit of socket
 (4) it is not permitted in school (5) skin irritation of stump (6) Other reasons (state)-----
 (e) What is the attitude of the principal and teachers?-----
 (f) What is the attitude of the school children?-----
 (g) What is the attitude of neighbors and friends?-----
 (h) Does he like to play with other children? Yes----- No-----
 (i) Does he prefer to stay at home? Yes----- No-----
8. If your child was fitted with an arm and hook prosthesis:
 (a) List activities he does with its help.
 (1) Dressing and personal care (Examples: opening toothpaste tubes, pulling on socks, lacing shoes.)
 (2) Eating (Examples: use of knife and fork, use of bottle or can opener.)
 (3) Work (Examples: hammering nails, using spray gun, putting clips on paper, carrying three or more packages.)
 (4) Social (Examples: wearing of hook or hand to various social activities, opening wallet or purse.)
 (b) Which of these you listed is he able to do without the hook? (List)
 (c) Does he do these faster with the hook? Yes----- No----- Sometimes-----
9. If your child has an artificial hand as well as a hook:
 (a) How many hours a day does he wear the hook?-----
 (b) How many hours a day does he wear the hand?-----
 (c) Does he wear the hand only for dress occasions such as church, parties, etc.? Yes----- No-----
10. (a) Have you purchased another limb since the Division made one available? Yes----- No----- When?----- Why?-----
 (b) Have you purchased extra parts for the original limb? Yes----- No-----
 If "yes," What?-----
 (c) If you changed to another limb, give reasons why?-----
 (1) Is present limb: (Check or circle)
 a. Better than b. As good as c. Not as good as original
11. How often does your child return to clinic for re-check examinations? (Circle)
 (a) Every 3 months (b) Every 6 months (c) Every 9 months
 (d) Every year (e) Over a year
12. How often has the limb required repair or adjustment for length?
 (a) Every 3 months (b) Every 6 months (c) Every 9 months
 (d) Every year (e) Over a year
13. If your child has had his first limb replaced, how long did the first limb remain satisfactory?
 (Circle) (a) 1 year (b) 2 years (c) 3 years (d) Other (state)-----
14. How do you think we can be more helpful to children like yours?