### Clinical Trial of Social Worker Assistance in Childhood Chronic Illness

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Abstract

Children with chronic illnesses have a doubled risk of developing psychosocial maladjustment - emotional problems, behavior disorder or difficulties in social relationships. Social work support and counselling aims to reduce this secondary morbidity, and is a common form of hospital-based psychosocial service. The first randomized controlled trial of this type of intervention was carried out to evaluate its effectiveness in treating and preventing maladjustment. This thesis describes how child behavior outcomes were assessed before and 4 months after a 6 month period of social worker assistance in 173 children randomized to intervention, and in 169 controls, all with chronic illnesses.

No significant difference between intervention and control groups in the overall prevalence of maladjustment was found. There was no evidence to support a therapeutic or preventive effect of social work counselling on child behavior outcomes, nor was there improvement in child perceived competence. A search for treatment interactions failed to reveal any sub-group that benefitted from the intervention, and restriction of the analysis to individuals who actually received the intervention does not alter any of these conclusions.

Measurement problems, co-intervention, or other forms of bias cannot account for the negative results. It is speculated that if social work support is to be effective, it should be targetted, potent, of adequate duration, and possibly integrated within specialist clinic services. III

#### Résumé

Les enfants atteints de maladies chroniques présentent deux fois plus de risques de développer une mésadaptation psychosociale, des problèmes émotifs, des troubles du comportement ou des difficultés dans leurs rapports sociaux. Le support et les conseils des travailleurs sociaux ont pour but de réduire cette morbidité secondaire, ce qui représente une forme courante de services de type psychosocial en milieu hospitalier. Il s'agit d'une première expérience pour déterminer l'efficacité de ce type d'intervention dans la prévention et le traitement de ces mésadaptations. Cette thèse décrit comment le comportement des enfants fut évalué avant et 4 mois après une période de 6 mois d'intervention des travilleurs sociaux auprès de 173 enfants pour le groupe expérimental, et 169 enfants pour le groupe contrôle.

Aucune différence significative n'a été trouvée entre les deux groupes dans la prévalence globale des mésadaptations. Il n'y a aucune preuve en faveur d'un effet thérapeutique ou préventif de l'intervention des travailleurs sociaux sur le comportement des enfants ni sur la perception qu'a l'enfant de sa compétence. L'étude des interactions n'a pas révelé de sous-groupes spécifiques qui auraient pu benéficiér d'une intervention. De plus, une analyse limitée aux individus qui ont reçu l'intervention ne change aucunement ces conclusions.

Ces résultats négatifs ne peuvent s'expliquer par des problèmes de mesure, de co-intervention, ou par d'autres formes de biais. Un effet latent n'est pas exclu. On postule que les interventions des travailleurs sociaux pour être éfficaces, doivent être spécifiques, d'une durée adéquate, et possiblement intégrées à une clinique particulière.

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Preface

For nearly 60 years, evidence has accumulated to support the belief that chronic illness in children causes an increase in emotional problems, both for the children themselves, and possibly for their mothers and siblings as well (Pless and Pinkerton 1975; Nolan and Pless 1986). Although not yet subject to empirical investigation it is also probable that the disability imposed by such emotional disorder is greater than that resulting from the illness itself. Furthermore, parent-reported prevalence of disability attributable to childhood chronic illness has increased over the past 25 years in the US (Newacheck and Budetti 1985), and in Canada (Wilkins and Adams 1983). Despite the weight of this evidence, very few attempts have been made to comprehensively treat, and more importantly, prevent psychosocial disorder in this context. Where interventions have been introduced, rigorous scientific evaluations of their effectiveness have been conspicuously absent (Olbrisch 1979; Johnson 1979; Drotar 1981; Rinaldi 1985; Nolan and Pless 1986).

This thesis describes the evaluation of a psychosocial intervention aimed at reducing the impact of chronic illness on children and their families. Furthermore, this study of the effects of a novel application of a traditional service represents the first assessment, based on sound epidemiologic principles, of social work effectiveness in any context. In order to understand the relevance of such a project, the scope and magnitude of childhood chronic illness, particularly with respect to its psychosocial correlates and consequences, will be defined. The few previous attempts at evaluating psychosocial interventions will be appraised, and the evidence for modifiers of the risk of maladjustment will be reviewed.

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LITERATURE REVIEW

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#### 1. The Impact of Chronic Physical Disorder

The period prevalence of all chronic physical disorder (CPD) for ages 0-20 years, including multiple handicaps, approximates 10 to 12 percent (Pless and Douglas 1971; Pless 1982; Gortmaker and Sappenfield 1984; Gortmaker 1985). Both the prevalence and actual numbers have increased in recent decades, due to a combination of improved survival for several conditions, and a cohort effect resulting from the-"baby boom" of the 1950's (Gortmaker and Sappenfield 1984). Asthma and sensory impairments represent the most common categories of these disorders (Table 1). Dramatic improvements in survival from certain conditions, notably malignancies, cystic fibrosis and spinal dysraphic states, have occurred in the last 20 years, although the incidence of most conditions has remained stable (Gortmaker and Sappenfield 1984).

One way of describing the negative health impact of a chronic illness is through parent-reported limitation of day to day activities. The point prevalence of US children (aged 0-17 years) with activity limiting conditions has increased from 1.8 to 3.8 percent between 1960 and 1981 (National Center for Health Statistics 1981; Newacheck, Budetti and McManus 1984; Newacheck, Budetti and Halfon 1986). This ascertainment of disability, based on responses to questions in the ongoing National Health Interview Survey is corroborated by data from the Canada Sickness Survey of 1950-51, and the Canada Health Survey of 1978-79 (Wilkins and Adams 1983). Prior to 1970, the change in prevalence was partly due to a cohort effect, but also to technical factors associated with change in questionnaire design. The more recent increase may be attributable to a change in parent perception of disability, especially in relation to the emergence of learning disorders as a recognized activity impairment (Kovar and Meny 1981; Newacheck, Halfon, and Budetti 1986). Improved survival of low birth weight infants, and better access to health care for the poor are not thought to have been important contributers (Newacheck, Budetti, and Halfon 1986). Respiratory diseases, speech, special sense and intelligence related impairments, and mental and nervous system disorders, together account for 50% of all

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Table 1: Prevalence estimates for chronic physical disorders for children aged 0 - 20 years in the USA - 1980. (Modified after Gortmaker and Sappenfield 1984).

Disorder	Prevalence per 1000
Asthma	38.0
Visual Impairment	30.0
Hearing Impairment	16.0
Congenital Heart Disease	.7.0
Seizure Disorder	3.5
Cerebral Palsy	2.5
Arthritis	2.2
CNS Injury	2.16_
Diabetes Mellitus	1.8
Cleft Lip/Palate	1.5
Down Syndrome	1.1
Sickle Cell Disease	0.46
Neural Tube Defects	0.45
Cystic Fibrosis	0.20
Hemophilia	0.15
Leukemia	0.11
Phenylketonuria	0.10
Chronic Renal Failure	0.08
Muscular Dystrophy	0.06
TOTAL _	107.4

childhood activity limitations (Newacheck, Halfon, and Budetti 1986).

Another important indicator of the burden of chronic illness is health service utilization. In 1979, for example, the 3.8% of children with activity limitations described above, accounted for 9% of all physician visits and 30% of all inpatient hospital days (National Centre for Health Statistics 1981). National Health Interview Survey data also indicate that 13% of visits to pediatric practices are for chronic problems, while the figure is 10% for family practitioner visits, and more than 30% for other specialists (Gortmaker and Sappenfield 1984).

The content and quality of health care provided to children with chronic illnesses has been the subject of a number of recent investigations (Pless, Satterwhite, and Van Vechten 1976, 1978; Palfrey, Levy, and Gilbert 1980; Stein, Jessop, and Reissman 1983; Smyth-Staruch *et al.* 1984). These studies show that both hospital-based specialist care and community provided services fail to meet the needs of chidren with chronic illnesses. Although health service utilization rates may superficially appear high, they do not tell the whole story about what the perceived needs for services are, nor whether the service provided is efficacious or desirable.

A community-based physician survey in New York State (Pless, Satterwhite and Van Vechten 1976) disclosed that public health nurses, social workers, mental health workers, physiotherapists, and vocational rehabilitation specialists were infrequently used in the care of children with asthma, epilepsy, heart diseases, arthritis, diabetes and cerebral palsy. The problem is often more tangible in hospital sub-specialty clinics, where important medical, developmental and psychosocial problems may be ignored or relegated to low priority (Pless, Satterwhite, and Van Vechten 1978; Palfrey, Levy, and Gilbert 1980). A case-referent study from the Cleveland area (Smyth-Staruch *et al.* 1984) indicated that 369 children aged 3 to 18 years with cystic fibrosis, myelodysplasia, cerebral palsy, and multiple physical handicaps attending specialist clinics at 2 major teaching hospitals used hospital services ten times more than 456 randomly sampled community referent subjects (Table 2). Chronically ill children were 4.5 times more likely to have used mental health or social work services during the previous year. Social workers were used by 30% of cases but only by 1% of referents. However, neither illness severity, nor social status was related to mental health service utilization. What these studies do not indicate is whether those who were in receipt of services required them, and whether the services were efficacious. More importantly, perhaps, they also do not tell us whether those who were not

Table 2: Health service utilization by Cleveland children with chronic physical disorders (CPD: cystic fibrosis, cerebral palsy, myelodysplasia, and multiple handicap). From Smyth-Staruch et al. 1984.

Service-	CPD	Referents	
Heeritelizations	2 4 07	6.01	
Mean Days in Hospital <sup>†</sup>	17.3	6.2	
Physician Visits	98%	88%	
Specialist Visits	79%	42%	
Mean Number of Visits*	8.9	3.3	
Mental Health & Social services	36% <sup>-</sup>	8%	
Mean Number of Service Occasions†	9.4	8.3	
Mean Number of Visits*	3.3	0.6	
Social Worker Usage*	30%	1%	
Total services	99%	97%	
Volume of Services*	78.8	7.8	

† for those receiving the service only. \* overall

receiving assistance could have benefited from appropriate and effective social support. The negative psychosocial impact of chronic illness is germane to an examination of the scope and efficacy of social and mental health services provided to ill children. A review of investigations conducted over the past 15 years that have documented an association between psychosocial disorder or maladjustment and childhood chronic illness is contained in Appendix 1 (Nolan and Pless 1986). This review concluded that:

- i) a causal link between chronic illness and emotional problems exists, and
- ii) the relative risk of emotional problems in childhood chronic illness is in the vicinity of 2 (relative to children without chronic illness).

In addition, the need for the development and evaluation of interventions aimed at reducing the additional handicap of psychosocial disorder was emphasized. The plethora of studies in the pediatric and psychological literature which have consistently documented the dysfunction-associated stress of chronic illness stands in stark contrast to the dearth of reported attempts to deal with it.

#### 2. Interventions

Psychosocial interventions in childhood chronic illness have been designed to ameliorate or prevent psychological difficulties directly or indirectly related to the child's medical condition, and include supportive and behaviour-altering strategies (Johnson 1979). Specifically, the following problem areas have been addressed (Johnson 1979; Drotar 1981):

i) relieving illness-related reactions to stress,

ii) treating illness-related personality problems,

iii) preparing for medical experiences,

iv) preparing for death,

v) managing behaviour problems,

and.

vi) habilitation/rehabilitation.

#### Literature Review 6

In addition, various psychosocial interventions have been employed in an attempt to improve medical outcomes, such as diabetic control, the frequency and severity of asthma attacks, headaches, and symptoms of inflammatory bowel disease (Olbrisch 1977; Rinaldi 1985). Recent reviews of all of the above interventions highlight the paucity of sound evidence upon which to base planning for efficacious health services in this area. The problem resides both with recurrent methodologic inadequacies when evaluations have been carried out (Olbrisch 1977; Sechrest and Cohen 1979; Nolan and Pless 1986), and more fundamentally, with the absolute rarity of any evaluative research at all (Drotar 1981; Drotar and Bush 1985; Garfunkel 1986; Nolan and Pless 1986). In particular, a thorough literature search, employing the MEDLARS (*Medline and Psychinfo*) electronic storage and retrieval system, together with "manual" searches using key references in the medical, psychological and social work literature, revealed only one controlled evaluation of social worker effectiveness in the area of childhood chronic illness, and it will be shown below that this study was scientifically entirely inadequate (Nolan and Pless 1986).

There has been, however, considerable interest in finding and evaluating effective psychosocial techniques to improve the medical management of some specific, generally prevalent chronic diseases, such as asthma and diabetes. A representative sample of such studies is summarized in Table 3. Much attention has been paid to teaching self-management skills to asthmatic children and their parents. The program of Fireman and co-workers (1981) is but one example of many which have been reviewed elsewhere (Thoresen and Kirmil-Gray 1983; Bruhn 1983). These apparently successful interventions are based on various behavioural models, particularly social learning theory and the health belief model (Bruhn 1983). Similarly, Kaplan *et al.* (1985) employed a social learning intervention to improve diabetic control (represented by lower hemoglobin  $A_1$  levels), and Golden *et al.* (1985) used a rigid heirarchical set of medical, educational and psychosocial strategies to demonstrate a similar, apparently beneficial effect on diabetic control. Unfortunately, their results are inconclusive because of the inherently weak

Reference	Disorder	Age	Design	Sample Size	Assignment	Outcome	Intervention	Result
Fireman et al 1981	Asthma	2 -14	2 group, parallel, posttest only	13 interv 13 control	Age-matched, sequentially assigned	Symptom & medical diary School attend records ER visits and hospitalizations	Nurse educator asthma educ'n & self management behavior skills Four 1 hr individ and two 2 hr group sessions. Telephone access & monitoring	Sig fewer asthma attacks, school absences Fewer hospitalizations and ER visits at 1 yr
Golden <i>et al</i> 1985	Diabetes	3 mo -17	l group, pretest- posttest.	44	-	Incidence of ketoacidosis Hemoglobin Aj	Herrarchical set of medical, educational & psychosocial interventions (psychotherapy)	Sig reduction in incidence of ketoacidosis, and in HbA <sub>j</sub> level, at 6mo No effect of psychother
Kaplan et al	Diabetes	13	2 group,	21	Random after	Hemoglobin A <sub>1</sub>	Social learning	Sig. lower HbA
1985		-18	pretest- posttest.		stratification on sex	Rand instrument for diabetes knowledge, behavior and attitudes Means Ends Problem	intervention by psychologist over 3 wk camp Control group received educational intervention only	but no published comparison between assignment gps on other ' outcomes HbA/ correlated
			.``	۱ ،		Solving Test (MEPS)		with positive behavior, attitudes scales, MEPS (at 4mo).

#### Table 3 Studies of psychosocial interventions with medical outcomes

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Reference	Disorder	Age	Design	Sample Size	Assignment	Quicome	Intervention	Result
Pless & Satterwhite 1972, 1975a	Range of chronic physical disorders.	6 -15	2 group, parallel, pretest- postiest.	56 interv 42 control	Random after stratified on Family Function Index	California Test of Personality Coopersmith. Children s Manifest Anxiety Scale	l year family counsellor Nonprofessional mature women acting as advocates and counsellors	60% interv subjects v 41% controls had sig improved psychological status, at 1 yr
Adler 1973	Muscular dys trophies	7 -17	2 group, paraliel, pretest- posttest.	10 interv 10 control	Not stated	Figure drawings Koppitz rating scale	l week camp Psychologist counsellor	Four-fold decline in emotional indicators(P< 05) Controls no
McCraw & Travis 1973	Diabetes	7 -15	2 group, parallel, pretest- postest.	33 interv 26 control	Selected matched controls	Coopersmith Children s Manifest Anxiety Scale	3 wk camp No specific description of activities.	Sig improved self-esteem for females only, at 4 mo
Kupst <i>et al</i> 1983	Merungitus	1 mo -10	3 group, parallel, pretest- postiest	6 total interv 6 moderate 7 standard	Random	Family Behavior Checklist Family Coping Scale Current Adjustment	Social worker or professional counsellor Total daily counselling & emotional support. Moderate "supportive but not aggressive"	No difference between groups, at 1-2 yr
Stein & Jessop 1984a.c. 1986	Range of chronic physical disorders.	5 -11	2 group, parallel, pretest- postlest.	33 home care 37 standard. (at 6 & 12 mo) At 5 yr, total sample 49	Random after stratufied on Judged Ability to Cope, and Overa Burden Index	PARS II. Psychiathc Symptom Index(mother)	l yr nurse, pediatrician, home care	Sig better on PARS II at 6 mo with trend at 12 mo At 5 yr, home care sig better on PARS II

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uncontrolled, pretest-posttest design. In a crude way, the effectiveness of psychotherapy was also evaluated in this study, and not surprisingly, the investigators detected no measurable effect. Very small numbers of subjects, selection bias, and again the uncontrolled study design almost guaranteed this result.

Five studies of psychosocial interventions aimed at psychosocial outcomes are summarized in Table 4 As far as can be determined from the literature search cited above, this list represents a complete census of controlled evaluations in the area of childhood chronic illness

An innovative and pioneering study by Pless and Satterwhite (1972,1975a) was the first to grapple with the problem of how to effect positive change in the emotional status of children with chronic illnesses. Their novel approach employed nonprofessional ("lay") family counsellors over a 1 year period to act as child and family advocates, and counsellors It was prompted by the Rochester Child Health Survey of a random community sample of 209 chronically ill children, which disclosed a striking need for many forms of assistance " ..... these needs included explanations about the nature of the child's illness, the utilization of various supportive, professional, and paraprofessional workers; effective coordination of existing services; help with behavioural and educational problems; and above all, the therapeutic benefits to the mother of a sympathetic listener" (Pless and Satterwhite 1972:403). As a result, six counsellors - women aged 32-51 years, all with their own families, and all with a university education - were chosen to provide the intervention. They received five 6-hour training sessions covering "the nature of chronic diseases, effects of chronic illness on the family, counselling techniques, advocacy, community resources, principles of health education, and the use of the health literature." These counsellors worked an average 10 hours per week with 8 assigned families (a total of 56 children in the intervention group), and spent approximately 55% of their time with the families, undertaking direct verbal tasks such as education, counselling and psychotherapy. The rest of their time was allocated to service acquisition, advocacy and social activities with the patient.

The evaluation employed 42 control subjects with chronic illnesses who received standard services. The assignment procedure was random, following stratification on a measure of family functioning. The pretest-posttest evaluation was based on a battery of paper and pencil measures including the California Test of Personality, the Children's Manifest Anxiety Scale, the Coopersmith Self-Esteem Inventory, and the Behaviour Symptom rating. On these measures, improvement in psychologic status over 1 year was judged to have taken place if the majority of the child's test scores increased. Improvement was noted in 60% of counselled children, and 40.5% of control children (P= 04, two tailed), and was greater in low risk (i e fewer problem) families

Based on these favourable results, this program was subsequently extended and adapted to the specialty clinics at the Strong Memorial Hospital in Rochester, and while not objectively evaluated, it was described as "successful" (Rice, Satterwhite, and Pless 1977)<sup>1</sup> Unfortunately, a comprehensive report of results on individual outcome measures used in the lay counsellor study has never appeared in the literature, and the summary description of "improvement" versus "no improvement" on a heterogeneous group of measures (addressing diverse psychologic constructs) does not do justice to the imagination shown in conceiving the intervention, nor to the careful attention paid to study design in the pursuit of internal validity.

Adler (1973) evaluated her own effectiveness as a counsellor to 10 children with various muscular dystrophies in a 1 week camp study. In this study, which was apparently never published except as a dissertation abstract, the experimenter "spent the camp period interacting continually... in ways designed to foster social approval, maximize use of potential abilities, and encourage staff and peer group acknowledgement of existing talents". Based on her own assessment of human figure drawings and sociograms

<sup>&</sup>lt;sup>1</sup> At this time, a randomized controlled trial is in progress at the Boston Robert B. Brigham Hospital. Lay family counsellors are providing psychosocial support to children with chronic arthritis and their families (personal communication, Pless 1986). Counsellors in this instance are older mothers of children who have, or have had, arthritis.

portraying subjects and their friends, she found that the experimental group drawings indicated a four-fold decline in "emotional indicators" (signs of emotional disturbance based on the Koppitz standard rating scale), as well as a significant increase in developmental indicators, whereas controls showed no improvement in either area.

Because this investigator apparently conducted all aspects of this study including group assignment (method not stated), baseline and postintervetion measure administration, interpretation and scoring of results - uncertainty about the maintenance of adequate scientific standards of objectivity remains. The report of such a dramatic therapeutic effect from a relatively nonspecific and innocuous intervention, together with the small sample size makes this study even less credible.

Another camp study apparently employed no special intervention apart from the camping experience itself (McCraw and Travis 1973) and involved diabetic campers matched on age, sex, race, socioeconomic status, and duration of diabetes, with control subjects, also diabetic. Using measures of self-esteem (Coopersmith Self-Esteem Inventory), and anxiety (Manifest Anxiety Scale), significant improvement in self-esteem was reported for females only. However, this study also suffered from several methodologic shortcomings, particularly questions about selection bias prior to, at, and following assignments (especially differential attrition), inadequate description of the intervention, and a lack of standardization of pre- and postintervention assessments and analysis.

A small study of the longer term emotional impact of bacterial meningitis (Kupst *et al.* 1983) is the only controlled evaluation of social worker effectiveness that could be identified in the context of childhood illness, chronic or acute. A social worker and a professional counsellor provided counselling and emotional support to families in the period following diagnosis and during convalescence from bacterial meningitis. On measures of family behaviour and coping, as well as child behaviour, the small sample size makes it no surprise that no difference was detected between intervention and control groups at 1 to 2 years following diagnosis.

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The most recent, and most scientifically acceptable intervention evaluation is the randomized controlled trial from the Bronx Municipal Hespital Center in New York City (Stein and Jessop 1984a, 1984b, 1986). Over 200 children with a wide range of chronic disorders were randomized to receive either a comprehensive home care program or standard care. Home care focussed on the whole family and its needs, and sought to foster patient independence and to maximize rehabilitation and adjustment. It was provided by a general pediatrician and pediatric nurse practitioners Pretest-posttest assessments on a measure of child adjustment called the Personal Adjustment and Role Skills Scale (PARS II), and on a measure of maternal psychiatric status (Psychiatric Symptom Index), were conducted on three occasions - baseline (prerandomization), 6 months, and 12 months - for the 70 children in the appropriate age range. After adjusting for pretest scores with analysis of covariance, home care subjects did significantly better at 6 months on both child and maternal measures, but the results were less impressive at 12 months. The intervention was continued for an average of 11 months. A recent addendum (Stein and Jessop 1986) provides further evidence for the efficacy of this form of home care. At an average of 5 years following randomization, the 49 subjects available for retest on the PARS II yielded results with large and statistically significant scores favoring those who had received home care. Although this analysis is for only 49 of the original 209 subjects randomized (or of the 70 reported in the 6 and 12 month analysis), and therefore requires caution in assuming freedom from selection bias (Greenland 1977), it offers gratifying evidence for the pronounced, enduring, and above all, measurable benefit of comprehensive psychosocial care for children with CPD.

There are at least two other similar intervention programs with pediatric nurse practitioners underway at present, although their evaluation is not yet completed (personal communication, Pless 1986). They will be referred to briefly since they underline both the recognition of the importance of psychosocial support, and the need for its evaluation (Garfunkel 1986). One is a controlled study in rural Northern Florida which compares nurse practitioner "outreach" psychosocial support with standard care for control children from other counties. Although not restricted to children with chronic illnesses, all subjects are from families receiving Crippled Children's Service benefits. The other is the New York State Program of Coordination of Care for Chronically III Children which employs nurse practitioners to coordinate services and provide support to children with chronic illnesses. Formal evaluation of this service is in the planning phase, but it is important to note that neither of these studies employs randomized assignment of subjects.

#### 4. Modifiers of Psychosocial Eunction in Chronic Illness

Understanding the distribution and determinants of any disorder, and particularly planning therapeutic and preventive interventions, requires knowledge of the prevalence and potency of "causative" agents, *and* of the factors that change the relationship between the host and these agents (Cassell 1976). Rutter has identified several key problems in successfully preventing psychosocial disorders (Rutter 1982). First, ensuring that an efficacious intervention reaches its target population. Second, understanding that short-term improvements may not necessarily lead to enduring long-term benefits (Kagan 1980). Third, recognizing the need to start interventions early in childhood, even though "critical periods" of development do not exist. This is because patterns of failure, once established, tend to persist. Fourth, exploration of the cost-benefit aspect is important, and must take account of disadvantages, or side-effects of any intervention. Most fundamentally, however, Rutter reminds us that bridging the gap between the identification of a damaging factor, and knowing how to eliminate or reduce its effect, is the first and crucial step.

Bearing this in mind, it seems appropriate to review the evidence for modifiers (or risk factors) of psychosocial function in chronic illness. Broadly speaking, candidate modifiers can be conceptualized as personal or environmental. Personal factors include demographic and biologic characteristics, together with individual susceptibility. Environmental factors can be thought of as being in the social, or medical environment (Table 5).

1. Demographic Factors age sex socioeconomic status **2** Biologic Factors type of disorder brain involvement severity visibility unpredictability age of onset duration of illness 3. Individual Susceptibility locus of control personality 4. Social Environmental Factors family functioning parental psychologic state 5. Medical Environmental Factors continuity of care access to care

Table 5: Candidate modifiers of psychosocial function in childhood chronic illness.

Demographic tactors: The risk of emotional problems in the general population increases with age (Rufter, Tizard, and Whitmore 1981), and the same is true for children with CPD (Pless, Roghman, and Haggerty 1972). Boys are at greater risk than girls (Rutter 1982), but specific interactions with chronic illnesses have only been recorded in a few situations, notably girls with hearing impairment, and boys with congenital heart disease (Heller *et al.* 1985). Data from the 1970 British birth cohort indicate that families with disabled children were significantly more likely to be living in suboptimal housing circumstances (Cooke and Lawton 1985), while others have shown that there is a prominent association between economic stress and psychosocial outcomes (Stein and Reissman 1980; Stein and Jessop 1986).

Biologic factors: The notion that risk of psychosocial disorder is linked to specific disease entities has not been supported by the bulk of evidence from both adult (Cassileth et al. 1984), and childhood studies (Pless and Pinkerton 1975; Stein and Jessop 1982; Breslau 1985; Heller et al. 1985). There have been some suggestions that children with sensory

impairments are at increased risk with respect to children with other medical disorders, but the evidence is scanty (Haggerty, Roghmann, and Pless 1975; Pless 1984). There is, however, abundant evidence that cerebral involvement (especially mental retardation) in CPD is an important predictor of emotional problems (Rutter, Tizard, and Whitmore 1970; Steinhausen and Wefers 1976; Breslau and Marshall 1985; Breslau 1985). Pless and others advocate the so-called "non-categorical" approach to the study and management of psychosocial consequences of chronic illness, emphasizing the commonality of the chronic illness experience for children (Pless and Pinkerton 1975; Stein and Jessop 1982).

Enthusiasm has not been sustained for the notion of a specific psychosomatic causal relationship for disease (Moos 1979). It should be noted, though, that even sophisticated studies of large birth cohorts have not capitalized on the strengths of the prospective longitudinal design to tease out the temporal relationships between disease onset and the evolution of emotional symptoms (Nolan and Pless 1986).

The relationship between disease severity and the risk of psychsocial disorder is less clear (Pless 1984). Recent studies provide conflicting evidence about this association, and a large part of the problem relates to the lack of a standardized severity index or health status instrument, particulary one that is valid and reliable across disease categories (Eisen *et al.* 1979; Williams 1979; Newacheck, Halfon, and Budetti 1986). In the Monroe County survey (Pless and Satterwhite 1975b), a measure of severity based on parent report of interference with daily activities was used (Pless and Graham 1970), together with multiple measures of psychosocial maladjustment. "Only in one half of the measures (was there) a direct relationship between the severity of the disability and the frequency of maldjustment. In most of the others the relationship (was) curvilinear, maladjustment being more frequent in the severely disabled and the nondisabled groups, and less in those with intermediate levels of disability" (Pless and Satterwhite 1975b:88).

This same phenomenon was noted in a sample of children with chronic arthritis (McAnarney et al. 1974). In studies of children with asthma and cystic fibrosis (Steinhausen and Schindler 1981; Steinhausen, Schindler, and Stephan 1983), severity was the most important predictor of psychopathology in cystic fibrosis patients, but not among patients with asthma, after controlling for measures of family functioning and life events. Similarly, Harper (1983) found no evidence of a linear relationship between degree of impairment in adolescents with muscular dystrophy and other orthopedic problems, and scores on the Minnesota Multiphasic Personality Inventory In contrast, McNichol et al. (1973) studied a cohort of children aged 7 to 14 years, and reported that "behavioral disturbances occurred more often and at a statistically significant level only in the small group of children with severe and continuing asthma". Gath et al. (1980) noted that poor diabetic control was directly related to psychiatric disorder and reading retardation, but again, this cohort study failed to address the issue of the temporal sequence and its relationship to causality. In another cohort study, Heller and her associates (1985) assessed children with congenital heart disease, cleft lip and palate, and hearing impairment on two occasions, one year apart. They found that disease severity (on a simple 3-point ordinal scale) was directly related to both the persistence and onset (over the one year period) of maladustment as assessed by the Child Behavior Checklist of Achenbach and Edelbrock (1983). Data from the home care study of Stein and Jessop indicated that psychosocial disorder was not related to traditional medical morbitity measures (days hospitalized, bed days), but was related to school absence and functional impairment on their own measure of functional status (Stein and Jessop 1984b,d).

One possible clue to understanding the apparently conflicting evidence in relation to disease severity comes from a consideration of the disorder's "visibility" \_\_\_\_\_In a prevalence survey of 2,454 randomly selected adult applicants for disability benefits, Zahn (1973) found that physical characteristics that clearly indicated the presence of sickness or disability were associated with *better* interpersonal relations (i.e. self-assessment of family, peer, and other relationships). Furthermore, in a study of young adult survivors of ind-stage renal disease, Beck *et al.* (1986) showed that visibility (cushingoid appearance, obesity, scars, orthopedic aids, short stature) was inversely correlated with identity stability (on a self-image scale) and social maturity (on the Vineland Social Maturity Scale). Finally,

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Jessop and Stein (1985) analyzed results from the total cohort of 209 children who were participants in their randomized trial of home care (Stein and Jessop 1984a,c) and found that on a variety of measures of psychosocial function, it was children with normal appearance who had poorer outcomes on three-quarters of the significant analyses of variance. The mothers of children of normal appearance were less satisfied with care, and the condition was reported to have greater impact on the family. These mothers also had more psychiatric symptoms, and their children were reported to have poorer functional status.

Pless (1984) has argued that the degree of visibility of a disease, and the likelihood that this forces the child to recognize himself as a "disabled person" is the force behind this process. The ambiguity produced by a "marginal" state, or personal indecision about incapacity, was first elaborated by Wright (1960). A related phenomenon is the impact that the unpredictability of a disease process might have on psychosocial function. In the analysis of the home care intervention data by Jessop and Stein (1985), it was found that mothers of children with conditions where it was necessary to watch for, or expect change, perceived a more negative impact of the illness on the family and had more psychiatric symptoms themselves.

Unfortunately, the important question about the role that age of onset of disease plays in modifying the effect of psychosocial disorder has not been addressed by appropriate empirical investigation, and the same applies to duration of illness particularly after controlling for age, and age at onset, effects.

Individual susceptibility: The characterization of personality characteristics that modify the risk of emotional problems in the face of illness-imposed stress is rendered difficult in studies of children and their families that take place *after* the diagnosis of the disease has been made. Studies such as that of Perrin and Shapiro (1985) identify the differences between healthy and diseased populations on such characteristics as health locus of control. They interpret their observations (i.e. beliefs in the control of their health by chance and by powerful others were significantly stronger in children with chronic illnesses, and their parents than among healthy children and their parents) as the *effects* of the chronic disorder, and its management. The conclusion about the direction of this putative cause-effect relationship seems premature to say the least, and evidence from large scale prospective studies is awaited before an unbiased assessment of the role of individual predisposition can be made.

Social environmental factors: The social environment, or "psychological situation" (Barker et al. 1978), is a concept that grew out of the intellectual tradition attributable to social psycholgists Kurt Lewin and Egon Brunswick (Moos 1979). It specifies the influences that parents, teachers and other children have on a child's behavior. Realization of the importance of the family "microenvironment" has led to attempts to measure "family functioning" which have resulted in the development of several self-report instruments that have been used, usually cross-sectionally, in chronic illness populations. Although there is no entirely satisfactory measure of family function, there does seem to be abundant evidence that family dysfunction is associated with emotional problems in these children, but again, the direction of the relationship remains uncertain (Pless, Roghmann, and Haggerty 1972; Pless and Satterwhite 1973; McNichol et al. 1973; Friedrich 1979; Lewis and Khaw 1982; Steinhausen, Schindler and Stephan 1983; Sabbeth 1984; Kovacs et al. 1985). Even studies with prospective data that antedate the onset of CPD have not provided the necessary temporal evidence to dissect the risk that family dysfunction confers for emotional problems, apparently the result of confusion about the importance of clearly defining causes and effects in this area. This applies too, to the association of maternal psychological distress with the presence of childhood CPD, another well documented association based mainly on cross-sectional studies (Tew and Laurence 1973; Gayton et al. 1977; Friedrich 1979; Burden 1980; Breslau, Staruch, and Mortimer 1982). British cohort data do show, however, that families with disabled children generally fail to receive as much support from relatives, friends and neighbors (Cooke and Lawton 1984).

Medical environmental factors: In chronic illness, the medical environment is

conceived of as a subset of the social environment. The impact that components of the health care system have on child psychosocial function has been explored mainly for acute illness, especially in relation to preparedness for surgery (Skipper and Leonard 1968). The importance of patient and parent education with respect to psychosocial function in chronic illness has been emphasized (Van Vechten, Satterwhite, and Pless 1977), but this has not yet been subjected to thorough empirical investigation (Nolan *et al.* 1986). Satisfaction with care has been studied in chronic illness, and it appears that seeing the same doctor is associated with improved satisfaction with specialty care (Breslau and Mortimer 1981; Breslau 1982).

#### 5. Social Work Intervention

Mental health services are provided to chronically ill children and their families by a wide range of professionals, including nurses, psychologists, psychiatrists and social workers. There is considerable variation between centres and sub-specialty clinics in the way services are provided and to whom they are available. The lay counsellor and home care interventions described above are examples of relatively unusual or innovative approaches to providing care. The relatively ubiquitous involvement of social workers in the care of children with chronic illnesses underlines at the same time their appeal when designing a "new" approach to the reduction of psychosocial disorder, and also the need to evaluate the effectiveness of social workers operating in this context. The traditional role for social workers has been to organize and mobilize existing resources, but the modern social worker is involved in the assessment of barriers to social functioning, and intervention to expedite behavioral changes (through psychotherapy for example) as well as changes in social conditions (Travis 1970; Rudolph et al. 1985). This metamorphosis has evolved in the absence of controlled evaluation of practice performance in any context, especially in childhood chronic illness. There have been calls from inside the social work profession to conduct such research (Rudolph et al. 1985), and from outside (Rutter 1982), and these calls played a part in the decision to conduct the present study.
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Contemporary social work practice has its theoretical basis in a number of social and behavioral models. This is not surprising, given the multifaceted and eclectic nature of the social work role. Briefly, a popular general model of psychosocial functioning that is both advocated and practised widely, is a *psychosomatic-ecological* model (Lipowski 1973) which views people in dynamic interaction with their environment - physical *and* social (Moos 1979). In the social work context, the "case" is conceptualized as the patient and the relevant features of his "life space", including the health organization (Germain 1977). The harmony, or "fit" between people and their environments can affect, and is in turn affected by, their health (Coulton 1981). Coulton theorizes that "person-environment fit" refers to the degree of congruence or correspondence between an individual's needs, capabilities, and aspirations and the resources, demands, and opportunities characteristic of the environment" (Coulton 1981:26).

The candidates for modifiers of psychosocial function in childhood chronic illness (Table 5) may be incorporated into this theoretical perspective (Figure 1). Components of both environmental and personal systems interact and jointly impinge on the child, whose perception of these factors results in arousal which in turn motivates adaptation efforts. To the extent that these are successful, adaptive or maladaptive change in both physical and mental functional status will occur. These changes transact with the environmental systems in dynamic interplay (Moos 1979). In practical terms, the tasks for the social worker providing assistance to a child with a chronic illness and his family include:

- i) enlarging problem solving and coping abilities,
- ii) obtaining physical resources,
- iii) making organizations responsive,
- iv) facilitating interactions between the patient and other individuals in his environment,
- v) improving communication between the patient, family and the institution,
- vi) influencing social and environmental policy (Rudolph et al. 1985).



An important theoretical implication of the social work role is the <u>capacity</u> to prevent as well as treat emotional problems. This is not a common or conventional situation for the hospital social worker, due largely to severe constraints in available staff and time and the simultaneous heavy demands of crisis intervention, particularly an ever increasing need for the child protection role. Nevertheless, it was proposed that the social worker had the professional training and expertise necessary to undertake the dual role of treating and preventing emotional problems. Prevention here was defined in terms of both primary (preventing the onset), and secondary prevention (preventing the progression) of psychosocial disorder (Feinstein 1985) The approach to the evaluation of success in achieving prescribed outcomes was conceived in terms of effectiveness, rather than

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efficacy, and to this extent, this study is, according the conceptualization of Schwartz and Lellouche (1967), a *pragmatic* rather than an *explanatory* exercise. In particular, there was a deliberate attempt made to restrict the intervention to the usual practices of social workers, with the exception of an increased emphasis on prevention. This would maximize generalizability of the results, and demonstrate the effectiveness of the intervention in a structure that is already largely in place **STUDY HYPOTHESES** 

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# **Study Hypotheses**

The principal question addressed by this study was to what extent does counselling and support for families by social workers reduce or prevent psychosocial maladjustment among children with chronic illness? Prior to its commencement, it was predicted that, compared to the effects of standard care in the control group, social work intervention would result in

i) a lower overall prevalence of patient maladjustment,

ii) more maladjusted patients becoming adjusted (therapeutic, or "curative" effect),

iii) maladjusted patients demonstrating superior improvement in behavior, irrespective of whether or not they are no longer maladjusted (secondary prevention effect),

and, iv) fewer adjusted patients becoming maladjusted (primary prevention effect)

It was reasoned that these positive changes would be associated with improvements in the child's perceived competence, especially in relation to general self-esteem and perceived physical competence, and also in improvements in maternal psychological state and family functioning. Furthermore, it was predicted that these healthy changes would result in fewer contacts with other health service providers.

**METHODS** 

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# 1. Design

A random assignment 2-group parallel comparison, with pretest and posttest was the design chosen to evaluate the effectiveness of the intervention. Such a randomized controlled trial maximizes the internal validity of any assessment of an interventior (Campbell and Stanley 1963) The intervention group received counselling and social support from social workers. A control group received no special social services. They did, however, receive a "neutral" stimulus to control for the increased contact with the hospital. An outline of the study procedure is depicted in Figure 2



Figure 2: Study Protocol

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Following assessment of eligibility, and after informed consent hed been obtained, subjects were interviewed and baseline measures administered. Subsequently, subjects were stratified by the clinic from which they had been recruited, and randomly assigned with equal probability to either intervention or control group. Intervention subjects were randomized a second time within clinic strata to one of 4 study social workers who would deliver the intervention over the subsequent 6 month period. There was a 10 month interval between baseline (Time 1), and second measurements (Time 2). This meant a 4 month delay from cessation of social work contact to the time of the second assessment for intervention subjects. A detailed description of each step of this procedure follows.

# 2. Study Population

Selection process: Subjects were selected from 11 specialty clinics at the Montreal Children's Hospital (MCH). These clinics were chosen to be broadly representative of the full spectrum of chronic physical disorders. The rationale for this choice was based on a desire to reasonably represent this spectrum, but not upon any specific *a priori* conviction about need for assistance, or risk for psychosocial disorder by patients with any particular condition. The heads of these clinics were contacted and persuaded to allow their patients to be considered for the study. Outpatient clinic appointment lists, clinic records and gersonal files from these clinics were used to identify potentially eligible subjects. Only currently enrolled patients were identified. This meant that appointment lists for the preceding 6-12 months were screened for candidates.

Inclusion and exclusion criteria: The following eligibility criteria were dictated by constraints imposed by the outcome measures (age, sensory impairment, cognitive capacity, language); by the need to obtain as clear an estimate of treatment effect as possible, uncontaminated by pre-intervention social interventions; and by logistic factors relating to both the intervention and follow-up of subjects (urban residence, survival for study duration, language). Most importantly, eligibility required the presence of a chronic physical disorder.

a. chronic physical disorder: Subjects were required to be actively followed in a specialty clinic for a physical disorder of at least 3 months' duration. Follow-up was

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considered "active" if return appointments had been made on at least an annual basis. b. age: At the time of enrolment, subjects had to be between 4-15 years. This constraint was defined by the main outcome measure (Child Behaviour Checklist or CBCL) which had been validated for children aged 4-16 years, and given the elapsed time between first and second measurements, the oldest cohort members would be within the reference age range.

c. Montreal urban residence: Because of budget restrictions for the assessments, and realistic working conditions for the intervention social workers, subject residence was restricted to the Montreal urban region

d. normal intelligence: The child behaviour and perceived competence measures had been validated for children without mental retardation Hence, eligibility was restricted to children attending normal school, and known to be mentally competent

e. absence of severe sensory impairment: Children with profound deafness, or who were blind were excluded because the perceived competence measure had been validated only for children who could see or read the questionnaire, and hear the interviewer's instructions.

f. language: French and English are the working languages in the Montreal Children's Hospital. Bilingual social workers were required for the study, and measures were translated into French. At least one parent, and the child were therefore required to speak either French or English.

g. survival: Subjects thought by clinic personnel unlikely to survive 1 year from enrolment were considered ineligible to minimize attrition from the cohort.
h. prior intervention: To minimize carry-over contamination of any effect observed during the study period, families receiving psychotherapy or active social support in any form from a psychiatrist, psychologist, social worker, nurse or other counsellor in the 6 months prior to assessment were excluded prior to randomization. In addition, potential subjects were asked if pre-existing arrangements or contracts

with other mental health or social service agencies meant that study social workers would not be used during the intervention period, and if so, they too were excluded. The receipt of government or other financial benefits and similar forms of economic assistance did not affect eligibility.

Sample size and power: Sample size estimates were based on group prevalence of maladjustment (on the principal outcome measure, decsribed below) at the post-intervention assessment. In addition, power calculations were carried out using continuous scores on the principal measure.

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a. prevalence estimates: It is conceivable that the intervention could exert both a therapeutic and a preventive effect. Individuals abnormal at Time 1 (baseline, or prerandomization measurement) could become normal by Time 2 (postintervention measurement), while individuals who were normal at Time 1 could be prevented from becoming abnormal at Time 2. Previous experience based on a similar cohort of patients with CPD (Heller *et al* 1985), using the CBCL, suggested that the baseline prevalence of maladjustment would be in the region of 15%, and without intervention over the succeeding year could deteriorate to between 20% and 30%. Sample size estimates were calculated

using 1-tailed  $\alpha$ -values of .05 because it was not reasonable to expect that social workers would foster maladjustment. The most likely result was considered to be a simultaneous therapeutic and preventive effect such that intervention would result in a reduction in overall maladjustment prevalence from 15% at Time 1 to 10% at Time 2, while the control group prevalence increased from 15% to 20%. This represents a 33% change in each direction, or a 10 percentage point difference (.10 versus .20) in the Time 2 prevalences of maladjustment for intervention and control groups respectively. Sample sizes estimates were obtained from the Tables of Fleiss (1981). These in turn are calculated from this formula:

$$\mathbf{n}' = \left\{ Z_{\alpha} \sqrt{2\pi(1-\pi)} - Z_{\beta} \sqrt{\pi_{1}(1-\pi_{1}) + \pi_{c}(1-\pi_{c})} \right\}^{2}$$

$$\frac{\pi_{1} - \pi_{c}}{\pi_{c}}$$

where n' is the sample size estimate per group,

Z is a critical value of the normal distribution,

 $\alpha$  is the probability of a Type I error,

 $\beta$  is the probability of a Type II error,

 $Z_{\alpha}$  is the Z-value for  $\alpha$  (2 $\alpha$  for 1 tailed estimates),

 $Z_{\beta}$  is the Z- value for  $\beta$  (in the lower tail only),

 $\pi_1$  is the hypothesized proportion achieving the outcome in the intervention group,  $\pi_c$  the hypothesized proportion achieving the outcome in the control group,

and  $\pi$  is  $(\pi_1 + \pi_c)/2$ 

The following sensitivity analysis (Table 6) displays sample size estimates and power for the scenario described above (on line 1 of Table 6), together with 2 other possible outcomes where there would be no change in the baseline prevalence for the intervention group, but a 10% to 15% point deterioration in the control group. On the basis of these estimates, a total sample size of 350 (175 per group) would be needed to achieve

80% power. In other words, with this sample size and a 1-tailed  $\alpha$  set at .05, we could be

Baseline Prevalence of Maladjustment	Post-intervention Prevalence of Maladjustment			Power
(both groups)	Intervention	Control	N per group	(1-β)
.15	.10 _	.20	176	.80
.15	.15	.25	151	.65
.15	.15	.30	144	.90

Table 6: Power based on prevalence of maladjustment on CBCL,  $\alpha = .05$  (1-tailed).

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80% certain of not missing a 5% change in both directions for intervention and control groups. Power was somewhat less satisfactory (65%) for a situation in which there was no change in overall prevalence in the intervention group but a 10 percentage point difference with respect to the control group. There was adequate power (90%) to detect a difference greater than or equal to 15 percentage points.

**b.** continuous outcomes: Using the behaviour problem summary T-score from the CBCL as a continuous score confers the advantage of the extra information that categorization ignores. The power analysis used for this approach was that described by Cohen (1977) in which a standardized effect size is the parameter of interest. For 2 independent samples, the effect size (d) is the difference in their arithmetic means  $(m_I-m_C)$ 

standardized by the (common) standard deviation ( $\sigma$ ), which is:

$$d = m_{I} - m_{C}$$

where the units in the numerator and denominator cancel, and the effect size is seen in terms of units of common standard deviations<sup>1</sup>. Using the power and sample size tables of Cohen (1977: Tables 2.3.2 and 2.4.1), the following estimates were obtained for a sample size between 160 and 170 per group (Table 7).

Table 7: Power to detect specified effect sizes with 160-170 subjects per group.

Effect Size (d)	Power (1-β)	α	
0.2	.6973	.05 (1-tailed)	
0.3	.8588	.05 (2-tailed)	
0.3	.9294	.05 (1 tailed)	

1,2 Footnotes at bottom of next page.

Therefore, a sample size of 160 -170 per group is  $adequate^{2}$  (Power .69 - .94) to detect a small effect size of 0.2 to 0.3 with a 1-tailed  $\alpha$  of .05.

# 3. Enrolment Procedures

Consent and ethical considerations: With any comparative trial, there are separate issues of consent for intervention and control status. Consent to participate in the study as an intervention subject implies consent to be submitted to the procedure under investigation. In this study, the social work intervention represented no risk to life or health (as indicated by the unidirectionality of the null hypothesis), and was an "overlay" of services above and beyond existing clinic resources. In the control group, subjects were provided with continued access to all the usual clinic and hospital services, so that there was no question of withdrawal of facilities, and no threat to life or health.

It was, however, anticipated in the planning phase of this study that completing the behaviour problem questionnaires could result in some parents recognizing problems that had not surfaced previously. As a precaution, clinic staff were made aware of this possibility prior to the commencement of the study. Consent forms in English and French (Appendix 2) were signed by the mother or father or both parents at the time of the first interview, following final screening for eligibility, and before baseline measurement.

Assessment of eligibility: Screening for eligibility prior to randomization was carried out in four phases (Figure 3). Identification of subjects from computerized outpatient appointment lists and clinic records was followed by age and diagnosis screening. Access to the centralized hospital patient computer data base provided information missing from

<sup>&</sup>lt;sup>1</sup> Cohen (1977) has related effect size to well known differences between groups to assist in understanding what small to large effect sizes might be. For example, a small effect size (d = 0.2) represents the difference in mean IQ between twins and nontwins, or the size of the difference in mean height between 15 and 16 year old girls. A medium effect size (d = 0.5) is one large enough to be visible to the naked eye, and is equivalent to the difference in mean IQ difference between holders of the Ph.D. degree and typical college freshmen, or the mean difference in height between 13 and 18 year old girls.

<sup>&</sup>lt;sup>2</sup> The summary behaviour problem T-score on the principal outcome measure, the Child Behavior Checklist, is a standardized score with a standard deviation of 10. An effect size of 0.2 common standard deviations is equivalent to 2 points on this scale.



outpatient and clinic records. In this preliminary phase (Phase I), subjects who were seen in clinics for once-only consultations, and who were not given follow-up appointments, were excluded. Similarly, home addresses outside the Montreal urban region and age less than 4 or greater than 15 years resulted in omission. If the head of the clinic, or clinic co-ordinator were aware of current or recent psychosocial assistance being provided to a family, it was excluded. More than 800 subjects were considered at this stage, of whom, 615 were thought to be eligible, and were mailed an introductory letter (Appendix 2). This introduced the study, and informed them that someone would telephone within 1-3 weeks to arrange an interview.

The telephone call represented Phase II of the screening process, and consisted of a structured interview (Appendix 3) which was conducted by a trained interviewer who probed for information about type of school attended by the subject, presence of sensory impairment, language spoken and whether psychosocial support was being received. If still considered eligible, and if verbal consent was given by the parents, an appointment was made by the interviewer for a home visit, usually within 1 to 2 weeks.

The home interview (Phase III) began with further specific questions (Appendix 4) about recent psychosocial support. Finally, where questions about eligibility had arisen during this interview, a final review (Phase IV) was undertaken by the project administrator and the principal investigator (TN). In some cases, referral back to clinic staff or to the hospital record was necessary to confirm the presence of a chronic disorder, and in others checks were made with the Social Work Department about the extent and timing of social services. Following the screening process, 474 subjects remained eligible. **Baseline assessment**: This assessment took place at the first home interview (see Figure 2), and since this was a pretest-posttest design, it included prerandomization administration of outcome measures (see Section 5, below). This interview was conducted by a trained interviewer using a standardized questionnaire (Appendix 4). The respondent was the 'mother in 88%, the father in 4% of cases, and both parents in 7%. Data were collected on a range of demographic variables, the details of which are given in *Results*. **Stratilication, blocking and study group assignment**: A decision was made to

stratify subjects by the clinic from which they had been recruited to avoid the chance occurrence of an imbalance in the number of subjects within individual clinics in each assignment group. Although specific diagnosis was not considered an important prognostic factor for psychosocial maladjustment, it was felt that published results would be more credible to the practicing clinician. Accordingly, 11 strata (for the 11 clinics) were constructed and subjects were randomized with equal probablility, following baseline assessment (see Figure 2), to either intervention or control group A block size of 8 was employed to further prevent imbalance within strata, and the whole procedure was carried out using the PLAN procedure in the SAS statistical package (SAS Institute 1985)

For subjects assigned to intervention, a second randomization (with block size of 4) to one of four study social workers was carried out, preserving the clinic stratification. This meant that each of the four social workers was assigned approximately equal numbers of subjects from each clinic. The randomization procedure was carried out in the following manner The principal investigator prepared the randomization schedule with the PLAN procedure and the project administrator transferred the schedule from the computer printout to a record book, with separate sections for each of the 11 clinics As interviewers returned questionnaires, they were vetted by the department secretary for last minute exclusions due to ineligibility, and  $catalo_{\hat{k}}$  .ed, by clinic, in order of arrival at the office This sequence was matched to the randomization schedule, without alteration, by the project administrator Neither she, nor the secretary were permitted any alteration either to arrival sequence, or to the randomization schedule. Lists of subject details were prepared in batches as they became available for the social workers These lists contained names, addresses, phone numbers and clinic names The order of names on these lists was in the sequence that interviewing had taken place, that is approximately 10 weeks from the first to the last subject This order was, broadly speaking, the order in which social workers contacted families A copy of the list of intervention group subjects was kept by the secretary in the social work department. She was instructed to monitor all new referrals to that department (apart from those to study social workers), and to notify the principal investigator if a referred patient was a study subject. This procedure was designed to avoid co-intervention within the intervention group, over and above that prescribed for the study. As it happened, this did not occur.

## 4. Intervention

Description and schedule: The intervention, namely social support and counselling, was provided by 4 social workers based at the Montreal Children's Hospital A minimum intervention was defined to ensure uniformity of a basic level of support to all families, but social workers were at liberty beyond this minimum to engage in whatever activity they considered appropriate and necessary for their clients. This included "upward" referral to psychiatric or psychological personnel, or to community-based health professionals. The criteria for minimum intervention were

- 1. a 6 month period of attachment,
- 11 2 personal contacts with the child and parent,
- iii a home assessment (which could double for one of the personal contacts),
- iv. monthly telephone calls,
- v contact with the whole family, including father and other siblings.

Funding was available for two full-time equivalent positions The decision to hire 4 social workers on a half-time basis was made to reduce the dependence of observed effects on individual social workers, and to provide more flexibile working hours

Recruitment and description of social workers: Four social workers (3 females and 1 male) were recruited from the Ville Marie Social Service Agency, the department within the Quebec Provincial Department of Social Affairs responsible for professional staffing of hospitals and social welfare agencies in the region served by the Montreal Children's Hospital Attempts were made to hire social workers already employed by MCH, but problems with loss of seniority, overtime requirements and lack of suitable applicants necessitated seeking workers through Ville Marie. Applicants were interviewed by the heads of Ville Marie and the Department of Social Services at MCH. Selection was based on the usual requirements for pediatric social workers. These included personal characteristics, relevant experience, bilingual proficiency, and formal qualifications. Details

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of the four social workers hired for the study are given in Table 8

Social Worker	Age	Sex	Qualification	Experience
1	40	F 🍌	Master of Social Work	4yr hospital, institutional and private adolescent and family services.
2	40	Μ	Bachelor of Social Work	lyr private practice.
3	32	F	Master of Social Work <sup>†</sup>	2yr in mental health and planned parenthood settings
4	31	F	Bachelor of Social Work	lyr general hospital, lyr MCH.

Table 8	: Social	worker	charac	teristics.
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Master of Social Work awarded during study period.

These social workers were hired for a 9 month period to allow for training and accrual of their clientele, together with an opportunity to complete records, clinical logs and study questionnaires relating to individual clients following completion of the attachment period. **Training:** Special training was kept to a minimum. As outlined in Section 5 of the Introduction, the decision to focus on social workers as the providers of the intervention in this study was made because, unlike nonprofessional family counsellors or even public health nurses, they are already part of the health care system which is broadly responsible for the psychosocial needs of children with chronic diseases and their families. Therefore, after taking account of the specific aims of the intervention under investigation, it was considered important to replicate as closely as possible the conventional mode of social worker professional activity.

A two-phase orientation and training schedule began with a 2 hour briefing period by the principal investigator, project administrator, the head of the Social Services Department and the two senior supervising social workers. Study social workers were

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given a copy of the study protocol with all sections relating to outcome measures, analysis and references deleted They were introduced to the notion of the non-categorical approach to chronic illness, and their preventive role was emphasized Primary emphasis was placed on promoting child self-esteern. Secondly, the importance of fostering a realistic perception of personal strengths and weaknesses, and of creating a better understanding of the true nature of the disease impact on children, especially the way in which individual patients might feel they were perceived by others, was emphasized. This approach was of course complementary to the specific therapeutic role of dealing with immediate problems.

The parent (especially maternal) role in dealing with the difficulties of a chronic illness was also a specific focus Developing positive, adaptive patterns of intra-family communication was seen as an important target. So too, was facilitating communication with clinic staff, especially in relation to information about the medical aspects and future implications of the child's condition Minimizing the economic impact of the illness was specified as a major, practical contribution to be achieved where possible through the appropriate, resourceful utilization of hospital, community and governmental aid.

The second phase of the training period was supervised by senior social workers from MCH, and included familiarizing the social workers with the operating procedures and policies of the hospital service. Medical records for all patients were studied, summarized and discussed with supervisors by the study social workers prior to the first contact.

Supervision and quality control: A senior MCH departmental social worker acted as supervisor for the 4 study social workers. She conducted weekly group meetings where problems with individual clients were discussed, advice sought and progress monitored. The principal investigator attended most of these meetings for a 15 to 30 minute period in order to maintain surveillance of prescribed procedures and to facilitate communication with clinic medical staff when required. Each social worker's client log was available for regular

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scrutiny, and a cover sheet detailing occasions of contact was monitored from time to time **Record keeping:** Social worker logs consisted of a summary contact sheet (Appendix 5), designed to assist the social worker in monitoring contacts with clients, and to serve as a rapid summary of case status should a telephone or other similar impromptu consultation occur This sheet also allowed auditing to ensure that subjects had not been neglected with respect to the minimum intervention. Social workers also kept a comprehensive set of case notes, as would be the case in usual practice In addition, a clinical summary of all important events and final staus was prepared on termination of service

**Compliance**: The issue of treatment compliance is somewhat more abstract for a social intervention such as the one under investigation, than it is, for example, for a pharmacologic agent. Identification of subjects who did not receive the prescribed treatment was achieved through reports by their assigned social workers. The major source of noncompliance was outright refusal to see the social worker, even after signing the consent form and agreeing to do so, if randomized to the intervention group. These events were easy to identify and will be reported in the Results. Since no true placebo could be offered to the control group, an equivalent estimate of compliance could not be obtained.

**Control stimulus:** Although there is considerable skepticism (because of a lack of widespread evidence) over whether the so-called "Hawthorne effect" is an important problem in the evaluation of social interventions (Cook and Campbell 1979), it was decided that a token control stimulus would be administered to compensate for the "aura" of the extra attention from the hospital associated with the social work intervention. Consideration of a suitable proxy for this effect led to two procedures that were also designed to facilitate follow-up and minimize subject attrition. First, following randomization, control families were notified by telephone of their control status. Specifically, they were told that no social worker would visit them from the research project, but that an interviewer would contact them again in approximately 1 years' time for a second interview. A trained research assistant conducted the phone call according to a rigidly prescribed schedule (Appendix 6)

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Although subjects were warmly thanked for their continued participation in the study, the caller was strictly instructed not to engage in any discussion about the subject or parents, especially in relation to any perceived psychosocial problems. Second, a letter (Appendix 7) was sent at the midpoint of the intervention period to all control families. This letter again thanked them for their cooperation in the study, reminded them of the forthcoming second interview, and asked for notification of any change of address. A copy of the hospital newsletter (usually circulated to friends of the hospital, staff etc.) was included as a token of appreciation

## 5. Outcome Assessment

The purpose of this study was to evaluate the effectiveness of social worker-provided support and couselling in the treatment and prevention of psychosocial maladjustment. The primary outcome is based upon the child's actual behaviour, as reported by the parent. Related outcomes include the child's perceived competence, and the mother's psychological state. Measures of the effect of the child's illness on family functioning and the overall social and economic impact on the family were also considered relevant and potentially modifiable, either directly or indirectly, through the intervention, as was the impact on health service utilization.

The choice of paper and pencil measures of the the various constructs outlined above was guided by the need to use standardized, recognized instruments of known validity and reliability. This serves the additional purpose of enhancing the utility of the study results for researchers in other centres, including replication if appropriate. It also made the study economically feasible, since a comprehensive individual psychiatric assessment of 345 subjects and their families twice within a year would be unrealistic, and probably unnecessary.

The following description of the standardized instruments used in the study includes a general outline of the measure, its origin, the construct it addresses, the structure and content of the questionnaire, subscale structure, scoring procedures and finally psychometric properties. Where possible, test validity, specifically content validity, criterion-referenced properties and discriminant and convergent aspects of construct validity, will be described. Test reliability, when assessed, will include a discussion of properties of internal consistency, reproducibility and evidence for observer variability. Subsidiary measures, that is measures not directly related to outcome assessment, will also be described. These relate to assessment of functional status, and the parents' and social workers' questionnaires designed to tap subjective perceptions of the intervention experience.

Child Behaviour Checklist: The Child Behaviour Checklist (CBCL) of Achenbach and Edelbrock (Achenbach 1978,1979; Achenbach and Edelbrock 1979, 1983) was the principal outcome measure (Appendix 8). It consists of two parts: the Child Behaviour Profile which contains behaviour problem scales, and the Social Competence Scales This measure was empirically derived in response to a recognized lack of standardized procedures for describing child behaviours. The scales were constructed from principal components analyses of CBCL's filled out by parents of children referred for outpatient mental health services. Development of the scale was conducted separately within 3 age groups, namely 4 to 5, 6 to 11, and 12 to 16 years, since these age categories represent important transitions in cognitive, physical, educational and social-emotional development. The Child Behaviour Profile is generated from 118 parent-completed items<sup>1</sup> (Appendix 8:3-4).

The sum of the raw scores from these 118 items is standardized to a mean of 50 and a standard deviation of 10. This total is called the summary behaviour problem T-score, and is the principal outcome measure for this study. This score can be viewed as # "representing a dimension of behavioural problems analogous to the construct of general

<sup>&</sup>lt;sup>1</sup> The items are statements about behaviour, and are scored on a 0-2 scale. They include, for example; "Cries a lot (item 14); Gets in many fights (item 37); Feels too guilty (item 52); Unhappy, sad or depressed (item 103)". The parent is asked to respond "Not True, Somewhat or Sometimes True, or Very True or Often True", to each item for their child ".....now or within the past six months".

ability represented by total scores on intelligence tests " (Achenbach and Edelbrock 1983:70).

Boys			Gırls			
4-5 yr	6-11 yr	12-16 yr	4-5 yr	6-11 yr	12-16 yr	
Aggressive	Aggressive	Aggressive	Aggressive	Aggressive	Aggressive	
Somatic	Somatic	Somatic	Somatic,	Somatic	Somatic	
Schizoid	Schizoid-Anx	Schizoid	Schizoid-Anx.	Schizoid-Obs.	Schizoid	
Social withd.	Social withd.	Hostile withd.	Social withd.	Social withd.	Depressed-Withd.	
Depressed	Depressed		Depressed	Depressed	Depressed-Withd.	
Delinquent	Delinquent	Delinquent	-	Delinquent	Delinquent	
	Hyperactive	Hyperactive	Hyperactive	Hyperactive	Immature hyper	

Table 9. CBCL narrow-band subscales for behaviour problems.

Factor analysis-derived behaviour problem subscales are also constructed from the 118 questions Standardized T-scores are generated for each of these subscales Table 9 displays the subscales by age-sex group. Note that only Aggressive, Somatic Complaints, Schizoid, and Withdrawal subscales exist across all 6 age-sex categories Only 5 (4.2%) of the 118 behaviour problem items that could specifically refer to a chronic physical illness, or its symptoms: "Allergy (item 2), Asthma (item 4); Bowel movements outside toilet (item 6), Constipated, doesn't move bowels (item 49); Wets self during day (item 107)" Since this is a randomized trial, and especially since subjects were stratified by clinic (and therefore diagnosis) before randomization, these do not represent an issue for confounding.

The Social Competence Scales (Appendix 8.1-2) are constructed from 10 items relating to questions about the type and level of social and sporting activities, and hobbies that the child is engaged in at the time of completion of the CBCL. They include questions to the parent about scholastic performance. Standardized T-scores for activities, social and school subscales are derived from these items<sup>1</sup>, in addition to a summary social competence T-score.

The CBCL data were entered directly from the questionnaire onto an IBM

<sup>1</sup> There is no school subscale for 4-5 year olds.

personal computer using the entry and scoring program supplied by the authors of the scale (Achenbach and Edelbrock 1985). This interactive program handles each questionnaire, one at a time, in 3 separate steps: first, responses to all social competence and behaviour problem items are entered; second, a *verification* step requires a repetition of entry of these responses, but the second entry is checked against the first, item by item, and the keyboard operator is alerted if discrepancies occur, allowing the appropriate correction to be made.

Finally, the verified data are processed in the scoring step of the program. The output consists of raw scores, and standardized T-scores for the summary results (behaviour problems, and social competence), as well as for the narrow-band behaviour problem subscales.

The CBCL was chosen as the principal outcome measure for this study because of its well-documented and impressive psychometric properties. Its *content* validity whether the CBCL items represent the domain it intends to measure - is evident from perusal of the 118 behaviour problem items (Appendix 8:3-4), selected on the basis of concern to both parents and mental health workers. Referral for mental health services was the "gold standard" chosen to assess the *criterion-related* validity of the CBCL, made necessary by the absence of established, universally accepted diagnostic criteria. A normative group of children was randomly selected from the general population. There were significant (P<.001) differences between demographically-matched referred and nonreferred children on all CBP scoreş and subscores for all age-sex groups. The cross-validation procedure employed by Achenbach and Edelbrock (Achenbach and Edelbrock 1983:68) indicated that using the 90th centile of the summary behaviour problem score as a cut-off, test sensitivity was 76.1% and specificity 89.1%. For a prior probability of referrable behaviour disorder of 20%, this represents a predictive value positive of approximately 63%, and a predictive value negative of 94%.

Construct validity, involving coherence in the results of other measures intended to reflect the hypothesized variables in different ways (Cronbach and Meehl 1955), was satisfactorily defined with concurrent assessments on the Connors Parent Questionnaire

(1973), and the Quay-Peterson Revised Behaviour Problem Checklist (1983), using a clinically referred reference sample of Canadian and US children (Achenbach and Edelbrock 1983).

With respect to reliability, intraclass correlation coefficients greater than .90 were obtained between item scores obtained from mothers filling out the CBCL at 1-week intervals, mothers and fathers filling it out for clinically referred children, and 3 different interviewers obtaining CBCL's from demographically matched triads of children. Item stability over 3 months for mothers' ratings of individual items was .84 for behaviour problems and .97 for social incompetence items. For total behaviour problem and social competence scores, and for subscale scores, the median 1-week test-retest correlation was .89 for mothers' ratings. The median correlation between mothers' and fathers' ratings was .66. As a measure of test sensitivity to change, parent ratings on an inpatient sample showed significant decreases in behaviour problem scores on most subscales over a 3 month period. For outpatients, 6- and 18-month treatment periods resulted in significant decreases in behaviour problem scores for all age-sex groups, and for 6-11 year olds, significant improvement in competence scores.

Child and Adolescent Adjustment Profile: The Child and Adolescent Adjustment Profile, or CAAP (Ellsworth 1981), is a 20 item instrument which purports to measure 5 factor-analyzed areas of psychosocial adjustment (Appendix 9). These subscales are labelled Peer Relations, Dependency, Hostility, Productivity and Withdrawal, with 4 items for each subscale <sup>1</sup>. There is no subscale for depression or anxiety <sup>2</sup>. The parent completes the questionnaire, and the reference period is the preceding month. The anchor points for responses to the 8 questions in the Peer Relations and Productivity sections are: *rarely*, *sometimes, often , and almost always*. For the other 3 subscales, they are *never, rarely*, *sometimes, and often*. The CAAP is a refinement of the PARS II Scale, which was a 55 item, 6 factor scale derived from an original pool of 292 items selected from a review of previous studies, with input from mental health workers (a reflection of *content* validity)<sup>2</sup>. Scoring is carried out by the coder on the questionnaire, using a template. Responses are recorded as 1 (for never or rarely) to 4 (often, or almost always). Raw scores range from 4 to 16 for each of the five subscales. Higher scores represent negative characteristics on Dependency, Hostility and Withdrawal subscales, and positive attributes on Peer Relations and Productivity subscales.

The validation sample consisted of 203 normal children and adolescents (3-19 years), 90 individuals referred to mental health centres (assessed before, and 3 months after treatment) and 89 probationers. With respect to *criterion-related* validity, the pretreatment referred group scored significantly worse on Hostility and Withdrawal subscales than all other groups. The normals did significantly better on all subscales except Hostility. The posttreatment referred group showed significant improvement (P<.01) on Dependency, Hostility and Withdrawal. Within the normal group, older children scored significantly less on Dependency, and younger children significantly less on Productivity. This is the only evidence provided by the authors of the CAAP for *construct* validity. Internal consistency

 $\alpha$ -coefficients ranged from .8 to .9 for the 5 subscales. Test-retest reliability (one week interval) resulted in correlation coefficients of between .8 and .9 (not adjusted for attenuation). The authors of the CAAP have not provided evidence upon which to justify using cut-off points to classify adjustment vs. maladjustment. The profile sheet that accompanies the measure (Appendix 10) specifies areas of good, average and poor adjustment based on standardized T-scores for each subscale. The demarcation of average-poor adjustment

All items are in the form of questions; e.g. "During past month, has he/she .....laughed and smiled easily? (item 4); Become discouraged when attempted something on own? (item 6); Picked quarrels with others? (item 11); Made full use of abilities? (item 15); Appeared indifferent and uninterested in things? (item 19)".

<sup>&</sup>lt;sup>2</sup> Reduction to 20 items was undertaken using the following criteria: (1) sensitivity of items to pre- and posttreatment differences on youngsters referred to mental health centres, (2) item sensitivity to group differences (normals vs. delinquents vs. children referred to mental health centres), (3) magnitude of factor loading on one of the 5 factors, and (4) internal consistency, and test-retest stability. It is important to note that items relating to anxiety and depression were dropped from the scale construction prior to assembly of the PARS II Scale, and therefore also from the CAAP (Ellsworth 1981:2). The anxiety-depression factor did not hold up across all age-sex groups, and its omission represents a serious drawback for the use of this scale as a comprehensive measure of child behavior.

corresponds to 1 standardized standard deviation below the standardized mean. This is equivalent to raw scores of approximately: < 11 (Peer Relations), >12 (Dependency), > 12 (Hostility), < 9 (Productivity), and >9 (Withdrawal). Misclassification rates based on these cutoffs are unknown.

Perceived Competence scales: Self-concept measurement is important in relation to mapping the impact of all kinds of life stress, particularly chronic illness. The relationship between perceived competence and behaviour disorder is not well worked out, and this is at least partly attributable to problems with measurement. The Perceived Competence (PC) scales developed by Harter (Harter 1982, 1983; Harter and Pike 1984) recognize that the assumption of Coopersmith (1967) and others that children do not make distinctions among domains in their lives such as cognitive competencies, physical skills, popularity, physical characteristics and acceptance by parent, is open to serious question. Harter proposed that children possess a general sense of self-worth or self-esteem over and above specific self-evaluative judgements within specific life domains. This global self-evaluation is not, however, a simple additive combination of the discrete domains. As a result, her factor-analyzed scales for school-aged children contain subscales including a general self-esteern or self-worth factor, but no overall summary score. Three versions of the PC scales were used in this study. The Pictorial Scale of Perceived Competence and Social Acceptance for young children (Harter and Pike 1984) was used for children who were aged 4 to 6 years at the time of baseline assessment (Appendix 11). It was administered by a trained interviewer, in the home and in the absence of parents or other siblings. It consists of 24 items, and exists as a preschool-kindergarten version, and a grade 1-2 version, the minor differences relating mainly to the different levels of literacy and numeracy between these groups.

Two general constructs, perceived competence and social acceptance were defined for this scale, with 2 subscales within each construct. These are Cognitive and Physical Competence, and Peer and Maternal Acceptance. There is no self-worth subscale

for this measure, since theoretical and empirical evidence indicated that younger children are probably not capable of making judgements about their overall worth as persons.

Administration of the instrument involves the use of a "structure alternative format"<sup>1</sup>. Scoring is done from an answer sheet by the coder, using a template, with scores for each item varying from 1 (low perceived competence or acceptance) to 4 (high perceived competence or acceptance). The scores for each of the 6 items per subscale are summed and averaged to give 4 separate scores, with a possible range of 1 to 4 for each of the subscales. For older children, two versions were used. The original PC scale (Harter 1982) was used for children aged 8 to 12 years. Its revision (Harter 1983), the Self-Perception Profile for Children, had been validated for children in the 13-16 year age group, and it was for this age group that it was used in this study. Both these measures use the "structure alternative format", but are not accompanied by pictorial representations of the items. The subject reads and marks his or her copy of the questionnaire, while the interviewer reads the questions aloud to the subject. The PC (Harter 1982) scale contains 28 items, with 4 subscales of 7 items each, which are scored in the same way as the pictorial version (Appendix 12). The subscale titles are Cognitive Competence, Social Competence, Physical, Competence and General Self-esteem. The revised Self-Perception Profile for Children (Harter 1983) has 36 items, with 6 subscales of 6 items each, also administered and scored in the same way (Appendix 13). The subscale titles are Scholastic Competence, Social Acceptance, Athletic Competence, Physical Appearance, Conduct and Behaviour, and General Self-worth. Scoring is carried out by the coder directly from the questionnaire, using a template.

The PC and and its revision are validated for administration by an interviewer who is present during administration (either individually, or in a group). Since this was the only measure to be completed by the child in this study, a difficult situation presented itself

<sup>&</sup>lt;sup>1</sup> From a handbook of paired pictorial representations of dual statements, the interviewer reads to the child: "This girl has lots of friends to play with. (points to figure). This girl doesn't have very many friends to play with (points to figure). I want you to tell me which of these girls is the most like (child's name)". If the child nominated the latter, she is then asked, "Do you have a few, or hardly any friends?" (item 2).

during the design phase. The presence of school-aged children at the interview in the home necessitated restricting home visits to evenings or weekends. In addition, the baseline measurement was scheduled to take place in the Fall and Winter, and the funding for the study could not be delayed Following successful field trials, it was decided, therefore, to administer these instruments over the telephone subsequent to the home interview. Procedures were designed to facilitate this with the interviewer reading the statements of the scales to the subject over the telephone, while the subject followed with his or her own copy of the measure at home. The interviewer (and not the subject) marked the child's verbal responses to the questions for each proposition. A detailed description of the procedures involved, and the results of factor analyses and internal consistency analysis of the baseline results on the telephone administered measures is given in Appendix 14. These analyses showed that Harter's factor structure and reliabilities were reasonably well replicated, and it was concluded that telephone administration did not interfere with the tapping of specified domains as outlined in the original descriptions of the measure.

Validation of a perceived self-competence measure relies principally on convergent and divergent evidence for *construct* validity, since no criterion reference exists. Apart from factor patterns that were clean and consistent with *a priori* theoretical specifications, the authors of the scales have relied on correlations with other assessments or subject characteristics that reflected aspects of perceived competence. For the Pictorial Scale of Perceived Competence and Social Acceptance for young children, 91 subjects were asked about specific cognitive and physical skills and why they felt they were competent or not competent in these areas. More than 95% gave coherent and consistent reasons for their self-assessments. This convergent evidence was supplemented by strong discriminative associations of school failure with poor cognitive competence scores, lower peer acceptance scores for new pupils at kindergarten and school, and lower scores on physical competence for children who had been preterm infants. Published internal consistency  $\alpha$ -coefficients varied from .52 to .85. Assessments of validity for the PC scale in older children has been far more extensive (Harter 1982). Evidence from over 2,700 assessments is summarized in Table 10, which documents high internal consistency and test-retest reliability for all subscales, together with the evidence for construct validity. For the revised version of this scale, used in this study for 13-16 year olds, Harter's evidence (Harter 1983) and our own (Appendix 14) supports a 5 factor structure on the basis of a principal components analysis with Promax rotation, and a sixth General Self-worth factor based on theoretical considerations. Subscale internal consistency  $\alpha$ -coefficients ranged from .75 to 84 in her sample of 748 Grade 6 and 7 children. There are no published data at this time to provide evidence for construct validity of this revision

Malaise Inventory: The so-called "Malaise Inventory" is a 24 item<sup>1</sup> self-administered scale originally used in the Isle of Wight Survey in the 1960's (Rutter, Tizzard and Whitmore 1970; Appendix 15) It was derived from the Cornell Medical Index (Brodman *et al.* 1949), with fourteen of the twenty-four questions being taken directly from it. These and the 10 new items were chosen by Rutter and Graham "to sample, in a small number of questions using simple language, the different types of emotional disturbance commonly seen in adults." (Rutter, Tizard and Whitmore 1970.339).

For the baseline, assessment mothers were not specifically directed to a reference penod beyond the content of the question itself (often, most of the time, etc) However, at the second measurement, they were asked to answer these questions only in relation to the preceding 6 months. Unfortunately, documentation of psychometric properties of this scale is meagre. The Isle of Wight study reported that mothers of children without problems scored significantly lower than mothers of children with physical or

<sup>&</sup>lt;sup>1</sup> Each item is a short question to which the respondent replies by circling either 'yes' or 'no'. The items mainly reflect somatic symptoms and accompaniments of depression; e.g. "Do you feel tired most of the time?" (item 2); Do you usually wake unnecessarily early in the morning?" "Have you ever had a nervous breakdown?" (item 24).

Domain	Internal Consistency	Test-Retest Reliability*	Construct Validity		
	Coefficient a		Convergence	Discrimination	
Cognitive Competen	75- 83 ce	78	Teacher-Subject. r = .4 Age trend by year: r = .28, .32, 5, .55 <i>lowa Test of Basic Skills</i> : r = .27, .4, .45, .45	Learning disabled children had signific antly lower scores	
Social Competer	75- 84 nce	75, .8	Roster & Rating Scale § r = .59	Athletic 6 <sup>th</sup> graders signific antly higher scorers than nonathletic pupils	
Physical Competer	77- 86 nce	8, 87	Gym Teacher Ratings r = .62	Athlefic 6 <sup>th</sup> graders significantly higher scorers than nonathletic pupils	
General Self- Esteem	73- 82	.69	Highest intercorrelations with other subscales r = .4-58	-	

Table 10 Perceived Competence Scale for children: test properties.<sup>†</sup>

<sup>T</sup>derived from Harter, 1982

\*Corrected for attenuation

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psychiatric disorders A test-retest measure of reliability (2 month interval), resulted in a correlation of .91, based on a sample of 35 mothers. Rutter, Tizard and Whitmore (1970:340) report that the scale was able to differentiate "moderately well between parents with and without psychiatric disorder (as determined from information obtained at interview)." Scores of 6, 7 or 8 and greater have been advocated as meaningful to represent "above average disturbance" (Rutter, Tizzard and Whitmore 1970; Burden 1978, 1980, Pless 1986), but there is no published evidence to assess misclassification rates based on these scores. A conservative decision was made, therefore, to use a cut-off of 8 or greater in all

categorical analyses involving this measure. It is recognized that this measure leaves a lot to be desired, in the absence of a thorough documentation of its properties. Nevertheless, its *content* validity, brevity, and rudimentary support for *criterion-related* validity was enough to sustain its retention in this study, though demanding caution in the interpretation of results.

Family function measure: There is, as yet, no adequate measure of family function (Walker and Crocker 1987). For the purposes of this study, the Family Functioning Index (FFI) of Pless (Pless and Satterwhite 1973) was used as the basis for an attempted new 7 item scale<sup>1</sup> relating to this domain (Appendix 16) Scoring of 2,1 and 0 for each item results in a maximum score of 14 which reflects the best possible level of family function on this measure. Single parents score 0 for the last 2 items, the inherent assumption being made that the absence of a partner reflects a disadvantage in this domain.

Impact on Family Scale: This instrument was designed to measure the effect of the child's condition on the family's adaptation (Stein and Reissman 1980; Appendix 17). There are two versions of this scale, one with a factor analysis solution based on a relatively middle class sample of 100 families (Stein and Reissman 1980), and the other based on data from a sample (N=207) with a much higher proportion of urban poor (Stein and Jessop 1985). The former version was chosen because of the demographic characteristics of the Montreal population.

The measure has 32 items, of which 24 are scored and used to construct the 4 subscales (Financial (4), Familial/Social (9), Personal Strain (6) and Mastery (5)) which are summed to give a Total Impact score. Statements are read by the interviewer to the parent who responds on a Likert scale of "Strongly agree, agree, disagree, or strongly disagree" for

<sup>&</sup>lt;sup>1</sup> There are 5 items which relate to family life in general, eg. "Would you say, all in all, that your family is happier than most others you know, about the same, or less happy?" (item 1). The reference period is the preceding 6 months, and the questions were administered by the interviewer. The last 2 questions relate specifically to spouse/cohabitant relationships, eg. "Do you feel that the relationship you have with...... (name) is better than most, about the same, or worse than most other couples have with each other?" (item 6).

each item. The score of 4 is given to the response which reflects most impact, so that the maximum Total Impact score is 96.

*Content* validity in this scale was sought by choosing items from a pool generated from qualitative data in patient interviews, literature reviews and contributions from clinicians experienced in the total care of children with chronic illnesses. The factor analysis produced a factor pattern consistent with the hypothesized relationships within the

various sub domains of this construct. Internal consistency  $\alpha$ -coefficients varied from 60 (Mastery) to .86 (Familial /Social) for the subscales, and was 88 for Total Impact Further validation has been carried out on the second version of this scale only (Stein and Jessop 1985) Total Impact scores were positively correlated with low education, low family income, the presence of welfare, mothers' perception that the child is difficult to care for, poor functional status of the child, hospitalizations, other health care utilization, school absence and many other measures provided convergent evidence for *construct* validity **Parent questionnaire**: This questionnaire (Appendix 18) was specifically designed for the postintervention assessment of parents' experiences with the social workers. Fourteen questions required categorical responses, and there were 2 open-ended questions. The intent was to document the perceived helpfulness or harm attributable to the social work in relation to the child, the parent and the family as a whole. Parents were also asked about specific attributes of the social worker, including knowledge of the child's illness (and whether this was important to them), empathy, perception of problems, resourcefulness and counselling skills.

Social worker questionnaire: Social workers also completed a questionnaire (Appendix 19) for each of their attached families at the completion of the study period. This was designed to document the social worker's perceptions of child, maternal and family psychosocial functioning, level of intervention required, obstacles to intervention, proportion of total time with individual family members, services provided and above all, perceived response attributable to the intervention. There were 20 items, all requiring categorical

### responses.

Service utilization: Parent-reported occasions of health service utilization were also used as an outcome measure. These included visits to MCH clinicians, visits to non-MCH clinincians and hospitalizations. The reference period for ascertainment of these events was the preceding 6 month period.

Subsidiary measures: Apart from controlling for residual confounding following randomization, the identification of possible effect modifiers is important to detect subgroup effects which contribute to an overall group effect, or effects that are real, but masked by a lack of effect in the balance of the group. Significant interactions between treatment and subgroup characteristics provide clues for the testing of future hypotheses (Simon 1982)

> a. socioeconomic status: Green (1970) described a method for the imeasurement of socioeconomic status (SES), valid for use in health behaviour settings. Based on regression-derived weights, a 2-factor Green score is generated from information about maternal level of schooling, and occupation of the head of the household. Years of maternal schooling is translated to a score from a table provided by Green Similarly, occupation of the head of the household is scored from a comprehensive manual of occupations. A weighted sum of these 2 numbers gives the Green SES score according to this formula:

0.7 (maternal education) + 0.4 (occupation of household head) = Green score.

For the purposes of this study, the Green score was categorized arbitrarily to broadly represent 4 SES groups: scores less than 50 (lowest SES), 50 - 59 (low SES), 60 - 69 (high SES), and 70 and above (highest SES).

**b.** functional status: The possible non-linear relationship of functional status to psychosocial morbidity was discussed in the Introduction. The 18 items that had been resolved under the the title "General Health" in the Functional Status II

measure of Stein and Jessop (1982,1984) were chosen as the index of functional status for this study (Appendix 20). Each question relates to specific activities of the child over the preceding 2 week period. If the respondent answers in the affirmative, the interviewer asks "Was this due to illness?". Examples include "Eat well? (item 1); Seem lively and energetic?; and Participate in hard exercise or play?" (item 15). Scores are only assigned if the behaviour is attributed to illness - one for "some of the time", and zero or two for "never or rarely, or almost always" depending on the question. A high score reflects dysfunction. For the purposes of categorical analysis, scores were grouped into 4 categories. no dysfunction (0), mild dysfunction (1-2), moderate dysfunction (3-4), and "severe" dysfunction ( $\geq 5$ )

### Procedures:

a. translation and pretesting of measures: All measures were administered in French and English by bilingual interviewers. The CBCL had been previously translated and successfully used in other Quebec studies (Heller *et al.* 1985). Professional translators, experienced in the health field, were hired to translate all measures. After resolution of problems with occasional difficulties in expression, these translated measures were back translated into English by another experienced translator. Pretesting was carried out on a number of parents of hospitalized children, and children not connected with the study. These included normal children and children with chronic diseases. A similar procedure was undertaken in developing a protocol for the telephone administration of the PC scales. b. Interviewer training: Experienced female bilingual interviewers were screened and selected on the basis of past work in health research, aptitude, sensitivity and reliability. Group training sessions were conducted by the principal investigator and project administrator. These included role-played interviews and question-answer sessions. Interviewers were monitored closely by the project administrator, including documenting duration of interview and frequent personal and telephone audits of progress and difficulties.

For the administration of the Pictorial Perceived Competence Scale to 4-6 year olds, interviewer training was combined with pretesting of translated instruments on young children not involved with the study. For the most part, the Time 2 interview was also conducted in the home of the subject. An attempt was made to blind the interviewers to the randomization group status of the family in the following way. The interview was structured to begin with the parent-completed principal outcome measures, namely the CBCL and CAAP. Interviewers were instructed not to discuss any study-related issues with the parent or child until all measures were completed. To facilitate this, the demographic questions and the parent social worker questionnaire were administered last. Each interviewer's package contained a sealed envelope in addition to the standard questionnaire. The parent social worker questionnaire, or the shorter token questionnaire for control subjects, with balancing sheets of blank paper resided in this envelope, and it was not unsealed until all other measures had been completed.

c. coder training and data quality control: As described above, the scoring procedure on the main outcome measure, the CBCL, involves a verification phase at data entry to ensure accuracy at this level. Since the scoring of the CBCL itself is performed by an author-supplied personal computer program, adequate quality control was maintained. Manual coding and data entry was carried out with all other measures. On the CAAP and Malaise Inventory, every coded questionnaire was audited by a different coder, as was the entered data on the computer data base. The Impact on Family scale, family function measure and Perceived Competence scales were audited at the rate of 15-20% of questionnaires and entered data (based on a 1 in 5 to 1 in 7 systematic sample). The paucity of important errors made further auditing unnecessary. The parent social worker, and social worker questionnaires were audited in a similar manner. Templates were used for all coding activities, where relevant.

Scheduling the Time 2 measurement (posttest): Timing of a posttest usually depends upon the anticipated temporal pattern of the subjects' response to intervention. The
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central issues are time to effect, and duration of effect. Effects may be immediate, or delayed (latent), and temporary or enduring. In behavioral research, the decision is frequently complicated by the necessity for a retrospective reference period for reported behavioral effects of an intervention may be difficult to predict, both in terms of qualitative aspects, as well as their timing. Such was the case with the present study, and the choice of a 4 month delay from intervention to posttest (10 months from Time 1) reflected these uncertainties. In addition, the more practical problem of subject attrition militated against a second measurement during the harsh Canadian winter, and since funding constraints meant that the baseline interviews would take place in the last quarter of the year, advancing the posttest by 2 months from the originally planned 12 months to 10 months seemed a reasonable compromise in the absence of a compelling argument to the contrary The choice of a 4 month delay also allowed a short period for the emergence of possible latent effects, and for insignificant transient effects to subside. Inability to detect these effects was not a high price to pay, given the essentially pragmatic nature of this investigation.

### 6. Analysis

Three approaches to the analysis of results were followed. Simple comparisons of *proportions* on relevant outcomes measured at Time 2 was the first and most basic approach. Second, the conceptualization and development of *rates* which captured specific information about both therapeutic and preventive aspects of the intervention led to a more informative comparison between intervention and control groups. Third, taking advantage of all the information contained in continuous scores, comparisons of group and subgroup *means* provided the most sensitive analysis.

In addition, there were 2 levels of analysis. The *primary analysis* refers to the analysis of all subjects who were randomized, and for whom data were available. The *secondary analysis* indicates a restricted analysis of those intervention group subjects who " were not discovered to be ineligible following randomization, and who actually received the social work intervention. Because of the very real risk of differential susceptibility to postrandomization exclusion from the analysis between intervention (where surveillance is more intense), and control subjects, this type of analysis is especially subject to selection bias (Peto *et al* 1976, 1977).

Comparison of simple proportions: Categorization of scores on the principal outcome measure, the CBCL, based on the summary behaviour problem T-score cut-off of 63 results

in classification of children as maladjusted (score > 63), or not maladjusted (score  $\leq$  63). Similar dichotomies on the other relevant outcome measures were also used for children (CAAP) and mothers (Malaise Inventory). In order to increase the power of the analysis, the stratified randomization was taken account of in the analysis (Green and Byar 1978). The stratifying variable (clinic) formed the strata for the analysis. This analysis was carried out using the Mantel-Haenszel statistic (Mantel and Haenszel 1959), which is based on a series

of  $2 \times 2$  tables of this general form are constructed:

## $2 \times 2$ table for the *i*<sup>th</sup> stratum Response

	Maladjusted	Normal		
Intervention	a <sub>i</sub>	b <sub>i</sub>	$a_i + b_i$	
Control	ç	$d_i$	$c_i + d_i$	
Total	$a_i + c_i$	$\mathbf{b}_i + \mathbf{d}_i$	N <sub>i</sub>	

Within the *i*<sup>th</sup> stratum, the rates  $a_i / (a_i + b_i)$  and  $c_i / (c_i + d_i)$  are compared. The Mantel-Haenszel method uses a variance-weighted stratum-specific average of rates to calculate a  $\chi^2$  statistic with 1 degree of freedom to test the null hypothesis of no difference between overall intervention and control proportions (or rates). This statistic is calculated from the following expression, for k strata:

$$\chi^{2}_{MH} = (|\Sigma a_{i} - \Sigma (a_{i} + c_{i})(a_{i} + b_{i})| - 0.5)^{2}$$

$$N_{i}$$

$$\Sigma^{K}_{i=1} [(a_{i} + c_{i})(b_{i} + d_{i})(a_{i} + b_{i})(c_{i} + d_{i}) / N^{2}_{i}(N_{i} - 1)]$$

These analyses were carried out using the SAS FREQ procedure (SAS Institute 1985). Transition rates: The use of simple proportions on outcome measures at Time 2 ignores chance-associated inequalities in these proportions at baseline. It also fails to capture the bidirectional "flux" (simultaneous improvement and deterioration that may represent therapeutic and preventive aspects of the intervention, respectively) that may occur and be concealed by an overall measure.

*Positive transition rates* (PTR) were defined as those individuals classified as abnormal (on respective outcome measures) at baseline who are classified as normal on the basis of Time 2 scores on the same measure, expressed as a proportion of all those abnormal at baseline on that measure. This represents a "cure" rate, and is a marker for the social workers' *therapeutic* efficacy. This rate controls for differing baseline prevalence of abnormal scores between intervention and control groups. It too was adjusted for stratification in the Mantel-Haenszel procedure, as described above.

The negative transition rate (NTR) corresponds to those subjects, normal at baseline, who became abnormal at Time 2, as a proportion of all those normal at baseline. This is a form of "lapse" rate, or marker for social worker preventive efficacy<sup>1</sup>. These rates

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<sup>&</sup>lt;sup>1</sup> Strictly speaking, the complement of the negative transition rate (1 - NTR) is the marker of efficacy.

were expressed both as proportions in intervention versus control groups, and as risk ratios, with the control group as the denominator. Appropriate confidence intervals were constructed around both the differences in proportions, and the risk ratio (or relative risk) estimates (Katz 1978). SAS calculates the 100 (1- $\alpha$ ) % confidence interval for the risk ratio (RR) as:

[RR.exp(-Z. $\sqrt{V}$ ), RR.exp(Z. $\sqrt{V}$ )]

where:  $Z=100(1-\alpha/2)$  percent point of the Normal (Z) distribution, V=variance(ln RR).

Outcomes as continuous measures: To achieve the main goal of clinical trial design, equal susceptibility of the comparison groups to the intervention (Feinstein 1985), randomized group assignment is employed. Even if randomization is used, however, all of the prognostic factors may not be perfectly balanced, particularly in smaller studies (Rothman 1977; Lavori et al. 1983). In pretest-posttest experiments, the most important covariate is the pretest score, and when stratified assignment has not been undertaken on the basis of this score (Brogan and Kutner 1980), its variation is usually controlled for in the analysis by analysis of covariance (ANCOVA), where the dependent variable is the posttest score and the covariate is the pretest score (among others). This procedure assumes (a) the pretest population distributions of the comparison groups are equal (even though their sample means, are not) and (b) the treatment affects means, not the slope of the regression line of posttest on pretest or the variance of the conditional distribution of posttest given pretest (Laird 1983). In order to simultaneously test the two distinct null hypotheses that (a) individual comparison groups do not change (no change within each comparison group between Time 1 and Time 2), and (b) there is no difference in change between comparison groups (no treatment effect), Laird (1983) proposed regressing the gain score on the pretest score. The gain score is the difference between posttest and pretest scores. Since the SAS package routinely provides output for ANCOVA in the GLM procedure for t tests of both these null

hypotheses, this approach was used. Laird (1983) has shown that ANCOVA on the gain score and posttest scores are algebraicly equivalent.

Other covariates adjusted for using this manoeuvre included the stratifyingvariable, clinic, for the same reasons as in the case of proportions (Friedman, Furberg, and DeMets 1985), age, sex, Green score and the interval between measurements.

The regression model had the general form

 $_{,}Y = \beta_{0} + \beta_{1}X + \beta_{2}Z + \beta_{3}K + \beta_{4}XZ + \varepsilon$ 

where:

 $Y = Gain \ score \ (posttest - pretest)$ 

X = Pretest score

Z = Design variable for assignment group

K = Other covariate(s)

and,  $\varepsilon = error$ .

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The critical assumption for ANCOVA is that of parallelism (Kleinbaum and Kupper 1978),

or that  $\beta_4 = 0$  which was checked for in all models tested. Regression assumptions relate to normality in the distribution of the residuals, and variance constancy (homoscedasticity), which were also evaluated in all models constructed.

RESULTS

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This section is divided into four parts. **Part A** describes the study population, baseline characteristics of patients and their parents, and results on the baseline measures in relation to comparability of intervention and control groups, together with a description of the degree of maladjustment that exists in the study population based on published reference or norm values. **Part B** details the Time 2 results on each of the outcome measures. **Part C** contains results pertaining to parents' perceptions of the intervention experience, documentation of the intervention, and social workers' perceptions of their own effectiveness. Because of the amount of data generated by this study, detailed results of most sub-group analyses have been appended (Appendux 32). **Part D** consists of a summary of all results.

## PART A

#### 1. Subjects

Ineligible subjects: A total of 615 subjects were contacted by mail following preliminary eligibility screening, and 141 of these (23%) were excluded on closer questioning for reasons set out in Table 11. Of these ineligible subjects, 25 (18%) were rejected because of prior or current psychosocial assistance. This represents 5% of all otherwise eligible subjects, and indicates that a very small proportion which could be considered to be amenable to intervention was excluded at this stage. Because of their inaccessibility, it is also unlikely that the 50 untraceable subjects were significant users of psychosocial services. refusing subjects: Of the remaining 474 eligible families, 129 (27%) refused to participate in the study (Figure 3). The principal reason was unwillingness to accept social work assistance (Table 12). The total number of nonparticipating eligible subjects who could be considered members of the true sampling frame is therefore 154 [25 + 129], or 31% of the 499 [474 + 25] subjects eligible on all criteria except recent psychosocial support. In other words, 70% of the original sampling frame participated in the study.

Data were obtained on the demographic characteristics of consenting and refusing subjects (Table 13), and the only noticeable difference was the higher proportion of English-speaking families among the refusers (62% versus 49%). Refusal rates varied from 16% to 40% in the clinics from which subjects were recruited (Table 14), the high rate in the

Reason	N	%
Language no Erench or English	30	
Prior or current psychosocial assistance	25	177
Mental retardation	8	5 7
No chronic illness	13	9.2
Moving or deceased	6	4.3
Untraceable	50	35.4
Total	141	100.0

Table 11. Reasons for ineligibility.

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# Table 12. Reasons for refusal by eligible subjects

Reason	N	%
Didn't want social worker	30	23.3
No time or not interested	39	30.2
Previous study or other personal reasons	18	14.0
No reason given	42	32 7
Total	129	100.0



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Figure 3 Subjects and follow-up

	Consented	Refused
Age (years)	9.7 (SD 3.2)	10.6 (SD 3.3)
Sex (males)	54%	53%
Language (English)	49%	62%
Socioeconomic status (Green score)	58.5 (SD 9.6)	56.7 (SD 9.6)
N	345 (72.8%)	129 (27.2%)

Table 13. Demographic characteristics in eligible subjects.

Clinic	Consented	Refused	%Refusal
Arthritis	20	6	23
Asthma	<b>ŕ</b> 0	25	26
Cardiology	18	12	40
Cerebral palsy	6	2	25
Cleft lip/palate	20	5	25
Diabetes	64	29	31
Hearing	51	18	26
Renal	39	17	30
Respiratory	21	8	28
Sickle disease	21	4	16
Spina bifida	15	3	17

Table 14. Consenting and refusing subjects by clinics.

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**Results 63** 

cardiology clinic being attributed to their recent involvement in other research projects. randomized subjects: Subject attrition was minimal at the Time 2 assessment. Of 345 subjects who were randomized only 2 were lost, both from the intervention group (Figure 3) One 12 year old boy died unexpectedly following elective cardiac surgery. Another boy returned with his mother to Portugal for an indefinite period. One control group subject failed to complete both pages of the Child Behavior Profile Complete pretest-posttest assessments exist for 173 intervention and 169 control subjects on this measure (99.1% follow-up). level of analysis: The primary analysis refers to the outcome on the Child Behavior Profile for these 342 subjects. Secondary analysis (Figure 3) applies to subjects who actually received social work assistance. Nineteen subjects assigned to intervention (11% of 173) failed to receive it: the parents of fourteen refused to see the social worker even after giving written consent at the baseline interview, four others were discovered to be ineligible after scrutiny of the initial, detailed social worker assessment - three because of formerly undisclosed ongoing psychosocial assistance and one because of absence of a true chronic illness. Finally, one subject randomized to intervention was inadvertently ascribed control status as a result of clerical error. Table 15 shows that these nineteen subjects were more likely to be boys, with mild or no physical disability, and to have systemic disorders such as diabetes, renal problems, or sickle cell disease. They were also more likely to have been maladjusted on the CBCL at baseline and to have been assigned to social worker A.

## 2. Baseline characteristics

comparability: Patient and family demographic characteristics, together with clinical details (illness duration, age at diagnosis, functional status), are depicted in Table 16. Specific medical diagnoses are documented in Appendices 21-31b. These data illustrate how the randomization process yielded comparable comparison groups on these characteristics. Given that randomization was properly carried out, stochastic tests of the similarity of the demographic complexion of intervention and control groups are meaningless (Rothman 1977; Friedman, Furberg, and deMets 1985), but it is informative to note that

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	Received Assistance	Did Not Receive Assistance	
	% (N=154)	% (N=19)	
Sex (male)	55.2	68.4	
Functional impairment*			
none or mild	83.7	94.8	
moderate to severe	16.3	5.2	
Socioeconomic status			
Green score ≤59	70.0	47.3	
Green score ≥60	30.0	<b>52.7</b> ( <i>y</i>	
Diagnostic class <sup>†</sup>			
systemic	34.4	52.6	
cardiorespiratory	33.1	21.1	
sensory 🛊	14.3	15.8	
motor	11.7	10.5	
cosmetic	6.5	0	
Social Worker			
Α	24.7	31.6	
<b>B</b> '	25.3	15.8	
С	24.0	26.3	
D	26.0	26.3	
Maladjusted on CBCL¥	15.6	21.1	

 Table 15: Intervention group subjects - contrast between those who received social worker assistance and those who did not.

\*from functional status instrument.

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†systemic-diabetes, renal, sickle cell disease; cardiorespiratory-asthma, respiratory, cardiology; sensory-hearing impaired; motor-cerebral palsy, spina bifida, arthritis; cosmetic-cleft lip/palate. ¥CBCL Summary Behavior Problem T-score.

Characteristic	Intervention	Control
N	173	170
Age	9.6 (3.5)	9.7 (3.1)
Sex (males)	57%	50%
Birth order (1st. born)	50%	48%
Canadian birth	94%	96%
Illness duration (years)	5.9 (3.7)	. 6.1 (3.5)
Age at diagnosis	3.7 ( 3.7)	3.6 (3.4)
Functional impairment*		
- none	69%	71%
- mild	15%	15%
- moderate	5%	4%
- severe	11%	10%
Language (English)	42%	55%
Socioeconomic status†	57.8 (9.7)	59 2 (9.5)
Single parent	13%	15%
Working mother	43%	49%
Maternal age	37.3 (5.5)	37.1 (5.8)
Maternal education (years)	11.4 (3.3)	12.0 (3.0)
Spouse age	40.5 (6.8)	40.9 (7.2)
Spouse education (years)	12.6 (4.0)	12.6 (3.8)

## Table 16: Baseline characteristics of patients and parents

Values are means (\$D) and proportions. \* From functional status measure.

† Based on a 2-factor Green score (Green 1970).

**N** 4 there is a higher proportion of English-speaking families in the control group (55% versus 42%) and a slightly greater number of males in the intervention group (57% versus 50%). The tables of medical diagnoses (Appendices 21-31b) reveal no major imbalance within clinics on disease severity, insofar as this can be inferred from the diagnostic label or type of associated medical morbidity.

## 3. Baseline measures

comparability: Since this study uses a pretest-posttest design, comparability at baseline on the pretest measures is of some importance, even though statistical control of any chance associated imbalance between comparison groups is used to eliminate the residual confounding. Once again, stochastic testing is irrelevant at this stage. On the child behavior measures (CBCL and CAAP), there is good balance on all scales and subscales (Table 17).

With regard to the CAAP (Table 18), the study sample scored essentially the same as controls on the positive attribute subscales (Peer Relations and Productivity), but noticeably worse on the negative subscales (Dependency, Hostility, and Withdrawal).

On the three Perceived Competence scales, randomization conferred good comparability for the assignment groups on all subscales (Table 19). There is no difference greater than about 0.4 of a common standard deviation between the 2 groups Randomization also produced a reasonable balance between intervention and control groups on the mother and family measures (Table 20).

Median and mean parent-reported occasions of health service utilization in the 6-month period prior to baseline assessment are depicted in Table 21. The intervention group experienced a higher median number of MCH doctor vists in this period compared to control subjects (1.83 versus 1.48) and a similarly higher median number of hospital admissions (0.09 versus 0.07).

Assessment of the internal consistency of the novel 7-item family function measure revealed  $\alpha$ -coefficients of .53 (Time 1) and .61 (Time 2), indicating unacceptable intratest reliability for this scale and therefore necessitating its removal from consideration.

Scale	Intervention	Control	
Major scales:			
Behavior Problems	55.0 (9.8)	55.6 (9.5)	
Socializing	42.9 (8.5)	42.3 (8.9)	
Activities	45.8 (8.2)	45.5 (8.9)	
Scholastic†	46.3 (8.8)	46.4 (9.4)	
Narrow band subscales:			
Delinquent	58.3 (4.1)	59.0 (4.6)	
Aggressive	58.2 (5.4)	58.8 (5.6)	
Hyperactive	59.5 (6.7)	59.2 (6.1)	
Schizoid	59.6 (6.0)	59.9 (5.4)	
Somatic	60.1 (6.9)	60.7 (6.9)	
Withdrawn	59.6 (6.1)	60.3 (6 2)	
Depressed	58.9 (5.7)	58.6 (5.2)	

Table 17. Child Behavior Checklist. baseline means (SD).

NOTE: CBCL norms are standardized to mean=50, SD=10.

 $^{\dagger}N=144$  intervention & 154 control subjects in the school age range.

Scale	Intervention	Control	Reference
Peer relations	13.7 (2.4)	13.7 (2.3)	13.2
Dependency	9.0 (3.0)	9.0 (2.9)	10.0
Hostility	8.7 (2.7)	8.7 (3.0)	9.6 ,
Productivity	13.0 ( <b>2.9</b> )	13.0 (3.0)	41.7
Withdrawal	6.6 (2.7)	6.7 (2.8)	7.2

Table 18: Child and Adolescent Adjustment Profile: baseline means (SD).

Age group	Subscale	Intervention	Control	Norms †
4-6 years	Cognitive competence	3.2 (0.80)	3.1 (0.74)	3.5 (0.40)
	Physical competence	2.9 (0.77)	3.0 (0.86)	3.3 (0.43)
	Peer acceptance	2.8 (0.67)	2.8 (0.74)	3.0 (0.56)
	Maternal acceptance	2.9 (0.70)	2.6 (0.69)	2.9 (0.59)
	N	38	32	255
7-12 years	Cognitive competence	2.9 (0.73)	3.0 (0.73)	2.8 (0.62)
<b>J</b>	Social competence	3.3 (0.77)	3.1 (0.61)	2.8 (0.65)
	Physical competence	2.7 (0.68)	2.7(0.67)	2.8 (0.67)
	General self-esteem	3.2 (0.79)	3.0 (0.60)	2.9 (0.60)
	N	92	94	1040 - 2093
13-16 years	Scholastic competence	3.0 (0.67)	3.1 (0.66)	2.9 (0.61)
,	Social competence	3.2 (0.73)	3.2 (0.69)	3.0 (0.63)
	Athletic competence	2.9 (0.68)	2.8(0.72)	2.9 (0.65)
	Physical appearance	30(063)	2.9(0.85)	2.8(0.69)
	Conduct & behaviour	32(051)	32(051)	30(0.57)
	General self-worth	32(0.62)	3 3 (0 56)	31(0.60)
	N	41	38	748

Table 19: Perceived Competence scales baseline means (SD).

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† Norms are sample size weighted averages of values published by Harter and colleagues (Harter 1982; Harter 1983; Harter and Pike 1984).

Table 20: Malaise Inventory and Impact on Family Scale baseline means (SD).

Scale	Intervention	Control	CPD norms
Malaise Inventory †	4.6 (3.96)	4.4 (3.76)	3.4 - 4.8**
Total impact *	46.8 (9.75)	46.1 (9.66)	59.0 (9.48)
-Financial	8.1 (2.69)	8.0 (2.48)	10.4 (2.20)
-Family-social	17.0 (4.49)	16.5 (4.86)	22.1 (4.90)
-Strain	13.0 (3.74)	12.8 (3.76)	16.6 (3.50)
-Mastery	8.8 (2.21)	8.8 (2.27)	10.0 (1.98)

\* N=173, 170 for intervention and control groups respectively. CPD = chronic physical disorders.  $\uparrow$  N=173, 169.

\*\* see text for discussion.

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Service	Interver	ution	on Consrol	
	Median	Mean (SD)	Median	Mean (SD)
Visits to MCH doctors	1.83	2.5 (3.44)	1.48	2.3 (3:53)
Other doctor visits	0.17	1.3 (5.49)	0.17	0.7 (2.21)
Hospital admissions	0.09	0.2 (0.55)	0.07	0.2 (0.44)

 

 Table 21: Parent-reported health service utilization: Baseline medians and means (SD) for occasions of service in preceding 6 months.

With respect to the CBCL and the CAAP, similarity in mean scores for comparison groups did not ensure identical distributions of scores across each group. This important point is illustrated in Table 22, where, despite close proximity in mean values for both the child behavior measures, there is a striking disparity in the proportion classified as maladjusted (on the CBCL Behavior Problem Scale and CAAP Hostility subscale) according to the published cut-offs cited in the Methods section. On the CBCL, the mean Summary T-scores for maladjusted subjects in each comparison group - intervention 69.3 (SD 4.64) versus control 68.8 (SD 3.40) - indicate that fewer Intervervention group subjects (N=28) scored higher than Controls (N=41). These discrepancies have obvious implications for the interpretation of proportions of maladjusted subjects at Time 2.

level of morbidity: The group means on the CBCL Behavior Problem Summary T-score are approximately one-half a standard deviation above the the general population reference mean of 50 (Table 17). On the narrow-band behavior problem subscales, the difference is between 0.8-0.9 standard deviations. The Social Competence Scales reveal a less dramatic group deviation from the norm. The Socializing T-score means are approximately 0.7 standard deviations below reference and the Activities and School T-scores are about 0.3-0.4 standard deviations below the reference norms. All these results on the CBCL are in the direction of greater maladjustment.

The CAAP reference means (Table 18), based on a very small sample (SD's are not available), give a different picture. On all subscales the study group means are better than reference values. This is puzzling and calls into question the nature of the reference population used in the development of this scale.

On the Pictorial Scale of Perceived Competence and Social Acceptance (4-6 year olds), study subjects scored below norm reference means on all subscales by amounts varying between 0.93 (Cognitive Competence) and 0.24 (Maternal Acceptance) norm standard deviations (Table 19). Inspection of the mean values reveals that study subjects scored better than norms on Cognitive Competence ( by 0.23 norm SD's), Social Competence (by 0.55 norm SD's), and General Self-esteem ( by 0.37 norm SD's). They did slightly worse on Physical Competence (by 0.13 norm SD's). Group means were identical on Athletic Competence.

Rutter, Tizard, and Whitmore (1970) report mean Malaise Inventory scores for healthy mothers of children with chronic illnesses to be 3.4, and for healthy mothers of children with psychiatric disorders to be 4.8, indicating the greater proximity of both intervention and control group mothers' scores to those of the latter reference group (Table 20).

Baseline scores on the Impact on Family Scale (Table 20) are strikingly lower (i.e. better) than the published values from families of children with chronic illness in the New York City area (Stein and Reissman 1980), possibly reflecting large socioeconomic differences between the Montreal and New York populations.

Measure	Intervention	Control
	%	%
•	(N=173)	(N=170)
CBCL Behavior Problem	16.2	24.3 <sup>†</sup>
Summary T-score		X
СААР		
Peer relations	9.8	10.0
Dependency	11.0	11.2
Hostility	12.7	21.9 <sup>†</sup>
Productivity	9.0•	12.5
Withdrawal	17.3	18.9 <sup>†</sup>
Malaise Inventory	18.5	18.3

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 Table 22: Baseline measures - percent abnormal in intervention and control groups.

N=167, <sup>†</sup>N=169, N=168.

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## Part B Overview

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The findings on the CBCL indicated that on the Behavior Problem Scale, there were no significant differences between intervention and control groups in the Time 2 prevalence of maladjustment, positive transition rates, negative transition rates or adjusted Time 2 scores. Similar results were obtained on the Social Competence Scales (Acivities, Socializing and Scholastic subscales), and on the narrow band behavior problem subscales.

On the CAAP, there was a significant difference on only one subscale - intervention subjects scored significantly better on the Hostility subscale at Time 2. However, prevalences and transition rates were not significantly different on any subscale.

**Results on the Perceived Competence Scales did not reveal any evidence for enhanced self-esteem in intervention subjects.** 

Maternal psychologic function was no better for intervention mothers, to the extent that it was reflected by maladjustment prevalence, transition rates and adjusted Time 2 scores on the Malaise Inventory. Similarly, there was no significant difference in Impact on Family adjusted Time 2 scores, nor was there a significant difference in reported health service utilization.

## PART B

## 4. The Child Behavior Checklist

prevalence and transitions: The prevalence of maladjustment on the principal outcome measure, together with results for positive and negative transition rates are shown in Table 23. For intervention group subjects, the maladjusted proportion increased by 14% (from 16.2% to 18.5%), while the control group prevalence fell 12% (from 24.1% to 21.2% - risk ratio (RR) 0.87; P=.51; 2-tailed). As a result, the baseline difference of 7.9 percentage points narrowed to 2.7 percentage points at Time 2. Transition rates give an indication of what changes produced this narrowing of the gap in overall maladjustment proportions between assignment groups. Social work assistance produced a superior positive transition rate of 42.9%, compared to 34.1% in the control group (RR 1.24; P=.55; 2-tailed). However, somewhat surprisingly, social worker counselled children were also 50% more likely to become maladjusted during the study period - negative transition rates were 11.0% and 7.1%, respectively (RR 1.48; P=.32; 2-tailed). None of these differences is statistically significant, regardless of whether 1- or 2-tailed tests are used.

gain scores: Analysis of covariance was used to adjust Time 2 scores and gain scores (Time 2 minus Time 1 scores) for pretest scores, the stratifying variable, clinic, and other possible residual confounders - age, sex, Green score and the interval between pretest and posttest. The results of these analyses are displayed in Table 24 for the the major scales of the CBCL. On the main outcome, there was very slight improvement for both assignment groups between Time 1 and Time 2, as evidenced by the adjusted gain scores (0.4 and 0.2 for intervention and control respectively). Neither change was statistically significant (P=.55 and .73). Covariate adjustment made only small differences to the crude Time 2 mean scores, and it is apparent from either crude or adjusted Time 2 scores that intervention and control group outcomes are almost identical (P=.86). The narrow confidence interval indicates that even a very small difference is unlikely to have been missed by chance (95% 2-tailed confidence interval -2.1, 1.7). Gain scores were also analyzed by classifying

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	Interve	Intervention		Control		95% Confidence		
	%	N	%	N	RR*	hmits for RR	Р	
Baseline	162	173	24 1	170		-	-	
Time 2	18 5	173	212	170	0 87	057,133	51	
Positive transition	42 9	28	34 1	41	1 24	0 62, 2 45	55	
Negative transition	11.0	145	71	126	1 48	0 69, 3 15	32	

Table 23.	Child Behavior Checklist Behavior Problem Summary T-score	proportions
	maladjusted and transition rates	

\*RR is the Mantel-Haenszel estimate of the risk ratio (intervention relative to control) adjusted for the stratifying variable, clinic. Confidence limit estimates are test-based

Scale	Intervention		Control					Difference¥		
	Crude	Adjusted	Adjusted Adjusted		Crude	Adjusted	Adjusted	P†	95% C1*	p•
	Time 2	Time 2	Gain		Time 2	Time 2	Gain			
Summary	54.5	55.1\$	-04	55	55 6	55 3	-0 2	73	-21,17	86
Behavior Problems	<b>(0</b> .77)	(0 67)	I		(0 73)	(0 67)	T			
Activities	45,9	46.0§	03	65	44 6	44 3	-13	11	-0 5, 3 9	14
٩	(0 68)	(0 76)	I		(0 72)	(0 81)	w			
								•	э.	
Socializing	43 1	41 9	-08	31	43 2	42 5	-0 2	81	-27,15	58
-	(0°67)	(0 78)	w		(071)	(0 77)	w			
Scholastic	46.4	47.25	08	30	46 3	457	-0 7	33	-06,36	16
	(0.71)	(0 74)	1		(071)	ູ່ (0 76)	w			

### Table 24: Child Behavior Checklist results on major scales

Frefers to contrast between intervention and control groups §indicates group with superior outcome 1 = improvement, W = worsening in scores from Time 1 to Time 2 P-values are 2-tailed and based on ANCOVA †H<sub>0</sub> Gain = 0. Gain score is Time 2 score minus Time 1 score within that group on that measure

\*95% 2-tailed confidence limits, and P-values for H<sub>0</sub>: Intervention mean - Control mean Values are means (SE)

Table 25:	Change on CBCL Behavior Problem
	scores between Time 1 and Time 2.

Change	Intervention	Control _
Improved or Same	128	133
	74.0%	78.7%
Detenoration	45	36
	26.0%	21.3%
Total	173	169

Improved or same refers to gain scores < 0.5 SD'(5 points)

Deterioration if gain score  $\ge 0.5$  SD  $\chi^2 = 0.81$ , P = .37

Table 26: CBCL narrow band behavior problem subscales.

Subscale	Interventio	n	' Control			
	Time 2	Gain	Time 2	Gain	Р	
Delinquent N	58 7 (0.35)§ 163	0.0	59.0 (0.35) 162	0 1	.75	
Aggressive N	- <b>58.3 (0.3<del>6)</del></b> 173	-0.2	<b>58.6</b> (0.36) 169	0.1	.73	
Hyperactive N	59.0 (0.44) · 158	-0.4	58.8 (0.43)§ 163	-0.6	.67	
Schizoid	<b>5</b> 9.0 (0. <b>4</b> 1) 173	-0 8	58.2 (0.41)§ 169	-1.7 *	.08	
Somatic N	<b>6</b> 0.0 (0. <b>4</b> 6) 173	-0.4	60.1 (0.46)§ 169	-0.5	.80	
Withdrawn N	<b>5</b> 9.9 (0. <b>4</b> 6)§ 173	0.0	60.4 (0.46) 169	-0.4	.43	
Depressed N	59.1 (0.46) 137	0.4	59.1 (0.45) 142	0.5	.76	

Values are means (SE) for adjusted Time 2 T-scores and adjusted gain scores.

\*Significantly different from zero (P =.0001). § indicates group with superior outcome.

P-values (2-tailed) based on ANCOVA. For rounded gain scores, zero < 0.04.

reductions of 0.5 standard deviations (5 points) or more as "improvement"; increases of the same amount or more as "deterioration"; and changes between these limits (0.5 SD > gain > -0.5 SD) as "no change". The results are depicted in Table 25, where the first two categories have been grouped under the heading "improved or same". Within the intervention group, the behavior of 26% of children worsened by this criterion, while the proportion was slightly less for control subjects (21%, P=.37)

On the Social Competence Scales of the CBCL, there was an equally unimpressive difference in outcomes between intervention and control groups (Table 24). There was improvement on both the Actituties and Scholastic Scales for the intervention group, while the adjusted mean scores for control subjects worsened, although the difference between groups was only 1.7 and 1.5 respectively (Activities: P=.14, 95% CI on difference -0.5, 3.9, Scholastic P=.16, 95% CI on difference -0.6, 3.6). There was also worsening of scores on the Socializing Scale, more so for intervention subjects. Again, however, this change was trivial and nonsignificant (P=.31 and .81 respectively), and more importantly the difference between comparison groups was also marginal (difference=0.6, P=.58, 95% CI on difference -2.7, 1.5).

narrow band subscales: Aggregation of results across age-sex categories was carried out for the narrow-band behavior problem subscales of the CBCL. These results are displayed in Table 26. There is a striking correspondence between comparison groups in Time 2 adjusted mean scores on all subscales. Negative gain scores indicate improvement for social worker counselled children on Aggressive, Hyperactive, Schizoid and Somatic subscales, and deterioration on the Depressed subscale, but no change was statistically significant. For control children, improvements were also noted. With the exception of the Schizoid subscale (P=.0001), these gains were not significant.

Subgroup analyses also failed to disclose any significant effects (Appendix 32). By randomly assigning intervention group subjects to social workers, analysis of variation in social worker effects was made possible, although a basic premise of this study

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Scale	· · ·	Social W	'orker		Control
	$\mathbf{A} = \mathbf{c}$	В	С	D .	
			3		
Behavior Problems	54.2	54.8	55.4	56.0	55.3
	(1.08)	(1.10)	(1.10)	(1.07)	(0.67)
	.32	. <b>60</b> ,	. <b>99</b> `	.55	-
Activities	45.6	44.6	46.0	47.5	44.3
	(1.21)	(1.23)	(1.24)	(1.22)	(0.81)
	.37	. <b>9</b> 0	.24	.02	
			ţ		
Socializing	41.7	43.0	41.6	41.7	42.5
	(1.26)	(1.30)	(1.30) °	(1.25)	(0.77)
	.62	.60	.58	59	-
Scholastic	47.4	45.8	46.1	47.1	46.3
	(1.17)	(1.21)	(1.22)	(1.19)	(0.71)
•	.43	.60	.82	.57	-

Table 27: CBCL: individual social worker effects.

Values for each cell are from top to bottom: adjusted Time 2 mean, SE, P-value for

 $H_0$ : SW<sub>n</sub> mean - Control mean. No inter-social worker contrast approached statistical significance.

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was that "typical" social workers would deliver a uniform intervention that would reflect a "real life" situation. To test whether differences in practice style, experience and other intangible factors had produced variation in outcomes beyond those expected by chance, analysis on the major scales of the CBCL was conducted. Table 27 shows that no strong or systematic pattern of variability in outcomes by social worker occurred. For the clients of social worker D, there was a significantly better outcome on Activities than for the contol group as a whole (P=.02), but there was not a single significant difference between social workers on any of these outcomes, even without adjusting the alpha level to take account of the multiple hypothesis tests.

Restricting the analysis to those subjects who actually received the intervention (secondary analysis) does not alter any of the conclusions based on the full analysis of CBCL results described above <sup>1</sup>.

## 5. Child and Adolescent Adjustment Profile

prevalence and transitions: Bearing in mind the differences between comparison groups in prevalence of maladjustment at baseline on this measure (see Table 22), particularly on the Hostility subscale, and to a lesser extent on Productivity, inspection of Table 28 reveals that counselling was associated with a lower Time 2 group prevalence of maladjustment on Peer Relations, Dependence and Hostility, but higher on Productivity and Withdrawal. The risk ratios vary between 0.62 (Dependence) and 1.60 (Productivity) for treatment group maladjustment, although no difference is statistically significant. Figure 4 illustrates the

<sup>1</sup> Excluding the 19 subjects who did not receive the intervention, the Time 2 prevalence of maladjustment on the Behavior Problems Scale is 18.2% for the 154 intervention subjects, and of course remains at 21.2% for the 169 controls ( $\chi^2 = .46$ , P=.50). The positive transition rates are 45.8% and 34.1%, respectively ( $\chi^2 = .87$ , P=.35), and the negative transition rates are 11.5% and 7.0% ( $\chi^2 = 1.55$ , P=.22). The crude Time 2 means for Summary Behavior Problem scores were also compared using a simple 2-sample t-test, after excluding these 19 intervention group subjects. The restricted intervention group mean was 54.4 (SE 0.82, N=154), a reduction of 0.1 from the crude mean for the complete group and still not significantly better than the control mean (P=.26, 2-tailed).

CAAP Scale	Intervention	Control		95% Confidence	
·	<b>%</b>	%	RR*	limits for RR	Ρ
Peer Relations	9.8	12.4	0.79	0.43, 1.45	.46
Dependence	8.1	13.1	0.62	0.33, 1.16	.13
Hostility	12.1	18.3	0.67	0.40, 1.10	.11
Productivity	12.2	7.7	1.60	0.84, 3.05	.15
Withdrawal	16.8	12.9	1.30	0.78, 2.17	.32`
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Table 28: Child and Adolescent Adjustment Profile: maladjustment at Time 2.

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Table 29: Child and Adolescent Adjustment Profile: transition rates.

CAAP Scale		Intervention		Со	ntrol	95% Confidence			
		%	N	.%	N	RR*	limits for RR	Р	
Positive Transit	tion	Rate	s					<u> </u>	
Peer Relations		47.1	17	58.8	17	0.48	0.18, 1.29	.15	
Dependence		68.4	19	52.6	19	1.31	0.66, 2.59	.44	
Hostility		68.2	22	48.6	37	1.32	0.84, 2.09	.23	
Productivity		46.7	15	71.4	21	0.65	0.20, 2.10	.47	
Withdrawal		46.7	30	62.5	32	0.61	0.34, 1.10	.10	
Negative Transi	itio	n Rate	 25						
Peer Relations		5.1	156 -	9.2	153	0.56	0.25, 1.26	.16	
Dependence		5.2	154	8.7	149	0.61	0.26, 1.39	.24	
Hostility		9.3	151	9.2	131	0.96	0.46, 2.00	.92	
Productivity		7.2	152	4.8	145	1.54	0.63, 3.77	.34	
Withdrawal	A	9.1	143	7.3	137	1.28	0.58, 2.86	.54	

\*RR is the Mantel-Haenszel estimate of the risk ratio (intervention relative to control) adjusted for the stratifying variable, clinic. Confidence limit estimates are test-based.





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changes on the subscales between Time 1 and Time 2. No pattern can be discerned that meaningful.

Superior positive transition rates were recorded for treatment subjects on Dependence (68.4% versus 52.6%, RR 1.31, P=.44) and Hostility (68.2% versus 48.6%, RR 1.32, P=.23) subscales (Table R14). However, there were equally striking positive transitions made by maladjusted control subjects on the other three subscales, although no intervention-control contrast was statistically significant. The negative transition rate results for the CAAP are depicted in Table 29. On only one subscale, Dependence, was there a superior outcome for counselled children in terms of both negative and positive rates (NTR 5.2% versus 8.7% in controls, RR 0.61, P=.24).

gain scores: The same pattern of outcomes for intervention subjects is seen on Peer Relations, Dependency and Hostility in the analysis of covariance adjustment of Time 2 scores (Table 30). The control group did better on Productivity and Withdrawal. Only with Hostility, however, did the difference approach statistical significance (P=.04). A closer look at this result on the Hostility subscale reveals that the adjusted gain scores were -0.6 for counselled children and -0.1 for controls (P=.002 and .54, respectively for the H<sub>o</sub>: Gain=0). In other words, while both groups improved, there were significantly greater reductions in parent-reported hostile behaviors for counselled children than for controls. Subgroup analyses are detailed in Appendix 32.

#### 6. Perceived Competence Scales

Results for all versions of the Perceived Competence Scales are given in Table 31. For the sixty-eight 4-6 year olds (38 intervention, 30 control), Time 2 scores on the Pictorial Scale of Perceived Competence, adjusted for the same set of covariates as for the CBCL and CAAP, show that there is remarkably little difference between the two comparison groups. Gain score analysis showed the following: both groups had decreased scores on Cognitive Competence (P=.10 and .38, for intervention and control, respectively); on Physical Competence counselled children did not change, but control subjects improved

,	Intervention	Control	95% confidence interval on difference	P-valuç
Peer relations	13.9 (0.19)§	13.6 (0.19)	-0.2, 0.8	.33
Dependency	8.6 (0.22)§	9.0 (0.22)	-1.0, 0.2	.20
Hostility	8.1 (0.19)§	8.5 (0.19)	-0.9, 0	.04
Productivity	12.9 (0.23)	13.1 (0.23)§	-0.8, 0.4	.40
Withdrawal	6.7 (0.19)	6.5 (0.19)§	-0.3, 0.7	.30

Table 30: Child and Adolescent Adjustment Profile: adjusted Time 2 means (SE).

§ indicates group with superior outcome.

Age group	N	Subscale	Intervention	Control
4-6 years	68	Cognitive Competence	2.9 (0.16)	3.0 (0.17)§
		Physical Competence	2.9 (0.15)	3.1 (0.15)§
		Peer Acceptance	3.0 (0.13)§	2.9 (0.14)
		Matemal Acceptance	2.6 (0.12)	2.7 (0.13)§
7-12 years	184	Cognitive Competence	3.0 (0.06)	3.0 (0.06)
		Social Competence	3.1 (0.07)	3.2 (0.06)§
		Physical Competence	2.7 (0.06)	2.7 (0.06)
	,	General Self-esteem	3.1 (0.07)	3.1 (0.07)
13-16 years	74	Scholastic Competence	<b>3</b> .1 (0.08)§	<b>3</b> .0 (0. <b>09</b> )
		Social Competence	3.2 (0.10)	3.2 (0.10)
۰ ۲		Athletic Competence	2.8 (0.10)	3.1 (0.10)§*
		Physical Appearance	2.8 (0.10)	3.0 (0.11)§
		Conduct & Behaviour	3.3 (0.10)§	3.2 (0.08)
		General Self-worth	3.4 (0.10)§	3.2 (0.09)

Table 31: Adjusted Time 2 means (SE) on the Perceived Competence scales.

§ indicates group with superior outcome. P=.04; all other intervention v. control contrasts, P > 0.2

(P=.39); on Peer Acceptance, intervention subjects improved (P=.33), and controls' mean gain score was zero; on Maternal Acceptance, both groups showed deterioration (P=.27 and  $^{\circ}.67$ , respectively).

For the 184 children aged 7-12 years at baseline (91 intervention, 93 control), outcomes on the Perceived Competence Scale were even more similar when assignment groups were compared (Table 31). Gain scores showed that both groups improved on Cognitive Competence (P=.25 and .41, respectively); had unchanged group means on Physical Competence; and had worse scores on General Self-esteem (P=.64 and .46, respectively). On Social Competence, there was a deterioration in counselled children's scores (P=.16), while control children's scores were unchanged.

For the 74 older children (37 in each group), a similar pattern for adjusted Time 2 means on each of the six subscales of the Self-perception Profile is depicted in Table 31. On three subscales (Scholastic, Conduct and Behavior, General Self-worth), there was improvement for intervention subjects over baseline, while control group adjusted mean gain scores were zero. On Athletic Competence and Physical Appearance, gain scores showed that intervention subjects worsened, while controls improved.

#### 7. Mother and Family Measures

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Malaise Inventory - prevalence and transitions: The baseline prevalence of abnormal scores was approximately equal for intervention (18.5%) and control groups (18.3%). Following social worker assignment, there was a small decrease to 17.9% in the intervention group, while the proportion increased to 18.8% for control mothers (RR 0.94, P=.78: Table 32). Rates of positive and negative transition for mothers were more similar when comparing assignment groups than they were on the CBCL for children. In the intervention group, 41% versus 39% of depressed control mothers were reclassified as normal at Time 2, while 11% versus 9% of mothers normal at Time 1 became abnormal at Time 2 (Table 32). None of these contrasts is statistically significant.

Restricting the analysis to the 154 families who actually received social

worker assistance increases the Time 2 prevalence of maternal depression on this scale to 18.8%, exactly the same as the controls.

Malaise Inventory - gain scores: After residual confounder control by analysis of covariance, Time 2 means on the Malaise Inventory indicated a slight, but insignificant advantage (P=.61) for counselled mothers (Table 33). Gain scores showed that both groups

Table 32: Malaise Inventory: proportions maladjusted and transition rates.

	Intervention		Control			95% Confidence			
đ	%	N	%	N	RR*	limits for RR	Ρ		
Baseline	18.5	173-	18.3	169	-		-		
Time 2	17.9	173	18.8	170	0.94	0.60, 1.47	.78		
Positive transition	40.6	32	38.7	31	1.01	0.54, 1.89	.97		
Negative transition	10.6	141	9.4	138	0.91	0.43, 1.92	.81		

\*RR is the Mantel-Haenszel estimate of the risk ratio (intervention relative to control) adjusted for the stratifying variable, clinic. Confidence limit estimates are test-based.

Table 33: Malaise Inventory : adjusted Time 2 means (SE).

	Intervention	Control	95% confidence interval on difference	P-valuc
Malaise Inventory	<b>4.2</b> (0.29)§	4.4 (0.29)	-1.0, 0.6	.61

§ indicates group with superior outcome.

improved Time 1 scores (by 0.3 and 0.1, respectively). Secondary analysis of crude Time 2 means for the 154 mothers who had actual social worker contact reflected a negative change similar to that seen in the maladjusted proportion with the restricted analysis. The intervention group mean (4.3, SE 0.34) was greater than that for controls (4.2, SE 0.31, P=.80).

Impact on Family Scale - gain scores: Results on the Impact on Family scale are depicted in Table 34. On all subscales, there was a highly significant improvement in Time 2 scores over baseline  $(P < .001)^1$ , and this improvement was greater for the intervention group on all subscales except Mastery. However, the differences between intervention and control group adjusted Time 2 means are not significant.

At Time 2, mothers were asked by the interviewers whether their child's physical health had changed since the baseline assessment. Results on the Impact on Family Scale were examined according to whether parent responses to this question were "better", "same", or "worse". On the Financial subscale, there were superior scores for mothers of children reported to have had deterioration in physical health since baseline when compared to equivalent controls (mean gain -1.2 versus 0.8, P=.04; N=12 and 6, respectively). Apart from this subgroup no intervention-control contrast approached statistical significance. One-way analysis of variance of gains on the Total Impact score and subscale scores showed no significant main effect for individual social workers.

## 8. Health Service Utilization,

Mean parent-reported visits to Montreal Children's Hospital physicians in the six month period prior to the Time 2 interview increased slightly for intervention patients,\_\_\_\_\_ and decreased for controls (adjusted<sup>2</sup> Time 2 means 2.9 and 2.3, respectively; P=.13: Table 35), compared to the corresponding period prior to baseline (Table 21). The situation was reversed, however, for reported visits to nonhospital physicians, where intervention group

<sup>&</sup>lt;sup>1</sup> The Pearson product-moment correlations between Time 1 and Time 2 scores are, for intervention and control groups respectively: Total Impact .51, .46; Financial .57, .54; Strain .62, .59; and Mastery .42, and .51. Even though not corrected for attenuation, these poor test-retest correlations raise the possibility that this measure may be unstable over time. Perusal of a sample of the most dramatically improved questionnaires revealed that there was a tendency at the second interview to rate items at the positive extreme of the 4-point Likert scale, whereas at Time 1 the same parents had more often chosen 2's or 3's. The order of administration of the various measures was different at the second interview because of the attempt to "blind" the interviewers to assignment status until after the parent had completed the CBCL and CAAP. These 2 instruments had therefore preceded the Impact on Family Scale, the reverse of the situation at the baseline interview. The possibility of a response set also exists, but this was not evident on any other measure. <sup>2</sup> Footnote on page 87.

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	Interventi	on	Control	95% confidence	
t	Time 2	Gain	Time 2	Gain	interval on difference
Total impact	40.6 (0.79)§	5.8	41.5 (0.79)	4.9	-3.1, 1.3
-Financial	6.6 (0.23)§	1.4	6.9 (0.23)	1.2	-0.9, 0.3
-Family-social	13.6 (0.40)§	3.1	13.8 (0.40)	2.9,	-1.3, 0.9
-Strain	10.7 (0.31)§	2.3	· 11.0 (0.31)	1.9	-1.2, 0.6
-Mastery	9.8 (0.72)	-1.0	9.8 (0.22)	-1.0	-0.6, 0.6

Table 34: Impact on Family Scale: adjusted Time 2 means (SE) and gain scores.

§ indicates group with superior outcome.  $P \ge 0.3$  for all intervention v. control contrasts. All adjusted gain scores significantly differ from zero (P < .001).

Table 35: Parent-reported health service utilization for 6 month period prior to interviews.

<sup>4</sup> Service	Intervention				Control			P-value	
	Time 1 Median	Time 2 Median	Crude T2 Mean	Adjusted T2 Mean	Time k Median	Time 2 Median	Crude T2 Mean	Adjusted T2 Mean	l
Visits to MCH doctors	1.83	1.43	2.5	2.9 (0.27)	1.48	1.29	2.1	2.3 (0.27),	.13
Other doctor visits	0.17	0.18	0.8	0.5 -(0.23)	0.17	0.22	0.9	0.9 (0.23)	.23
Hospital admissions	0.09	0.07	0.2	-	0.07	0.08	0.2	-	.68†

<sup>†</sup> Median test  $\chi^2 = 0.17$ . Parenthetical values are SE for adjusted means above.

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#### \*

# Table 36\*Reported psychosocial service utilization in the intervalbetween Time 1 and Time 2.

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		r 
16	10	.25
(9.2%)	(5.9%)	
6	3	.32
(3.5%)	(1.8%)	Ľ
13	11 -	72
(7 5%)	<b>(6.5%)</b>	
- 2	9	.03
(1.2%)	(5.3%)	
9	12	.47
(7.1%)	(5.2%)	
33	33	.89
(19.2%)	(19.6%)	
	$ \begin{array}{c} 16\\ (9.2\%)\\ 6\\ (3.5\%)\\ 13\\ (7.5\%)\\ 2\\ (1.2\%)\\ 9\\ (7.1\%)\\ 33\\ (19.2\%) \end{array} $	$ \begin{array}{cccccccccccccccccccccccccccccccccccc$

† includes physical therapists, speech therapists and clergy.

parents reported a decrease (adjusted Time 2 mean 0 5), and controls an increase (0.9, P=.23) Overall, there was a slight excess of all doctor visits in the intervention group (3 4 versus 3 2, P=74), although these differences were not statistically significant, a conclusion confirmed by the nonparametric analysis. There was a very low incidence of reported hospitalizations and little to separate the groups (Time 2 medians 0 07 and 0 08, P=68)

Reported utilization of psychosocial services (apart from study social workers) also showed a small excess by treatment group families for all categories except one (Table 36) Nurses or nurse counsellors were 4.5 times more likely to have been consulted by control families than by intervention families (P= 03). The comparison of proportions of families in the major assignment groups who received *any* additional services (individual service categories were not necessarily exclusive) suggested that co-intervention had not occurred, insofar as parent-reported occasions of service is concerned. This conclusion is supported by control subjects' response to one of the Time 2 interviewer's questions : "Did the fact that you were not assigned to the social work assistance group cause you to seek help elsewhere for any problems or difficulties that came up at the first interview?" Of 169 subjects who responded to this question, only 8 (5%) replied in the affirmative.

<sup>&</sup>lt;sup>2</sup> ANCOVA models were fit to physician utilization data in the same way as for analyses of other measures. This was not an entirely satisfactory exercise, due to problems with moderate nonnormality in the distribution of residual values, and homoscedasticity. Dependent variable transformations made only modest improvements in the model fit, although there was correction of the variance problem. However, results are reported for the modelling approach for the untransformed dependent variables, because it was judged that the assumption violations did not invalidate the results. Less informative distribution-free tests were also used (median test, Kolmogorov - Smirnov 2-sample test), and produced results consonant with the adjustment procedures
## PART C

#### 9. Parents' Perceptions of Intervention

The 154 families who received social worker assistance were surveyed for their subjective interpretations of the value of this experience. In 76% of cases respondents considered the amount of social work contact they had had to be "about right"; "too little" in 8%; and "too much" in 16%. There was a clear indication that parents consider medical knowledge of specific children's diseases to be important for social workers assisting such families. Only 19% felt that disease and treatment knowledge was of little, or no importance Parental assessment of this knowledge in the social workers to whom they were attached indicated that just over two-thirds (69%) thought that their social worker knew a moderate to great amount about aspects of their child's illness.

In Table 37, responses to 6 questions that relate to the perceived value of the social workers are cross-tabulated with CBCL transition status. This allows description of perceived value by changes in child maladjustment status during the trial. Although no single group stands out on any one question, it is apparent from items 1, 3, 4, and 5 that the highest rates of perceived value occurred for children who were classified as becoming maladjusted during the study (negative transitions). With regard to perceived benefit in terms of improvement in child behavior (item 4), it is equally surprising that the lowest rate (18%) occurred in children whom the CBCL classification was one of improvement (positive transition).

Social worker assistance	Positive Transition	Negative Transition	No Transition - Maladjusted	No Transition - Not Maldad'd	Total	Р
			T <u>r</u>			
1 Was helpful to you	7	10	7	63	87	.62
	63 6%	71 496	53 9%	54 3%	56 5%	
2. Was helpful to your	5	6	6	47	64	.97
child.	45.5%	, 42.9%	46.2%	40 5%	41 6%	
3 Helped child cope	4	* 6	4	28	42	.43
with illness.	36.4%	42.9%	30.8%	24.4%	27. <b>5%</b>	
4. Improved child's	2	6	4	28	40	.33
behavior.	18.2%	46.2%	30.8%	24 1%	26 196	
5. Will be helpful	4	5	5	27	41	.43
for child's future coping with illness.	36.4%	38.5%	38.5%	23 9%	27.3%	e
6. Should be continued.	10	9	12	76	107	.16
	90.9%	64.3%	92.3%	70 4%	73 3%	
TOTAL	11	14	13	115	154	

Table 37: Parents' perceptions of study social worker value by CBCL transition status.

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Table 38: Comparison of parents' perceptions of study social worker value by subjective(Survey question: Do you have any problem with ......(child'sname) behavior?) and objective (CBCL Behavior Problem score) classification ofchild behavior disorder at Time 2.

Social worker	Survey Question		P	CBCL Classi	Р	
assistance	Problem	No problem		Maladjusted	Not Malac	īd
		7				<u> </u>
1. Was helpful to your	17	46	.03	12	52	.74
child.	58.6%	37.1%		44.4%	40.9%	
2. Helped child cope	15	27	.001	10	32	.22
with illness.	51.7%	22.0%		37.0%	25.4%	
3. Improved child's	14	26	.002	10	30	.12
behavior.	50.0%	21.0%		38.5%	23.6%	

Table 39: Agreement between positive parent responses to the question: "Do you have any problem with ......(child's name) behavior?", and classification of maladjustment based on the summary T-score of the CBCL Behavior Problem Scale.

<b>•</b> • • • • • •			
Maldjusted	Not Maldjusted	Total	
32	28	60	
36	244	280	
68	272	340	
	32 36 68	32 28 36 244 68 272	

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CBCL classifications of maladjustment at Time 2 on the Behavior Problem Scale. A striking finding is that on all three questions to parents concerning social worker value, there is a significant association of valued social worker service with perceived behavior problems in the child, though this association is much less striking with the CBCL classifications. When children were reported as having either behavior problems, or difficulty getting along with other children or adults, there was a similar pattern suggesting parental appreciation of social worker benefit. On these survey questions, there was little difference between intervention and control groups in parent reporting of behavior problems (19.6% versus 16.8%, respectively: P=.51), or social difficulties (8.5% and 8.9%:P=.89). Unfortunately, however, these questions were not administered at baseline.

Agreement between parental classification of their child as having a behavior problem and the CBCL classification is modest (Table 39), there being agreement in 81% of cases when 69% agreement would be expected by chance (kappa = .39).

### 10. Documentation of the Intervention

Documentation of the intervention process was carried out by using a questionnaire completed by social workers for each client at the termination of their attachment. Data concerning both activities and practice style, together with social workers' perceptions of their own efficacy and reception by family members were analyzed.

Over 92% of all telephone and personal contacts were initiated by the social workers. A three week mid-study survey of their logs showed that 40% of contacts were by telephone, 26% were in the office and 7% in the patient's home. At this time also, social workers documented that 28% of contacts were scheduled follow-ups according to the protocol, while 27% were for specific consultations around problems, providing requested information, or for therapy. Paper work accounted for 24% of their time and 10% were attempted phone calls, or arranged meetings that were not successful through unavailability or failure to attend.

There was some variation in practice style between social workers, reflected in

the proportion of time spent with different family members (Table 40). No social worker spent more than about one tenth of their time with the child alone. In fact two out of three children never saw the social worker alone. More than two-thirds of contact time was spent with the mother, with or without the child, and social worker B spent 29% of his time with the whole family. The social workers did not meet the father in 38% of those families where a father lived in the family home.

With regard to services provided, 23% of families were receiving some form of government or other financial aid at study commencement, but a further 24% were considered eligible and were referred for aid. During the study period, less than 3% were referred for psychological or psychiatric services, and at the time of study cessation, two-thirds were not referred for continuation support services. Of those who were, half were referred for psychological or psychiatric help, and one-quarter for hospital or community-based social work services.

% contact	Social Worker				Total	
time with	Α	В	С	D		
Patient alone	8.7	3.2	10.5	5.4	6.9	
Mother alone	20.9	33.5	26.8	30.6	28.0	
Mother & patient	47.6	26.0	40.8	46.8	40.3	
Family	17.9	29.1	12.7	12.1	18.0	
Father alone	3.2	6.7	4.3	3.3	4.4	
Siblings alone	1.7	1.7	5.1	1.6	2.5	
N	<b>38</b> .	39	37	40	154	

Table 40: Mean percent of contact time that social workers spent with family members.

Social workers reported that the most common cause of their inability to effect positive change in 83 families where they considered it desirable was resistance on the part of

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parents or patients (33%). All felt frustrated by the relatively short attachment period permitted by the study and this was reflected in their belief in 22% of cases that the main obstacle to efficacious intervention was lack of time. Their strong feelings about this difficulty are also reflected in the trends of the reception they received from patients and mothers over the study period (Figure 5). There was a clear "warming up" period, particularly among mothers by the midpoint of the study, with continued improvement, as would be expected by the sixth month. At that time, social workers considered 58% of mothers to be warm or enthusiastic about their contact with them.

#### **11. Social Workers' Perception of Their Effectiveness**

In 45 cases (29%), social workers considered that they had made effective contributions to improvements in child behavior. In 20 (44%), this was attributed to therapeutic activities directed specifically at the child; in 13 (29%), it resulted from general support and encouragement; and in 6 (13%) it was thought to be secondary to benefits to the mother resulting from therapy directed at her. In 65 mothers (42%), significant contributions to improved psychosocial functioning were mainly attributed to therapy (38%), extra support (31%), and secondary changes resulting from therapy directed to the child (16%).

Social workers judged that 45 children (29%) showed improved behavior by the end of the study period; 103 (66%) were considered unchanged and 6 (4%) were thought to have become worse. There was considerable variation between social workers'

assessments of these changes ( $\chi^2_{df6} = 20.36$ , P=.002). For example, social worker B considered 51% of his children to have improved, while social worker D felt that only 13% of hers had done so. These judgements of behavior changes were compared to CBCL classifications (Table 41). Positive transitions were regarded as "improved"; persistent maladjustment, or maladjustment at neither time 1 nor Time 2 as "unchanged'; and negative transitions as "worse". There was poor agreement, due largely to 38 subjects "misclassified" by social workers as "improved". Because the CBCL classification uses a cut-off (of 63) on a continuum, this is not really a fair comparison, since improvements may have been

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substantial on either side of the cut-off without actually crossing it in either direction.

Children's ability to adjust to any present or future illness-related stress was also rated on a 10-point scale (10 =outstanding resilience; 0 =not able to adjust at all). All considered that overall improvement had occurred (Table 42); and ANCOVA adjustment (for clinic, Time 1 score, sex and age) of gain scores on this scale revealed that for social workers B and C this positive change was highly significant. Because these paired ratings were made simultaneously at the end of the study, however, the quantification of the change between these assessments is difficult to compare between social workers with any confidence.

With respect to changes in mother's psychosocial function, social workers considered 26% to have improved, and 71% to have remained the same. Again, there was

considerable variation between the social workers' assessments of this transition ( $\chi^2_{df6}$  = 20.2, P= .003), with social worker D judging only 8% of her mothers to have improved.

Social Worker	CBCL classification					
judgement	improved	no change	worse			
improved	4	38	3			
no change	7	87	9			
worse	0	3	3			

Table 41: Social worker versus CBCL classification of child behavior change.

Weighted kappa = .07

Table 42: Social worker's own ratings of patients' ability to adjust to chronic illness at commencement and termination of assignment. Score for each child was based on a 10 point scale<sup>†</sup> in response to the following question: "How did you rate this child's ability to adjust to any present or possible future stresses of his/her chronic illness?".

Social Worker	N	Time 1 mean (SD)	Time 2 mean (SD)	Adjusted Time 2 mean (SE)	Adjusted gain	P*
Α	38	5.3 (2.1)	5.6 (2.0)	6.0 (0.17)	0.22	.20
В	39	6.0 (1.2)	6.5 (1.0)	6.2 (0.17)	0.50	.004
С	37	6.1 (2.4)	6.6 (2.3)	6.3 (0.17)	0.53	.002
D	40	5.6 (1.9)	6.0 (1.8)	6.1 (0. <del>16)</del>	0.32	.05

†scale anchored from 0 (not able to adjust at all), through 5 (about average), to 10 (outstanding).

\*P-values based on ANCOVA, for  $H_0$ : Gain = 0. For all inter-social worker comparisons, P >.16.



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# PART D

### 12. Summary of Findings

With respect to the study hypotheses, it is concluded that:

- 1. The social work intervention is not associated with a reduction in the overall prevalence of child or maternal maladjustment.
- 2. According to results on the CBCL, there is no significant result to indicate a therapeutic effect of the intervention on child behavior disorder.
- 3. No primary preventive effect was observed negative transition rates are not significantly different.
- 4. No secondary preventive effect was observed interactions of treatment by maladjustment statu's at Time 1 are not significant.
- 5. There is no significant difference between intervention and controls on any measure of child behavior except the Hostility subscale of the CAAP (P=.04), a difference which favoured intervention.
- 6. General self-esteem and perceived physical or athletic competence were not enhanced by social work counselling.
- 7. No measurable beneficial effect on the social and economic impact of chronic illness on the family can be attributed to social work assistance.
- 8. A small but significant increase in consultation of nurses or nurse counsellors by control subjects was reported, but there was no overall difference between the comparison groups with respect to health service utilization.
- 9. Secondary analysis restricting the comprison to subjects who actually received the intervention does not alter any of these conclusions.

No a priori hypotheses were specified in relation to sub-group differences. More detailed aspects of the subgroup analyses that were carried out are appended (Appendix 32). Table 43 summarizes all results with P-values less than .05, but no attempt is made to adjust the comparisonwise error rate to take account of multiple hypothesis testing (Cupples et al. 1984). Even a simple Bonferroni adjustment would render insignificant all of the tabulated findings on behavior and perceived competence measures (Table 43). There does not appear to be a systematic pattern for any particular subgroup.

Outcome measure	Modifier	Sub-group In	tervention	Ċontrol	Р
Child Behavior Chec	klist				
Activities	gfunctional status	no disability	46.4§	44.0	.03
Socializing	clinic .	cardiology	49.1 <del>§</del>	41.0	.04
Socializing	clinic	cerebral palsy	26.9	40.0§	.04
Scholastic <sup>1</sup>	clinic	sickle cell	49.9§	42.9	.04
Scholastic	SES	Green ≤49	47.7§	43.1	.04
Scholastic	SES	Green 50-59	48.0§	44.4	.02
Child & Adolescent	Adjustment Profi	le	, ,		
Hostility	*	*	8.1§	8.5	.04
Hostility	clinic	hearing&clefts	7.6§	8.8	.03
Peer Relations	clinic	sickle cell	13.6§	11.1	.02
Dependence °	functional status	mild disability	7.6§	9.3	.03
Productivity	clinic	respiratory	14.2§	11.6	.03
Productivity	clinic	spina bifida	11.3	14.0§	.03
Malaise Inventory†	CBCL transition	positive transition	on -2.2§	0.9	.04
Self-perception Profi	ile		- * * * * * *		**#*****
Athletic Competence	age	13-16 years	2.8	* 3.1§	.04
Impact on Family Sc	ale				*****
Financial +	health change	worse	-1.2§	0.8	.04
Strain†	Malaise transitio	n T1 & T2 norma	1 -2.7§	-1.7	.02
Health service utiliza	tion			************	
MCH doctor visits	functional status	mod. disability	5.5	2.0	.Ô2
MCH doctor visits	functional status	severe disability	<b>5.</b> 1	2.1	.002
MCH doctor visits	SES	Green ≤49	3.7	1.7	.02
MCH doctor visits	SES	Green 50-59	3.9	2.1	.003
Nurse consultation	*	*	1.2%	5.3%	.03

Table 43: Summary of findings where P < .05 for intervention v. control contrast.

Values are adjusted means or proportions. † gain scores. \* main assignment group contrast. (all subjects). § indicates group with superior outcome. SES=socioeconomic status by Green score.

# DISCUSSION

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The overwhelming conclusion to be drawn from this study is that no measurable short-term effect can be attributed to the social work intervention. How confident can we be that this result is not biased? Was it a fair comparison? Has an important effect been missed that was too small to be reliably detected given the available sample size? Did the intervention function, and did it reach its target? If the answers to these questions indicate that the result is valid, to what extent can it be generalized to other situations? What does it tell us that is useful for future innovations and research in this area?

#### 1. Measurement

appropriate construct: The first issue to consider is whether the right construct has been addressed The outcomes that were measured - child behavior (positive and negative attributes), self-esteem, maternal depression, and the social and economic impact of illness on the family - broadly reflect the domain of psychosocial function that defines the main areas of secondary morbidity in childhood chronic illness (Pless and Pinkerton 1975, Nolan and Pless 1986). It represents both an appropriate and relevant spectrum of health events which are specifically addressed by conventional social work practice (Travis 1976) misclassification: Secondly, has measurement error obscured a treatment effect - is the signal lost in the noise? Nondifferential random misclassification of the outcome of interest is a form of information bias which has been shown to distort the measure of effect towards the null, that is to a relative risk of one (Keys and Kihlberg 1963, Kleinbaum, Kupper, and Morgenstern 1982) Obviously, exposure misclassification cannot occur in the context of a randomized trial, since the assignment procedure guarantees exposure status - intervention or control - at least when the analysis is based on group composition at assignment Outcome misclassification alone does not produce a large bias, provided it is random, and nondifferential (affecting the comparison groups equally), and especially when test sensitivity and specificity are high. For example, estimates of sensitivity and specificity on the Behavior Problem Scale of the CBCL (for the summary T-score, using a cut-off of 63)

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extracted from data provided by Achenbach and Edelbrock (1983) are .76 and .89, respectively. The adjusted point estimate of the risk ratio for maladjustment on this measure at Time 2 is 0.87 (Table 23). Correcting this estimate for outcome misclassification, based 4 on the aforementioned sensitivity and specificity values, and using the method described by Copeland *et al.* (1977), reduces the risk ratio to 0.81 - a trivial change.

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timing: The third important point relates to the timing of outcome assessment. A major thrust of the intervention process was towards equipping children and parents with personal skills to better withstand future illness-related stresses. Assessing the response to social worker assistance almost immediately following attachment may miss latent effects yet to be realized. Since there are virtually no data from empirical studies to assess whether this is, or is not likely, it must be conceded that it is possible. In other areas there are precedents which suggest that it is at least reasonable to entertain this possibility.

The home care study of Stein and Jessop (1984a, c; 1986), for example, showed marginal benefits in terms of psychosocial outcomes at 6 and 12 months, but a quite striking advantage at 5 years, based on an average intervention period of 11 months. In a somewhat different context, a "sleeper" effect was discovered by Achenbach and co-workers (personal communication, T. M. Achenbach 1986) following psychosocial support to mothers of preterm infants during infancy (Mother-Infant Transaction Program). Apart from special counselling by a pediatric nurse during hospitalization, this apparently modest intervention consisted of only 4 home visits in the 3 months following discharge from hospital. Developmental outcomes assessed by these workers (Bayley and McCarthy cognitive scores) showed, at 1 year, no difference between early intervention subjects and controls. However, by 3 years, a definite advantage in developmental outcomes was detected, and at 5 years, preliminary data suggest this difference to be even more marked.

For these reasons, a third interview is planned as an extension to this evaluation for one and a half years following cessation of social worker assistance.

#### 2. Bias

Even randomized thats are subject to biases, although care was taken in the design and execution of this study to minimize these threats to internal study validity. The three broad areas of bias in epidemiologic research - information bias, selection bias, and confounding - will be examined for possible sources of systematic error that may explain whether or not a real effect of the intervention may not have been observed.

information bias: Another information bias may have arisen from interactions between interviewers and parents at the second interview. Although blinding interviewers to assignment status was not completely possible, the use of a sealed package to conceal beforehand whether the subject was to receive a questionnaire about the social worker experience was an attempt to have the parent complete the main outcome measure before there was any discussion of the social worker experience. Interviewers were strictly instructed not to discuss any aspect of the study until the CBCL and other outcome measures had been completed. As a result, it is unlikely that important distortions in parent responses on the CBCL occurred, and if they had, they would more likely have enhanced rather than detracted from perceptions of social worker efficacy in terms of improved child behavior. Similarly, a possible response set from intervention group parents would act to improve rather than worsen outcomes on all measures

selection bias: There was negligible loss to follow-up The primary and secondary analyses result in identical conclusions. There seems to be little opportunity for selection bias.

**residual confounding:** To the extent that measured covariates were available, this was controlled by analysis of covariance Adjustment made little difference to crude estimates, although the precision of the estimate was enhanced by this adjustment (Kleinbaum and Kupper 1978).

co-intervention: Confounding may also result from contamination of the control group as a result of study enrolment, such that control subjects seek additional psychosocial psychosocial assistance following sensitization at the baseline interview (Feinstein 1985) A small but significant number of control group families did indeed report seeking assistance from nurses attached to clinics, but overall there was identical psychosocial service utilization between comparison groups. Less than 5% of control subjects admitted that issues raised at the Time 1 interview had induced them to seek psychosocial help.

Consideration also needs to be given to the control stimulus. Was it too strong? It seems unlikely that a carefully restricted phone call, and a short neutral letter at the study midpoint could in any way exert a quantitatively important therapeutic effect.

#### 3. Power

The statistical power of this study to be reasonably sure of not having missed important differences by chance is illustrated by the confidence intervals around the risk ratio estimates On the CBCE Behavior Problem Scale, the 95% 2-tailed confidence interval around the point estimate is 0.57 to 1.33, intervention relative to control. Wider intervals were estimated around the transition rates (Table 23), and on the basis of these proportions, moderately large differences cannot be ruled out. It is quite a different matter, however, for results using the continuous outcomes on the CBCL and other measures. The difference of 0.2 points between intervention and control adjusted Time 2 Summary Behavior Problem scores is small, and the 95% confidence interval around this difference estimate is -2.1 to 1.7, representing an interval of approximately 0.2 SD either side of equivalence, a small effect size, as discussed in *Methods*.

### 4. Intervention

Before drawing conclusions about the intervention itself, we need to be sure that the intervention was delivered, and in the usual situation of, for example, a drug trial, to have some idea about compliance with treatment.

delivery of intervention: Even when the analysis is restricted to the 154 intervention subjects who received the social work assistance, the absence of a treatment effect persists. Scrupulous maintenance of a minimum intervention package ensured that none of these 154 families was ignored or forgotten by the social workers. It should be remembered too, that a mere 12 mothers, or 8%, considered that the amount of social worker contact was too little. Furthermore, in only 4 of these 12 cases were they mothers of children who made a negative transition on the CBCL, or were classified as maladjusted at both Time 1 and Time 2.

compliance: It is impossible to measure compliance in the context of this type of social intervention, at least in a way comparable to monitoring, say, compliance with drugs in a pharmacologic setting. Whether subjects "took their dose" of social work assistance is therefore a meaningless concept. In addition, the pragmatic nature of this effectiveness evaluation also renders the issue of compliance relatively unimportant.

was there something to intervene on?: The sampling frame baseline maladjustment rates on the CBCL depicted in Table 17 indicate that there was significant psychosocial morbidity in the study sample, at a level of about twice what would be expected in the general population. The overall prevalence of approximately 20% shows that there clearly was potential for remediation.

potency: Remembering that this study was an effectiveness evaluation of relatively standard social work practice, the relevant question in relation to whether the intervention was adequately "potent" must be asked in terms of conventional day-to-day practice. The caseload for each social worker was not heavy. Although between 37 and 40 families were seen by each social worker, there was never any question of inadequate time to perform perceived necessary duties, even with the increased data recording associated with the study. The social workers enjoyed the flexibility of their working hours and never felt compelled to work overtime.

targetting: Would social workers have been effective if it had been possible to target the intervention on children who were already maladjusted, or who were at greater risk of maladjustment? This is a question that cannot be answered by the available data, but even though not pressed for time in any serious way, it does seem reasonable and sensible to

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speculate that working longer with those children identified as having psychosocial problems would offer a better opportunity for remediation. The superior positive transition rate in the intervention group, while not statistically significant, suggests the possibility of therapeutic efficacy. The problem with preventive efficacy, and targetting individuals who are at risk for maladjustment, is that accurate identification of these children remains problematic. Furthermore, as Rutter (1982) points out, and as the results of this study graphically illustrate, there is also little empirical evidence for deciding how to prevent maladjustment even if high risk individuals could be more readily identified brevity: There is a strong suggestion, based on social workers' responses to the questionnaire, that the six month intervention period was too short to allow maximum effectiveness. This appears to be due mainly to the fact that it took several months for most families to "warm up" to the social workers, delaying entry into a mutually trusting relationship, and presumably hampering the delivery of efficacious services. working outside clinics: Social workers did not identify their functioning outside clinic teams as an impediment to their activities. Instead, they perceived this as a beneficial aspect of their mode of operation, citing the opportunity to act as a relatively independent observer of family interactions with clinic and other hospital staff. A patient load of children from 11 different clinics was often cited as a small difficulty, in terms of coming to grips, at least superficially, with details of the illness, its management, clinic staff members and clinic practices. Although social workers did not consider detailed knowledge of specific illnesses to be an important prerequisite for their effectiveness, the vast majority of parents seemed to think that it was. One could speculate that, despite the social worker's own feelings, working as a team member in a more conventional role within a small number of specialist clinics would facilitate their effectiveness.

prevention role: In this study, the novel aspect of social worker assistance was the focus on preventive intervention, aiming to build children's personal resources to better withstand future illness-related stress. Of course this is not an entirely new role for social workers,

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but at the same time it is true that crisis intervention occupies a large proportion of social worker time, at least in urban specialist hospitals. Anecdotal reports from the four study social workers indicated a rapid readjustment to this role. The most difficult practical problem for them in this regard, however, appeared to be in relation to monitoring apparently well-adjusted families with the pre-requisite monthly telephone calls. In the majority of cases, this became a well tolerated part of their daily activities. uniformity of social worker effectiveness: Did one social worker's poor results detract from the group mean of the intervention subjects as a whole, and account for the negative result? The evidence shows that the answer is a firm "no". On no scale was a particular social worker identified with significantly poorer outcomes than the others. Neither was any individual social worker systematically more effective than his or her colleagues

#### 5. Subjective Assessments of Benefit

A substantial proportion of parents did not find the social workers helpful to their child, even when they themselves considered their child to have a behavior problem. This somewhat gloomy finding was accentuated when viewed in terms of CBCL classification of maladjustment. By contrast, social workers appeared to overestimate the benefit of their assistance, and did poorly in identifying maladjusted children. Exactly why they this was so is an important question that deserves further investigation.

#### 6. Implications

generalization: Careful attention was paid in this study to documenting the characteristics of the sampling frame, so that the extent to which results may be generalized could be defined. It was shown first of all that 69% of the sampling frame participated in the study. While nonparticipating families were more likely to be English-speaking, they were otherwise remarkably similar on the basis of available data.

The medical diagnoses of subjects, documented in Appendices 21 to 31b, illustrate that a typical and broad range of simple to complex disorders was represented in these patients. Only 5% of consenting subjects had multiple major disabilities<sup>1</sup>. Therefore,

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the study population did not have unusual morbidity characteristics. The sociodemographic constitution of this Montreal urban sample reflected a diverse, predominantly urban population not unlike most other large modern cities. There is no reason to believe, nor data to suggest, that Quebec children are socially and culturally so different from other North American children as to make them not representative of them.

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The setting for this study, the Montreal Children's Hospital, is typical of tertiary pediatric referral centres throughout the Western world. The training of the study social workers is also typical of that required of social workers employed in these centres. It is important to note, however, that the study social workers did not have extensive experience in the area of childhood chronic illness. To this extent, generalization of results is limited to similarly experienced workers, although the question of how much social worker experience might improve efficacy has not been studied empirically. Furthermore, and since this was an effectiveness evaluation of "typical" social work services, results from a study of workers with 20 years' experience would have limited generalizability for the usual clinical situation.

The mode of operation of social workers in this study was in some ways novel, and in others typical of current practice. The negative result cannot be generalized to all social work in chronic illness - particularly not to efficacy in crisis intervention, nor to specific psychotherapeutic activities. Nevertheless, it remains inescapable that a global social work intervention of the type and duration examined in this study is not effective in short term remediation or prevention of maladjustment in chronically ill children. Previous attempts to demonstrate that psychosocial assistance by nonprofessional counsellors and a home care team (cited in the *Literature Review*) had shown marginal or uncertain benefits based on small samples. These studies are now joined by this investigation, the disappointing

<sup>&</sup>lt;sup>1</sup> defined as attending more than 1 specialist clinic.

findings of which point to the need for improvements in future intervention strategies, and their evaluation.

tuture interventions: The experience of this study underlines the importance of understanding the separate issues of prevention and treatment of psychosocial problems. Designing and implementing future strategies to address these dual challenges must take account of differing requirements to identify suitable subjects to intervene on - accurately classifying maladjusted individuals, and just as accurately pin-pointing those at greatest risk for future difficulties. This latter problem requires further basic research. Other types of intervention need to be assessed. Nurses working within specialty clinics may be in a particularly advantageous position to identify and treat maladjusted and at-risk children. The effectiveness of interventions beginning at a young age and/or at the time of diagnosis or first presentation of chronic illness also needs to be explored.

Any future evaluation should ensure that adequate numbers of subjects are enrolled to test separate hypotheses of prevention and treatment efficacy, as well as overall prevalence rates of maladjustment. In most centres this will require cooperation with other hospitals, employing a multicentre trial approach. The highest epidemiologic standards of rigorous evaluation should of course guide such efforts, with all the necessary attention to the additional demands of multicentre research (Friedman, Furberg, and DeMets 1985).

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# REFERENCES

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# REFERENCES

- Achenbach, T.M., Edelbrock, C. 1983. Manual for the Child Behavior Checklist and revised Child Behavior Profile. Vermont: Queen City Printers.
- Achenbach, T.M. 1979. The Child Behaviour Profile: An empirically based system for assessing children's behavioural problems and competencies. Int. J. Mental Health 7:24-42.
- Achenbach, T.M., and Edelbrock, C.S. 1979. The Child Behaviour Profile. II. Boys aged 12-16 and girls aged 6-11 and 12-16. *J Consult. Clin. Psychol.* 47: 223-33
- Adler, S.N.M. 1973. The stigma of handicap and its unlearning a social perspective on children with muscle disease and their families. *Dissertation Abstr. Intern.* 34(3B):1266-7.
- Allen, F.H., and Pearson, G.H.J. 1928. The emotional problems of the physically handicapped child. Br. J. Med. Psychol. 8:212-35.
- Amir, S., Galatzer, A., Frish, M., and Laron, Z. 1977. A sociological survey of 296 juvenile diabetics. *Pediatr. Adolesc. Endocr.* 3:82-9.
- Ahnsjo, S., Humble, K., Larsson, Y., et al. 1981. Personality changes and social adjustment during the first three years of diabetes in children. Acta Paediatr. Scand. 70:321-7.
- Appalone, C., and Gibson, P. 1980. Group work with young adult epilepsy patients. Soc. Work Health Care 6(2):23-32.
- Barker, R.G., Wright, B.A., Meyerson, L. et al. 1953. Adjustment to physical handicap and illness: a survey of the social psychology of physique and disability. New York: Social Science Research Council.
- Barker, R.G., et al., 1978. Habitats, environments and human behavior: studies in ecological psychology and eco-behavioral science. San Francisco: Jossey - Bass.

Boyle, I.R., di Sant'Agnese, P.A., Sack, S., et al. 1976. Emotional adjustment of adolescents and young adults with cystic fibrosis. J. Pediatr. 88:318-26.

- Breslau, N. 1982. Continuity reexamined: differential impact on satisfaction with medical care for disabled and normal children. *Med. Care* 20:347-60.
- Breslau, N. 1985. Psychiatric disorder in children with physical disabilities. J. Amer. Acad. Child Psychiatr. 24: 87-94.
- Breslau, N., and Mortimer, E.A. 1981. Seeing the same doctor: determinants of satisfaction with specialty care for disabled children. *Med. Care* 19:741-57.
- Breslau, N., Staruch, K.S., and Mortimer, E.A. 1982. Psychological distress in mothers of disabled children. Am. J. Dis. Child. 136:682-6.
- Britten, N., Wadsworth, M.E.J., Fenwick, P.B.C. 1984. Stigma in patients with early epilepsy: A national longitudinal study. J. Epidemiol. Community Health 38:291-5.
- Brogan, D.R., and Kutner, M.H. 1980. Comparitive analyses of pretest-posttest research designs. *The Amer. Statist.* 34:229-232.

đ

- Brodman, K., Erdmann, A.J., Lorge, I., Wolff, H.G., and Broadbent, T.H. 1949. The Cornell Medical Index: an adjunct to medical interview. J. Amer. Med. Assoc. 140:530-4.
- Bruhn, J.G. 1983. The application of theory in childhood asthma self-help programs. J. Allerg. Clin. Immunol. 72:561-77.
- Burden, R.L. 1978. An approach to the evaluation of early intervention projects with mothers of severely handicapped children: the attitude dimension. *Child Care Health Develop.* 4:171-81.
- Burden, R.L. 1980. Measuring the effects of stress on the mothers of handicapped infants: must depression always follow? Child Care Health Devel. 6:111-25.

- Bywater, E.M. 1981. Adolescents with cystic fibrosis: psychosocial adjustment. Arch. Dis. Child. 56:538-43.
- Campbell, D.T., and Stanley, J.C. 1966. Experimental and quasi-experimental designs for research. Chicago: Rand McNally.

Cassel, J. 1976. A contribution of the social environment to host resistance. Amer. J. Epidem. 104:107-23.

- Cassileth, B.R., Lusk, E.J., Strouse, T.B., et al., 1984. Psychosocial status in chronic illness: a comparative analysis of six diagnostic groups. New Eng. J. Med. 311:506-11.
- Connors, C.K. 1973. Rating scales for use in drug studies with children. Psychopharmacology bulletin: pharmacotherapy with children. U.S. Government Printing Office, Washington D.C.
- Cohen, J. 1977. Statistical power analysis for the behavioural sciences. New York: Academic.

Cook, T.D., and Campbell, D.T. 1979. Quasi-experimentation. Chicago: Rand McNally.

Coopersmith, S. 1967. The antecedents of self-esteem. San Francisco: W.H. Freeman.

Copeland, K.T., Checkoway, H., Holbrook, R.H., and McMichael, A.J. 1977. Bias due to misclassification in the estimate of relative risk. Amer. J. Epidemiol. 105:488-95.

Coulton, C.J. 1981. Person-environment fit as the focus of health care. Soc. Work 26:26-35.

Cowen, L., Corey, M., Keenan, N., et al. 1985. Family adaptation and psychosocial adjustment to cystic fibrosis in the preschool child. Soc. Sci. Med. 20:553-60.

Cowen, L., Corey, M., Simmons, R., et al. 1984. Growing older with cystic fibrosis: psychologic adjustment of patients more than 16 years old. *Psychosom. Med.* 46:363-76.

۴

#### References 112

- Cronbach, L.J., and Meehl, P.E 1955 Construct validity in psychological tests Psychol Bull 52:281-302
- Cupples, L A, Heeren, T., Schatzkin, A, and Colton, T 1982. Multiple testing of hypotheses in comparing two groups Ann Intern Med 100.122-9

<sup>9</sup> Daniels, S.R., Greenberg, R.S., and Ibrahim, M.A. 1983 Etiologic research in pediatric epidemiology J Pediatr 102.494-504

- Densen, PM, Ullman, DB, Jones, EW, et al 1970. Childhood characteristics as indicators of adult health status Public Health Rep 85 981-96
- Dorner, S. 1975 The relationship of physical handicap to stress in families with an adolescent with spina bifida Dev Med Child Neurol 17:765-76
- Drotar, D 1981 Psychological perspectives in childhood chronic illness J Pediatr Psychol 3 211-28
- Drotar, D., and Bush, M 1985 Mental health issues and services In, *Issues in the care of children with chronic illness* ed. N Hobbs and J.M Perrin San Francisco Jossey-Bass

Drotar, D., Doershuk, C.F., Stern, R.C. et al 1981 Psychosocial functioning of children with cystic fibrosis *Pediatrics* 67.338-43

- Eisen, M, Ware, J.E., Donald, C.A., and Brook, R.H. 1979 Measuring components of children's health status Med. Care 17 902-21
  - Ellsworth, R.B. 1981. CAAP Scale the measurement of child and adolescent adjustment Palo Alto<sup>•</sup> Consulting Psychologists Press, Inc

Feinstein, A.R. 1985 Clinical epidemiology Philadelphia. Saunders.

Fireman, P., Friday, G.A., Gira, C., Vierthaler, W.A., and Michaels, L. 1981. Teaching self-management skills to asthmatic children and their parents in an ambulatory care setting *Pediatrics* 68:341-8 Ĺ

- Fleiss, J L 1981 Statistical methods for rates and proportions New York John Wiley and Sons
- Friedman, L.M, Furberg, CD, and DeMets, DL 1985 Fundamentals of clinical trials 2d ed. Massachusetts Littleton
- Froese, A.P., Rose, V., and Allen, D.M. 1980 Emotional implications of primary familial hyperhipoproteinemia in childhood and adolescence. *Pediatrics* 65 469-72

Garfunkel, J.M. 1986 Family support does it work? (editorial) J. Pediatr. 108 934-5

- Gath, A, Smith, MA, Baum, J.D 1980 Emotional, behavioural, and educational disorders in diabetic children Arch Dis Child 55 371-5
- Gayton, WF, Friedman, SB, Tavormina, JF, et al 1977 Children with cystic fibrosis I Psychological test findings of patients, siblings, and parents Pediatr 59 888-94
- Germain, C 1977 An ecologic perspective on social work practice in health care Soc Work Health Care 3(1).67-76
- Golden, M.P., Herrold, A.J., and Orr, D.P. 1985 An approach to prevention of recurrent diabetic ketoacidosis in the pediatric population J. Pediatr. 107:195-200
- Gordon, M, Crouthamel, C., Post, E.M., et al. 1982 Psychosocial aspects of constitutional short stature. Social competence, behavior problems, self-esteem and family functioning J Pediatr 101:477-80.
- Gortmaker, S.L. 1985 Demography of chronic childhood diseases *Issues in the care of children with chronic illness*, ed. N. Hobbs and J M Perrin. San Francisco Jossey-Bass
- Gortmaker, S.L., and Sappenfield, W. 1984 Chronic childhood disorders: prevalence and impact. Pediatr Clin N. Amer 31:3-18
- Green, L.W. 1970. Manual for scoring socioeconomic status for research on health behaviour. Publ. Health Rep. 85: 815-27

- Green, S B., and Byar, D.P 1978. The effect of stratified randomization on size and power of statistical tests in clinical trials J Chronic Dis 31. 445-54.
- Greenland, S. 1977. Response and follow-up bias in cohort studies. Am J Epidemiol 106:184-7.
- Grey, M J, Genet, M, and Tamborlane, W V 1980 Psychological adjustment of latency-aged diabetics determinants and relationship to control *Pediatrics* 65 69-73
- Harper, D 1983 Personality correlates and degree of impairment in male adolescents with progressive and non-progressive physical disorders J Clin Psychol 39.859-67
- Harter, S 1982 The Perceived Competence Scale for children Child Develop 53 87-97
- Harter, S 1983 Supplementary description of the Self-perception Profile for children revision of the Perceived Competence Scale for children Manuscript. Colorado University of Denver
- Harter, S, 1985 Processes underlying self-concept formation in children In *Psychological* perspectives on the self, vol. 3, ed. J. Suls and A Greenwald. Lawrence Erlbaum.
  - Harter, S., and Pike, R. 1984. The Pictorial Scale of Perceived Competence and Social Acceptance for young children. *Child Develop* 55: 1969-82.
  - Harter, S., and Pike, R.G. 1982. The Perceived Competence Scale for children Colorado. University of Denver.
  - Heller, A., Rafman, S., Zvagulis, I., and Pless, I.B. 1985. Birth defects and psychosocial adjustment. Am. J. Dis. Child. 139:257-63.
  - Heller, A., Tidmarsh, W., and Pless, I.B. 1981. The psychological functioning of young adults born with cleft lip or palate: a follow-up study. *Clin. Pediatr.* 20:459-65.

Hoare, P 1984. The development of psychiatric disorder among schoolchildren with epilepsy Dev Med Child Neurol 26 14-9.

P

- Hunter, JE, Schmidt, F.L, and Jackson, GB 1982 Meta-analysis cumulating research findings across studies Beverly Hills. Sage Publications
- Jessop, D J., and Stein, R.E.K. 1985 Uncertainty and its relation to the psychological and social correlates of chronic illness in children. Soc Sci Med. 20.993-9
- Johnson, M R 1979 Mental health interventions with medically ill children a review of the literature 1970-1977 J Ped Psychol 4 147-63.
- Kagan, J 1980 Perspectives on continuity Constancy and change in human development, ed O G Brim, and J Kagan. Boston Harvard University Press
- Kaplan, R M, Chadwick, M W, Schimmel, L E 1985 Social learning intervention to promote metabolic control in Type 1 diabetes mellitus. pilot experiment results Diab. Care 8. 152-5.
- Katz, D., Baptista, J., Azen, SP, and Pike, M.C 1978 Obtaining confidence intervals for the risk ratio in cohort studies. *Biometrics* 34 469-74
- Keys, A, and Kihlberg, J.K. 1963. The effect of misclassification on estimated relative prevalence of a characteristic Amer. J Public Health 53:1656-65.
- Kleinbaum, D.G., and Kupper, L.L. 1978. Applied regression analysis and other multivariable methods Massachusetts: Duxbury
- Kleinbaum, D.G., Kupper, L.L., and Morgenstern, H 1982. Epidemiologic research London: Lifetime Learning Publications
- Kovar, M.G., and Meny, D.J. 1981. Better health for our children: a national strategy. The report of he select panel for the promotion of child health. Vol III. A statistical profile. U.S. Department of Health and Human Services, Publication No. 79-55071.

٩ړ ∽

Kovacs, M., Feinberg, T.L., Paulauskas, S., et al 1985. Initial coping responses and psychosocial characteristics of children with insulin-dependent diabetes mellitus J Pediatr. 106.827=34.

٩.

- Kumar, S., Powars, D., Allen, J et al. 1976. Anxiety, self-concept, and personal and social adjustments in children with sickle cell anemia. J. Pediatr. 88:859-63.
- Kupst, M.J., Schulman, J.L., Davis, A.T., and Richardson, C.C. 1983. The psychological impact of pediatric bacterial meningitis on the family. *Pediatr. Inf. Dis* 2:12-17
- Laird, N 1983. Further comparitive analyses of pretest-posttest research designs The Amer Statist 37 329-330
- Langner, T S., Gersten, J.C., McCarthy, E.D. et al 1976. A screening inventory for assessing psychiatric impairment in children 6 to 18. J Consult Clin Psychol. 44:286-96
- Lavigne, J V., Traisman, H.S., Marr, T.J., et al. 1982. Parental perceptions of the psychological adjustment of children with diabetes and their siblings. Diabetes Care 5:420-6.
- Lavori, P.W., Louis, T.A., Bailar, J.C., and Polansky, M. 1983. Designs for experiments - parallel comparisons of treatment. *NEJM* 309: 1291-8.
- Lewis, B.L, and Khaw, K. 1982. Family functioning as a mediating variable affecting psychosocial adjustment of children with cystic fibrosis. J. Pediatr. 101:636-40.
- Lipowski, Z.J. 1973. Psychosomatic medicine in a changing society: some current trends in theory and research. Compr. Psychiatry 14:203-15.
- MacLean, G., and Becker, S. 1979. Studies of the psychological adjustment of the hearing-impaired: adolescents and their families - a pilot study. Can. J. Psychiatr 24:744-8.
- McAnarney, E.R., Pless, I.B., Satterwhite, B., et al. 1974. Psychological problems of children with chronic juvenile arthritis. *Pediatrics* 53:523-8.

#### References 117

- McCraw, R K., and Travis, L.B. 1973. Psychological effects of a special summer camp on juvenile diabetics. *Diabetes* 22:275-8
- Mantel, N., and Haenszel, W. 1959. Statistical aspects of the analysis of data from retrospective studies of disease. J Natl Cancer Inst 22: 719-48.
- Meijer, A. 1980. Psychiatric problems of hemophilic boys and their families Int J Psychiatr. Med 10.163-72.
- Miettinen, O.S 1985. The "case-control" study valid selection of subjects J Chronic Dis 38.543-8.
- Moos, R H. 1979. Social-ecological perspectives on health In, Health psychology a handbook. ed G.C. Stone, F. Cohen, N E Adler, et al.. San Francisco Jossey-Bass.
- Newacheck, P.W<sup>-</sup>, Budetti, P.P., and Halfon, N. 1986 Trends in activity-limiting chronic conditions among children. *Amer. J Public Health* 76:178-84.
- Newacheck, P.W., Budetti, P.P., and McManus, P. 1984 Trends in childhood disability Amer. J. Public Health . 74:232-6.
- Newacheck, P.W., Halfon, N., and Budetti, P.P. 1986. Prevalence of activity-limiting conditions among children based on household interviews. J Chron Dis 39:63-71.
- Nolan, T., Desmond, K., Herlich, R., and Hardy, S. 1986. Knowledge of cystic fibrosis in patients and their parents. *Pediatrics* 77:229-35.
- Nolan, T., and Pless, I.B 1986. Emotional correlates and consequences of birth defects. J.Pediatr. 109:201-16.

Nunnally, J.C. 1978. Psychometric theory. 2d ed. New York: McGraw-Hill.

O'Dougherty, M., Wright, F.S., Garmezy, N., et al. 1983. Later competence and adaptation in infants who survive severe heart defects. Child Dev. 54:1129-42.

- Olbrisch, M.E. 1977. Psychotherapeutic interventions in physical health: effectiveness and economic efficiency. Amer. Psychol 32:761-77.
- O'Malley, J.E., Koocher, G., Foster, D., and Slavin, L. 1979. Psychiatric sequelae of surviving childhood cancer. Amer. J. Orthopsychiatr 49:608-16.
- Orr, D.P., Weller, S.C., Satterwhite, B., and Pless, I.B. 1984. Psychosocial implications of chronic illness in adolescence J. Pediatr. 104:152-7.
- Peckham, C., Butler, N. 1978 A national study of asthma in childhood. J. Epidemiol Community Health 32:79-85.
- Peto, R., Pike, M.C., Armitage, P., et al. 1976. Design and analysis of randomized clinical trials requiring prlonged observation of each patient. I. Introduction and design. Br. J Cancer 34: 585-612.
- Peto, R., Pike, M.C., Armitage, P., et al. 1977. Design and analysis of randomized clinical trials requiring prolonged observation of each patient. II. Analysis and examples. Br. J Cancer 35:1-39.
- Piers, E., and Harris, D. 1969. The Piers-Harris Childrens' Self-concept Scale. Nashville, TN: Counselor Recordings and Tests.
- Pless, I.B. 1980. Practical problems and their management. The practical management of the developmentally disabled child. ed. A. P. Scheiner, and I. F. Abroms. St.Louis: C.V. Mosby Company, pp 412-36.
- Pless, I.B. 1982. The epidemiology of physical and multiple handicap. Stress and disability in childhood. ed. N.R. Butler, and B.D. Corner. Bristol: Colston Papers, No. 34., Wright.
- Pless, I.B., and Graham, P. 1970. Epidemiology of physical disorder. Education, health and behavior. ed. M. Rutter, J. Tizzard, and K. Whitmore. London: Longman.
- Pless, I.B., and Pinkerton, P. 1975. Chronic childhood disorder promoting patterns of adjustment. London: Henry Kimpton.

- Pless, I.B., and Roghmann, K.J. 1971. Chronic illness and its consequences: observations based on three epidemiologic surveys. J Pediatr. 79:351-9.
- Pless, I.B., Roghmann, K., and Haggerty, R.J. 1972. Chronic illness, family functioning, and psychological adjustment. a model for the allocation of preventive health services Int J. Epidemiol 1:271-7.
- Pless, I.B., and Satterwhite, B. 1972. Chronic illness in childhood: selection, activities and evaluation of nonprofessional family counsellors *Clin Pediatr* 11:403-9
- Pless, I B., and Satterwhite, B B 1973. A measure of family functioning and its implications. Soc Sc Med 7. 613-21.
- Pless, I.B., and Satterwhite, B. 1975a The family counsellor Child Health and the Community ed R J Haggerty, K.J Roghmann, and I B Pless New York John Wiley and Sons. pp<sup>\*2</sup>88-303
- Pless, I.B., and Satterwhite, B. 1975b. Chronic illness. Child Health and the Community ed. R J Haggerty, K.J Roghmann, and I.B. Pless. New York: John Wiley and Sons. pp/78-94.
- Pless, I.B., Satterwhite, B., Van Vechten, D. 1976. Chronic illness in childhood. a regional survey of care. *Pediatr.* 58:37-46.
- Quay, H.C., and Peterson, D.R. 1983. Interim manual for the Revised Behaviour Problem Checklist. Florida: Applied Social Sciences, University of Miami.
- Rice, N., Satterwhite, B., and Pless, I.B. 1977. Family counsellors in a pediatric specialty clinic setting. Soc. Work Health Care 2: 193-203.
- Richman, L.C., Holmes, C.S., Eliason, M.J. 1985. Adolescents with cleft lip and palate: self perceptions of appearance and behavior related to personality adjustment. *Cleft Palate J.* 22:93-6.
- Rinaldi, R. C. 1985. Positive effects of psychosocial interventions on total health care: a review of the literature. Fam. Systems Med 3:417-26.

3

Rothman, K.J. 1977. Epidemiologic methods in clinical trials. Cancer 39: 1771-5.

- Rusk, H.A., and Taylor, E.J. 1946. New hope for the handicapped New York, Harper and Brothers Publishers.
- Rutter, M. 1982. Prevention of children's psychosocial disorders: myth and substance *Pediatrics* 70: 883-94.
- Rutter, M., Tizard, J., and Whitmore, K 1970. Education, health and behaviour psychological and medical study of childhood development New York: Wiley
- Sabbeth, B. 1984. Understanding the impact of chronic childhood illness on families *Pediatr. Clin N Amer.* 31:47-57.

SAS Institute Inc. 1985. SAS user's guide statistics Version 5 edition Cary, NC.

- Satterwhite, B B., Zweig, S.R., Iker, H.P., and Pless, I.B 1976. The family functioning index - 5 year test-retest reliability and implications for use. J. Compar. Fam Stud. 7: 111-116.
- Schwartz, D., and Lellouche, J. 1967 Explanatory and pragmatic attitudes in therapeutic trials. J. Chron. Dis 20:637-48.
- Sechrest, L., Cohen, R.Y. 1979. Evaluating outcomes in health care. Health psychology-a handbook. ed. G.C. Stone, F. Cohen, N.E. Adler, et al.. San Francisco. Jossey-Bass.
- Simon, R. 1982. Patient subsets and variation in therapeutic efficacy Br J. Clin. Pharm 14: 473-82.
- Simonds, J.F. 1977. Psychiatric status of diabetic children in good and poor control. *Pediatr. Adolesc. Endocr.* 3:8-16.
- Simonds, J.F., and Heimburger, R.E. 1978. Psychiatric evaluation of youth with cleft lip-palate matched with a control group. Cleft Palate J. 15:193-201.

Skipper, J.K., and Leonard, R.C. 1968. Children, stress and hospitalization: a field experiment. J. Health Soc. Behav. 9:275-87.

- Smith, M.S., Treadwell, M., and O'Grady, L. 1983. Psychosocial functioning, life change, and clinical status in adolescents with cystic fibrosis. J Adolesc Health Care 4:230-4.
- Smyth-Staruch, K., Breslau, N, Weitzman, M, and Gortmaker, S. 1984. Use or health services by chronically ill and disabled children *Med Care* 22:310-28.

SPSS<sup>x</sup> User's Guide. 1985 2d ed. New York McGraw Hill

- Starfield, B. 1985. The state of research on chronically ill children. Issues in the care of children with chronic illness ed N. Hobbs, and J M Perrin San Francisco Jossey-Bass
- Stein, R.E.K. 1978. Pediatric home care: an ambulatory special care unit. J Pediatr 92:495-9.
- Stein, R.E.K., and Jessop, D.J. 1982. A noncategorical approach to chronic childhood illness. Publ Health Rep. 97: 354-62
- Stein, R.E.K., and Jessop, D.J. 1984a. Does pediatric home care make a difference for children with chronic illness? Findings from the pediatric ambulatory care treatment study. *Pediatrics* 73.845-53.
- Stein, R.E. K., and Jessop, D. J. 1984b. Assessing the functional status of children. Monitoring child health in the United States: selected issues and policies. Cambridge, Massachusetts: Harvard University of Health Policy Research and Education.
- Stein, R.E.K., and Jessop, D. J. 1984c. Evaluation of a home care unit as an ambulatory I.C.U.. National Technical Information Service publication. Springfield: US Dept. of Commerce.

. . -
- Stein, R.E.K., and Jessop, D. J. 1984d. Relationship between health status and psychological adjustment among children with chronic conditions. *Pediatrics* 73:169-74.
- Stein, R.E.K., and Jessop, D.J. 1986. Long term mental health effects of a pediatric home care program. Paper presented at Annual Meeting of the Ambulatory Pediatric Association, Washington D.C.
- Stein, R.E.K., and Reissman, C.K. 1980. The development of an impact-on-family scale: preliminary findings. *Med. Care* 18: 465-72.
- Steinhausen, H.C., Borner, S., Koepp, P. 1977. The personality of juvenile diabetics. Pediatr Adolesc. Endocr. 3:1-7.
- Steinhausen, H.C., and Kies, H. 1982. Comparative studies of ulcerative colitis and Crohn's disease in children and adolescents. J. Child Psychol. Psychiatr 23:33-42.
- Steinhausen, H.C., and Schindler, H.P. 1981. Psychosocial adaptation in children and adolescents with cystic fibrosis. J. Dev. Behav. Pediatr. 2:74-7.
- Steinhausen, H.C., Schindler, H.P., and Stephan, H. 1983. Correlates of psychopathology in sick children: an empirical model. J. Amer. Acad. Child Psychiatr. 22:559-64.
- Sullivan, B-J. 1979. Adjustment in diabetic adolescent girls: 1. Development of the Diabetic Adjustment Scale. *Psychosom. Med.* 41:119-26.
- Tavormina, J.B., Kastner, L.S., Slater, P.M., et al. 1976. Chronically ill children: a psychologically and emotionally deviant population? J. Abnorm. Child Psychol. 4:99-110.
- Teare, J.F. 1984. Behavioral adjustment of children attending a residential school for the blind. J. Dev. Behav. Pediatr. 5:237-40.
- Tew, B., Laurence, K.M. 1973. Mothers, brothers, and sisters of patients with spina bifida. Dev. Med. Child Neurol. 15 (suppl. 29):69-76.

- Thompson, R.J. 1985. Delineation of child behavior problems: a basis for assessment and intervention. J. Dev. Behav. Pediatr. 6:37-50.
- Thoreson, C.E., and Kirmil-Gray, K. 1983. Self-management psychology and the treatment of childhood asthma. J. Allerg Clin Immunol 72:596-606.
- Travis, G. 1976. Chronic illness in children it's impact on child and family California: Stanford University Press.
- Van Vechten, D., Satterwhite, B., and Pless, I.B. 1977. Health education literature for parents of physically handicapped children - an update. Amer. J. Dis. Child 131:311-5.
- Walker, D.K., and Crocker, R. W. 1987. Measuring family systems outcomes. Evaluating Family Programs. ed. P. Weiss, and F. Jacobs. New York. Aldine.
- Walker, D.K., Gortmaker, S.L., and Weitzman, M. 1981. Chronic illness and psychosocial problems among children in Genesee County. Harvard School of Public Health.
- White, K., Kolman, M.L., Wexter, P., Polin, G., and Winter, R.J. 1984. Unstable diabetes and unstable families: a psychosocial evaluation of diabetic children with recurrent ketoacidosis. *Pediatrics* 73:749-55.
- Wilkins, R., and Adams, O.B. 1983. The healthfulness of life. Montreal: The Institute for Research on Public Policy.
- Williams, R.G.A. 1979. Theories and measurement in disabliity. J. Epidemiol. Comm. Health 33:32-47.
- Wright, B.A. 1960. Physical disability a psychological approach. New York: Harper and Row.
- Zahn, M.A. 1973. Incapacity, impotence and invisible impairement: the effects on interpersonal relations. J. Health Soc. Behav. 14:115-23.

## APPENDICES

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## Appendix 1. Manuscript.

Emotional Correlates and Consequences of Birth Defects.

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It is self evident that the occurrence of a birth defect or any chronic disabling condition creates a stressful experience for both parent and child. The result of this stress is frequently manifest as emotional problems or difficulties in social relationships. In the literature the term "psychosocial maladjustment" is often used to encompass both situations

To further define what is meant by "emotional" correlates is difficult. A clear distinction between this term, "behavioral disorders" and "maladjustment" cannot be made easily. In one sense the terms may be used interchangeably. It is easier to specify what they are not intended to

encompass, however For example, although many studies examine "personality disorders", or indeed seek to establish that a personality pattern exists which is peculiar to a particular disease, most writers agree that such patterns (which are unlikely to exist) cannot be equated with what is usually meant by emotional disturbance Similarly, although several investigators include measures of self-concept or self-esteem as part of the constellation of effects of interest, it is probably incorrect to assume that poor self-esteem, for example, is necessarily indicative of emotional disturbance. It is, however, reasonable to postulate that it may be an important link between the presence of a stressful physical illness and such disturbances. Similarly, neither mental retardation as such, nor learning disorders alone, are considered as either chronic disorders ( or birth defects) in the context of this review, nor are they to be regarded as facets of emotional disturbance

For the most part when investigators seek to establish the presence and/or extent of emotional correlates of chronic disorders, they are using this term as "short hand" to refer to the results of a variety of measures which, in general, are intended to assess a wide range of behavioral pathology similar to that seen among chidren with clinically diagnosed psychiatric disturbances of varying degrees of severity However, few researchers are precise in specifying the type of disturbance of interest. Thus depression, anxiety, psychopathic and neurotic problems, antisocial behavior and withdrawal are each of equal interest. In short, the term is operationally defined by the test or tests used to assess the

## outcome

In this paper the quality of the evidence for the increased risk of these children for psychosocial disturbances is examined. The children in question are those with the entire range of birth defects, as commonly recognized, and, in addition, we will examine some of the literature pertaining to analogous evidence related to children with other types of chronic physical disorders, not necessarily arising at birth.

The justification for doing so is both practical and theoretical. At the practical level there are many fewer studies devoted exclusively to emotional and social problems of children with birth defects alone More importantly, at the theoretical level, there appears to be little reason for making the distinction. Increasingly, over recent years, the evidence suggests that the specific nature of the disability or defect, is not an important determinant of its psychosocial consequences (Cassileth, Lusk, Strouse, *et al* 1984; Stein and Jessop 1982). Although on purely developmental grounds it would appear reasonable to assume that the age of onset of a condition might help predict the likelihood of these disturbances, relatively little solid evidence has been produced to support this view.

From the perspective of the clinician treating these children it often appears that a large proportion are affected emotionally or socially to a significant extent. Many investigators share this view. And, over the past 20 to 30 years a large body of literature has appeared which appears to support this conclusion, albeit only in part. It now seems that the proportion affected, although significantly greater than what would be expected among healthy children, only involves fewer than a third of all those with chronic disorders.

This report examines, not through a comprehensive review but rather through illustrative examples, the types of studies published over the last 10 - 15 years which offer varying degrees of evidence for the general hypothesis that "the presence of a birth defect or chronic disorder significantly increases the risk of emotional problems in childhood."

Such an exercise is, we believe, useful because it captures the spirit of the main advances that have been achieved in research in this field over the last several decades and points to where future research activity should be directed. There have been no

spectacular breakthroughs in our understanding of the relationship in question, but rather a gradual growth in the sophistication of the techniques used by investigators seeking to understand the association. These are represented by the increasing use of more complex, advanced and scientifically acceptable measures, designs and methods of statistical analysis

This development in methodologic sophistication is central to progress in this area because the underlying problem is extremely complex. Any investigator or clinician immediately realizes that the relationship being examined is influenced by many factors. A very large number of variables relating to the child, the illness, the family, the social environment, and the medical situation, may strengthen or weaken the association between defect and adjustment in epidemiologic terms, these variables may "confound" the true relationship (Kleinbaum, Kupper, and Morgenstern 1982) Further, it cannot be assumed that when many variables are involved that they are related in a simple, linear or additive, fashion. Thus the presence of one risk factor; for example, the severity of the condition, in combination with or alongside others such as social class or sex, may not result in a combined risk which is equal to the sum of the three. Technically, this issue of "effect modification" can be dealt with through the use of multivariate analyses.

These statistical statements parallel the multifactorial nature of the situation in real life. In science it is generally accepted that solid "proof" of a causal relationship may be impossible. It is often assumed, however, that when one or more of certain conditions obtain in a relationship, such as a very strong association, a clear time sequence, the absence of alternative explanations (i.e. plausibility), or a direct association between 'dose' and response, then it is reasonable to conclude that the relation in question is causal. Unfortunately, few studies are able to fulfil these criteria and it is for this reason, as well as the inherent and obvious impossibility of conducting studies in which children can be assigned randomly to disease and non-disease groups, and equally, the impracticality of situations where large numbers of healthy children can be studied prior to the onset of an illness, which makes the establishment of causal linkages so difficult. Nonetheless, the literature at present is sufficiently rich and has approached the question in such a wide variety

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of ways that reasonable conclusions can be drawn about the type and strength of the association that exists.

### Historical Background

The idea that abnormalities in physique, ranging from variations in stature to variations in appearance, as well as the presence or absence of visible and nonvisible defects and diseases, might have an effect on emotional development, can be traced to statements made in the 1600's (Barker, Wright, Meyerson, et al. 1953). Interestingly, then as now, divergent viewpoints were evident. While Sir Francis Bacon asserted that the effects of deformities were inevitably adverse, Robert Burton drew attention to the possibility that the presence of bodily imperfections "do not a whit blemish the soul" and might even "help and much increase the soul" and hence, presumably, lead to improved adaptation and adjustment The first paper published in the psychologic literature to address this question appeared in 1928 (Allen and Pearson 1928) and drew some conclusions similar to those made by many present day investigators. In the period following both World Wars there was a spurt in interest because of the problems of adaptation and rehabilitation surrounding disabled (and often disfigured) servicemen (Rusk and Taylor 1946). Throughout this latter period the field of social psychology was growing rapidly under the influence of Kurt Lewin and his colleagues. Numerous reports appeared which, based on the field theory procedures employed by these investigators, lent strength to the underlying hypothesis (Wright 1960). It was not, however, until the mid-60's that a fresh attempt to investigate these phenomena in children, using more sophisticated measures and approaches, was seen.

From that point to the present there has been a steady growth in both the number and scientific quality of publications. The former undoubtedly reflects a growing appreciation and acceptance of the view that those with chronic illnesses and birth defects have, on the whole, many similar problems which must be addressed by those providing care for them. The latter, the improvement in scientific quality of research in this field, is a direct consequence of the growing popularity of computerized procedures for statistical

analysis, alongside an increasing acceptance of the view that more rigorous research designs can be applied to these questions (Starfield 1985).

## **Cross-sectional Studies**

Most of the evidence in the literature arises from cross-sectional or prevalence studies, restricted to clinical settings. These investigations are characterized by the fact that for the purposes of the study the disease and the outcome are identified at the same point in time. Within this broad group three different approaches may be found The first is essentially a case series involving one or more groups of children with birth defects or chronic disorders without a comparison group of any kind. The second uses subjects from similar sources, often clinics, alongside a comparison or reference group ("controls") evaluated at the same time and in the same manner. The third is the traditional epidemiologic prevalence survey, using samples drawn from the community. In the case of the first approach, only the most modest conclusions about the correlation between a disorder and maladjustment can be drawn and little can be said about causality. These studies are inconclusive not only because they lack appropriate comparison groups (and hence there is no standard of reference for the interpretation of the frequency of emotional problems established), but also because it cannot be assumed that the emotional problems found did not exist prior to the onset of the physical condition. Although in the case of birth defects this possibility does not pertain, it is always a potential problem in any studies of conditions with onset later in childhood. In a very few such instances a case can be made for arguing that when a strong association is found, the causal direction may be reversed; that is, that the physical condition is "psychosomatic", having been produced by the underlying emotional disturbance. Although the evidence for this argument is much weaker than for the case under consideration (which may be viewed as a "somatopsychologic" relationship), the possibility of this altered time sequence explaining the association must be kept in mind.

Three important exceptions to the observation that such studies are inherently weak do, however, exist. The first pertains to instances where the data are analysed in an

analytic fashion in order to explore hypothesized differences among subgroups within the sample whose characteristics differ in a specific fashion. For example, useful information may be gained about possible risk factors by comparing the differences in rates of emotional maladjustment among those in the sample who are males versus females those with diseases that are visible or nonvisible, or those whose families possess certain characteristics versus others where these characteristics are absent. Although the same limitation regarding inferences about causality remain, such within group analyses render many cross-sectional studies far more useful and interesting than they may appear in the light of the fundamental limitations of this design.

The second exception involves those instances when the measures of emotional functioning used are standardized using healthy children to provide normative data for purposes of comparison. Although many important questions have been raised about the legitimacy of using such norms for purposes of comparison with sick or disabled children, the consensus appears to be that providing the measure does not contain a large number of items whose responses by sick children are "built in", the use of standardized measures is a readily acceptable way to overcome the absence of a suitable comparison group.

A further difficulty with such measures is that the standardization is usually based on healthy populations. Thus the norms used for purposes of comparison may be considered to be biased against children with health problems. A more fundamental objection relates to the question whether emotional functioning among healthy children is a valid basis for comparison with children who are unwell or whether some other standard, based only on populations with physical disorders would be preferable. This is a philosophic issue which cannot be resolved without much further debate.

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In the case of the second approach an attempt is made to compare the frequency of emotional disturbance in healthy and chronically ill groups, preferably using an assessment in which the measure is applied "blindly". An important problem among controlled studies is the selection of appropriate "control" groups. This is not an easy task. Although in one respect sibling controls would appear ideal because they have been subjected

to the same influences as the affected child, they are nevertheless imperfect for two reasons. First, siblings may themselves be disturbed more often than other healthy children as a result of factors related to the sibs' illness. Second, with the exception of twins, it is often impossible to find a sibling close enough in age and of the same sex.

Other controls that have been used pose limitations of a different kind e.g those selected from among the child's friends. In this case the danger is that of over-matching for personality and other characteristics that help determine friendship ties Controls from the child's class at school are often a good compromise, limited chiefly by the inevitable differences in the family environment. Finally, for some studies, hospital controls are a reasonable choice although it is not necessarily the case that the amount of stress experienced by a child hospitalized for some reason other than a chronic illness is identical to that of a case so defined.

In the case of the third approach, "prevalence surveys", these involve a defined population and therefore avoid the critical risk of selection bias inherent in most other studies especially those involving hospital-based cases (Kleinbaum, Kupper, and Morgenstern 1982). Further, this approach permits an accurate estimate of the "true" relative risk and therefore, for both reasons, this is the optimal form of the cross-sectional design

## Case-referent studies

To the best of our knowledge there are no case-referent studies which have addressed the issue of the risk of maladjustment associated with chronic disorders. Such a study would entail defining as "cases" children with emotional disturbance and sampling a referent group from the same base population that yielded the cases (Miettinen 1985) An attempt would then be made to determine what proportion of each group had or had had a chronic illness.

Short of a true experimental design, a genuine cohort study should provide the most conclusive evidence about a causal relation between a physical problem and its

emotional consequences. A sample of children are studied serially at different points during their development. This permits the sequence of events to be clearly established.

Two types of such studies may be considered based on the population that is sampled. In the first, and more common, selected cases of children with chronic disorders with or without appropriate non-cases ("controls") are observed over varying lengths of time with respect to the evolution of emotional disorders. In the second, the true birth cohort, a large population of all births over a given period are identified and followed until all events of interest are observed. In this situation it can be clearly ascertained that no emotional disturbance preceeded the onset of the illness. Children who develop a chronic disorder would then be followed further in time to determine if and when emotional problems occur Such a design, a true prospective study, requires a very large number of children because of the relative rarity of chronic disorders in the general population. Nonetheless, there remains the problem in both cases of choosing a suitable comparison group.

An alternative is a historical cohort study in which the point of departure is usually some point in time after all the pertinent information has been obtained. Thus the investigator looks back in time to determine the sequence of events of interest, using data not necessarily collected with the specific research question in mind that is of primary interest to the investigator.

### **Intervention Studies**

A randomized controlled trial (RCT) remains the "gold standard" for clinical research, and contributes more than any other design to an understanding of causal relations Randomizing subjects to chronic illness and observing its effect on maladjustment in relation to a control group is obviously not possible. This fact emphasizes the importance of non-experimental (or observational) studies in this context.

The clinical trial (randomized or otherwise) approach has been used, however, to evaluate the effectiveness of certain strategies aimed at reducing the emotional impact of a chronic disorder. We might postulate that a certain consequence of chronic illness is an intervening variable (e.g self-esteem) in a causal pathway resulting in emotional problems. If an intervention is chosen to modify this intervening variable (say counselling specifically directed at improving self-esteem), and a reduction in psychosocial disorder is observed under controlled conditions, then it can reasonably be inferred that the illness is, at least in part, specifically (and causally) related to the emotional disorder

At a more practical level, and perhaps more importantly, this form of evaluation research offers most to clinicians and health planners by objectively evaluating the relative worth of new programs and innovative treatments (Starfield 1985).

## **Results**

In the section that follows a selection of reports representative of each category of design discussed previously is presented. The selection is based on publications appearing for the most part in peer refereed journals published since 1970. A comprehensive review and critique of earlier reports appears in Pless and Pinkerton (Pless and Pinkerton 1975). The papers cited are not intended to be inclusive of all pertinent reports related to the emotional consequences of chronic disorders, although they are drawn from a thorough search of the literature using the *MEDLARS* (Medline and Psychinfo) electronic storage and retrieval system.

We set out to conduct a quantitative review (or meta-analysis, Hunter, Schmidt, and Jackson 1982) of publications in this area but it soon became apparent that the diversity of outcome measures, study designs, and analyses in relation to the relatively small number of studies makes this impracticable. Consequently, rather than attempting to assess all, or even a majority of the papers individually or collectively, a few have been selected arbitrarily from each category of design to illustrate the strengths and limitations of-that genre of research.

Table 1 lists 17 publications (Dorner 1975; Boyle, di Sant'Agnese, Sack, et al. 1976; Tavormina, Kastner, Slater, et al. 1976; Simonds 1977; Amir, Galatzer, Frish,

and Laron 1977; Sullivan 1979; MacLean, Becker 1979; O'Malley, Koocher, Foster, and Slavin 1979; Grey, Genet, and Tamborlane 1980; Bywater 1981; Heller, Tidmarsh, and Pless 1981; O'Dougherty, Wright, Garmezy, et al. 1983; Smith, Treadwell, and O'Grady 1983; Harper 1983; Cowen, Corey, Simmons, et al. 1984; Teare 1984; Richman, Holmes, Eliason 1985) which essentially constitute "case series" without any control or comparison group. They comprise only children with one or more chronic disorders - most of which do, in fact, represent birth defects in the broad sense. All but two focus on a single disorder (e g diabetes or cystic fibrosis). Most have relatively small sample sizes (10 include less than 50 subjects). To compensate for the absence of suitable comparison groups of children free of a chronic illness, however, many use outcome measures which are standardized; that is, they have normative reference scores from which some comparisons can be made.

In general, the assessment of emotional disturbance is based on clinical assessments or paper and pencil measures administered to the child or parent. Notably, no single measure predominates and accordingly it is not possible to compare results with one another. However, it is striking that mostof the findings, point to elevated rates of emotional disturbance based on the measures used. Exceptions are found in the reports by Tavormina (Tavormina, Kastner, Slater, *et al.* 1976), in which a variety of instruments were used, often with conflicting results; MacLean, who used a clinical assessment alone in a small sample of deaf children (MacLean and Becker 1979); and Teare in a similarly small sample of children with visual impairments (Teare 1984).

In spite of the large number of findings pointing to excessive maladjustment among these samples, however, conclusions about causality must be drawn with extreme caution because of the severe restrictions inherent in this essentially very weak design.

Table 2 summarizes 19 case studies (McAnarney, Pless, and Satterwhite 1974; Kumar, Powars, Allen, et al. 1976; Steinhausen, Borner, and Koepp 1977; Gayton, Friedman, Tavormina, et al. 1977; Simonds and Heimburger 1978; Gath, Smith, and Baum 1980; Froese, Rose, and Allen 1980; Meijer 1980; Steinhausen, and Schindler 1981; Drotar, Doershuk, Stern, et al. 1981; Gordon, Crouthamel, Post, et al. 1982; Lewis and

Khaw 1982; Steinhausen and Kies 1982; Lavigne, Traisman, Marr, et al. 1982; Steinhausen, Schindler, Stephan 1983; Hoare 1984; Thompson 1985; Breslau 1985; Cowen, Corey, Keenan, et al. 1985) in which a control group is included and assessed in a fashion presumably identical to that of the group with chronic disorders. In general the same range of conditions is represented as shown in Table 1. Most studies, with three important exceptions, (Drotar, Doershuk, Stern, et al. 1981; Hoare 1984; Breslau 1985) involve samples of between 30 and 70 subjects, and in general, the controls are "group matched" often by age, sex, and social status. The exceptions are controls involving siblings, and, on occasion individual or pair matching, a procedure, which if analysed appropriately provides greater statistical power.

In these studies the measures used to assess emotional disturbances again vary widely, with paper and pencil tests, often comprising behavioural inventories, predominating. Unfortunately, as in the previous example of case series, few of the studies use identical measures, although in several instances the Piers-Harris self-concept test (Piers and Harris 1969) is used, and in others, the Child Behavior Checklist (Achenbach and Edelbrock 1983) is the measure of choice.

Although the results again quite consistently support the general hypothesis, in only 6 of the studies was it clear that the difference was statistically significant. However in view of the relatively small samples involved, it is very likely that most studies lacked the statistical power to detect differences of reasonable magnitude, even when such differences actually existed (Fleiss 1981).

Perhaps the most convincing set of findings are those reported by Breslau (Breslau 1985) based on a group of 304 children with a variety of major physical disorders (cystic fibrosis, cerebral palsy, myelodysplasia, etc.) compared with a random sample of 360 healthy children in the same age range, from the same community. The measure used was the Psychiatric Screening Inventory (Langner, Gersten, McCarthy, *et al.*' 1976) completed by the mother and the data were analysed using an analysis of covariance in which income and maternal education were controlled. The principal findings are noteworthy; first that the rate

of severe psychiatric impairment was nearly 2.5 times greater among the disabled children than among the controls (27% vs 11%); second, that there were no differences of importance between the disease groups themselves; third, that it was those with CNS involvement, and particularly those with mental subnormality as one component of their condition, who were the most severely affected emotionally.

In general, the results of studies using comparison groups provide stronger evidence of causality if it is assumed that the non-diseased children are similar to those with diseases in all other relevant respects. Notwithstanding power considerations, it is worth noting that although the trend of the results from these studies is in the same direction as those reviewed previously, less than one third reached statistical significance. Finally, it must also be noted that the nature of the emotional disturbance was extremely varied - a result which is hardly surprising in view of the wide diversity of measures used.

Table 3 summarizes the results of three prevalence surveys (Pless and Roghmann 1971; Walker, Gortmaker, and Weitzman 1981) based on large population samples (ranging from over 1,000 to over 3,000) in which children with chronic illnesses were proportional to the rate which they would be expected in the general population. These surveys are of importance not only because of their size and relative freedom from selection bias in the choice of subjects with chronic disorders, but also because they have tended to use a range of measures with generally impressive psychometric properties. Of equal importance, the nature of the design is such that the proportions of emotionally disturbed children with chronic disorders can be compared directly so that the prevalence ratio approximates the relative risk (RR; Daniels, Greenberg, and Ibrahim 1983). Thus, although as the data in the table indicate, the actual proportions affected differ widely - the excess ranging from 10% in one study to perhaps 18% in another, the unadjusted RR in each exceeds 2.0. In these studies, the general strategy of analysis employed was to compare those with disorders with all the remaining healthy children. In the Isle of Wight survey (Pless and Roghmann 1971), for example, a screening procedure, using the Rutter A and B tests, (Rutter, Tizard, and Whitmore 1970) was followed by systematic psychiatric

evaluations of all found to be positive. The result was that 17% of those with chronic physical disorders were judged to have a significant emotional disturbance, compared with only 7% among the remaining, healthy children. This represents a crude relative risk of 2.4 but unfortunately, in this study as well as the others cited in this category, only univariate analyses were performed.

Table 4 summarizes the results of 8 follow-up, or prospective studies (Pless and Roghmann 1971, Densen, Ullman, Jones, et al. 1970; Peckham and Butler 1978; Ahnsjo, Humble, Larsson, et al. 1981; Orr, Weller; Satterwhite, et al. 1984; Britten. Wadsworth, and Fenwick 1984; Kovacs, Feinberg, Paulauskas, et al. 1985; Heller, Rafman, Zvagulis, and Pless 1985). Three of these are based on data from true birth cohorts (Pless and Roghmann 1971; Peckham and Butler 1978; Britten, Wadsworth, and Fenwick 1984) comprising samples of all births in a single year followed over periods of 20 or more years. The prospective design permits not only a more valid assessment of the strength of the association, but also should, ideally, provide more conclusive evidence about the causal sequence of events. The samples in these studies have a wide range - from over 13,000 in the NCDS cohort described by Peckham and Butler (1978) to only 60 or 70 in the relatively c short term follow up studies of Ahnsjo et al. (1981) and Kovacset al (1985), both of which deal with diabetes. None of the basic outcome measures are identical. They include "mental disorders" as a basis for draft rejections, behavioral symptoms as observed by parents or teachers, self report inventories, Rorschach tests and psychiatric evaluations. Analyses of both the 1946 and 1958 British Birth Cohorts have so far failed to exploit the unique opportunity afforded by the cohort design to observe sequential events. We are therefore deprived of the chance to establish whether the children with chronic disorders who later displayed emotional problems were unequivocally free of such problems prior to the onset of their physical disorders. The more recent (non-population based) study by Kovacset al. (1985) attempted to address this problem albeit through recall bias susceptible parent reported prevalence of pre-diabetic psychosocial difficulties. There was a doubling of the maladjustment rate by this crude measure following onset of diabetes, but a substantial

recovery by 9 months after diagnosis Nonetheless, the results of these surveys provide further evidence in support of the basic premise that these conditions may be followed by emotional problems of some significance.

Few attempts have been made to evaluate the effect of health promoting interventions to prevent maladjustment among these children. Details of 3 studies are depicted in Table 5 and demonstrate impovement in evaluation methods and study design over the last 15 years (McCraw and Travis 1973, Pless and Satterwhite 1975, Stein and Jessop 1984) An assessment of the impact of diabetic camp (McCraw and Travis 1973) on self-esteem and anxiety was fraught with threats to internal validity Problems with subject selection and attrition, timing of pre- and post-intervention assessments and analysis, together with dubious outcome measures that only partly reflect maladjustment mean that the study results are very difficult to interpret.

By comparison, the family counselor project (Pless and Satterwhite 1975) stratified subjects on a measure of family function prior to random assignment to treatment or control group. This innovative program showed a marginally significant benefit in terms of several, more appropriate outcome measures.

Finally, the randomized controlled trial from New York (Stein and Jessop 1984) has come closest to modern standards of objective evaluation After stratifying subjects on scores from measures of family resources and the child's burden of illness (a proxy for "severity"), randomization of 209 subjects to either a home care program or standard care was undertaken Scores on the psychometrically sound Pars II (Ellsworth and Ellsworth 1982) measured the impact of 6 and 12 months of the home care program, not too dissimilar to what is, or should be, available in many modern treatment centres. Significantly better improvement in adjustment was recorded in the treatment group at 6 months, though this effect was less evident at 12 months, possibly hampered by the relatively small sample size available in the appropriate age range for assessment by the Pars II. Since both of the most recent studies employed an intervention focussed on alleviating specific illness-related stresses (physical, economic and emotional) it is reasonable to infer that the observed

reduction in maladjustment was at least in part attributable to an illness-specific effect. All 3 studies however, suffer from samples too small to reliably detect small to moderate treatment effects

#### Conclusions

Although it is evident that few of the studies cited in this review provide conclusive evidence to support the hypothesis that a chronic disorder is associated with later emotional problems in a causal manner, overall it is reasonable to conclude that such a relation does exist. However, it is clear that the risk of this outcome, while not exceedingly large, is of sufficient magnitude to be of concern to clinicians. In broad terms it may be safely assumed that at least twice as many children with these disorders have a high probability of experiencing what must be regarded as a "secondary handicap" of potentially great importance in the development of the child.

The task of the clinician is to identify those among the population with chronic disorders for whom the risk is greatest and to provide them with whatever additional services seem most likely to prevent this outcome or diminish its impact. This task is by no means an easy one for several reasons. First, there are still too few adequately controlled studies which provide guidelines for determining the characteristics of those at greatest risk. Some data suggest that certain types of disability may modify susceptibity to emotional disturbances; e g the results reported by Jessop and Stein (1985) pointing to the non-visibility of the disorder that of Heller, Rafman, Zvagulis, and Pless (1985) which suggests the possible importance of the type of disability in combination with gender, and other results highlighting the importance of family functioning as a possible predictor (Lewis and Khaw 1982; Steinhausen, Schindler, and Stephan 1983; Pless, Roghmann, and Haggerty 1972).

Second, the relative scarcity of intervention studies makes it difficult to recommend with confidence what type of services are likely to be most effective. The comprehensive home based program described by Stein and Jessop (1984) is a clear exception, as are the findings of the program involving family counselors (Pless and

Satterwhite 1975) More general principles, emphasising the importance of the pediatrician playing the role of counselor, coordinator and advocate, have also been put forward (Pless 1980) but have not been subjected to systematic evaluation.

Accordingly the challenge for future research in this area is clear. It must first delineate more clearly those factors associated with the child, the illness, or the family which serve to modify the risk for maladjustment as the table reflects Further, it must both encourage more intervention studies of adequate size and design, and evaluate them rigorously in order to determine those most likely to be effective with the most modest use of available resources.

Finally, it should be clear that there still remains a large need for better measures both of outcome and of risk factors such as functional status or other proxy measures of severity and better constructed, more thoroughly analysed studies, especially those employing case-referent or cohort designs. For these to be of the greatest possible value, however, there is above all, an urgent need to adopt a standard measure of emotional disturbance so that the findings may be compared with one another.

#### ACKNOWLEDGEMENTS

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Ref Ø	Yr.	First Author	Disorder	Sample Size	Age (Yr)	Outcome Measure(s)	Maladjustment Prevalence or other Major Finding
12	1975	DORNER	Spina Bifida	63	13-19	Clinical assessment	66% depressed 50% severely isolated
13	1976	BOYLE	Cystic Fibrosis	27	13-30	Clinical assessment, Rohrshach, Draw-a- person, Thematic apperception.	48% poor or fair daily coping 78% isolation or hostility
14	1976	TAVORMINA	Diabetes Cystic Fibrosis, Hearing Impaired, Asthma	1 <b>44</b> \$	5-19 «	Piers-Harris Self Concept, Junior Eysenck Personality Inventory, Missouri Child- ren's Picture Series, Psychological Screening Inven- tory	All sample > norm (P<0.01) but Deaf < norm (P<0.05) All sample=norm Hearing higher scores but NS Sample > norm on aggression and activity. Hearing less conforming, more aggressive. Diabetes more aggressive, active. All sample > norm on alienation. Diabetes & Hearing > norm on alienation, defensiveness
 15	1977	SIMONOS	Diabetes	40	6-18	Clinical assessment	7.5% serious psychiatric disorders
16	1977	AMIR	Diabetes	292	0- adult	Clinical assessment & questionnaire	51.7% emotional adjustment problems
17	1979	SULLIVAN	Diabetes	105	12-16	Diabetic Adjustment Scale	Approximately 7% maladjusted.
18	1979	MacLEAN	Hearing- Impaired	20	13-20	Clinical assessment	5% maladjusted
19	1979	O TRALLEY	Nalignancies	113	5-36	Rutter & Graham Interview, Clinical assessment ("Combined adjustment rating")	36% mildly malacqusted 23% moderate-severely (Total 59%)

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TABLE 1: CASE SERIES: UNCONTROLLED OR NORM-REFERENCED TESTS ONLY

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Table 1 Continued on next page.

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Table 1 continued. 20 1980 GREY Diabetes 20 7-13 Rodgers' parent 55% mod-severe maladiustment interview, Coopersmith selfesteem inventory 21 1981 BYNATER Cystic 27 12-16 Clinical assessment, 63% "misery" in previous year. 7% behavior problems at school Fibrosis Rutter Child Scale B2 (Teacher) 22 1981 HELLER 95 Cleft Lip/ 18-Structured interview 33% marginal or inadequate Palate adult based on school and psychosocial functioning. work achievement, past and present family life. O'DOUGHERTY Transposition Behavior Rating Scale \*...behavioral difficulties 23 1983 31 mean of Great were prominent in a subgroup age (Examine) Arteries 9 yr. Achenbach Symptom of these children."\* Checklist (Parent) -----24 1983 SMITH Cystic 26 12-18 Tennessee Self Group mean at 90th centile on Fibrosis Concept Scale general maladjustment scale. 1983 HARPER Minnesota Multi-25 Duchenne 44 Duchenne: 60% depressive feelings mean Muscular phasic Personality 47% maladjustment Dystrophy, 17 Inventory Orthopedic: 48% maladjustment Orthopedic impairment 1984 176 Cornell Medical Emotional Disturbance: 19% 0 mod-severe 26 COWEN Cystic 16-Fibrosis adult Index 43% Q " 27 1984 TEARE Visually 23 Mean Achenbach CBCL Total score - normal range Introversion Score - Sample > Norm (P<0.05) 11.5 impaired 47% poorly adjusted 1985 36 14-17 Behavior Problem 28 RICHMAN Cleft Checklist (Quay-Lip/ Palate Peterson) \*No data are given for BRS or Achenbach. X

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ref ₽	Year	First Author	Disorder	Cases C	antrols	Age (Yr)	Control Selection	Outcome Measure(s)	Ma ladjustment
29	1974	MCANARIEY	Javentile Orranic Arthritis	42	æ	6-17	Group metch on age, sex, SES	Cooperswith Self Esteen Inventory, Onildren's Manifest Anxiety Scale, California Test of Personality	Parent measures: Emotional health not excellent in 64% cases vs. 40% controls (NS) Teacher measures: Low adjustment cases 33% vs. controls 9% (NS)
30	1976	KLIMPR	Sickle Cell Disease	29	29	12-18	Group metch on age, ethnicity	General Arxiety Scale for Ohildren (Sarason), Piers-Harris Self-Concept Scale, Califormia Test of Personality	Controls (PCO.005) more anxious. Controls (PCO.001) higher on self concept. No difference in overall adjustment.
31	1977	steinhausen	Djabetes	56	61	<b>8-18</b>	Group match on age, sex, SES	Children's Personality Quest, Hanburger Neurotizishus Extraversionsskala Fur Kinder Und Jugentliche	No difference
32	1977	gandin	Qystic Fibrosis	33	31	5-13	0 ldest sibling	Piers-Harris Self-Concept Scal, Missouri Children's Picture Series, Holtzman Inkolot Test	P No difference (Matched analysis not done)
33	1978	Sidones	Cleft Lip/ Palate	40	40	6-18	Group metch on age, sex, SES	Clinical assessment, Behavior questionnaire (Parent)	No difference
34	1980	gath	Diabetes	76	70	5-16	Next child on class list of same sex	Teacher Questionnaire, Rutter B2 Behavior Scale for Teachers, Clinical assessment	Cases 20% v. controls 1.3% behavioral deviancy at school (NS). 20% of cases exptianal disturbance but no comparable figure given for controls (clinical).
35	1990	FROESE	Familiai Hyperlipo- protetnemia	43	23	2-19	Siblings	Connor's Parent Questionnaire, Clinical assessment	No difference overall. (Platched analysis not done.) Hale cases significantly more impulsive/hyperactive female cases significantly higher on on perfectionism.

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#### TABLE 2: CASE SERIES WITH CONTROLS

TABLE 2 CONTINUED ON NEXT PAGE

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36	1980	NELJER	Hemophilia	20	20	Not Stated	Frequency metch on age, sex, SES	Manifest Affect Rating Scale, Mother Child Questionnaire	Cases significantly more hostile, defiant.
37	1961	STEDNHALSEN	Cystic Fibrosis	36	36	5-18	Trequency auton on age, sex, SES	Clinical assessment (mother)	58% of cases v. 31% of controls had definite psychiatric problems (of slight to marked degree).
38	1981	OFOTAR	Qystic Fibrosis, other Respiratory Illnesses	108	122	3-13	Stblings of OF patients, unmatched healthy children	Lauisville Behavior Checklist School Behavior Checklist	Parent rating: 19% maladjusted in cases v. 5-8% in controls. Teachers: No difference
39	1982	EDREDM	Constitutional Short Stature	23	23	6-12	Matched ('findividual) on IQ(WISC-R), ŞES, age, sex	Achenbach CBOL, Piers-Harris Self-Concept Scale	Cases signif. higher CBCL Total Behavior Problem Scores
<b>4</b> 0	1982	LENIIS	Cystic Fibrosis, Astima	57	27	7-12	Frequency match on age, sex,SES	Quay-Peterson Behavior Problem Onecklist, Piers-Hannis Self-Concept Scale	Cases significantly more maladjusted than controls (frequency of behavior problems) No difference in self-concept.
41	1982	STEINHALSEN	Inflamatory Bowel Disease	ע	17	7-18	Individually matched on age, sex, SES	Graham and Rutter Parent Interview, Rutter Children's Behavior (CBQ), Clinical assessment	Psychiatric disorder Cases 60% vs. controls 18% CBQ: Cases significantly higher subscores for emotional disorders.
42	1982	Lavigne	Diabetes	41	43	6-16	Individually matched on sex and age.	Achenbach (280).	Male cases significantly more inter- nalizing and externalizing symptoms. Group mean 0.8-0.9 SD above controls. Females no difference. (Matched analysis not done).
43	1983	STEDHALSEN	Qystic Fibrosis, Asthma	72	36	4-14	Frequency metch on age, sex, sib. rank, SES	Adapted Graham and Rutter Parent Interview	No direct comparison between cases and controls. Multiple regression used to examine predictors of the outcome measures for CF, asthma and control groups separately.

TABLE 2 CONTINUED ON NEXT PAGE

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## TABLE 2 CONTINUED

44	1994	HD <b>ARE</b>	Setzure Disorder, Diabetes	. 113	113	5-14	Individual metch by class, age,sex	Rutter Teacher's Scale Rutter Parents'Scale	Chronic Epilepsy cases 48% v. controls 13% Disturbed* Orronic Diabetes cases 17% v. controls 3% Disturbed* New Epilepsy cases 45% v. controls 10% Disturbed* New Diabetes cases 17% v. controls 7% Disturbed (NS). (Matched analysis not done).
 4 <del>5</del> -	1985	THOMPSON	Diabetes, Cystie Fibrosis	119	Not Stated	Not Stated	No antiching. Healthy controls from pediatrician's office. Psychiatric controls from Community Guidance Clinic.	Missouri Children's Behavior Checklist	Mean subscale scores not different from controls, and less than psychiatric group.
46	1985	BRESLAU	Cystic Mpelody- splasia, Multiple Physical Disorders Fibrosis, Cerebral Palsy	304	360	3-18	Random sample from Cleveland area.	Psychiatric Screening Inventory (Mother)	All cases 27% v. controls 11% for severe psychiatric impainment. Between disease groups, no differences on parent conflict, - regressive anxiety subscales. Overall, these higher than controls. (Analysis of covariance controlling income and maternal education)
47	1985	COMEN	Qystic Fibrosis	41	31	2-5	Healthy daycare children (no watching)	Preschool Behavior Questionnaire (modified Rutter CBQ)	No significant difference overall, but CF significantly higher on hostile- aggressive subscale-
16-	Not st	atistically	significant		<b>SD=</b> 9	Standard	Deviation	* Statistically significant	
									END OF TABLE 2

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Ref f	Year	First Ashor	Site of Survey	Sampling Procedure	Age (yr)	Sample Size	Outcome Measure(s)	Maladjustment
22	1971	ALESS	Isle of Wydt(UK)	Entire population surveyed.	9-11	3271	Psychiatric assessment (Rutter & Graham) after screening by standardized parent and teacher questionnaires.	17% in OPD, 7% in others. (RR 2.4)
52	1971	PLESS	Marroe County, Rochester (MY)	Systematic sample of house- holds, and random sample of children from these households.	6-16	1756	California Test of Person- ality; Coopersmith Self- Esteum Inventory; Children's Manifest Anxiety Scale; Couen Teacher's Behavior Scale; Kearsley Behavior Symptom Questionnaire; Parent Questions about Behavior.	23-30% in CPD, 13-16% in others. (RR 2.3)
<del></del>	1981	WALKER	_# Genesee County, Michigan	Cluster sample of children from random sample of households.	0-17	3072	4 questions to parent from Rochester survey, about tochavior, social, learning and school problems.	3.5-20.68* with CPD, 2.8% in whole sample had behavior problem. (RR 1.3-7.4) 3.8-35.38* with CPD, 1.8% in whole sample had social problem. (RR 2.1-19.6).

## TABLE 3: PREVALENCE SURVEYS

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#### TABLE 4: COHORT STUDIES

Ref	Year	First Author	Disorder	Cohort	Sample Size Cohort (Disorder)	Age (Yr)	Data Source	Outcome Measure	Finding
56	1970	DENSEN	All Physical Problems	Retrospective stratified sample of males from New York City public ele- mentary schools. All with physical problems.	3511 (851)	0-18	School Records	Draft rejection on "mental" grounds.	Rejection rates in those with: Physical disorders, 7.63 No problems, 0.73 RR=10.9 (Univariate analysis only)
52	1971	PLESS	All Orronic Physical Disorders	Sample of 1946 birth cohort: National survey of U.K. Prospective. All chronic physical disorders.	<b>4649</b> (537)	0-15	Repeated interviews and exam- inations (Parents, Teachers & childnen)	Behavioral symptom questionnaires.	Parent report of behav. symptoms: Physical disorders 25%, others 17% (RR 1.5) Teacher rated nervous/aggressive OPD 35%, others 31% (RR 1.3) Child report (neurotic); OPD 14%, others 11% (RR 1.3) (Univariate analysis only)
57	1978	PEDCHAN	Asthum	1958 birth cohort (sample). National Ohild Development Study (Britain). Prospective. All those with asthm.	13509 (1664)	7 and 11	Parents, Teachers	Rutter Home Behavior Scale (Parent), Bristol Social adjust- ment Guide (Teacher)	Significantly higher scores on parent scale in asthma children. Dose response effect observed. No difference on Bristol after controlling for sex social class. (Multivariate analysis controlling sex, social class).
58	1981	ANS.D	Diabetes ,	Incident cases of diabetes and controls. Individual matching of 30 controls on sex, age, parent occupation, family characteristics. Time 1 measurement within 5 mo. of diagnosis and Time 2, 3 years later	64 cases, 30 controls	4-17	Psychia- trists	Clinical assessment, Rorschach Test	No difference detected at T1 or T2. Diabetics showed increase in aggression from 20% to 30%, controls a decrease from 16 to 7% (PK0.05)
59	1994	orr	All Orronic Physical Disorders	From 1% rendom sample of Monroe Co. households in 1968. Two measurements at 8 year interval.	144	13- 22	Interviewers Subjects	, Structured Interview, California Psychological Inventory.	OPI Score Average in 27% cases and 15% former cases

TABLE 4 (CONTINUED)

60	1994	BRITTEN	Epilepsy	Mational Survey (1946) sample of U.K. birth cohort.	5362 (46)	0- 26	Hospital records and subjects	Hospital admission or other treatment for psychiatric, emotional problems, between ages 15 and 26 years.	18% of cases vs. 6.8% of non-cases had outcome (RR 2.7). Univariate analysis.
ଶ	1985	KOVACS	Diabetes	Newly diagnosed subjects. Retro- spective ascertain- ment of outcome prior to diagnosis.	74	8- 13	Intervier Schedule for Children	Psychiatric disorder OR at least 4 notable symptoms or signs of distress.	Parent-reported prevalence of pre- diabetic psychosocial difficulty 18%, and by study criteria 14% had psychiatric disorder. Time 1 prevalence (at 2-3 weeks) 36%. At 9 months, 93% recovered.
62	1985	HELLER	Cleft Lip/ Palate, Heart disease, Hearing defects.	Subjects recruited from clinic lists. Two measurements at 1 year interval.	140	4-13	Structured interview; Parent, child	Achembach Child Behavior Checklist. Children's Self Report psychiatric Rating Scale.	Prevalence of maladjustment 33% at Time 1, 24% at Time 2. (Univariate analysis)

## TABLE 5: INTERVENTION STUDIES

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Ref #	Year	First Author	Disorder	Age (Yr)	Sample Size	Assignment Procedure	Outcome Measure(s)	Intervention	Result
63	1973	MECRAN	Diabetes	7-15	33 Treatment 26 Control	Frequency matching of age, sex, race, SES, duration of diabetes. Controls chosen from variety of physician sources.	Coopersmith Self-Estem Inventory. Onildren's Manifest Anxiety Scale.	3 week camp. No specific descrip- tion of activities.	Significant improvement in self-esteen measure for female campers only. Improvements in scores for all subject regardless of treatment/control status.
64	1975	PLESS	Wide runge of chronic physical disorders.	6-15	56 Treatment 42 Controls	Random after stratification on Family Function Index	California Test of Personality; Coopersmith Self-Esteen Inventory; Children's Manifest Anxiety Scale	Family Counsellor Program. Duration 1 year. Trained non- professional mature women acted as family counsellors.	60% treatment subjects vs. 41% controls showed improved psychologic status (P<0.05).
65	1994	STEIN	Wide range of chronic physica) disorders.	<b>0-11</b>	105 Treatment 104 Control	Random after stratified on Judged Ability to Cope, and Overall Burden Index.	Personal Adjustment & Role Skills Scale (PAPS II), Functional Status Measure.	Pediatric Home Care Program. Team care by Pediatrician, nurse practitioner, with access to social worker, psychiatrist etc. Pretest, and Post-Test measures at 6 months, 12 months.	Significantly better improvement in adjustment at 6 months in treatment group (P=0.04), with trend in same direction at 1 year (P=0.08). (N=37,33 for these data.) No difference in functional status measure at either time.

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Appendix 2. Consent form.

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# L'Hôpital de Montréal pour Enfants The Montreal Children's Hospital Department of Community Pediatric Research



UN HÓPITAL D'ENSEIGNEMENT + MIGHT UNIVERSITY + A TEACHING HOSPITAL

Dear Parent.

We are writing to invite your participation in a Monureal Children's Hospital research project being carried out in cooperation with the staff of the clinic that your child attends. This research is concerned with the effects on children and their families of various childhood illogsses, and whether it is possible to reduce the stress that illnesses produce Coping with a physical illness is often in/itself a major problem for a child, but there s no doubt that there can be an extra burden due to the added financial, travelling and time commitments that must be borne by the whole family

The study will involve an how Top's interview by one of our research staff, either in your home or at the hospital, depending on your preference. A confidential guestionnaire will be completed for the mother and the child Following this, a research social worker will get in touch with some of the families that have been interviewed. This social worker will get to know the patient and family during the next 6 months in order to provide any assistance that is required and to be available as a counsellor to the family. Whether or not families are contacted by the social worker, they will all contribute to receive their usual clinic services, just as they have in the past. Finally, one year after the first interview, all families in the study will be given a second questionnaire

One of our staff will telephone you in the next few weeks to find out whether you are willing to take part in the research - Arrangements to suit you and your child will then be made for a time and place for the interview

we sincerely hope that you will be able to participate in this important research project. The results of this study will prove very valuable in planning support services for families of children with chronic illnesses not just in Montreal, but throughout the world. If you have any questions about the study, our researcher will try to answer them when she gets in touch with you in the near future.

When you decide to participate in the study, please sign the form below and retain it for the interviewer Should your deride not to join us in this research, or if you feel it necessary to withdraw from the study after it starts please rest assured that the future care of your child at the hospital will in no way be affected

With many thanks "

Terence M Nolan MD Pediatrician and Principal Investigator

Project Director

## Consent to Participate in the Study

1 agree to take part in this study understanding that my child and I will be asked some questions involving about 1 hour of our time. Foilowing this I understand that our family may be chosen by a lottery method to be introduced to a Montreal Children's Hospital social worker who will be available to us for a 6 month period for any assistance or advice that we may require I agree to a second interview to be held I year after the first. I understand that all information will be kept strictly confidential by the research team. I am free to withdraw from this study at any time without penalty to me or to the future care of my child at the Montreal Children's Hospital

•			0
Signature of the Parent		date	
Signature of the Interviewer	న	date	•
2300 TUPPER, MONT	LÉAL. OUÉBEC H3	H 1P3 •	934-4400 (514) 2000 (514)

Appendix 3. Telephone interview.

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## TELEPHONE INTERVIEW

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Hello, this is(name of intervie Pediatric Research at the Montreal Childre	wer) calling from the Department of Community ren's Hospital. May I speak to Mrs. (Mr)?
• Are you busy now?(If yes:) When ca	an I call back?
	-
1) Have you received a	letter describing our study?
YES	NO NO
Do you have any questions about it?	I'd like to send you a copy of the letter. Could I verify your address and postal code? I'll call you again in about 1 week.
YES- NO	L
Answer any questions.	
2) Have you had a change	ce to make a decision about
participating in our	r study?
YES	
	Is there any special reason why you have not made up your mind? (LOG) Can I give you more information now to help you decide?
3) Are you interested	I'll call back in about a week to find out what you have decided.
YES <b>(</b>	NO .
I'd like to ask you some questions:	Would you mind telling me why you have decided not to participate? (LOG)
Verify child's : name, age, clinic Does child attend: regular school, special class in a regular school, special school	(Provide more information and reassurance if necessary. Leave our number: 934-4400 loc 2667, so that they can call back if they change their minds)
Last clinic visit: Next clinic visit:	
Has anyone in the family had the services of a psychiatrist, a psychologist, a social worker, a nurse? *For how long? When was the last time?	、 、
ARRANGE INTERVIEW:	
<b>O</b> N.B. <u>All children attending the AUDIOLOGY</u> must be at home at the time of the in	clinic; i.e. those with hearing problems terview in order to complete the HARTER.
All children between 4 and 6 years of interview so that they can complete t	age must be at home at the time of the her HARTER.
* See Interviewers' Introduction	

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## Appendix 4. Interviewer's questions at baseline and Time 2.

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## Montreal Children's Hospital Department of Community Pediatric Research

## First interview Child Health Study

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1 Child's Name			
first na	ne	family name	
2 Child's MCH ID Number 4 Child's Sex EMale EF		3 Child's Age	months
5 Name of Clinic that Child Attend	ts		
6 Name of Illnessor Reason that (	Child Attends This Clinic	• · ·	
7 Date of Interview	Day Month Year		
8 Respondent	DMother DFather DC	ther(specify)	
9 Location of Interview	OSubject's home OMCH	Olher(specify)	<i>.</i>
10 Time Interview Commenced			
11 Time Interview Completed	12. D	uration of interview(minutes)	
13 Consent form signed by	DMother DFather DOther(	specify).	
14 Alternative Contact Address/F	hone No of Friend or Relative	. <i>,</i> .	
15 Name of Interviewer	····		· · · · · · · · · · · · · · · · · · ·
Contents of Package	<ol> <li>Personal Details (Interviewer</li> <li>Family Function (Interviewer)</li> <li>Impact on Family (Interviewer)</li> <li>Malaise Inventory (Interviewer)</li> <li>Functional Status (Interviewer)</li> <li>Achenbach Scale (Parent)</li> <li>CAAP (Parent)</li> <li>Harter Scale (Interviewer &amp; 1)</li> </ol>	) r) pr) r) ©	

Note "The illness" refers in all questions(unless otherwise stated) to the study illness, that is, the illness for which the child attends the MCH clinic.
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18	<ul> <li>I would like you to tell me a and ages, and the number <u>Name</u></li> </ul>	little about your family and who lives in y of years of formal education (school) con <u>Relation</u> <u>Age Living at Home?</u>	your home Po npleted " <u>School</u>	erhaps you <u>CEGEP</u>	university	e their na <u>Total '</u>
		Mother		.00	.00	
		Spouse				
•	+ + + + + + +	Child in Study 🔿 🔿 🔿 🔿	➡□□.			
			· · ·		~	
	a.,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,					
9	"Apart from the problem that	is the reason for(n	ame of child)	attending t	the -	-
.9 L	"Apart from the problem that (name of List here	ns the reason for(n MCH clinic), what other health problems o	ame of child) r diseases do	attending t es he∕she l	the - have?"	-
 19 L	"Apart from the problem that (name of List here	is the reason for(n MCH clinic), what other health problems o	ame of child) r diseases do	attending t es he∕she i	the - høve?"	-
19 L	"Apart from the problem that (name of List here	Is the reason for(n MCH clinic), what other health problems o	ame of child) r diseases do	attending t es he/she i	the - have?"	-
19 L	"Apart from the problem that (name of List here	Is the reason for(n MCH clinic), what other health problems o 	ame of child) r diseases do 	attending t es he/she to have th	the	- for which
19 L	Apart from the problem that (name of List here	Is the reason for(n MCH clinic), what other health problems o 	ame of child) r diseases do 	attending t es he/she i to have th	the fave?	fgr which
	"Apart from the problem that (name of List here	Is the reason for(n MCH clinic), what other health problems o 	ame of child) r diseases do 	attending t es he/she to have th te occasion	the have? ne condition is did you co	for which
19 L	"Apart from the problem that (name of 	Is the reason for(n MCH clinic), what other health problems o (name of child) when he/she was fi (name of clinic)?" 6 membles, that is, since June, on how Ibecause of his/her(name of	ame of child) r diseases do  rst diagnosed many separat illness)?"	attending t es he/she to have th e occasion	the have?" he condition	for which
19 L	"Apart from the problem that (name of List here	is the reason for(n MCH clinic), what other health problems o (name of child) when he/she was fi (name of clinic)?" 6 menths, that is, since June, on how because of his/her(name of	ame of child) r diseases do 	attending t es he/she to have th e occasion	the have?" ne condition is did you co	for which ome to the e of child

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<ul> <li>24 If nespitalizations eccurred (Q.23 above) ask. "As a result of these hospitalizations, how many days would you estimate(name of child) spent in hospital in that 6 menth period?"</li> <li>25 * Over the past 12 menths, have you or your family received any services from ?*</li> </ul>	in total
25 <sup>•</sup> Over the past 12 menths, have you or your family received any services from 2 <sup>-</sup>	
25 Over the past 12 menths, have you or your family received any services from ?"	
a physical therapist?" DNo DYes	
"a speech therapist?" DNo DYes	
a psychologist?" DNo DYes, the last occasion was months ago Type of help	
.a psychiatrist?" DNo DYes, the last occasion was Domonths ago. Type of help	
an occupational therapist?" DNo DYes	
genetic counselling?" DNo DYes	
a social worker?" DNo DYes, the last occasion was months ago Type of help	
a nurse?" DNo OYes, the last occasion was months ago Type of help	
anyone else?" DNo DYes Specify source of help	.,
26 " Just this has some shout the same 3 means they may down here.	
school as a result of his/her illness?"	UIII
27 "Are you mercied on living with comerce?"	
If The', PROBE	
Dwidowed Dseparated	
20       If response to U.27 was either divorced, widowed, never married, or separated, ask         "Are you now living as a single parent?"       If yes	••••••••••••••••••••••••••••••••••••••
29 If response to Q.28 was YES, ask "How long have you been a single parent?" [], [], []	
29 If response to Q.28 was YES, ask "How long have you been a single parent?" [], [_], [_] years months	
<ul> <li>29 If response to Q.28 was YES, ask "How long have you been a single parent?"</li></ul>	hrs/wk
<ul> <li>29 If response to Q.28 was YES, ask "How long have you been a single parent?",,,,,,,</li></ul>	hrs/wk hl
<ul> <li>29 If response to Q.28 was YES, esk "How long have you been a single parent?"</li></ul>	hrs/wk hl
<ul> <li>29 If response to Q.28 was YES, ask "How long have you been a single parent?"</li></ul>	hrs/wk ht
<ul> <li>29 If response to Q.28 was YES, ask "How long have you been a single parent?"</li></ul>	hrs/wk ht

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End of Personal Details Section.

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		PAGE 1 OF	a a ∎ a tim	E 2 INTERVIEW	
	<b>IN</b>	terviewer's Questi For All Subjects	enneire	(continued from BLANK	cover sheet 22
1. "Thinking back over the pee the Montreal Children's Ho hts/her(neme	t 6 me epital v of film	with	parate occasions dic (name of child) bace	l you come to juse of	(23-24)
. Tin the same 6 seasts perio	d, how i	meny visits to <b>other</b> d	<b>lectors</b> accurred d	j6	(25-26)
. "In the same 6 menth period	d, how r	many admissions to	hespital accurred	due	(27-28)
to(name of child) (	illness/	?" (0,3 above) ank . "A	s a result of these h	aspita)izations.	
how many days in total wor hospital in <b>thet 6 month</b> p	uld you leriod?'	oot imoto	( name o	f child) spent in	(29-31)
days				BLANK	(82)
5. " Since the time of the first i	ntervie	w, have you or your fa	mily received any s	ervices from	
" prychologist?"	' <b>(11</b> %) ()	ElYes> W YES, 1	who received servi	<b>045</b> ?	
			and whet was reaso	<b>n</b> ?	
" psychiatrist?"		Cives> If YEB,	who received servi	<b></b>	
	•	•	and what was reaso	a?	
"		Cityes> If YEB,	who received servi	<b></b>	
("apart from the project sec	iai yerk		and what was reaso	n?	
"	<b>Cilio</b> 0	CIYee> If YEB, 1	who received servic	<b></b> ?	
	ò	•	and what was reaso	n?	
"any other social support		Cives. Specify source	of help		

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who received services?	 J

ENTERVIEVER: If any above services received, probe and describe in detail on the back of this page what the nature, extent and externe of the services were.

and type of assistance received....

and what was reason?.....

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	> If Yes, describe	(4)
		·····
8. "Since the time of t	the first interview, has your child's health	
	- 10 improved?"	( •
	30 become worse?"	. (40
9. "Do you have any r	problem with(child's name) behaviour?"	
	0 1	
	D No D Yes	(47
10. "Does	(child's name) have any learning problems?"	
	0 1	
	CINO CIYes	(4)
11. "Does		r children and/or adu
	0 1	
	D No D Yes	(49
12, "Has		lwark?"
	0 1	
	CINo CIYes	(50
13. "Hee	(child's name) aver been asked to leave school?"	
10. 1100		
	CINO CIYes	(5)
14. "Since the time of	i the first interview, whet change ( if any) has there been in yo	ur marital status?"
1 Dno change 2	Linkar Frou SLSoper ekok, for morry mear Frou? TLSoper eko Destatelitikan SChwidowed	

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		100
		(50)
	THER ONE CHENCE FOR BELOW PORTON T. FIGURE	(57)
FATHER/PARTNER Dur	namploved now, but was employed at time of first interviewD MOTHER	{/
Q <b>e</b> m	played now, but was unemplayed at time of first interview	12
<b>D</b>	still employed in same tab.	13
Ω	stillemploved but in new job	14
0	still unemployed	15
0	not app?/cable because no father/partner or mother	{8
6 "Lines we had one conte	Bi with other families that you know were also taking	(58)
o. Heve you had any contact		(50)
part in this study?"	OLINO ILITES> IT TES, PIKUBE,	(23)
	Were the contacts with families who were receiving help	
	from Project social workers?	
	ODNo 10Yes> If Yes,	(60)
	How much contact occurred?	(61)
9. "Have you been involved DNo 10Yes> If Yes,	in any other studies or projects in the last 6 months?" , "Did you complete questionnaires or answer questions similar to those you have been asked in this study?"	(62)
9. "Heve you been involved CINo 101Yes> If Yes, CINo 102Yes> If Yes,	in any other studies or projects in the last 6 months?" , "Did you complete questionnaires or answer questions similar to those you have been asked in this study?" ettempt to identify which questionnaires or specific questions were used and also who conducted the study.	(62) ,(63)
9. "Heve you been involved CINo 10Yes> If Yes, CINo 10Yes> If Yes,	in any other studies or projects in the last 6 months?" "Did you complete questionnaires or answer questions similar to those you have been asked in this study?" ettempt to identify which questionnaires or specific questions were used and elso who conducted the study.	(62) ,(63) <b>(64-65</b>
9. "Heve you been involved ONo 10Yes> If Yes, ONo 10Yes> If Yes,	in any other studies or projects in the last 6 months?" "Did you complete questionnaires or answer questions similar to those you have been asked in this study?" ettempt to identify which questionnaires or specific questions were used and elso who conducted the study.	(62) ,(63) <b>(64-65</b>
9. "Heve you been involved CINo 101Yes> If Yes, CINo 101Yes> If Yes, O. "Did a social worker from person ?	in any other studies or projects in the last 6 months?" "Did you complete questionnaires or answer questions similar to those you have been asked in this study?" ettempt to identify which questionnaires or specific questions were used and also who conducted the study.	(62) ,(63) <b>(64-65</b>
9. "Heve you been involved ONo 10Yes> If Yes, ONo 10Yes> If Yes, O. "Did a social worker from person ?	in any other studies or projects in the last 6 months?" "Did you complete questionnaires or answer questions similar to those you have been asked in this study?" attempt to identify which questionnaires or specific questions were used and also who conducted the study.	(62) ,(63) (64-65 (64-65 (66)
19. "Heve you been involved DONo 107es> If Yes, DONo 107es> If Yes, 20. "Did a social worker from	in any other studies or projects in the last 6 months?" "Did you complete questionnaires or answer questions similar to those you have been asked in this study?" ettempt to identify which questionnaires or specific questions were used and elso who conducted the study. 	(62 ,(63 (64-

o to next page ---->>>

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PAGE 4 OF 4

### INTERVIEWER -----> NOW OPEN SEALED ENVELOPE.

If it contains "<u>Questions for Families ATTACHED to Social</u> <u>Workers</u>", give it to the parent to complete now. You may assist if requested to do so by the subject.

If it contains "<u>Questions for Families NOT ASSIGNED to Social</u> <u>Workers</u>", you administer the questions to the parent.

If this is one of the few families assigned to social workers which refused to see the social worker at all, then proceed directly to the "Wrap Up".

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#### WRAP-UP

#### INTERVIEWER---->

1. Ask the parent if they would like to add anything else, or to make any final comments.

Arrange for telephone edministration of "Herter" (if not done in person).
 Arrange for telephone edministration of "Herter" (if not done in person).
 Mention the possibility of a future interview in about 1 year depending on funding.
 Ask for a contect (eg. perent, friend).
 Nome:
 Relationship:
 Address:

Telephone: .....

5. Thank parent for their participation. Give letter of appreciation to parent.



Appendix 5. Social worker summary sheet and contact log.

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SUMMARY SHEET AND CONTACT LOG

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AT A S OF	
NAME	

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Date of Initial Con	ţact:									
Date of Final Conta										
Initial Assessment	Complet	ed:		Date	:	يونان ولدكوه كالمر		Place	:	
Home Visit complete	d			_Date	:					
lst Visit completed	d			_Date	:			Place	:	
2nd Visit completed	d			Date	:			Place	:	
Telephone calls:	1,	<sup>°</sup> 2	3	4	5	6	7	8	9	10
	11	f2	13	14	15	16	17	18	19	20
	21	22	23	24	25	26	27	28	29	30
	31	32	33	34	35	36	37	38	39	40
	41	42	43	44	45	46	47	48	49	50

late	Time	Dura- tion	Flace	Contact Origin	Remarks \
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Appendix 6. Telephone protocol for notifying controls.

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#### Telephone Protocol for Notifying Controls:

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Purpose of the telephone call to control group:

-thank parent for participation -notify parent of their status as control -maintain contact with this group -notify parent of second interview in the fall

Procedure:

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-identify yourself

-thank parent for their participation in study

- notify parent that no Social Worker will be contacting them (from the study), but that their continued participation in the study remains essential to the success of the whole project

-ask them to notify us of any change of address

-inform them that we will be contacting them for another interview in the fall ,

Appendix 7. Letter to control families at study mid-point.

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# L'Hôpital de Montréal pour Enfants The Montreal Children's Hospital



DEPARTMENT OF COMMUNITY PEDIATRIC RESEARCH

Dear Parent,

We are writing to let you know that the research project on children with chronic conditions in which you kindly agreed to participate is presently going well.

Our interviewers will be contacting you sometime after August to arrange a time to complete the second questionnaire. So, if you plan to <u>change your address</u> before then, please <u>let</u> <u>us know</u> so that we will be able to reach you.

Finally, we want to express our appreciation for your involvement in the study and we hope you will find the enclosed newsletter of interest.

With thanks,

Yours truly,

I lok 4

T. Nolan, M.D.

I. Tragali,

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Appendix 8. Child Behavior Checklist.

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CHILD BEHAVIOR CHECKLIST FOR AGES 4-16

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For office use only ID #

CHI	LD'S AE		<i></i>			-	PARENT'S school teed even if part	TYPE OF WORI ther, homeniaker ant does not live	(Please be speci laborer lathe ope with child)	lic-for exem rator shoe si	ple auto m elesman, ar	iechanic higi my sergeant
8EX	□ Boy □ Girt	AGE	, í	RACE		-	FATHI TYPE	ER'S OF WORK	•	<u> </u>		<u>*</u> *
TOD	AY'S DATE	-4	CHILD'S	BIRTHDATE			TYPE		· · · · ·			·····
- Mo	Dev	ν,	Mo	Dav	٧r		THIS J	FORM FILLED O	UT BY			
	Uay						C	Mother			, 	
GRA IN SCH	NDE IOOL						] ],	Father	(v)		<b>D</b>	
l.	Please list the s to take part in. F baseball, skating	ports your ch or example	nlid most li swimming, ding, bike	¥•s	Compa same a does h	ired to othinge, about e/she-spe	her childre t how muc and in eact	n of the th time n?	Comp same each	ared to oth age, how y one?	er childri rell does	n of the he/she do
	riding, fishing, e	tc			Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above
			•		П		П			П	Ē	Π
	· · · · · · · · · · · · · · · · · · ·											, <b>_</b>
	D											
•	c				$\cup$	L		${\color{black}{\sqcup}}$		, LJ	$\sqcup$	
IL.	Please list your activities, and g For example sti crafts, singing.	child's favori emes, other t emps, dojis, t etc (Do not in	ite hobbies than sports books, plan nclude T V	 	Compa same a does h	ared to ot ige, abou ie/she spe	her childre t how muc and in eacl	on of the ch tìme h?	Comj same each	ared ta oti age, how t one?	ner childr well does	en of the he/she do
	None	·			Qpn'i Know	Less Than Average	Average	- More Than Average	Don't Know	Bel <i>ow</i> Average	Average	Above' Average
	Ł	·										
	b		•									
		-	<u></u>		D				` D			
- <u></u> III.	Please list any o teams, or groups	rganizations, s your child b	, clubs, belongs to.		Compi same i each?	ared to ot age, how	her childre active is h	en of the e/she in	. <u></u>			Å
					Don't Know	Less Active	Average	More Active				
	Ł			<b>N</b>								+
	b											
	c											
IV.	Please list any je has. For example making bed, etc	obs or chores 5. paper route	s your child s, babysitti	t ng,	Compa same a carry ti	ired to oth ige, how t hem out?	her childre well does i	n of the he/she	۰.			
	. None			۲	Don't Know	Below Averace	Average	Above Averace				
	- )				<b></b>		Г	<u> </u>		$\checkmark$		
_	]	•		<u> </u>						-		
	, •				L	L						
	.*							_				

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V. 1. About how many close irlende dass your child have		one [] 1	0:	2 or 3	4 or more
2. About how many times a week does your child do th	'. Ings with the	um? 🗆 ki	r Des than 1	🗌 1 or 2	3 or more
· · · ·			be		
н. '			•	<b>۰</b>	
I. Compared to other children of his/her age, how well doe	s your child	*			· · · · · · · · · · · · · · · · · · ·
· · · · · · · · · · · · · · · · · · ·	Worse	About the same	Better		
a Get along with his/her brothers & sisters?		, L			
b Get along with other children?					
c. Behave with his/her parents?				•	
d Play and work by himself/herself?		ب ;			
I. 1. Current school performance-for children aged 6 and	i older:		<b>.</b>	<b>Ab - - - - -</b>	
	philas	Leiom sasisõe			18 <b>4</b> .
a. Reading or English					4
b Writing					-
C Arithmetic or Math					1
d Spelling					÷
Other academic sub- e				. 🗆	
tory, science, foreign f					
g				, D	
2. Is your child in a special class?					
💭 No 🛛 . 🛄 Yëswhat kind?	ä				
<b>`</b>					
3. Has your child ever repeated a grade?	· · · · · · · · · · · · · · · · · · ·	•			
No Yes-grade and reason					
			•		
				``````````````````````````````````````	`
4. Has your child had any academic or other problems in	school?				
No Yes-please describe	`.				
			-	•	
When did these problems start?					
Have these problems ended?					
No Yes-when?					

0	1	2	57.	Physically attacks people	0	•		84	Strange hebeylor/desortbol:
	1	2	<b>58</b> .	Picks nose, skin, or other parts of Body (describe):		•	4	04.	
ſ	Ŀ			80	0	1	2	85	Strange ideas (describe):
J				•				•	* 3
0	1	2	<b>59</b> .	Plays with own sex parts in public 16			,		
U	1	2	60	Plays with own sex parts too much	0	.1	2	86	Stubborn, sullen, or irritable
0	1	2	<b>61</b> .	Poor school work	0	1	2	87	Sudden changes in mood or feelings
0	1	2	62	Poorly coordinated or clumsy	0	1	2	88	Sulks a lot
0	1	2	63.	Prefers playing with older children 20	0	• •	2	80	, Suepicioue
0	1	2	64.	Prefers playing with younger children	0	1	2	· 90	Swearing or obscene language
0	•	2	85	Petuses to talk			•		<b>- - - - - - - - - -</b>
01	1	2	66	Repeats certain acts over and over	0	1	2	91	Talks about killing self
•	•	7	•••	compulsions (describe)		•	4	92	Tarks of walks in sleep (Gescribe)
				•				^	с
	-				0	1	2	<b>9</b> 3	Talks too much 5
0	1	2	67	Runs away from home	0	1	2	94	Teases a lot
0	1	2	<b>68</b> .	Screams a lot 25			_		
~		•		Operative bases this as to set	• 0	1	2	95. 00	Temper tantrums or hot temper
U N	1	2	70	Secretive, Keeps things to self	0	1	2	90	ININKS ADOUT SEX TOO MUCH
	•	•	70.	Sees mings that aren't there (describe)	0	1	2	97	Threatens people
					0	1	2	98	Thumb-sucking
				-					•
					0	1	2	99	Too concerned with neatness or cleanline
n	•	2	71	Self conscious for eacily emberraged	0	1	2	100	trouble sleeping (describe)
0	1	2	72.	Sets fires					
				~					
-				•					
D	1	2	• 73	Sexual problems (describe)	0	1	2	101	Truancy, skips school
D	1	2	· 73	Sexual problems (describe)	0 0	1 1	2 2	101 102.	Truancy, skips school Underactive, slow moving, or lacks energy
D	1	2	· 73	Sexual problems (describe)	0	1 1	2 2 2	101 102.	Truancy, skips school Underactive, slow moving, or lacks energy
D	1	2	· 73	Sexual problems (describe)	0 0 0	1 1 1	2 2 2 2 2	101 102. 103 104.	Truancy, skips school Underactive, slow moving, or lacks energy Unhappy, sad, or depressed Unusually loud
0	1	2	· 73 74	Sexual problems (describe)	0 0 0 0	1 1 1 1	2 2 2 2 2	101 102. 103 104.	Truancy, skips school Underactive, slow moving, or lacks energy Unhappy, sad, or depressed Unusually loud
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) ) )	1 1 1 1	2 2 2 2 2	73 74 75 76 77.	Sexual problems (describe) 		1 1 1 1 1 1	2 2 2 2 2 2 2 2 2 2 2 2	101 102. 103 104. 105 108 107.	Truancy, skips school Underactive, slow moving, or lacks energy Unhappy, sad, or depressed Unusually loud Uses alcohol or drugs (describe) Vandalism Wets self during the day
	1 1 1 1	2 2 2 2 2	73 74 75 76 77.	Sexual problems (describe) 		1 1 1 1 1 1 1	2 2 2 2 2 2 2 2 2 2 2 2	101 102. 103 104. 105 108 107. 108	Truancy, skips school Underactive, slow moving, or lacks energy Unhappy, sad, or depressed Unusually loud Uses alcohol or drugs (describe) Vandalism Wets self during the day Wets the bed
	1 1 1 1 .	2 2 2 2 2	<ul> <li>73</li> <li>74</li> <li>75</li> <li>76</li> <li>77.</li> </ul>	Sexual problems (describe) 30 Showing off or clowning Shy or timid Sleeps less than most children Sleeps more than most children during day and/or night (describe):		1 1 1 1 1 1 1 1	2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	101 102. 103 104. 105 106 107. 108 109	Truancy, skips school Underactive, slow moving, or lacks energy Unhappy, sad, or depressed Unusually loud Uses alcohol or drugs (describe) 
	1 1 1 1 ,	2 2 2 2 2 2	<ul> <li>73</li> <li>74</li> <li>75</li> <li>76</li> <li>77.</li> <li>78.</li> </ul>	Sexual problems (describe) 		1 1 1 1 1 1 1 1 1	2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	101 102. 103 104. 105 108 107. 108 109 110	Truancy, skips school Underactive, slow moving, or lacks energy Unhappy, sad, or depressed Unusually loud Uses alcohol or drugs (describe) Vandalism Wets self during the day Wets the bed Whining Wishes to be of opposite sex
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	1 1 1 1 1 1 1	2 2 2 2 2 2 2 2 2 2 2 2 2 2	<ul> <li>73</li> <li>74</li> <li>75</li> <li>76</li> <li>77.</li> <li>78.</li> <li>79</li> <li>80</li> <li>81</li> </ul>	Sexual problems (describe) 		1 1 1 1 1 1 1 1 1 1	2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	101 102. 103 104. 105 108 107. 108 109 110 111 112 113.	Truancy, skips school Underactive, slow moving, or lacks energy Unhappy, sad, or depressed Unusually loud Uses alcohol or drugs (describe) Vandalism Wets self during the day Wets the bed Whining Wishes to be of opposite sex Withdrawn, doesn't get involved with othe Worrying Please write in any problems your child h that were not listed abover
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	1 1 1 1 1 1 1 1 1 1	2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	<ul> <li>73</li> <li>74</li> <li>75</li> <li>76</li> <li>77.</li> <li>78.</li> <li>79</li> <li>80</li> <li>81</li> <li>82</li> <li>83.</li> </ul>	Sexual problems (describe)		1 1 1 1 1 1 1 1 1 1 1 1 1	2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2 2	101 102. 103 104. 105 106 107. 108 109 110 111 112 113.	Truancy, skips school Underactive, slow moving, or lacks energy Unhappy, sad, or depressed Unusually loud Uses alcohol or drugs (describe) Vandalism Wets self during the day Wets the bed Whining Wishes to be of opposite sex Withdrawn, doesn't get involved with othe Worrying Please write in any problems your child he that were not listed above

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Appendix 9. Child and Adolescent Adjustment Profile. ĩ

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		Answei	r Challing	
	DURING LAST MONTH, HAS HE/SHE T (Please answer each statement Rary below)	ely Some- times	often A	4 Îmost Nways
(CAAP SCALE)	1. Tried to get along with others?			
	2. Joined others freely of own accord?			
	3. Invited others to play with him/her?			~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~
Name of Youngster Being Rated	4. Laughed and smiled easily?			
· · · ·				
your name	<u> </u>		Chadaaa	
1. Today's Date Month Day Year	DURING LAST MONTH, HAS HE/SHE T (Please answer each statement ` . Neve below)	Answer 2 er Rarely	Some- times	Often
2. Your Relationship to Youngster (Check one)   (1) Mother (stepmother, foster mother)	5. Wanted help in things he/she could have done on own?			·
(2)Father (stepfather, foster father)	<ol> <li>Became discouraged when attempted.something on own?</li> </ol>			Ţ
(4) Counselor	7 Asked for help when could *			
(5)Other (please specify)	8. Asked unnecessary questions instead of working on own?			
(1) Male (2) Female				
4. Age 5. Grade in School		Answer	Choices	· .
INSTRUCTIONS:	DURING PAST MONTH, HAS HE/SHE 1 (Please answer each statement Neve below)	2 er Rarely	Some- ( times ,	4 Often
<ul> <li>A. Please describe this youngster's behavior as you have observed it during the past month by answering each question.</li> <li>B. Please answer all questions on this and the reverse page, even though you may feel somewhat unsure of some answers.</li> </ul>	<ul> <li>9. "Flared up if couldn't have own way?</li> <li>10. Become upset if others did not agree with him/her?</li> </ul>			
in the box under the Answer Choices" like this	11. Picked quarrels with others?			
DPYRIGHT 1977 by IPEV Int'1. Reproduction by any process without written permission violates copyright laws. 'ublished by Consulting Psychologists Press. Inc.	12. Not responded to discipline?		- 🖂 🗌	
77 College Ave., Palo Alto, CA 94306		·		- <b>A</b> -

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COMMENTS:

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<b>6</b>			Answer (	hoi ces	
DURI (PLe belo	NG LAST MONTH, HAS HE/SHE ase answer éach statement w)	Rarely	2 Some- times	3 Often	4 Almost Always
13.	Worked hard at tasks or assignments?			•	
14.	Stayed with work or assignment until finished?				
15.	Made full use of abilities?	·			{
16.	Done work carefully?			· ·	
	-				
			Answer (	choi ces	
DURI (PLe belo	(NG PAST MONTH, HAS HE/SHE case answer each statement w)	Never	2 Rarely	3 Some- times	4 Ofter
17.	Sat and stared without doing anything?				
18.	Done things very slowly?				
19.	Appeared indifferent and uninterested in things?				
20	Daydreamed?				
20.					

Thank you for providing the information requested. Please check back to make sure you have not missed answering any questions.

If you would like to make any comments about the person you have rated, please use the opposite section for this.

Appendix 10. Child and Adolescent Adjustment Profile: scale profile.

#### CAAP SCALE PROFILE

(HOME AND COMMUNITY)

	<b>—</b>		r				
	<u>T</u> !	SCORES		ADJUSTMENT A	ND FUNCTIO	ING	
	G 0 0 D				4		
,	A D J U	70 -		5	5		
	S T M E N	65 -		6	6	16	4
	Ť	60 -	16	7	<u> </u>	- 15	
	A V E		15	8	8	14	, ,
-	R A G E	55 -	14	9	9	13	- 6
	A D	50 -	- 13	- 10 -		- 12	, 7
	J U S T	45		11	10	11	8
	M E N	+) - - - -	12	12	11	10 . 9	9
	-	40 -	11	13	- 12 -		10
	P 0 0	35 -	10	14	13	_8 0	10 -
	A D J		9	15	14	6	. 12
	U S T M	30 -	8	16	15	5 7 4	13
	E N T	25 -	7		16		14-16
		20 -	4-6 PEER RELATIONS	DEPENDENCY	HOSTILITY	PRODUCTIVE	WITHDRAWN
	PR	E					
	SC BA			· · · · · · · · · · · · · · · · · · ·			
	sc	ORE				•	
	CH	ANGE					
	INU	KN I					

BACKGROUND
YOUNGSTER'S
RATER'S NAME
RELATIONSHIP
(1) Mother 🔗
(2) Father
(3) XXX Teacher (Use Profile on Reverse Side)
(4)Counselor
(5) Other
SEX Male
Female
AGE
GRADE
DATE 1ST CAAP Ho Day Yr
DATE 2ND CAAP Ho & Day Yr

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Appendix 11. The Pictorial Scale of Perceived Competence and Social Acceptance for Young Children.

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#### INSTRUCTIONS

The child is given a sample item at the beginning of the booklet and instructed as follows

I have something here that s kind of like a picture game and it s called WHICH GIRL IS THE MOSTLIKE ME. I m going to tell you about what each of the girls in the picture is doing

Sample In this one (examiner then points to picture on the left) this girl is usually kind of happy and this girl (examiner points to the picture on the right) is usually kind of sad. Now I want you to tell me which of these girls is the most like (Child's Name)

After the child has pointed to the picture appropriate for her, the examiner points to the circles directly below that picture and emphasizes the key qualifying words to help the child refine her choice further. The examiner should always start with the extreme (larger) circle and proceed to the smaller circle. Thus, if the child points to the happy picture in response to the question concerning which is most like her, the examiner would say

Are you always happy? (pointing to the larger circle)

Or are you usually happy? (pointing to smaller circle)

Occasionally a child will point to the middle of the two pictures and say that both are like her. The examiner should then say. Yes sometimes we do feel both ways, but if you had to pick which one of these girls is the way you are *most* of the time which one would you choose?

The number value corresponding to the child's choice should be recorded on the Scoring Sheet for Individual Child Responses. Any comments should be recorded in the space provided at the bottom of the sheet.

The examiner continues for each plate reading the descriptions verbatim as she/he points to the picture accompanying each description. In some pictures there is a target child central to the description designated by an arrow pointing to that child. Be certain that on these items you point to that particular child.



ITEM 2

This girl has lots of friends to play with Do you have

.....

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This girl doesn't have very many friends to play with Do you have A whole lot of friends to play with 0,R Pretty many Hardly any friends A few OR 3 ÷ 2 1 10

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# Appendix 12. Perceived Competence Scale for Children.

HARTER 7-12

"What I Am Like"

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Child	's Name	Name ID Number							
Really	Sort Of	Left Hand Side	EXAMPLES	Right Hand Side 🕈	Sort Of	Really			
R	S	A. Some kids would rather play outdoors	BUT	Other kids would rather watch TV	<u>11.05</u> S	R R			
R	<b>3</b>	B.Some kids never worry about anything	BUT	Other kids occasionally worry about things	S	R			

\*\*\*\*

Really	Sort Of	Left Hand Side	8-	Right Hand Side 🕈	Sort Of	Really
True	_True			_	_True_	_True_
1 R	9	Some kids feel that they are very good at their schoolwork	BUT	Other kids worry about whether they can do the school work assigned to them	S	R
2 R	S	Some kids find it hard to make friends	BUT	For other kids it's pretty easy	S	R
3 R	S	Some kids do very well at allkinds of sports	BUT	Others don't feel that they are very good when it comes to sports	S	R
4 R	S	Some kids (ee) that there are a lot of things about themselves that they would change if they co	BUT	Other kids would like to stay pretty much the same	3	R
5 R	S	Some kids feel like they are just as smart as other kids their age	BUT	Other kids aren't so sure and wonder if they are as smart	S	R
6 R	3	Some kids have a lot of friends.	BUT	Other kids don't have very many friends	S	R
7 R	S	Some kids wish they could be a lot better at sports	BUT	Other kids feel they are good enough	S	R
8 <b>R</b>	S	Some kids are pretty. sure of themselves	BUT	Other kids are not very sure of themselves	9	R
9 R	S	Some kids are pretty slow in finishing their school work	BUT	Other kids can do their school work quickly	S	F
10 R	S,	Some kids don t think they are a very important member of their class	BUT	Other kids think they are pretty important to their classmates	S	R
11 R	S	Some kids think they could do well at just about any new outdoor activity they haven't tried before	BUT	Other kids are afraid they might not do welfat outdoor things they haven't ever tried	S	F

HARTER 7-12

## "What I Am Like"

Really True	<u>Sort Of</u> Irue	Left Hand Side		Right Hand Side 🜩 💈	ort Of True	Realli
2 R	S	Some kids feel good about the way they act	BUT	Other kids wish they acted differently	3	R
3 R	S	Some kids often forget what they learn	BUT	Other kids can remember things easily	S	R
4 R	S	Some kids are always doing things with a lol of kids	BUT	Other kids usually do things by themselves	S	R
5 <b>2</b>	S	Some kids feel that they are better than others their age at sports	BUT	Other kids don't feel they can play as well	S	R
6 R	S	Some kids think that maybe they are not a very good person	BUT	Other kids are pretty sure that they are a good person	9	R
7 R	S	Some kids like school because they do well in class	BUT	Other kids don't like school b they aren't doing very well	iecause S	R
8 R	S	Some kids wish that more kids liked them	BUT	Others feel that most kids do like them	9	R
9 R	S	In games and sports some kids usually watch instead of play	BUT	Other kids usuallyplay rather than just watch	S	R
20 R	S	Some kids are very happy being the way they are	BUT	Other kids wish they were different	S	R
21 R	S	Some kids wish it was easier to understand what they read	BUT	Other kids don't have any trouble understanding what they read	S	Ŗ
22 R	S	Some kids are popular with others their age	BUT	Other kids are not very popular	9	۶
23 R	S	Some kids don't do well at new outdoor games	BUT	Other kids are good at new games right away	S	P
24 R	8	<ul> <li>Some kids aren't very happy with the way they do a lot of things</li> </ul>	BUT	Other kids think the way they do things is fine	S	R
25 R	S	Some kids have trouble figuring out the answers in school	BUT	Other kids almost always can figure out the answers 0	S	R
26 R	S	Some kids are really easy to like	BUT	Other kids are kind of hard to like	S	f
27 R	S	Some kids are among the last to be chosen for games	BUT	Other kids are usually picked first	3	
28 R	S	Some kids are usually sure that what they are doing is the right thing	BUT	Other kids arent so sure whether or not they are doing the right thing	S	ĺ

Appendix 13. Self-perception Profile for Children.

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	Name o	f Subject	:		ID Number		
			SAMPLES	SENTER	NCE		
	Really True for me	Sort of True ◄ for me	- LEFT WAND SIDE		RIGHT HAND SIDE -	Sort of True for me	Really True for m
(a)	R	S	Some kids would rather play outdoors in their spare time	BUT	Other kids would rather watch T V	S	R
•	) <b>•</b> • • • •					* • •	<b>••</b>
	Really True for me	Sort of True for me	· LEFT HAND SIDE		RIGHT HAND SIDE 🕳	Sort of True for me	Really True for me
1	R	s	Some kids feel that they are very good at their school work	BUT	Other kids worry about whether they can do the school work assigned to them	S	R
2	R	S	Some kids find It <i>hard</i> to make friends	BUT	For other kids it's pretty easy	<sup>بر</sup> عہ S	R
3	R	S	Some kids do very well at all kinds of sports	BUT	Others <i>don't</i> feel that they are very good when it comes to sports	S	R
4	R	S	Some kids are happy with the way they look	BUT	Other kids are <i>not</i> happy with the way they look.	S	R
5	R	S	Some kids often do not like the way they behave	BUT	Other kids usually like the way they behave	S	Ŗ
Б	R	S	Some kids often get mad at themselves	BUT	Other kids are pretty pleased with themselves	S	R
1.	R	S	Some kids feel like they are just as smart as as other kids their age	BUT	Other kids aren't so sure and wonder if they are as smart	S ,	R
			Some kids have slot of		Other hids don't have		

	<sup>a</sup> Really True for me	Sort of True for me	- LEFT HAND SIDE		RIGHT HAND SIDE -	Sort of True for me	Realig True for me
9	R	s	Some kids wish they could be alot better at sports	BUT	Other kids feel they are good enough at sports	S	° R
10	R	S	Some kids are happy with their height and weight	BUT	Other kids wish théir height or weight were different	S	R
11	R	S	Some kids usually do the <i>right</i> thing	BUT	Other kids often <i>don't</i> do the right thing	S	R
12	R	\$	Some kids <i>don't</i> like the way they are leading their life	BUT	Other kids do like the way they are leading their life	S	R
13 .	R	S	Some kids are pretty slow in finishing their school work	BUT	Other kids can do their school work <i>quickly</i>	S	R
14. **	R	S	Some kids are kind of hard to like	BUT	Other kids are really easy to like	S	R
<b>´</b> 15	R	S	Some kids think they could do well at just about any new outdoor activity they haven't tried before	BUT	Other kids are afraid they might <i>not</i> do well at outdoor things they haven't ever tried.	s ,	R
16.	R	Š	Some kids wish their body was <i>different</i>	BUT	Other kids <i>like</i> their body the way it is	S	R
17.	R	S	Some kids usually act the way they know they are supposed to	BUT	Other kids often <i>don't</i> act the way they are supposed to.	S	R
18	R	S :	Some kids are happy with themselves most of the time.	BUT	Other kids are often not happy with themselves.	S	R
19	R	S	Some kids often forget what they learn	BUT	Other kids can remember things easily.	· s	R
20	R	S	Some kids are always doing things with alot of kids	BUT	Other kids usually do things by themselves.	S	R

rd.

-	• •	Really True for me	Sort of True for me	LEFT HAND SIDE		RIGHT HAND SIDE	Sort of True for me	Really True for me
0	21	R	5	Some kids feel that they are <i>better</i> than others their age at sports	BUT	Other <sub>l</sub> kids <i>don't</i> feel they can play as well	S	R,
	22	R	- 5	Some kids wish their physical appearance was different	BUT	Other kids <i>like</i> their physical appearance the way it is	S	R
<b>6</b> 4	23	R	S	Some kids usually get in <i>trouble</i> because of things they do	BUT	Other kids usually <i>don't</i> do things that get them in trouble	S	R
	24 «	R	S	Some kids like the kind of person they are	BUT	Other kids often wish they were someone else	S	R
	25	R	s	Some kids do very well at their classwork	BUT	) Other kids don't do very well at their classwork.	S	R
	26	R	S	Some kids wish that more kids liked them	BUT	Others feel that most kids <i>do</i> like them	S	R
	27.	R No	S	In games and sports some kids usually watch instead of play	BUT	Other kids usually <i>play</i> rather than just watch	S	R
	28	R.	S	Some kids wish something about their face or hair looked different	BUT	Other kids <i>like</i> their face and hair the way they are	S	R
	29.	R	S	Some kids do things they know they , shouldn't do	BUT	Other kids <i>hardly ever</i> do things they know they shouldn't do	5	R
	30	R	S	Some kids are very happy being the way they are	BUT	, Other kids wish they were different	S	R
	31	R	S	Some kids have <i>trouble</i> figuring out the answers in school	BUT	Other kids almost always can figure out the answers	S	R
	32.	R	S	Some kids are popular with others their age	BUT	Other kids are not very popular	S	R

		Really True for me	Sort of True for me	-LEFT HAND SIDE		RIGHT HAND SIDE	Sort of True for me	Really True for me
Cr	33	R	S	Some kids <i>don't</i> do well at new outdoor games	BUT	Other kids are <i>good</i> at new games right away.	S	R
۱۰ ,   ,   ,   ,   ,   ,   ,   ,   ,   ,	34	R f	S	Some kids think that they are attractive or good tooking	BUT	Other kids think that they are <i>not</i> very attractive or good looking	, S	R
	35	R	S	Some kids are usually very <i>kind</i> to others	BUT	Other kids wish they would be kinder to others	S	R
	<b>36</b> .	R	S	Some kids aren't very happy with the way they do alot of things	BUT	Other kids think the way they do things is fine	S	้า R

That's it ! Thank you very much .

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Appendix 14. Psychometric analysis of Perceived Competence Scales administered over the telephone.

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#### Introduction:

Telephone administration of the Perceived Competence Scale for children (PC), and its revision, the Self-Perception Profile for children (SPP), has not been undertaken before. Because of the logistic difficulties outlined in the *Methods* chapter of this thesis, this mode of testing was imposed upon us. Although the "structure-alternative format" was specifically employed by Harter to reduce the child's tendency to give socially desirable responses<sup>1</sup>, the replacement of the face-to-face administration with the relatively impersonal telephone technique could conceivably have altered the responses of the child in such a way as to render the results incomparable to those of the reference population.

If there was a quantitatively important contribution to the published factor patterns and subscale scores from this response set, then a different, or at least far less clear factor pattern could result from responses elicited over the telephone. In addition, subscale internal consistency  $\alpha$ -coefficients would be expected to deteriorate.

#### Method:

Baseline (Time 1) data for children aged 7 to 16 years, were analysed. A total of 236 children were interviewed over the telephone: 158 aged 7 to 12 years were administered the original 28 item Perceived Competence Scale; a further 78 were tested on the 36 item Self-perception Profile. In addition, 43 children in the 7 to 12 year age range were personally administered the PC scale because of immaturity, difficulty with speech or hearing impairment making telephone communication difficult. Data from 11 similar children in the older age group are not reported on because of the small sample size.

Principal compenents extraction of factors was carried out using the FACTOR procedure in SAS (SAS Institute 1985), or in SPSS<sup>x</sup> (SPSS<sup>x</sup> User's Guide 1986). Oblique rotation (Promax solution) was employed, allowing correlation among

<sup>&</sup>lt;sup>1</sup> The correlation between perceived competence ratings and scores on Crandall's Children's Social Desirability scale was .09, whereas the Coopersmith Self-esteem Inventory correlated .33 with the Crandall measure (Harter 1982).
#### **Appendix 14: Harter Telephone Administration**

subscale scores, consistent with the theoretical basis for the development of these scales and indeed, replicating the analyses undertaken by Harter (Harter 1982; 1983). An eigenvalue greater than 1 0 was the threshold used for factor selection. Pearson correlations between subscales were also calculated. Estimation of Cronbach  $\alpha$ -coefficients for subscale internal consistencies (Nunnally 1978) was carried out with the RELIABILITY procedure in SPSS<sup>x</sup> (SPSS<sup>x</sup> User's Guide 1986). The few missing values were recoded to the group modal value for that item.

### **Results:**

The oblique solution for scores on the PC scale produced 4 relatively clean factors consistent with the published data (Table H1). Although the emergence of these 4 factors was unequivocal, there appeared to be some item redundancies, as evidenced by item communalities less than 0.5 for several items across all subscales. On Physical Competence and General Self-esteem there were a small number of items which loaded moderately on Cognitive Competence (items 8, 11, 23 and 28). In particular, item 8 (Sure of myself), and item 28 (Sure I am doing the right thing) appeared to be perceived by children as relating to confidence with scholastic pursuits. Item means are generally higher than those reported by Harter, and commented on in the *Results* section of this dissertation. Item standard deviations of around 1.0 were similar to those previously reported, and indicated similarly adequate item variability. Subscale intercorrelations were weaker than reported by Harter, suggesting an even better separation of the subdomains of perceived competence than she proposed children to be capable of making (Table H1.1).

For comparison, the factor pattern for the 43 subjects in the same age range who were administered this scale in person (Table H2) reveals a far less satisfactory solution. Although 4 factors were extracted, there is considerable obfuscation of the second and third factors, and to a lesser extent the first. These subjects were children with severe hearing impairment, and particularly younger children, some of whom were considered by parents and/ or interviewers to be immature.

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Table H1	Factor pattern (oblique rotation) and item communalities (h <sup>2</sup> ) for the Perceived
•	Competence Scale Subjects aged 7 to 12 years Time 1 measurement.
	Telephone administration. [N=158]

Subscale and Item Description	Cognitive	Social	Physical	General	h²	mean	SD
Cognitive Competence: 1. Good at schoolwork	74 65 52 64 62 35 58				.59 39 32 .40 .39 25 43	3 2 3 0 2 6 2 9 3 3 2 8 2 9	1 00 1 13 1 21 1 07 0 97 1 17 1 06
Social Competence: 2 Easy to make friends 6 Have a lot of friends 10 Important to classmates 14 Do things with kids 18. Most kids like me 22 Popular with kids 26. Easy to like	( 38)	77 75 23 64 44 44 50			.54 .56 33 .47 .33 .37 .46	3 1 3 4 3 1 3 1 3 1 3 1 3 1 3 1 3 4	1 11 1 03 0 93 1 03 1 14 0 95 0 86
Physical Competence:3. Do well at sports.7. Better at sports.11. Do well at new activity15. Good enough at sports19. Play rather than watch23. Good at new games.27. First chosen for games	( 39) ( 40)	( 48)	65 63 .22 .83 .61 .36 26		.55 .45 .34 .70 .47 .33 .47	2.6 2 5 2.8 2 5 3 1 2 8 2 8	1 20 1 28 1 06 1 10 1 07 1.02 1 06
General Self-esteem: 4. Want to stay the same 8. Sure of myself 12. Feel good with way I act 16. Am a good person 20. Happy the way I am 24. Do things fine 28. Sure am doing right thing	(.50) (.46)	,		.57 .* .59 .33 .52 .45 .24	.41 .32 .54 .38 .36 .51 .37	3.0 3.0 3.0 3.4 3.3 3.2 2.9	1 20 1.02 1.09 0.83 1 01 0 91 1.05

Note.-Factor loadings ≤.35 not shown unless within factor -\*Loading <.15

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Subscale and Item Description	Cognitive	Social 1	Physical	General	h <sup>2</sup>	mean	SD
Cognitive Competence:							
1 Good at schoolwork	35			(68)	66	33	1 32
5. Just as smart as others	.24			(71)	75	30	1 45
9 Finish schoolwork quickly	.50				27	28	1 15
13. Remember things easily	.50				27	28	0.01
21 Understand what read	.45 34			(64)	68	22	1 47
25 Can figure out answers	48			(60)	76	29	1 47
Social Competence:							
2 Easy to make friends		62			57	30	1 07
6. Have a lot of friends		18		(79)	67	3.4	131
10 Important to classmates		40		( /4)	52	31	142
18 Most kids like me		14		(09)	63	26	1 44
22 Popular with kids		- 06	(50)	(75)	26	$\frac{2}{2}9$	1 02
26 Easy to like		02	(00)	(76)	<u>5</u> 9	33	1 37
Physical Competence:							
3 Do well at sports		<i>.</i>	82		67	27	111
7 Better at sports	( 50)	(61)	- 21		52	23	123
11 Do well at new activity .	(39)		52		23 62	27	100
19 Play rather than watch	(40)	(68)	- 27		53	30	107
23 Good at new games		(00)	15	(71)	73	30	141
27 First chosen for games			68	( ,	61	27	101
General Self-esteem:							
4. Want to stay the same.				66	.58	26	1 60
8 Sure of myself				.84	.78	31	1.40
12. Feel good with way I act		((2))		. /0	.0/	33	1.37
10. Am a good person		(03)		14	70	3.1	147
20. riappy the way I all				78	67	3.4	1 22
28. Sure am doing right thing				77	.80	3.1	1.32

Table H2Factor pattern (oblique rotation) and item communalities (h2) for the Perceived<br/>Competence Scale. Subjects aged 7 to 12 years Time 1 measurement Personal<br/>administration [N=43]

Note -Factor loadings ≤ 35 not shown unless within factor

Table H1.1:Subscale correlations for the Perceived CompetenceScale (N=158).Ages 7-12 yearsTelephone administrationReference values in parentheses (Harter 1982).

	Social	Physical	General *
Cognitive	.34 (.36)	17 (.29)	.21 (.49)
Social	-	15 ( 48)	.19 (.53)
Physical	-	-	04 (.44)

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The factor pattern for the SPP was very clearly consistent with the theoretical and empirical data (Harter 1983) which had suggested 5 subdomains in addition to the global General Self-worth factor not sought in the factor analysis (Table H3) There appeared to be less item redundancy on this measure. Item 7 (Just as smart) loaded on Conduct and Behavior, rather than on Scholastic Competence, and the reverse situation obtained for item 29 (Don't do things I shouldn't). Subscale correlations again indicated better separation than that suggested by previous data (Table H3 1), although the

Table H3.1:Subscale correlations for the Self-perception Profile (N=78)Ages 13-16 yearsTelephone administrationReference values in parentheses (Harter 1983)

Social	Athletic	Physical	Conduct &
Acceptance	Competence	Appearance	Behavior
.28 (.34)	.15 (.24)	25 (.32)	.24 ( 47) '
-	29 ( 44)	.26 (.38)	.14(21)
	-	.15 (.50)	.08 (.10)
	,	) _	.24 (.27)
	Social Acceptance .28 (.34)	SocialAthleticAcceptanceCompetence.28 (.34).15 (.24)-29 ( 44)	SocialAthleticPhysicalAcceptanceCompetenceAppearance.28 (.34).15 (.24)25 (.32)-29 (44).26 (.38)15 (.50)

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### Table H3 Factor pattern (oblique rotation) and item communalities (h<sup>2</sup>) for the Self-perception Profile for children Subjects 13-16 years Time 1 measurement. Telephone administration [N=78]

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Item Description	Scholasuc ompetence	Social Acceptance	Athleuc Competence	Physical Appearance	Conduct Behavior	h²
Scholastic Competence: 1 Good at schoolwork 7 Just as smart 13 Do schoolwork quickly 19 Remember things easily 25 Do well at classwork 31 Can figure out answers	56 07 60 71 61 56				( 43)	61 39 35 56 56 48
<ul> <li>Social Acceptance:</li> <li>2 Easy to make friends</li> <li>8 Have a lot of friends</li> <li>14 Easy to like .</li> <li>20 Do things with a lot of kind</li> <li>26 Most kids like me</li> <li>32 Popular with others</li> </ul>	ls	65 85 44 81 48 71				63 75 44 60 55 58
Athletic Competence: 3 Do well at sports 9 Good enough at sports 15 Good at outdoor activity 21 Better than others at sport 27 Play rather than watch . 33 Good at new outdoor gam	s (47) aes		60 76 39 80 39 72			63 63 42 66 52 64
Physical Appearance: 4 Happy with the way I loo 10. Happy with height & weig 16. Like body way it is 22 Like physical appearance 28. Like face and hair 34. Attractive or good looking	k ght S			66 56 83 77 64 57		50 42 63 72 49 55
Conduct & Behavior: 5 Like way I behave 11 Usually do the right thing 17 Act the way supposed 23. Don't get in trouble 29. Don't do things shouldn't 35 Kind to other	(36)				68 52 60 32 36 36	48 47 41 44 59 24

Note -Factor loadings  $\leq 35$  not shown unless within factor.

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differences were not as dramatic as for the 7 to 12 age group

A moderately high level of intratest reliability, or internal consistency, was

indicated by Cronbach- $\alpha$  coefficients ranging from 0.70 to 0.75 for the 158 seven to twelve year olds (Table H4).

Table H4: Internal consistency  $\alpha$ -coefficients

( <u>)</u>

Scale Version	Administration Sub-scales	Total	English	French	Reference Values
Perceived Con	mpetence Scale:				
7-12 yr	Personal Interview	N=43	N=17	N=26	
	Cognitive Competence Social Competence Physical Competence General Self Esteem	0.74 0.58 0.69 0.59	0 79 0 39 0 78 0 79	0 71 0 66 0 63 0 35	0.75-0 83 0 75-0 84 0 77-0 86 0 73-0 82
Perceived Cor	mpetence Scale:				
7-12 yr	Phone Interview	N=158	N=71	N=87	
	Cognitive Competence Social Competence Physical Competence General Self Esteem	0.75 0.74 0.72 0.70	0.79 0.78 0.75 0 68	0 72 0.70 0.71 0 72	
Self-perceptio	n Profile:				द
13-16 yr	Phone Interview	N=78	N=47	N=31	
	Cognitive Competence Social Acceptance Athletic Competence Appearance Conduct/Behaviour Self Worth	0.79 0.84 0.79 0.81 0.69 0.81	0.84 0.87 0.84 0.82 0.76 0.82	0.75 0.77 0.69 0.78 0.59 0.80	0.80 0.80 0.84 0.81 0.75 0.84

Consistently lower  $\alpha$ -values for French-speaking children suggested that translation and/or cultural differences had an effect on internal consistency. The substantially lower values for the 43 personally interviewed subjects reflected the less satisfactory factor solution. On the

SPP, with the exception of Conduct & Behavior,  $\alpha$ -values approximated or exceeded those cited by Harter (1983), though the estimates are again lower for French-speaking adolescents

### Conclusion:

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There is no reason to doubt, on the basis of these results, that telephone administration of these scales taps the same sub-domains of perceived competence proposed by Harter. In fact, they provide even further confidence for their use in a heterogenous chronic illness population, albeit with some caveats. In particular, there is evidence for instability in the factor structure together with relatively poor internal consistency in the data from the younger immature, and hearing impaired children. It is probable that the Pictonal version of the Perceived Competence measure would have yielded better results, in terms of the psychometric properties of the scale, for this subgroup Appendix 15. Malaise Inventory.

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### Malaise inventory



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"I am now going to ask you some questions about your own health. Simply answer YES or NO to these questions."

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### PLEASE BING THE CORRECT ANSWER

Do you often have back-ache?	Ya	No
Do you feel tired most of the time?	Ya	No
Do you often feel miserable or depressed?	Yes	No
Do you often have bad headaches?	Ya	No
Do you often get worried about things?	Yes	No
Do you usually have great difficulty in falling asleep or		
staying asleep?	Yes	No
Do you usually wake unnecessarily early in the morning?	Yes	No
Do you wear yourself out worrying about your health?	Yes	No
Do you often get into a violent rage?	Yes	No
Do people often annoy and irritate you?	Yes	No
Have you at times had a twitching of the face, head or		
shoulders?	Yes	No
Do you often suddenly become scared for no good reason?	Yes	No
Are you scared to be alone when there are no friends near you?	Yes	No
Are you easily upset or irritated?	Yes	No
Are you frightened of going out alone or of meeting people?	Yes	No
Are you constantly keyed up and juttery?	Yes	No
Do you suffer from indigestion?	Yes	No
Do you often suffer from an upset stomach?	Yes	No
Is your appetite poor?	Ya	No
Does every little thing get on your nerves and wear you out?	Yes	No
Does your heart often race like mad?	Yes	No
Do you often have bad pains in your eyes?	Yes	No
Are you troubled with rheumatism or fibrositis?	Yes	No
Have you ever had a nervous breakdown?	Yes	No
	Do you often have back-ache? Do you often tired most of the time? Do you often feel miserable or depressed? Do you often have bad headaches? Do you often get worried about things? Do you usually have great difficulty in falling asleep or staying asleep? Do you usually wake unnecessarily early in the morning? Do you wear yourself out worrying about your health? Do you often get into a violent rage? Do people often annoy and irritate you? Have you at times had a twitching of the face, head or shoulders? Do you often suddenly become scared for no good reason? Are you scared to be alone when there are no friends near you? Are you casily upset or irritated? Are you constantly keyed up and jittery? Do You suffer from indigestion? Do you often suffer from an upset stomach? Is your appetite poor? Does every little thing get on your nerves and wear you out? Does your heart often race like mad? Do you often have bad pains in your eyes? Are you croubled with rheumatism or fibrositis? Have you ever had a nervous breakdown?	Do you often have back-ache?YesDo you feel tired most of the time?YesDo you often feel miserable or depressed?YesDo you often have bad headaches?YesDo you often get worried about things?YesDo you usually have great difficulty in falling asleep orstaying asleep?Staying asleep?YesDo you usually wake unnecessarily early in the morning?YesDo you usually wake unnecessarily early in the morning?YesDo you often get into a violent rage?YesDo people often annoy and irritate you?YesHave you at times had a twitching of the face, head orshoulders?Yes you constantly become scared for no good reason?YesAre you constantly keyed up and jittery?YesDo you often suffer from an upset stomach?YesIs your appetite poor?YesDoes every little thing get on your nerves and wear you out?YesDo you often have bad pains in your eyes?YesAre you constantly keyed up and jittery?YesIs your appetite poor?YesDo you often have bad pains in your eyes?YesAre you constantly keyed on your nerves and wear you out?YesDost every little thing get on your nerves?YesHave you often have bad pains in your eyes?YesAre you constant often race like mad?YesHave you ever had a nervous breakdown?Yes

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\* Fibrositis is muscular aches and pains.



\*

Now go on to the next section.

Appendix 16. Family function questionnaire.

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#### PARE1 OF 1

### **Family Function Itoms**

"I am now going to ask you the questions about your family life, and how you see it in comparison to other families you know. This time, however, i want you to think only about your family over the past 6 months."

 "Would you say, all in all, that your family is happier than most others you know, about the same, or less happy?"

> D happier D same D less happy

"Would you say disagreements in your household come up more often, about the same, or less often than in other families you know?"

> D more often D less often

"Would you say that compared to most families you know, you feel less close to each other, about the same, or closer than other families do?"

Diass close Disame Dicloser

4. "Do you find it easy, not so easy, or difficult to talk about your problems with someone else?"

D easy D not so easy D difficult

"If a problem comes up in the family, and if help is available, do you find it easy, not so easy, or difficult to take advantage of that help?"

> D not so easy difficult

### Ask Questions 6 and 7 <u>only</u> if respondent is married and/or living with someone.

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6. "Do you feel that the relationship you have with......(name of husband, wife or other) is better than most, about the same, or worse than most other couples have with each other?"

better then most
seme
worse then most

no disegreements
 accesionel disegreements
 frequent disegreements

#### End of Family Function South

Appendix 17. Impact on Family Scale.

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### IMPACT ON FAMILY SCALE

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"You were asked the following questions last year about having a child with a chronic illness. I'm going to ask these questions again now, but I want you to concentrate on your feelings during the last 6 months only. For each statement I read, please tell me whether at the present time you would strongly agree, agree, disagree, or strongly disagree with the statement."

		Strongly Agree	Agree	Disagree	Strongly Disagree
	The illness is causing financial problems for the family	1	2	3	4
	Time is lost from work because of hospital appointments	1	2	3	4
ς.	I am cutting down the hours I work to care for my child	1	2	3	4
d.	Additional income is needed in order to cover medical expenses	1	2	3	4
€.	I scopped working because of my child's illness	l	2	}	<u>ن</u>
f.	Because of the illness, we are not able to travel out of the city	1	2	3	4
g .	People in the neighborhood treat us specially because of my child's illness	<b>i</b> ,	2	3	÷
h.	We have little desire to go out because of my child's illness	ι.	2	3	
1.	It is hard to find a reliable person to take care of my child	l	2	3	
j.	Sometimes we have to change plans about going out at the last minute because of my child's state	1	2	3	4
k.	We see family and friends less because of the illness	l	2	3	<u></u>
1.	Because of what we have shared we are a closer family	l	2	3	4

			Strongly Agree	Arree	<u>Disagree</u>	Strongly Disagree
• •	<b>6</b> .	Sometimes I wonder whether my				
		child should be treated "specially"	· •	2	٦	. <b>b</b>
L#		or the same as a normal child	/	2		· •
	۵.	My relatives have been understanding and helpful with my child	1	<b>,2</b>	3	4
	0.	I think about not having more children because of the illness	_ <u>ı</u> ^	2	3 .	4
Ū	7	DO NOT ask question "p" if the respor	dent is a	SINGLE	PARENT.	-
•	p.	My partner and I discuss my child's problems together	1	2	3	4
	٩.	We try to treat my child as if he/she were a normal child	L	2	3	4
Ţ.	۲.	I don't have much time left over				
•		for other family members after				F
1		caring for my child	1	2	3	4
		Relatives interfere and think they know what's best for my child	1	۴ ۲	3	4
, 1	٤.	Our family gives up things because of my child's illness	1	2	3	4
-	u.	Fatigue is a problem for me because of my child's illness	1	2	3	· 4
	<b>۷.</b>	I live from day to day and don't plan for the future	1	2	3	4
	۷.	Nobody understands the burden I card	ry L	2	3	4
	<b>X.</b>	Traveling to the hospital is a strain on me	1	2	3	4
	<b>y</b> .	Learning to manage my child's illness has made me feel better about myself	Ť	2	3	· 4
	8.	I vorry about what will happen to wy child in the future (when he/she grows up, when I am not around)	1	2	3	4
0	44.	Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable	بې' ۱	2	, J	4

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Only ask the following ouestions if there are siblings in the household. If there are none, go on to next page.

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		Strongly Agree	Agree	Diserre	Stroagly Diserce
: : 1	It is hard to give much attention to the other children because of the needs of my child	L	2	3	4
1	Maving a child with an illness makes me worry about my other children's health	1	2	3	4
•	Ŷ				
	Only ask the following questions i younger than 4 years, go on to new	lf sibling( ct page,	s) <sub>,</sub> are	4years or d	older. If
	There is fighting between the children because of my child's special needs '	1	>		
	-		•	۔ 	4
	My other children are frightened by his/her illness	1	2	3	4
	My other children are frightened by his/her illness My other children seem to have more illnesses, aches and pains than most children their age	1	2	3	4

Appendix 18. Parent questionnaire.

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	Families Attached to Social Workers		PAGE 1 OF 5					
<u> </u>	QUESTIONS FOR FAMILIES WHICH H ATTACHED TO A SOCIAL WO	AVE BEEN RKER	ID 1-6 caerci#75 7					
	*PARENTS PLEASE NOTE THAT NEITHER SOCIAL W SEE THESE OR ANY OF YOUR RESPONSES IN THIS	YORKERS NOR CLINIC STAFF WILL INTERVIEW.	group 8 BLANK 9 Q. type 10					
	PLACE AN "X" IN THE BOX THAT BEST DE TO EACH QUESTION (D)	PLACE AN "X" IN THE BOX THAT BEST DESCRIBES YOUR RESPONSE TO EACH QUESTION (D)						
	1. During the 6 month study period, did you feel that the contact with your social worker was							
		I less than you would have liked						
	-	I more than you would have liked						
	2. How much do you think your social v	worker knew about your child's filne	<b>85</b> ? (12)					
ľ í		🗆 Very little						
		A small emount						
		🗆 A moderate amount						
		🗆 A greet deal						
	3. How important do you think it was knowledge of the child's illness?	for your sociel worker to have a det	ailed (13)					
1		Not important at all						
		🗆 Of little importance						
		🗇 Quite important						
		U Very important	•					
	4. Overall, how helpful has your socia	l worker been to y <u>ou, personally</u> ?	(14)					
		🛛 Very helpful						
		🛛 Quite helpful						
-		O Neither helpful nor harmful						
$\mathbf{O}$	-	Quite hormful						
· • • • •		u very normiul						
		Please go to next page>						

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Families Attenhad to Seciel Workers

PAGE 2 OF 5

5. How helpful has your social worker been to your child? (15)

> O Very helpful D Quite helpfui Neither helpful nor hermful D Out to hermful D Very hermful

6. How helpful has your social worker been to ather family members (16)(e.g., your husband or partner, other children)? U Very helpful 🛛 Quite helpful [] Neither helpful nor hermful

D Quite hermful

- C Very hermful
- I Not applicable (no other family members)
- 7. A social worker working with families having children who have health problems could help in any of several ways. Please indicate how helpful your social worker has been in each of the following areas.

### Put on "I" over the bex that is the best choice for each question.

"How helpful was he or she with?"	Vary Heloful	Quite Helpful	Neither Helpful nor Hermful	Quite Hermiul	Very Hacathal	
a. "	٥	D	٥	۵	۵	(17)
b. "getting services for your family?"	D	D	٥	D	D	(18)
c. "hqlping to sort out problems with your tenily?"	٥	۵	0	0	0	(19)
d. "teaching you better ways to cope with your child's lilness?"	٥	D	٥	٥	٥	(20)
e. "	D	٥	0 r	۵	0	(21)
1. "	۵ ۳	۵	۵	D	0	(22)
Υ.			Please	o go to nex	t page	>

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	Families Attached to Social Workers	PAGE 3 OF
()	8. Thinking about your social worker, was he/she sympathetic in relation to your own difficulties or special problems?	(23)
	Very sympatheticQuite sympatheticQuite unsympatheticVery unsympathetic	ی ۲
	9. How well do you think your social worker was able to understand any problems or difficulties that you have been having?	(24)
	Understood very well Understood quite well Sidn't really understand well Didn't understand at all	
	Not applicable because I had no pro	blems
(	10. How well informed was your social worker about the resources and different types of assistance that may be available to you, and how to take advantage of them?	(25)
	<ul> <li>Very well informed</li> <li>Quite well informed</li> <li>Pretty uninformed</li> <li>Didn't know much at all</li> </ul>	
	11. If it were possible for this type of social worker assistance to become a routine part of the service offered by MCH clinics, how enthusiastic would you be for it to continue with your own family?	(26)
	<ul> <li>A very good idee</li> <li>Probably a good idea</li> <li>Probably not a good idea</li> <li>Definitely not a good idea</li> </ul>	
0	<ul> <li>12. How good an idea would this type of social worker service be for <u>other families</u> which have children attending MCH clinics?</li> <li>A very good idea</li> <li>Probably would be a good idea</li> <li>Probably not a good idea</li> <li>Definitely not a good idea</li> </ul>	(27)

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PLEASE CONTINUE ON THE NEXT PAGE .......

-

13. As a result of contact with your social worker, how do you feel about your ability to cope with any of the possible future difficulties that may arise as a result of your child's illness?

	I Much better equipped	(28)
4	A little better off	
	Not changed	
	A little worse off	
	I Much worse off	

14. As a result of contact with your social worker, how do you feel about your <u>child's ability</u> to cope with any of the possible future difficulties that may arise as a result of his/her illness?

Much better equipped (29)
A little better off
Not changed
A little worse off
Huch worse off

15. Describe in your own words what areas or specific needs your social worker was <u>not able</u> to assist you with.

.....

.....

(30-31)

)

PLEASE CONTINUE ON THE NEXT PAGE ----->

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16. Finally, we would like you to describe in your own words any espects of your experience with your project social worker that you feel are important or have not been covered in the questions so far.

(Your comments will be kept entirely confidential) (22-33)	)
	••
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Thank you very much. That is the end of the questionneire.

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PAGE 5 OF 5

Appendix 19. Social worker questionnaire.

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### COMMUNITY PEDIATRIC RESEARCH PROGRAM SOCIAL WORKERS QUESTIONNAIRE PSYCHOSOCIAL MALADJUSTMENT PREVENTION STUDY JULY 23, 1985

### +CONFIDENTIAL+ (DISK:SWSTUDY1 FILENAME:SWQ)

#### **DEFINITIONS:**

 CONTACT = Phone call, meeting, therapy session, home visit or any other occasion of service. \_\_\_\_\_
 SUBJECT = Child/adolescent who is subject of study.
 FATHER = Natural father or male who is usual father figure in the household.
 SIBLING = Brother or sister of subject.
 FAMILY = Mother and father(if there is one) and subject, with or without other siblings.

#### INSTRUCTIONS:

- 1. Complete 1 questionnaire per subject.
- Circle or write the number for response which is most appropriate.
- 3. This questionnaire should be completed immediately following termination of contact with each family.

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SUBJECT NAME:

SUBJECT ID:

DATE QUESTIONNAIRE COMPLETED:

DATE OF LAST CONTACT WITH FAMILY:

SOCIAL WORKER INITIALS:

1. At the beginning of your association with this family, what was the response to you like from:

	<u></u>	
c.	FATHER	$\square$
b.	MOTHER	
a.	SUBJECT	

Choose between: 1. hostility or rejection 2. difficult, contrary, defiant 3. cool, indifferent 4. polite, cautiously receptive, open 5. warm, accepting 6. very enthusiastic, embracing 7. NOT ABLE TO JUDGE 8. NOT APPLICABLE

(\*Note that the words used to describe these categories are only a general guide on a spectrum between rejection (1.) and enthusiastic acceptance (6.) at the two extremes.)

2. At the midpoint of the study (after three months): Was the response to you...?

(Choose between the same six alternatives as in Ql. above)



3. At the end of the study (after six months): Was the response to you...?

(Choose between the same six alternatives as in Ql. above)

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a.	SUBJECT	Ц
b.	MOTHER	
c.	FATHER	

4. Do you think that these reactions (overall) would have been very different for each individual if this had not been a research study?

	a.	SUBJ	ECT		
	b.	MOTH	IER		]
	c.	FATH	IER		]
CHOOSE	BETWEEN:	1.	No		
		2.	Yes		
		8.	Canr	ot	say

5. If you were to assign your families to categories based on the extent of your involvement with them, which would be the best description for your overall involvement with this family?

CHOOSE BETWEEN:

- Standard: That is, basic intervention protocol only.
- 2. Moderate: e.g., Facilitating access to resources, clarifying issues, providing information.
- 3. Heavy: e.g., Counselling, some use of other services, providing information, may have required handover on completion etc.
- 4. Intense: e.g., Therapy sessions, crisis resolution, referral to other services, family members required handover on completion. (Involvement need not be continuous to be defined as intense)

YOUR RESPONSE HERE:

6. In your opinion, what was the major or primary obstacle to working with this family? (CHOOSE ONE ONLY)

1. Attachment limited to only 6 months.

- Family members' perception of your role as "unreal" or as an "experiment".
- 3. Family members' perception of you.
- 4. Resistance to help offered.

5. Other. (specify).....

8. Not Applicable

YOUR RESPONSE HERE:

7. Roughly, what proportion of your total number of contacts with this family was initiated by a family member?

CHOOSE BETWEEN:

(

1. less than 10% 2. 10 - 50% 3. more than 50%

YOUR RESPONSE HERE:

8. How much of your total contact\* time with this family was spent with...?



SUBJECT	308
MOTHER	308
SUBJECT & MOTHER	208
FATHER	008
SIBLING(S)	00%
FAMILY	208

TOTAL

e.g.

100%

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(\*see front cover for definition of terms)

- 9. To the best of your knowledge, what services (except medical followwup) was this family receiving at the beginning of your attachment to them?
  - A. Financial Assistance/Allowance
    B. Non-MCH Social Worker
    C. MCH Social Worker
    D. School Psychologist
    E. Clinical or other Psychologist
    F. Psychiatrist
    G. Other (specify).....

CIRCLE ALL LETTERS THAT ARE APPROPRIATE.

- 10. What new services did you initiate or refer to (directly or indirectly) during your attachment to this family?
  - A. Financial Assistance/Allowance B. NonaMCH Social Worker C. MCH Social Worker D. School Psychologist E. Clinical or other Psychologist
    - F. Psychiatrist

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G. Other (specify).....

#### CIRCLE ALL LETTERS THAT ARE APPROPRIATE

11. Apart from basic support and availability, what do you feel has been your most important contribution during the study period to.....? (SUMMARIZE IN A FEW WORDS)

a.SUBJECT		
b. MOTHER		ר - יי נ י
c. FATHER	·	ר - ק קב - גו
d. SIBLING(	S)	
∉. FAMILY A	S A WHOLE	
(NOTE: Wri o	te 'NA' if you feel that no unusual contribution or could be made, or if not applicable.)	t n was
12. Based on you a scale of ability to a his/her chro (e.g.,Ø=not lØ=outstandi	ar initial assessment of the subject (child), on Ø through 10, how did you rate this child adjust to any present or possible future stresses onic illness. able to adjust at all, 5=about average, ang resilience)	's s of
	WRITE RESPONSE HERE:	
13. On the same on completi	scale, Ø to/10, how would you rate this subjection of the intervention period?	ct .
	WRITE RESPONSE HERE:	

14. Thinking about the subject, comparing the beginning of your attachment to the end, how would you rate his/her overal adjustment/behaviour?	1
<ol> <li>Improvement over the past six months, problems resolved, etc.</li> </ol>	3
2. No change. 3. Deterioration acquisition of new symptoms	
problems.	,
WRITE RESPONSE HERE:	
15. Thinking about the mother, comparing the beginning of you	ır
attachment to the end, how would you rate her ov adjustment/behaviour?	verall
1. Improvement over the past 6 months, problem resolved, etc.	ns
2. No change.	
3. Detioration, acquisition of new symptoms	,
or problems.	
WRITE RESPONSE HERE:	
16. Did you meet the father in this family?	
1. Yes	
8. NOT APPLICABLE (i.e. no father)	
WRITE RESPONSE HERE:	
17. If the answer to the above question was 'NO', what was the main reason?	
1. Father seemed to avoid contact.	
2. Mother claimed father not available.	
3. Impossible to arrange a suitable meeting time	•
this particular case.	
5. Other (specify)	
8. Not Applicable	•
WRITE RESPONSE HERE:	

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18. At the completion of the study, what was the main disposition of this family?

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<ol> <li>No further services organized.</li> <li>Transferred to MCH social worker.</li> <li>Transferred to community social worker.</li> <li>General referral made (name supplied, but a formal handover did not occur).</li> <li>Psychiatrist.</li> <li>Psychologist.</li> <li>Other (specify)</li> </ol> WRITE RESPONSE HERE:
19. Were you unable to obtain specific services for this family that you considered important and/or necessary?
1. Yes. Specify
· · · · · · · · · · · · · · · · · · ·
2. No.
WRITE RESPONSE HERE:
20. Tó what extent did any lack of knowledge on your part about this child's condition interfere with your ability to provide an appropriate service to this family?
1. No effect. 2. A moderate degree. 3. A major degree.
WRITE RESPONSE HERE:
<b>p</b> <sup>2</sup>
d & & & & & & & & & & & & & & & & & & &
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Appendix 20. Functional status measure.

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#### FUNCTIONAL STATUS 3

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12 "Here are statements that mothers have made to describe their children Thinking about the LAST TWO WEEKS did he/she \_(name of child), during

## If the answer to a question is followed by an

esterist", est Wes this due to the illness?"

		Never or rarely	Some of the <u>time</u>	Almost <u>alweys</u>	due to illnes <u>Yes</u>	Lhe s? <u>No</u>
١	Eat well?	0*	1#	2	1	0
2	Sleep well?	0*	1#	2	1	0
3	Seem contented and cheerful?	0*	1*	2	1	0
4	Seem to feel sick and tired?	0	1#	2 #	1	0
5	Occupy him/herself?	0 **	1 *	2	1	0
6	Ssem lively and energetic?	0 *	1#	2	۱	0
7	Sleep through the night?	0 *	1 🗮	2	1	0
8	Seem interested in what was going on around him/her?	0 #	1 🖷	2	1	0
9	Cut down on his/her usual level of play activity?	0	1 **	2*	1	0
10	Pick up and throw a ballor other object (in the intended direction)	l? 0 <sup>₩</sup>	1 **	2	1	0
11	Cut down on things he/she usually does?	0	1 **	2 **	1	0
12	Get involved in games and other play?	0*	1 #	2	1	0
13	Go up and down stairs without assisstance?	0 #	1#	2	1	0
14	Playgames by him/herself?	0#	1 🗮	2	1	0
15	Participate in hard exercise or play?	0*	۲.	2	1	0
16	Get undressed without help?	0 #	1#	2.	. 1	0
17	Play with other children?	0*	1*	2	1	0
18	During the past two weeks did(name of child)	No	Yes			
	Spend all or part of the day in bed?	0	۴ ا			
	(IF 'YES', ask 's" and 'b")					

a How many days did he/she stay in bed in the last 2 weeks?

2

0

1

Wet this

End of Functional Status Scale

b. Was this due to the illness?

Appendices 21 to 31b

Appendix 21. Eligible arthritis clinic subjects - medical diagnoses.

Appendix 22. Eligible asthma clinic subjects - medical diagnoses.

Appendix 23. Eligible cardiology clinic subjects - medical diagnoses.

Appendix 24. Eligible cerebral palsy clinic subjects - medical diagnoses.

Appendix 25. Eligible clefts clinic subjects - medical diagnoses.

Appendix 26. Eligible diabetes clinic subjects - medical diagnoses.

Appendix 27. Eligible hearing clinic subjects - medical diagnoses.

Appendix 28. Eligible renal clinic subjects - medical diagnoses.

Appendix 29. Eligible respiratory clinic subjects - medical diagnoses

Appendix 30. Eligible sickle cell disease clinic subjects - medical diagnoses.

Appendix 31a. Eligible spina bifida clinic subjects - medical diagnoses.

Appendix 31b. Eligible spina bifida clinic subjects - medical morbidity.

~			Total		Conse	ented
	Total	Refused	Consented	Untraced	Treatment	Control
Juvenile Chronic Arth	untis					
- monoarthritis	4	1	3	0	1	2
- pauciarthritis	11	2	7	2	3	4
- polyarthritis	8	1	6	1	4	2
Other†	6	2	4	0	2	2
TOTAL	29	6	20	3	10	10

### Appendix 21 Eligible arthritis clinic subjects

<sup>†</sup>Other=psoriatic arthritis, chondromalacia patellae, systemic lupus erythematosus, arthritis not yet diagnosed <

### Appendix 22 Eligible asthma clinic subjects

			Total		Consensed		
	Total	Refused	Consented	Untraced	Treatment	Control	
Episodic <sup>-</sup>							
infrequent episodes	37	15	19	3	7	12	
frequent episodes	18	2	12	4	4	8	
Chronic, mild							
infrequent episodes	12	3	8	1	4	4	
frequent episodes	2	0	2	0	2	0	
Chronic, moderate							
infrequent episodes	12	2	10	0	8	2	
frequent episodes	21	0	15	6	9	6	
Chronic, severe:							
infrequent episodes	0	0	0	0	0	0	
frequent episodes	7	3	4	0	2	2	
TOTAL	109	25	70	14	36	34	

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### Appendix 23 Eligible cardiology clinic subjects.

		Total			Consented		
	Total	Refused	Consented	Untraced	Treatment	Control	
Valvular disease	9	3	5	1	3	2	
Conduction problem	4	2	2	0	0	2	
Cyanotic disease	15	5	9	1	5	4	
Cardiomyopathy	1	0	0	1	0	0	
Acyanotic structural disease	6	3	2	1	1	1	
TOTAL	35	13	18	4	9	9	

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Appendix 24 Eligible cerebral palsy clinic subjects.

	Total					Consensed		
	Total	Refused	Consented	Untraced		Treatment	Control	
Diplegia	<sup>•</sup> 2	1	1	0		0	1	
Hemiplegia	4	0	4	0		2	2	
Quadriplegia	3	1	1	1		1	يوم 0	
TOTAL	9	2	6	1	•	3	3	

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## Appendix 25 Eligible clefts clinic subjects

			Total		Consensed	
	Total	Refused	Consented	Untraced	Trestment	Control
Cleft palate - submucous	5	1	3	1	3	0
Cleft palate	5	0	4	1	2	2
Cleft palate & lip	16	3	11	2	5	6
Pierre Robin syndrome	1	0	1	0	0	1
Cleft hp	2	1	1	0	0	1
TOTAL	29	5	20	4	10	10

Appendix 26 Eligible diabetes clinic subjects

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		Total			Consented		
	Total	Refused	Consented	Untraced	Treatment	Control	
Insulin Dependent	97	30	64	3	32	32	
Diabetes Mellitus							

# Appendix 27. Eligible hearing clinic subjects.

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	Total			Consented		
	Total	Refused	Consented	Untraced	Treatment	Control
Sensorineural deafne	ss					
mild-moderate	9	3	6	0	1	5
moderate-severe	24	6	17	1	11	6
severe-profound	19	4	12	3	6	6
severe-profound high or	15	3	11	1	5	6
mid-range frequency loss					<sup>ta</sup>	
Subtotal	67	16	46	5	23	23
Conductive deafness						
mild or fluctuating	4	1	3	0	2	1
moderate-severe	4	2	1	1	1	0
Subtotal	8	3	4	1	3	1
Mixed deafness						
mild-moderate	1	0	0	1	0	<b>`</b> 0
moderate-severe	1	0	1	0	0	1
Subtotal	_ 2	0	1	1	0	1
		*	<u> </u>			
TOTAL	77	19	51	7	26	25
## Appendix 28. Eligible subjects from the renal clinic.

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Total	Total Refused Consented Untraced			Consented Treatment Control			
15	4	1	0	12	8		
6	2	4	0	2	2		
2	0	2	0	1	1		
1	1	0	0	0	0		
23	7	14	2	10	4		
14	3	7	4	3	4		
61	17	37	ל	18	19		
	Total 15 6 2 1 23 14 61	Total Refused   15 4   6 2   2 0   1 1   23 7   14 3   61 17	Total Refused Total Consented   15 4 1   6 2 4   2 0 2   1 1 0   23 7 14   14 3 7   61 17 37	Total RefusedTotal ConsentedUntraced15410624020201100237142143746117377	Total TotalTotal ConsentedConsent UntracedConsent Treatment154101262402202011100023714210143743611737718		

\*Other Familial Mediterranean Fever (1), IgA nephropathy (1), post Henoch-Schonlein Purpura progressive disease (1), bladder extrophy (2), nephrocalcinosis (1), Prune Belly Syndrome (1), Juvenile Nephronophthisis (1), Tuberous Sclerosis (1), Familial Renal Dystrophy (1), Polycystic Disease (1), Renal Tubular Acidosis (1), post Hemolytic Uremic Syndrome (2)

Appendix 29 Eligible respiratory clinic subjects

			Consented				
	Total	Refused	Consented	Untraced	Treatment	Control	
Cystic fibrosis	25	6	19	0	11	8	
Esophageal atresia	1	0	1	0	0	1	
Asthma	1	0	0	1	0	0	
Kartagener syndrome	1	1	0	0	0	0	
Bronchiectasis	1	0	1	0	0	1	
TOTAL	29	7	21	1	11	10	

			Total	Consented			
	Total	Refused	Consented	Untraced	Treatment	Control	
Sickle Cell Disease (SS or SC)	37	4	21	12	11	LO	

## Appendix 30: Eligible subjects from the sickle cell disease clinic

## Appendix 31a Eligible spina bifida clinic subjects

		-	Total		Consented				
	Total	Refused	Consented	Untraced	Treatment	Control			
Spina bifida	18	3	13	2	6	7			
Unknown	1	0	0	1	0	0			
Diastematomyelia	2	0	2	0	1	1			
TOTAL	21	3	15	3	7	8			

# Appendix 31b. Morbidity in eligible subjects from the spina bifida clinic (morbidity categories not exclusive).

			Total		Consented				
	Total	Refused	Consented	Untraced	Treatment	Control			
Shunt	13	2	10	1	6	4			
Requires Aids	8	2	5	1	2	3			
Wheel Chair	5	1	3	1	2	1			
Conduit	1	0	1	0	1	0			
Catheterization	12	3	8	1	2	6			

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Appendix 32. Sub-group analyses.

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### Sub-group Analyses

#### **1. Child Behavior Checklist**

Behavior Problem Scale: Further analysis was carried out on Summary Behavior Problem scores by maladjustment status at baseline Did maladjusted children selectively benefit from social worker counselling? On this measure, the answer is a probable "no", as illustrated by the results in Table A32.1 There was a small advantage for treatment group children who were classified as maladjusted at Time 1, but the difference is far from significant (P= 88). Was there an interaction by age group? That is, for example, were social workers able to counsel younger children more effectively? Table A32.2 shows that 6-11 year olds did do better with counselling (P=.19), but control group 12-16 year olds did far better than children in the treatment group of the same age (P=.14).

Additional subgroup analyses investigating treatment interactions with clinic of origin (i.e. "diagnosis"), aggregated diagnostic class (i.e. systemic, cardiorespiratory, sensory, cosmetic and motor disorders - see note under Table 15), functional status, sex, and socioeconomic status failed to reveal, without exception, any effect that even approached conventional levels of statistical significance

Maternal transition status: CBCL Behavior Problem gain scores were analyzed within maternal transition strata defined by outcome on the Malaise Inventory (Table A32.3). Improvements on CBCL scores for the children of mothers who made positive transitions occurred in both intervention and control groups, but was more noticeable for counselled children (P=.58). For children of mothers who made negative transitions, or who were maladjusted on both measurement occasions, there was a small deterioration for the counselled group, and an improvement for the control children (P=.10 and .14, respectively). Children of mothers who were classified as not maladjusted at either time, were more likely to improve if they had been counselled (P=.26).

Socializing Scales: On the Social Competence Scales interactions were examined for the

same potential modifiers of treatment effect, and the following "significant" findings are reported for the sake of completeness. On the Activities Scale adjusted Time 2 means, counselled subjects with no physical disability did better than comparable control children (46.4 versus 44.0, P=.03). Analysis of the Socializing Scale showed that counselled cardiology clinic patients did better than cardiology controls (49.1 versus 41.0, P=.04), but that counselled children with cerebral palsy did worse than similar control children (26.9 versus 40.0, P=.04, N=3 per group). On the Scholastic Scale, sickle cell clinic intervention group subjects had superior scores to controls (49.9 versus 42.9, P=.04), and counselled children of parents with low-middle socioeconomic status (Green scores  $\leq$  59) did better than comparable controls (Green score  $\leq$  49: 47.7 versus 43 1, P= 04; Green score 50-59: 48.0 versus 44.4, P=.02).

#### 2. Child and Adolescent Adjustment Profile

diagnosis and disability: The few marginally significant interactions found are presented, although their importance remains uncertain. On Peer Relations, counselled children from the sickle cell clinic did better than controls (adjusted Time 2 means 13.6 and 11.1, P=.02). On the Hostility subscale, the treatment group superiority cited above seemed to be greatest among children with hearing impairment and clefts (sensory and cosmetic groups: 7.6 versus 8.8 in controls, P=.03). On Dependence, counselled children with mild physical impairment did better than controls (7.6 versus 9.3, P=.03), whereas children with more severe impairment, or no impairment at all, did worse than controls (not significant). Counselled respiratory clinic patients did better on Productivity (14.2 versus 11.6, P=.03), while their counterparts from the spina bifida clinic did worse than equivalent controls (11.3 versus 14.0, P=.04). No significant interactions were detected on the Withdrawal subscale. **social workers:** There was only one subscale where an individual social worker stood out from the others, and this was on Hostility. On the basis of unprotected contrasts (no

adjustment to the  $\alpha$  level was made), social worker A patients scored significantly better than controls (7.4 versus 8.5, P=.003), and better than social worker D patients (8.4, P=.04),

whereas adjusted means for the other two social workers were much closer to the adjusted control mean (8.2 each). On Productivity, social worker A's subjects did significantly better than those of social workers B and D (P=.04 and .02, respectively), but not social worker C patients or controls.

secondary analysis: Secondary analysis was carried out after excluding the 19 intervention group subjects who did not receive social work assistance. The modified Time 2 prevalences for maladjustment on the five subscales were: Peer relations 11.0% (P=.71); Dependence 7.8% (P=.12), Hostility 13.0% (P=.19); Productivity 13.7% (P=.08); and Withdrawal 17.5% (P=.25). Modified crude time 2 means were: Peer Relations 13.7 (P=.68); Dependence 8.4 (P=.31); Hostility 8.1 (P=.20); Productivity 12.7 (P=.18); and Withdrawal 6.7 (P=.51). The effect of this removal, which can be confirmed by reviewing Table R16, was to improve intervention group outcome only on Dependence, although the result is still far from being statistically significant. On Peer Relations and Productivity, a worsening of the intervention group outcome occurs in relation to controls, while no difference is made to the results on Hostility and Withdrawal. The contrast in crude means for Hostility is no longer significant, reflecting an increase in the standard error for the intervention group.

#### 3. Malaise Inventory

child's transition status: The relationship between change in maternal adjustment and transition by the child in maladjustment classification on the CBCL Behavior Problem Scale was explored by examining gain scores on the Malaise Inventory within children's transition strata (Table A32.4). These results show that counselled mothers of children who made positive transitions had reduced scores on the Malaise inventory (reflected by the negative gain score), while control mothers' scores increased (P=.04). For the mothers of intervention group children who made a negative transition, or who were maladjusted at both Time 1 and Time 2 (maladjusted - no transition), scores were inferior to the control group (P=.31 and .50, respectively). There was little difference between the main comparison

Appendix 32: Sub-group analyses

groups for mothers of children classified as not maladjusted at both Time 1 and Time 2. other interactions: Exploration of treatment effects restricted to mothers who were maladjusted at Time 1 on this measure revealed that counselled mothers did worse than controls (Table A32.5), though this slight disadvantage could easily have arisen by chance (P=.87). Subgroup analyses also failed to disclose any interactions of treatment effect with parent socioeconomic status or language, or child functional status, clinic of origin or diagnostic class. In addition, there was no evidence for variation in outcome by social worker in excess of that expected by chance, nor for a significant advantage for a group of mothers counselled by a specific social worker over control mothers.

#### 4. Impact on Family Scale

Examination of outcomes on the Impact on Family Scale by patient disability subgroups failed to demonstrate an advantage for intervention families at any level of physical impairment. Similarly, there was no significant interaction with levels of socioeconomic status, or clinic of origin and social work assistance on the Total Impact score, or any subscale score. Gain scores were examined within patient CBCL transition strata, as they had been for the Malaise Inventory. In addition, this approach was taken for Impact on Family outcomes by maternal transition status on the Malaise Inventory (Table A32.6). A marginally significant advantage for the intervention group can only be found on the Strain subscale for mothers who were not maladjusted at either Time 1 or Time 2 (P=.02).

#### 5. Health Service Utilization

Subgroup analyses of MCH doctor visits revealed that there was a significant excess of MCH doctor visits for intervention subjects of more severe physical disability (categories (P=.02 and .002, for moderately and severely disabled children), and of lower socioeconomic status (Green score  $\leq 49$ , P=.02; Green score 50-59, P=.003).

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Time 1 status	Intervention	Control	95% confidence interval on difference
Maladjusted	65.1 (1 65)§	65.5 (1 36)	-4.6, 38
Normal	52 6 (0 78)§	52.8 (0.82)	-2.4,20

Table A321 CBCL Behavior Problem Summary T-scores by status at baseline

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§ indicates group with superior outcome P > 0.7 for both intervention v control contrasts

Table A32 2	CBCL Behavior Problem	Summary	T-scores by	y age group
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Age group	In	ervention*	t	C		Р	
	Time 2	Gain	N	Time 2	Gain	N	U
4 - 5 years	54.3	0.43	25	55.6	1.73	13	58
	(1.41)			(1.95)			
6 - 11	54.3	-0.81	93	55.6	0 45	108	.19
	( 0.77)		,	(0.71)			
12 - 16	56.4	-0.27	55	54.5	-2.25	48	.15
	(1.00)			(107)			

Parenthetical values are SE of means immediately above. P-values (2-tailed) for Intervention-Control contrast are based on ANCOVA. No adjusted gain score was significantly different from zero.

Table A32 3. CBCL Behavior Problem gain score means according to maladjustment classification transitions for mothers on the Malaise Inventory during the Time 1 - Time 2 interval.

Time 1/Time 2 Change	Intervention	Control	Р
Positive Transition	-3 5§	-1.9	.58
Ν	13	12	
Negative Transition	3.5	-1.9§	10
Ν	12	13	
Maladjusted - No Transition	10	-2 5§	14
N	19	19	
Not Maladjusted - No Transition	-0 9§	02	.26
N	129	124	

§ indicates group with superior outcome. P-value from independent sample t-test on crude gain scores.

Table A32 4. Malaise Inventory gain score means according to maladjustment classification transitions for children based on the CBCL Behavior Problem Summary scores during the Time 1 - Time 2 interval.

Time 1-Time 2 Change	Intervention	Control	Р
Positive Transition	-2.2§	0.9	.04
N	12	14	
Negative Transition	1.1	-0.4§	.31
N	16	9	د
Maladjusted - No Transition	0.1	-0.4§	.50
N	16	27	
Not Maladjusted - No Transition	-0.4§	-0.3	.69
N	129	3 118	

§ indicates group with superior outcome. P-value from independent sample t-test on crude gain scores

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Time 1 status	Intervention	Control	95% confidence interval on difference
Maladjusted	9.1 (0.62)	9.0 (0.63)§	-1 6, 1.8
Normal	3.2 (0 32)§	3.4 (0.32)	-1.1, 0.7

Table A32.5: Malaise Inventory adjusted Time 2 means (SE) by status at baseline

§ indicates group with superior outcome P > 0.7 for both intervention v control contrasts

Table A32.6. Impact on Family Scale gain score means by transition status for children and their mothers on the CBCL Behavior Problem Summary score and the Malaise Inventory.

Preiest-Postiest Change	Total Impa	ct	Finar	ncial	Fam	lly-S	ocial	М	aster	y	Str	ain	
	ΙĊ	Р	i	СР	I	Ċ	P	Ι	С	P	I	С	Р
CBCL	<u> </u>										سويي		<u> </u>
Positive Transition N	-99-47 12 13	05 -	28 -	0.5 05	-5 2	-38	35	17	2.2	63	-36	-26	42
Negative Transition N	-30-24 169	.91 -	1.0 -	1099	-3 1	-2.2	73	22	26	70	-11	-18	71
Maladj'd - No Transition N	-76-3.5 1627	.20 -	1.8 -4	9.43	-3 \$	-19	.26	06	10	.52	-26	-16	42
Noi Mai'd - No Transition N	-5.3 -57 129 118	.74 -	1.2 -1	1.5.29	-30	-30	92	12	09	30	-23	-2 0	.39
Malaise Inventory													
Positive Transition N	-69-13 1312	13 -	080	).3 18	-2 4	-0.4	33	01	1.2	.29	-39	-2 3	.28
Negative Transition N	-0.5 -46 12 13	.34 -	0.2 -1	.6 .21	-2 3	-0.3	70	1.5	2.2	.57	0.4	-2.2	16
Maladj'd – No Transition N	-2.8 -5 2 19 18	.52 -	1.3 -0	).1 .27	-1.5	-27	.52	05	0.6	91	-0 6	-3 0	06
Not Mal'd - No Tr <b>ansi</b> tion N	-6.4 -5.5 129 124	.39 -	1.5 -1	.6 .79	-36	-3.2	.36	1.5	1.0	17	-27	-1.7	02

I = Intervention group, C = Control group, P = P-value from independent sample t-test on crude gain scores





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Appendix 33: Project Staff and Collaborators.

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## Appendix 33: Project Staff and Collaborators

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Project Coordinator:	Inta Zvagulis, B A
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	· · · · · · · · · · · · · · · · · · ·

## Specialty Clinic Staff:

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Arthritis Asthma Clefts Cardiology Cerebral Palsy Diabetes Hearing Nephrology Respiratory Sickle Cell Spina Bifida

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