2013

Social-Environmental Predictors of Health-Related Quality of Life in Youth with Spina Bifida

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Recommended Citation
Murray, Caitlin Beth, "Social-Environmental Predictors of Health-Related Quality of Life in Youth with Spina Bifida" (2013). *Master's Theses.* Paper 2242.
http://ecommons.luc.edu/luc_theses/2242

LOYOLA UNIVERSITY CHICAGO

SOCIAL-ENVIRONMENTAL PREDICTORS OF HEALTH-RELATED QUALITY OF LIFE IN YOUTH WITH SPINA BIFIDA

A THESIS SUBMITTED TO
THE FACULTY OF THE GRADUATE SCHOOL
IN CANDIDACY FOR THE DEGREE OF
MASTER OF ARTS

PROGRAM IN CLINICAL PSYCHOLOGY

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CHICAGO, IL
DECEMBER 2013

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER ONE

INTRODUCTION

Health-related quality of life (HRQOL) is a multidimensional construct including an individual's physical and mental health and psychosocial well-being (De Civita et al., 2005), and the measurement of HRQOL has been recognized as a key marker of health outcomes in pediatric populations (Eiser & Jenney, 2007). Due to medical and technological advances, an increasing number of individuals with chronic illnesses are living longer. As such, research that investigates improvements in HRQOL in youth with chronic illnesses has become essential. Indeed, the number of studies examining HRQOL in pediatric populations has increased markedly; spina bifida (SB) is one among several chronic illnesses that has received increased attention with regard to HRQOL assessment in the past decade (see Sawin & Bellin, 2010 for a review).

The experience of a chronic illness may have deleterious consequences on several aspects of a youth's life. In particular, SB is a relatively common congenital birth defect associated with a multitude of physical and cognitive impairments (e.g., orthopedic abnormalities, urinary and bowel difficulties; Fletcher & Brei, 2010) as well as individual and contextual social-environmental difficulties (e.g., poor social competence, a stressful family environment; Alriksson-schmidt, Wallander, & Biasini, 2007). Due to the range of physical, cognitive, and social impairments associated with this condition, youth with SB may be at an increased risk of reduced HRQOL. Research on HRQOL for children and adolescents with SB has begun to identify demographic, illness-related, and social-environmental factors that are associated with HRQOL. Elucidating factors that influence HRQOL is an important step in informing the development of interventions to improve HRQOL in youth with SB. Thus far, extant research investigating HRQOL in youth with SB has tended to focus on non-modifiable demographic and illness-specific correlates, such as age, gender, and degree of mobility impairment. Studies examining modifiable social-environmental factors on youth's HRQOL may be particularly important in informing future interventions for youth with SB.

In addition, despite the importance of this work, current research has several methodological weaknesses, including the utilization of mixed samples, small sample sizes, single informants, and cross-sectional designs. The current study seeks to address these weaknesses and bridge critical gaps in the literature by testing a longitudinal, multi-method and multi-informant model of individual and contextual social-environmental predictors of HRQOL in youth with SB across two independent studies (see Figure 1). The following sections provide a general overview of historical and current conceptualizations, measurement issues related to quality of life as a construct, and an extensive review of studies that have investigated demographic, illness-specific, and social-environmental correlates of HRQOL in youth with SB. Methodological weaknesses and gaps in current literature are identified and a detailed description of the current study is provided.

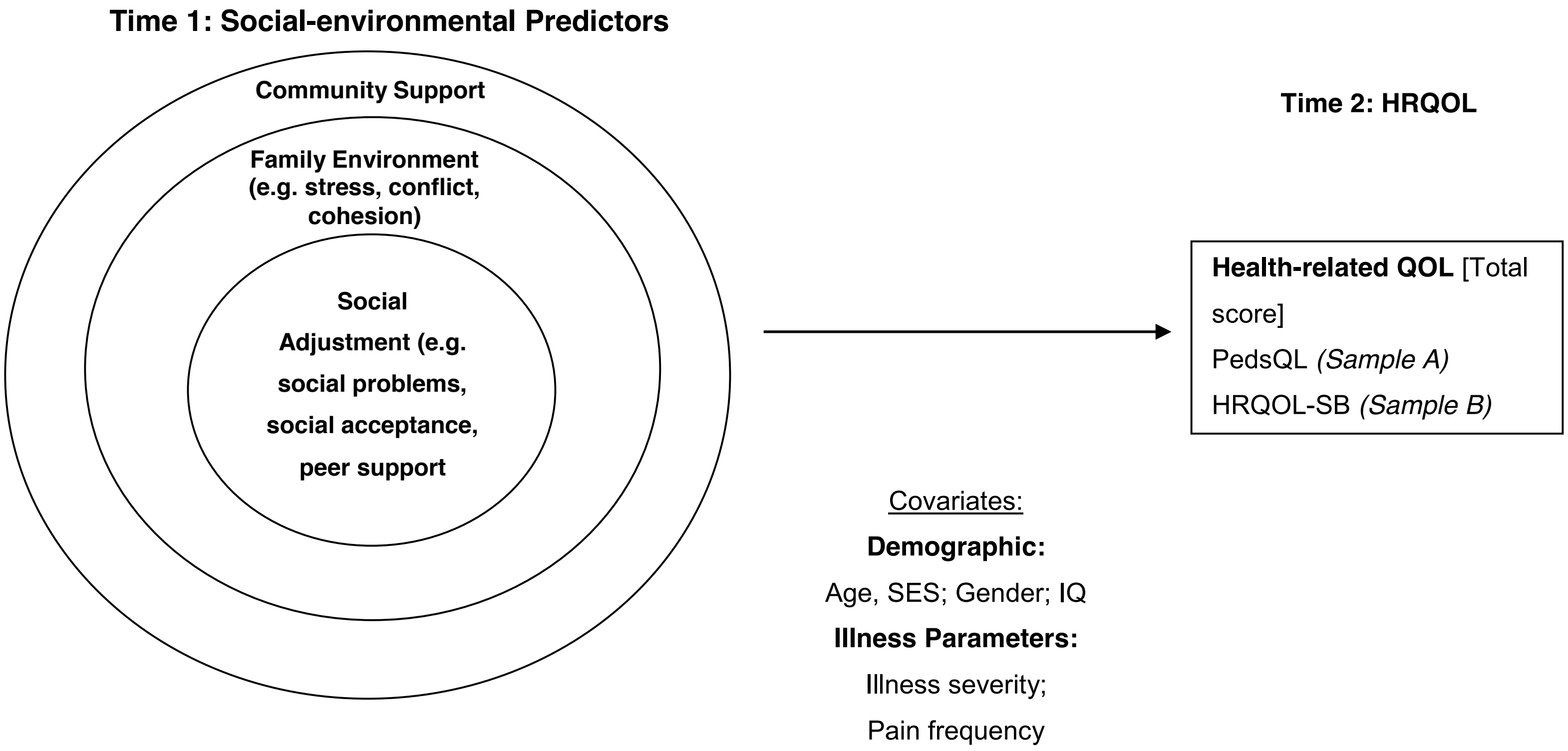


Figure 1. Study model: Social-environmental predictors of health-related quality of life in youth with spina bifida. Model tested in two samples: Sample A = 140 children with spina bifida (Ages 8-15 at Time 1; Ages 10-17 at Time 2); Sample B = 61 children with spina bifida (Ages 15/16 at Time 1; Ages 16/17 at Time 2).

CHAPTER TWO

REVIEW OF THE RELEVANT LITERATURE

Conceptualizing Quality of Life

In 1948, the World Health Organization (WHO) defined quality of life (QOL) as the presence of physical, mental, and social well-being, and not just the absence of disease (as cited in Testa & Simonson 1996). Since this time, the construct of QOL has received considerable attention and has undergone various conceptualizations. Two approaches to the assessment of QOL have emerged. Generic QOL assessment is based primarily on developmental models and takes a broader view of an individual's life, including relations with family and friends, job or school functioning, and life goals (Koot & Wallander 2001). Rapheal and colleagues, for example, created a measure of overall quality of life to assess an adolescent's satisfaction and the importance of various activities and concepts, such as health, sexuality, personal hygiene, and exercise (Raphael, Rukholm, Brown, Hillbailey, & Donato, 1996).

Conversely, HRQOL is based on developmental as well as health outcomes, and is a more specific measure of an individual's perceptions of well-being that may be impacted by his or her disease or condition. HRQOL typically addresses symptoms, functional status, psychological and social functioning, and an individual's perceived ability to participate in and enjoy physical and social activities, given the constraints of his/her health status (Eiser & Morse, 2001a).

Definition of Health-Related Quality of Life

Functional impairment and health-related quality of life (HRQOL) are often used interchangeably, but meta-analytic research suggests that there is an important distinction between these terms (Smith et al., 1999). The construct of HRQOL includes assessment of the individual's perception of the impact that a disease or condition has on his or her physical health status, as well as on the psychosocial health dimensions of emotional, social, and role functioning; HRQOL assessment focuses on the experience of the illness. Functional impairment, on the other hand, is a concept related to but distinct from HRQOL. Functional impairment has been defined as limitations in a person's ability to perform activities relevant to daily life including physical, social, and personal activities (Stein & Jessop, 1990). While functional impairment measures activity limitations due to a chronic disability or illness, health-related quality of life measures the perceived impact of an illness on an individual's physical and psychosocial functioning. In other words, the meaning of the illness to the individual (i.e., the individual's experience with the illness) is considered to be separate from functional limitations caused by disease process. Psychosocial health is a particularly component of HRQOL, and has been called the "hidden morbidity" in pediatric clinical practice due to the underidentification of psychosocial problems in routine pediatric care (Varni et al., 2002). The need to reveal and identify this hidden morbidity has led to increased support to use a quality of life construct that is multidimensional, consisting of physical, mental, and social health dimensions as delineated by the World Health Organization (as cited in Testa & Simonson 1996).

For patients with chronic health conditions, the goal of health care is to restore them to the fullest health possible by improving symptom management, treatment adherence, and their ability to cope with the negative impact of their condition. For this reason, some researchers have indicated that HRQOL may be more important than biomedical measures when assessing patients with chronic health conditions (Coons & Kaplan, 1993). Thus, to ensure that children receive the best medical care possible with qualified and competent professionals, it is essential that we assess their experiences as it relates to their chronic illness.

Measurement of Health-Related Quality of Life

In the past decade, there has been a dramatic increase in the number of measures of HRQOL in pediatric populations (Drotar, 2004). However, the measurement of HRQOL has presented a number of methodological challenges and debates. For one, researchers have developed and employed both generic and disease-specific HRQOL instruments, yet there is a lack of agreement regarding which are preferred. Generic instruments usually include a global or summary measure of multiple domains of HRQOL. Global ratings of HRQOL allow for comparisons across different groups (e.g. cancer vs. SB) and have undergone a significant amount of development and testing. Examples of these instruments include the Child Health Questionnaire (CHQ-50; Langraf, Abetz & Ware, 1996) the Pediatric Quality of Life Questionnaire (PedsQL 4.0^{TM}; Varni, Seid, & Kurtin, 2001), the Child Health and Illness Profile (CHIP; Starfield et al., 1995), and the Youth Quality of Life (YQOL; Edwards, Huebner, Connell, & Patrick, 2002). However, researchers have noted that these instruments may have limited utility in detecting clinically significant changes in an individual's condition over time (Quittner, 2003).

Unlike generic measures of HRQOL, disease-specific measures include items that address specific challenges associated with a given condition or illness. Several disease-specific instruments have been developed for children and adolescents, including asthma (Varni, Burwinkle, Rapoff, Kamps, & Olson, 2004), epilepsy (Cramer, Westbrook, Devinsky, Perrine, Glassman & Camfield, 1999) cancer (Goodwin, Boggs, & Graham-Pole, 1994; Varni, Katz, Seid, Quiggins, Friedman-Bender, 1998), cystic fibrosis (Modi & Quittner, 2003), diabetes (Ingersoll &Marrero, 1991), and SB (Parkin et al., 1997). Advantages include the ability to detect small but clinically meaningful changes, and a greater clinical relevance to patients, families, and healthcare providers. The Food and Drug Administration (FDA) has also recognized disease-specific measures of HRQOL as potential primary or secondary outcome measures in clinical trials (Goss & Quittner, 2007). However, such disease-specific measures do not permit comparisons across different illness groups.

More recently, unique challenges have emerged with the shift of HRQOL measurement from adults to children. First, new dimensions of functioning relevant to children and adolescents have been identified, such as social and academic functioning at school (Modi & Quittner, 2003). There has also been increased attention on creating developmentally appropriate measures, suited to the child's age, reading ability, and emotional maturity (Eiser & Jenney, 2007). Finally, HRQOL has historically been assessed using parent proxy reports. Researchers have noted special circumstances in which a child is too young, ill, or fatigued to complete questionnaire measures; otherwise, youth self-report is considered to be an essential source in the measurement of HRQOL. Although children with chronic illnesses and their parents may have higher agreement rates compared to healthy populations (Eiser & Morse, 2001b), research indicates that there is lack of congruence between child and parent proxy report of HRQOL, especially in the emotional and physical domains (Modi & Quittner, 2003; Theunissen et al., 1998). Thus, several researchers have emphasized the importance of assessing HRQOL from both the child and parent perspectives. Assessment of parents' reports of HRQOL may be especially valuable because of the parents' role in disease management and healthcare utilization (Eiser & Jenney, 2007).

Health-Related Quality of Life in Youth With Chronic Illnesses

Morbidity and mortality have historically been used to evaluate the efficacy of management and treatment of chronic illnesses. However, due to medical and technological advances, an increasing number of these individuals are living longer. As such, measuring and improving the quality of life in individuals with chronic health conditions has become increasingly important. Literature on HRQOL in pediatric populations has steadily increased in the past decade, and HRQOL has been studied in a variety of chronic medical conditions Available research in pediatric populations assessing HRQOL includes oncology (e.g., Varni, Limbers, & Burwinkle, 2007), arthritis (e.g., Tennant et al., 2001), cystic fibrosis (Modi & Quittner, 2003) chronic pain (e.g., Hunfeld et al., 2001), and SB (e.g., Sawin & Bellin, 2010).

The assessment of HRQOL has many research and clinical applications, and may be critical for several reasons. First, it provides useful information regarding illness burden and a child's progress and responsiveness to treatment over time. Second, HRQOL is a multidimensional construct that may provide a clearer picture of a child's functioning across several domains compared to the assessment of a single general domain. Finally, data on HRQOL can be used to compare the efficacy of medical or psychological interventions, establish the efficacy of new medications, and inform social policies.

Health-related Quality of Life in Youth with SB

SB is a relatively common congenital birth defect, occurring in 3 out of 10,000 live births in the United States (Centers for Disease Control and Prevention, 2010). This condition arises during the first month of pregnancy, during which the spinal column fails to develop fully, resulting in exposure of a portion of the spinal cord (Sarwark, 1996). Individuals with SB face a number of challenges, including physical and cognitive issues. Physical difficulties may include varying degrees of motor paralyses, sensory loss, orthopedic problems, and urinary and bowel incontinence (Fletcher & Brei, 2010). Myelomeningocele is the most common and most severe type of SB, and is associated with brain abnormalities, hydrocephalus, and cognitive impairments, including problems with planning, orientation, shifting attention, and working memory (Rose & Holmbeck, 2007). Youth with SB typically learn to follow a strict medical regimen, which may include taking medications, self-catheterization, following a specific bowel program, regular skin checks, and pressure relief exercises. Further, cognitive and executive function may have a significant impact on social adjustment difficulties, which are common in individuals with SB (Rose & Holmbeck, 2007; Devine et al., 2012).

Given the multitude of physical, neurocognitive, and social challenges associated with this condition, youth with SB have an increased risk for reduced quality of life (Cate, Kennedy, & Stevenson, 2002). In addition, advances in medical care, such as clean intermittent catheterization for management of neurogenic balder, have substantially reduced morbidity due to kidney disease in this population. Individuals with SB are now expected to live into adulthood, and the emphasis on medical care has shifted to improvement and enhancement of quality of life and promotion of independence in this population (Danielsson et al., 2008). In fact, a study by Cate and colleagues found that quality of life is dramatically impaired in children and adolescents with SB, such that parents reported lower quality of life (over one SD lower) compared to youth with other chronic physical conditions and psychiatric disorders (Cate, Kennedy, & Stevenson, 2002). However, thus far no studies have compared quality of life in youth with SB to healthy or chronically ill youth using a well-validated measure of HRQOL. Further, investigations of predictors and correlates of quality of life are essential. Research to date (see Sawin & Bellin, 2010) has found several correlates of HRQOL in youth with SB including: (a) demographic, (b) illness-related, and (c) social-environmental factors (e.g., social and contextual variables).

Demographic covariates of HRQOL. Common demographic correlates of HRQOL that have been investigated in this population include age, gender, and socioeconomic status (SES). As a child becomes older, the impairments and strains associated with their chronic illness may have a cumulative negative impact as the child becomes increasingly aware of the severity of their condition. Moreover, beginning in childhood, females with chronic health conditions may be at risk for worse psychosocial adjustment (e.g., depression; Sawin, Bellin, Roux, Buran, & Brei, 2009). However, available research examining the relationship between gender, age and HRQOL in youth with SB is equivocal. Generally, age and gender are not directly related to HRQOL (e.g., Cate, Kennedy, & Stevenson, 2002; Leger 2005; MacNeily, Morrell, & Secord, 2005; MacNeily, Jafari, Scott, Dalgetty & Afshar, 2009) with the exception of a few studies. For example, a study by Verhoef and colleagues conducted on youth with SB (ages 16-25) found that those older than 20 reported worse HRQOL in two domains of the SF-36: body pain and general health (Verhoef, Post, Barf, Van Asbeck, Gooskens, & Prevo, 2007). Similarly, another study on adolescents and emerging adults with SB (ages 12 to 21) found that older age was significantly associated with lower levels of parent-reported HRQOL (Sawin, Brei, Buran & Fastnenau, 2002). Additionally, Lemelle and colleagues found an age and gender interaction, such that older females had lower HRQOL scores than older men across many domains of the SF-36 (Lemelle, Guillemin, Aubert, Guys & Lottmann 2006).

The effect of socioeconomic status on child outcomes has been well documented and may be an important factor associated with HRQOL in children with SB. Socioeconomic status can have an influence on a multitude of domains in a child’s life, including health (e.g., healthcare access), schooling, physical environment (e.g. home and neighborhood environments), emotional well-being (e.g. stress), and family interactions

(Park & Turnbull, 2002). Moreover, children with disabilities may be more likely to live in low-income households; Park and Turnball found that twenty-eight percent of children with disabilities are living in families whose total income is below the poverty line compared to sixteen percent of children without disabilities (2002). Regardless, data on the relationship between SES and HRQOL in youth with SB is inconsistent; some studies have found that low SES is related to poorer HRQOL (Kulkarni, Cochrane, McNeely, & Shams, 2008), yet others have not supported this association (Sawin et al., 2002; Bier, Prince, Tremont, & Msall, 2005). Though findings are generally equivocal, the current study will include age, gender, and SES as covariates in analyses to control for possible effects of these demographics variables. Cognitive ability (i.e., IQ) has never been investigated as a correlate of HRQOL in youth with SB, but will also be included as a covariate in analyses due to evidence suggesting neurocognitive deficits negatively impact psychosocial outcomes in this population, particularly social adjustment and family relationships (Rose & Holmbeck, 2006; Holmbeck, Coakley, Hommeyer, Shapera & Westhoven, 2000).

Illness-related covariates of HRQOL. The majority of research investigating illness-related variables has shown no association between shunt status, continence, and HRQOL in youth with SB (Sawin et al., 2002; Bier et al., 2005; Leger, 2005; MacNeily et al., 2009; Muller-Godeffroy, Michael, Poster, Seidel, Schwarke, & Thyen, 2008; Lemelle et al., 2006). Kirpalani and colleagues did find relationships between several clinical variables (i.e., number of operations, bladder continence, and lesion level) and parent report of child HRQOL. However, examination of adolescent report of HRQOL revealed that only bowel continence was significantly related to reduced HRQOL. One unpublished study (using one of the samples included in the current study; Dissertation Abstract, Abad, 2008) found that higher lesion levels predicted higher levels of quality of life, which was a contradictory finding. However, this finding supports the "marginality hypothesis," which suggests that youth with less severe levels of disability might have more challenges with adjustment because they are unable to fit in with their able-bodied peers, but also do not identify with severely disabled children (Holmbeck & Faier-Routman, 1995). Additionally, research generally does not support an association between mobility impairment and HRQOL (Kirpalani et al., 2000; Muller-Godeffroy et al., 2008; Bier et al., 2005) with the exception of one study by Danielsson and colleagues (Danielsson, Bartonek, Levey, McHale, Sponseller, & Saraste, 2009). This study found that youth with limited functional mobility had significantly lower physical HRQOL.

Although several studies investigating illness-related correlates of HRQOL have shown equivocal results, strong and consistent data have indicated that painful somatic symptoms have a significant influence on HRQOL in youth with SB. Verhoef and colleagues found that pain was related to several domains of HRQOL in individuals with SB (age 16-35), including physical role, general vitality, and social functioning (Verhoef, Post, Barf, van Asbeck, Gooskens, & Prevo, 2007). Similarly, another study found that youth (ages 5-17) and young adults (ages 18-30) with SB who had chronic pain had significantly lower physical and psychosocial HRQOL scores (Wood, Watts, Hauser, Rouhani, & Frias, 2009). Further, a study investigating children ages 8-19 with SB found that pain intensity was significantly associated with the PedsQL total summary score of

HRQOL (Oddson, Clancy, & McGrath, 2006). In addition to a pain severity variable, an illness severity composite was created for the current study to take into account several of the above illness parameters, including lesion level, shunt status, and number of surgeries.

Social-environmental predictors of HRQOL. Although the majority research on HRQOL in youth with SB has primarily focused on demographic and illness-related variables (See Sawin & Bellin 2010), some studies have assessed the role of individual and contextual social-environmental factors. Sawin and colleagues found that adolescents with higher communication efficacy, and higher use of the coping strategy “developing social support” reported better overall quality of life (Sawin, Brei, Burnan, & Fastenau, 2002). General and disease-specific stress has also emerged as an important correlate of quality of life in adolescents with SB, such that higher levels of stress may be associated with decreased quality of life (Sawin, Brei, Burnan, & Fastenau, 2002; Alriksson-schmidt, Wallander, & Biasini, 2007). Life stress has been associated with numerous other negative outcomes in youth with SB, including increased levels of anxiety and depression, and lower levels of self-esteem (Murch & Cohen, 1989). From a developmental perspective, normative biological and psychological stresses faced in adolescence may exacerbate the stress of living with a chronic illness and disability, thus greatly impacting youths’ quality of life.

Additionally, several family factors have been examined in the literature; Sawin and colleagues found that increases in parental hope and decreases in parental overprotection predicted better HRQOL in youth with SB (Sawin et al., 2002). Similarly, Kirplani and colleagues found parental hope to be a better predictor HRQOL compared to other disease characteristics in children and adolescents with SB (Kirpalani et al., 2007). One study also found that maternal psychological distress predicted decreased quality of life (unpublished dissertation; Abad, 2007). Further, examining the broader social environment, Cate, Kennedy, and Stevenson found that family resources, as measured using parental report of self-efficacy as a caregiver and family financial and community support, was a significant predictor of quality of life in youth with SB (2002).

Using a stress-resiliency model, a recent study by Alriksson-Schmidt and colleagues (2007) examined more complex relationships between stress, quality of life, and the moderating effects of personal and social protective factors (e.g., social competence, family functioning, and peer social engagement) in a mixed sample of adolescents with a mobility disability. Although results indicated that social competence, family functioning, and peer social engagement did not function as moderators, these factors were found to be positive correlates of quality of life, independent of the level of stress exposure. Moreover, results indicated a cumulative effect of social competence, family functioning, and peer social engagement, such that having more of these factors predicted better quality of life.

However, there were several methodological issues with this study. For one, researchers included a mixed sample of adolescents with mobility disabilities (e.g., cerebal palsy, scoliosis and SB) and did not utilize a well-validated tool for measuring quality of life (Quality of Student Life Questionnaire; QSL.Q, Keith & Schalock, 1995). The authors proposed that strengths of this study included the use of parent and youth report of subjective (the QSL.Q; Keith & Schalock, 1994) and objective quality of life. Yet, objective quality of life was measured using two items from the quality of life module of the Behavioral Risk Factor Surveillance System (BRFSS; Center for Disease Control and Prevention): the number of days that physical and mental health was poor for the adolescent, respectively (Alriksson-Schmidt, Wallander, Biasini, 2007). These items ask individuals to retrospectively report the number of days perceived as (themselves or their daughter/son) being in poor mental or physical health. As such, these data seem to be indicative of subjective, rather than objective, quality of life. In addition, because results indicated stronger associations between the protective variables, stress, and quality of life for adolescent report compared to parent report, some of the reported findings could be attributed to common method variance.

General Issues With Current Research

Despite the variety of pediatric populations that have been assessed, much of the research to date has provided HRQOL data on only a few conditions. One study by Andelman and colleagues reviewed 688 articles and chapters on quality of life in children, and found that the majority of research conducted between 1967 and 1996 (40%) focused on children with cancer, asthma, rheumatic disease, or epilepsy (1999). Although research has increased in the past decade, there continues to be a paucity of research examining quality of life in youth with SB.

A recent literature search conducted by Sawin and Bellin (2010) found 39 studies addressing quality of life in individuals with SB of all ages. I conducted a similar literature search with a narrower age criterion to estimate the total number of research articles addressing QOL or HRQOL in youth (age range 5-19) with SB from 1990 to 2011. This review included articles from Medline, PsychInfo, and Cumulative index to Nursing and Allied Health Literature. The search was conducted using the key words "quality of life," "health-related quality of life," and "SB," and review articles and reference lists were examined to determine any additional potential studies. Using these methods, a total of fourteen studies were identified that evaluated quality of life in children and adolescents with SB.

My preliminary review of these studies revealed several key methodological issues. The majority (77%) used samples with broad age ranges (e.g., ages 1-18; 5-18), four studies included mixed samples (e.g. combining samples of cerebral palsy and SB), and four used a small sample size (< 30 participants). Of the total sample of studies, eleven (79%) used a single reporter, and only three utilized both parent and youth report. Specifically, three studies were conducted using youth report, and eight using only parent proxy report. Given that numerous researchers have noted that children have a unique perspective on illness burden (Eiser & Morse, 2001), additional studies using both child and parent proxy report of HRQOL is warranted.

Further, only half of these studies (57%) used well-validated measures of HRQOL. HRQOL instruments were classified as "well established" if they had extensive psychometric evidence (e.g. factor structure) and had been used in studies addressing SB published by more than one investigator or investigative teams. These same criteria have been used in previous evidence-based assessments of HRQOL in pediatric populations (Palermo et al., 2008; Sawin & Bellin, 2010). Well-established measures included the

Child Health Questionnaire (CHQ; Landgraf, Abetz, & Ware), the Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Rode, 1999) and the Short-Form health survey (SF-26; Ware, Kosinski, & Keller, 1996). As of yet, there are no well-established illness-specific measures of HRQOL for youth with SB. Finally, only a few studies investigated potential predictors of HRQOL in this population, and most did not use statistical procedures beyond cross-sectional, correlational analyses.

Beyond methodological issues, research investigating the impact of social-environmental factors on HRQOL in youth with SB is not comprehensive, and this field may benefit from identifying a broad range of social-environmental factors. Peer relationships and friendships are an important domain of development in youth, yet little attention has been devoted to social adjustment in youth with chronic illnesses (LaGreca, 1992). Treatment requirements and disease management may interfere with school attendance and the development of stable peer relationships (Olsson, Boyce, & Toumbourou, 2005). Moreover, youth with chronic illnesses and disabilities may have increased social difficulties and poorly developed social skills, likely due to impairments in the central nervous system. The majority of children with SB have hydrocephalus, which has been linked to nonverbal cognitive deficits resulting in difficulties in social interaction (Fletcher et al., 2005).

Indeed, research has consistently pointed to the salience of social difficulties experienced in youth with SB. Youth with SB may have higher rates of social isolation (Blum, Resnick, Nelson, & Germaine, 1991), social immaturity (Holmbeck et al., 2003), and smaller social networks compared to typically developing youth (Ellerton, Ritchie, &

Hirth, 1996). A recent study found that youth with SB generally have fewer close peer relationships, and may experience lower levels of companionship and security in their friendships (Devine, Holmbeck, Gayes, & Purnell, 2011). However, there is a paucity of research on the implications of social adjustment on HRQOL in youth with SB.

Family relationships are another critical component to any child or adolescent's healthy development. A focus on the impact of family functioning on HRQOL is essential, given the considerable influence of the family on psychosocial adjustment in youth with chronic illnesses (Drotar, 1997). The presence of a chronic illness may be a source of considerable stress in a family, and parents may become the primary support for maintaining medical regimens and encouraging a healthy lifestyle. Further, research has consistently indicated a direct link between family functioning (e.g., conflict, cohesion) and HRQOL across pediatric illness groups, such as youth with diabetes (Pereira, Berg-Cross, Almeida, & Machado, 2008), asthma (Sawyer, Spurrier, Whaites, Kennedy, Martin, & Baghurst, 2001), obesity (Janicke et al., 2007), and organ transplant recipients (Devine et al., 2011). Yet few studies have comprehensively assessed the impact of family environment, such as stress, conflict, and cohesion on HRQOL in youth with SB within a multi-level social-environmental model (see Figure 1).

The Current Study

Given the importance of the social environment to adjustment in youth with SB, and the relative dearth of knowledge in this area, the current study utilized a social-ecological model to investigate individual and contextual social-environmental predictors of HRQOL in youth with SB. Socio-ecological models (e.g., Bronfenbrenner, 1986) have provided a useful organizational framework for understanding the influence of a youth's social environment on HRQOL (e.g., Alriksson-Schmidt, Wallander, & Biasini, 2007). In this model, the individual is at the center, surrounded by expanding levels of social-contextual influence. A more comprehensive model of a youth's social environment would place the youth's individual social adjustment at the center, family environment at the next level, and the broader social world (e.g., community support) at the most distal sphere of social influence. Thus, this study investigated youths' individual social adjustment (e.g., social problems, social acceptance, and peer support), family environment (e.g., family stress, conflict, and cohesion), and community support as predictors of HRQOL in youth with SB. In addition, the impact of social-environmental factors on HRQOL, above and beyond demographic and illness-related parameters, was examined.

Finally, the current study sought to address several methodological issues that exist in studies to date. The use of single methods (e.g., subjective report only), single reporters (e.g., child or parent report only), newly established measures of HRQOL, and cross-sectional designs are among the most prominent weaknesses of current literature in this area. Thus, this study includes (a) child, mother, and father reports (b) a well-established measure of HRQOL (PedsQL; Varni, Seid, & Rode, 1999) (c) observational and subjective measures of family environment (i.e., of family conflict and cohesion) and (d) longitudinal data to predict future HRQOL. Further, the utility of this model was examined in two independent samples of youth with SB recruited from separate federal- and agency-funded studies to provide a cross-validation of the study hypotheses.

Hypotheses

The two studies from which these samples were recruited were developed independently, thus some constructs were assessed using different instrument measures. Most importantly, in the first sample of 140 youth and their parents (ages 8-15 at initial assessment; hereafter referred to as Sample A), the Pediatric Quality of Life Inventory (PedsQL; Varni, Seid, & Rode, 1999) was used to measure HRQOL. In the second sample of 61 youth and parents ages (ages 15-16 when a HRQOL measure was first used in this longitudinal study beginning when participants were 8-9 years old; hereafter referred to as Sample B), the Health-Related Quality of Life-SB (HRQOL-SB; Parkin, et al., 1997) was used to measure HRQOL. Please see the Methods section for further details of both Samples.

The first study aim of this study was to provide important descriptive information regarding HRQOL in youth with SB. Similar to previous research on proxy reports of HRQOL (i.e., Panepinto, O'Mahar, DeBaun, et al., 2005) moderate agreement (e.g., correlations) was expected between child self-report and care-giver proxy report of HRQOL in Sample A (*hypothesis 1)*. Second, it was expected that youth with SB would display impaired HRQOL across all domains (i.e., physical, emotional, social, school, and total HRQOL) compared to mean scores of healthy populations of youth; and would display lower mean scores compared to other illness groups (*hypothesis 2)*. HRQOL scores obtained in this sample were compared to a study conducted for the purposes of demonstrating reliability and validity of the PedsQL scales in healthy and chronically ill patient populations (Varni et al., 2001). This study by Varni and colleagues (2001) included children ages 5-18 with and without a chronic illness (N = 683 chronically ill; N = 730 without a chronic illness). Finally, as noted, impairments and strains associated with a chronic illness may have a cumulative negative impact as a child and their family becomes increasingly aware of the severity of their condition and the health of the child deteriorates. Thus, it was expected that HRQOL would significantly decrease over time (*hypothesis 3)*. For these first three hypotheses, *Sample A only* was utilized for several reasons: 1) The use of the PedsQL as a measure of HRQOL in Sample A allowed for comparisons with normed HRQOL data on chronically ill and healthy populations 2) Parent-report of HRQOL was *not* obtained for Sample B and 3) In Sample B, the HRQOL questionnaire for Time 1 (i.e., the Quality of Life in Epilepsy scale, or QOLIE) was different from the HRQOL questionnaire used at Time 2 (i.e., the HRQOL-SB; Parkin, et al., 1997), thus, an examination of changes in HRQOL over time could not be conducted in this sample.

The second aim of this study to examine social-envionmental predictors of HRQOL in both samples. In Sample A, it was expected that all social-environmental factors measured when youth were ages 8-15 would prospectively predict HRQOL (in youth ages 10-17) across both informants (e.g., child and parent; *hypothesis 4*). Specifically, it was expected that better social acceptance, peer support, family cohesion, and community support would prospectively predict improved HRQOL. Further, it was hypothesized that decreased social problems, family conflict and stress would prospectively predict improved HRQOL across informants. It was expected that social-environmental predictors of HRQOL would be significant above and beyond all demographic and illness-related variables, including age, gender, SES, cognitive ability, illness severity and pain frequency (*hypothesis 5*). The social-ecological model in this study conceptualizes intrinsic personal characteristics as the most proximal influence on child outcomes (with the child at the center). In accordance with this model, as well as research indicating the salience social deficits in children and adolescents with SB, it was expected that social adjustment variables (e.g., social problems, social acceptance, and peer support) would be the strongest prospective predictors of HRQOL in this sample (*hypothesis 6*).

Further, it was expected that the hypotheses 4-6 delineated above regarding socio-environmental predictors of HRQOL would be replicated in Sample B (*hypothesis 7*). Specifically, in Sample B, it was expected that individual and contextual social-environmental predictors measured when youth are ages 15-16 would prospectively predict HRQOL (in youth ages 16-17), across informants and above and beyond demographic and illness-related covariates. It was again expected that individual social adjustment variables would be most predictive of future HRQOL in this sample. Similar to Sample A, individual and contextual social-environmental predictors included social adjustment (e.g., social problems, social acceptance, peer support), family environment (e.g., cohesion, conflict, stress), and community support. Demographic and illness-related covariates included gender, SES, illness severity, cognitive ability and pain frequency.

CHAPTER THREE

METHODS

Participants

Recruitment and methodological procedures were similar for both samples. Participants were recruited from children's hospitals and a statewide SB association in the Midwest using recruitment letters. Families were also approached and given information about the study during regularly scheduled clinic visits. Interested participants were screened by phone or in person by a member of the research team, and were invited to participate if they met the following criteria: (1) diagnosis of SB, including MM, lipomeningocele, and myelocystocele, (2) ages 8-15 (*Sample A*) or ages 8-9 (*Sample B*), (3) involvement of at least one parent, (4) cognitive ability to complete questionnaires, and (5) residence within 300 miles of the laboratory to allow for home visits. Criteria regarding language proficiency differed between samples; lack of proficiency in English was an exclusionary criterion for *Sample B,* whereas participants proficient in English or Spanish were included in *Sample A*.

Sample A. Participants in this sample were recruited starting in 2006 as part of a larger NIH-funded longitudinal study examining neurocognitive, family, and social domains in youth with SB (e.g., Devine et al., 2012). Of the 246 families approached, 42% (N = 104) could not be contacted or declined to participate and two families did not meet inclusionary criteria, resulting in an initial sample size of 140 participating families. Children of families who declined participation did not differ from those who accepted participation with respect to type of SB (myelomeningocele vs. other), χ^2 (1) = .000, $p >$ .05, shunt status, χ^2 (1) = .003, $p >$ .05, or occurrence/nonoccurrence of shunt infections, χ^2 = 1.08, $p >$ .05.

The current study included two data collection waves from the larger study: Time 1 (N = 133 youth ages 8-15 years old; *M* = 11.4; 55.6% female), and Time 2 (N = 101 youth ages 10-17 years old; *M* =13.3). Of the 133 participants at Time 1, 87.9% had a diagnosis of myelomeningocele, 8.3% lipomeningocele, and 3.8% other. The majority of the children had spinal lesions in the lumbosacral or lumbar spinal regions (62.9%), whereas 19.0% and 18.1% had sacral and thoracic lesions, respectively. Additionally, 80.3% of the children had a shunt. With regard to ambulation methods, 81.1% of the children used braces and 61.4% used a wheelchair.

Sample B. Participants in this sample were recruited starting in 1993 as part of a separate, agency-funded (March of Dimes; e.g., Holmbeck et al., 2003) longitudinal study that included a stronger focus than Sample A on family relationships and psychosocial outcomes in children and adolescents with and without SB. This study has included six data collection waves thus far; data were first collected when youth were 8- and 9-years old, with subsequent data collection occurring every two years until youth were 18- and 19-years old. Of the 310 families that were approached during Time 1, 39% (N = 120) could not be reached or declined to participate, and 39% (N = 120) did not meet inclusionary criteria, resulting in an initial sample size of 70 participating families. Children of families who declined participation did not differ from those who accepted participations with respect to lesion level, χ^2 (2) = 0.62, *p* > .05, or type of SB (myelomeningocele vs. lipomeningocele), χ^2 (1) = 1.63, *p* > .05.

For Sample B, the current study utilized two data collection waves from the larger study: Time 4 (N = 61 youth ages 14-16, *M* = 14.5; 41% female) and Time 5 (N = 53 youth ages 16-18, *M* = 16.6; 46.2% female). These data collection waves were chosen due to the administration of a more reliable and validated HRQOL instrument (HRQLSB; Parkin et al., 1997) starting at Time 5; a 6-item quality of life scale (Quality of Life in Epilepsy scale (QOLIE) will be used to control Time 4 quality of life. Of the 61 participants still participating in the study at Time 4, 85.2% had a diagnosis of myelomeningocele, 9.8% lipomeningocele, and 4.9% other. Additionally, over half of the children had spinal lesions in the lumbosacral or lumbar spinal regions (54.1%), 19.7% were sacral, and 8.1% thoracic. Further, 72.1% of the children had a shunt, 62.3% of the children used braces to ambulate and 57.4 % used a wheelchair. Demographic information of both samples is provided in Table 1. Additionally, there were no differences in Time 1 levels of child-reported HRQOL between participants at Time 2 and non-responders in either sample (N of child non-responders in Sample A = 26; *t*(126) = -0.33 and N of child non-responders in Sample B = 9; *t*(59) = -1.71, *p*'s > .05. However, there was a significant difference in Time 1 parent-reported HRQOL in Sample A, such that parent non-responders reported lower levels of HRQOL (N of non-responders = 27; t(127) = -2.45, p < .05). For conceptual clarity related to describing two independent samples, Time 4 and Time 5 in Sample B will hereafter be referred to as Time 1 and Time 2, respectively.

Table 1. Youth Demographic Information of Samples A and B at Time 1

Characteristic	Sample A *n* = 140	Sample B *n* = 61
Age *M (SD)*	11.40 (2.48)	14.50 (.60)
Gender *(%)*		
Male	46.4%	59.0%
Female	53.6%	41.0%
Ethnicity *N (%)*		
Caucasian	53.3%	70.9%
Hispanic	27.9%	7.3%
African American	12.9%	5.5%
Other	5.7%	16.3%
Hollingshead SES, *M (SD)**	39.7 (15.9)	42.5 (11.0)

Note. Hollingshead SES are based on initial data from both samples (when children were 8-15 in Sample A and 8/9 in Sample B).

Procedure

The following is a description of the general procedures used for both study samples; unless otherwise noted, procedures were similar across the two samples. The sponsoring institution and hospitals' Institutional Review Boards approved these studies. Trained graduate and undergraduate research assistants conducted three-hour home visits at each data collection wave. Parental informed consent, child assent, and medical release forms were obtained prior to data collection at each visit. Parents and youth completed questionnaires, counterbalanced to control for order effects. Questionnaires included measures of social adjustment, family environment, community support, and HRQOL. Parents also completed a demographics and medical questionnaire.

In addition to completing study questionnaires, families from both samples participated in counterbalanced, structured videotaped interaction tasks that differed slightly according to study. Participants in Sample A completed: (1) a warm-up game (2) discussion of two age-appropriate vignettes, (3) discussion of transferring disease-specific responsibilities to the child, and (4) a conflict task. These videotaped interactions were coded using the macro-coding system developed by Holmbeck, Zebracki, Johnson, Belvedere, and Hommeyer (2007a, 2007b). Interaction tasks that were coded to obtain observational data on the family environment included: *vignettes, transferring of responsibilities,* and *conflict tasks*. In the vignettes task, families were given two age-appropriate vignettes of situations adolescents might typically encounter, and were asked to discuss possible resolutions to these situations. In the transferring of responsibilities task, families were asked to discuss one to two responsibilities that could be transferred from the parent to the child (e.g., independent catheterization). Finally, in the *conflict task*, families were first asked to complete a brief version of a measure called the Parent-Adolescent Conflict Scale called the Issues Checklist (IC; Robin & Foster, 1989) assessing the intensity of 20 common issues discussed between the parent and child within the past two weeks, some of which were specific to SB. Families were then presented with the five issues that they rated as most common and of highest intensity, and they were allowed to discuss and attempt to resolve three or more of these issues during the videotaped task. Families were given 10 minutes to complete each of these tasks.

Participants in Sample B completed: (1) a warm-up game (2) an unfamiliar game task (3) a structured family interaction task (SFIT; Ferreira, 1963), and (4) a conflict task, based on a procedure developed by Smetana and colleagues (1991). Interaction tasks coded in this sample included: the *unfamiliar board game*, *family interaction*, and *conflict* *tasks*, each of which was completed/discussed for a total of 10 minutes. In the *unfamiliar board game*, families were asked to play a game they had not yet encountered. In the *Structured Family Task*, families were first asked to complete a questionnaire individually, reflecting five commonly discussed family issues (e.g., “If your family won a contest, what would you want the prize to be?”). Families were then asked to engage in a joint dialogue and make decisions pertaining to each of these five questions. Administration of the *conflict task* was identical to that which was administered to participants in Sample A. Families in both samples received monetary compensation for completion of study procedures at each time point.

Measures

Unless otherwise noted, the following measures were assessed in both samples. See Appendix A for all observational and questionnaire measures.

Demographics. Parents completed a questionnaire that assessed several demographic factors. Demographic information regarding the parent included education, employment status, and income. Information regarding the child included gender, age, race, and ethnicity. The Hollingshead Four Factor Index for socioeconomic status was computed based on parents’ education and occupation (Hollingshead, 1975), with higher scores indicating higher SES.

Illness parameters

***Neurocognitive functioning*.** The Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999) was used as a measure of youths’ cognitive ability at time 1 in Sample A. The WASI is a well-validated measure of child intelligence, with normative means of 100 and standard deviation of 15. In the current study, the WASI vocabulary and matrix-reasoning subtests were utilized and an estimated full scale IQ (FSIQ) was computed. The WASI vocabulary subtest is a 42-item task used to measure child’s expressive vocabulary and verbal knowledge. The matrix-reasoning subtest was used to measure nonverbal fluid reasoning and general intellectual ability, requiring subjects to process and organize 34 visual patterns with shapes.

The Peabody Picture Vocabulary Test-Revised Edition (PPVT; Dunn & Dunn, 1981) was used as a measure of youths’ cognitive ability at time 1 in Sample B. The PPVT-R was administered by presenting each participant with a series of pictures. The examiner then stated a word describing one of the pictures, and asked the participant to point to the picture that described the word. The PPVT has shown high levels of validity and reliability, correlating moderately with other measures of verbal intelligence (Sattler, 2002).

Illness severity**.** Parents filled out a medical form and data was collected from medical charts to assess the following information: type of SB (i.e., myelomeningocele, meningocele, or lipomeningocele), shunt status, lesion level (i.e., sacral, lumbar, or thoracic) and ambulation method (i.e., ankle-foot orthoses [AFOs], knee-ankle-foot orthoses [KAFOs] or hip-knee-ankle-foot orthoses [HKAGOs] wheelchair, or no assistance). Based on previous research (e.g., Hommeyer, Holmbeck, Wills, & Coers, 1999), an overall illness severity composite score was computed according to a participant’s inclusion in a specific group for all of the above variables: shunt status (no = 1, yes = 2), myelomeningocele (no = 1, yes = 2), lesion level (sacral = 1, lumbar = 2, thoracic = 3), and ambulation status (no insistence/AFOs = 1, KAFOs/HKAFOs = 2, wheelchair = 3). Thus, scores ranged from four to ten, with higher scores indicating higher levels of severity.

***Pain frequency*.** In Sample A, pain frequency was measured using a pain questionnaire that assessed multiple aspects of pain experienced in the past three months (e.g., location, severity, duration, frequency). In the current study, one item was utilized to assess youths' perception of pain frequency, rated on a 7-point scale (0 = not at all to 6 = daily). In Sample B, pain frequency was measured using one question from the somatic subscale of the Child Behavior Checklist (CBCL; Achenbach, 1991). Youth reported on the extent to which aches and pains without known medical cause had been present in the past three months, rated on a 3-point scale (0 = not true, 1=somewhat or sometimes true 3= very true or often true).

Social-environmental predictors

***Social adjustment*.** In accordance with research utilizing similar friendship paradigms in youth with SB (Devine et al., 2011), child social adjustment was assessed using three constructs: *social competence*, *social skills,* and *peer social support*.

Social competence was evaluated using mother and father report on the Social Competence subscale from the Child Behavioral Checklist (CBCL; Achenbach, 1991). The CBCL requires respondents to rate each of 119 behaviors on a 3-point likert scale (0 = not true, 1= somewhat/sometimes true, 2 = very or often true). The CBCL Social Competence scale raw scores were computed by summing responses across the 9 items contained in the subscale. This subscale consists of questions regarding a) participation in organizations, clubs, teams, or groups, b) number of close friends, c) amount of time spent with friends outside of regular school hours, and d) behavior with others (i.e. how well the child gets along with their brothers and sisters, other kids, their parents) and behavior when alone (i.e., how well the child does things by themselves). Mean scores of all available mother and father were utilized in analyses, with higher scores reflecting greater social competence. Internal consistency for this measure is well established and was demonstrated to be adequate in families of youth with SB (Holmbeck et al., 2003).

Social skills was evaluated using mother, father, and teach report of Social Skills Rating System (SSRS; Gresham & Elliot, 1999). The SSRS is a standardized, norm-referenced instrument that assesses behaviors that are considered essential to social adjustment and adaptive functioning. On the parent and teacher forms, each item asks the respondent to rate how often the child demonstrates a particular social skill (e.g., makes friends easily, answers the phone appropriately, responds appropriately when hit or pushed by children) and how important the skill is to the child's development. Teachers and parents were asked to rate how often the child engages in the behavior, from "0 = never" to "1 = sometimes" to "2 = very often." The parent form consists of 38 items, the teacher form consists of 34 items. The SSRS has shown adequate to good internal consistency across forms (α = .51; Gresham & Elliot, 1990). In the current study, coefficient alphas for the social skills subscales ranged from .91 to .92 for the teacher form, and .88 to .94 for the parent form for both Samples A and B.

The Perceived Emotional/Personal Support Scale (PEPSS; Slavin, 1991) was used to evaluate *peer social support*. This measure asks youth to nominate three individuals from each of the three categories: family members, non-family adults, and peers. The current study utilized data on how respondents rate their peer relationships according to three dimensions: (a) how much they spoke with their friend about personal concerns, (b) how close they feel to their friend and (c) how satisfied they are with the support they receive from their friend. A total score was computed by averaging items across these three dimensions. The Peer Support subscale of the PEPSS has demonstrated adequate reliability and consistency (α=.89; Salvin 1991) and was adequate for the current study samples (α=.89 for both Sample A and Sample B).

Family environment. Three domains of family environment were assessed in the current study: family stress, conflict, and cohesion. All three constructs were assessed using subjective measures. In addition, family conflict and cohesion were examined using data derived from the observational coding systems.

The total score of the Family Inventory of Life Events (FILE; McCubbin, Patterson, & Wilson, 1982) was used to assess *family stress*. This 71-item measure examines family stress across several domains: intra-family strains, marital strains, pregnancy and childbearing strains, finance and business strains, work-family transitions and strains, illness and family care strains, losses, transition in and out, and family legal violations. Mothers and fathers report whether or not the family has experienced the event and total scores are calculated by summing all "yes" responses, with higher scores indicating higher levels of family stress. The FILE has shown adequate internal consistency (McCubbin, Patterson, & Wilson, 1982), and was adequate for the current study samples (α's = .84-.86).

The construct *family conflict and cohesion* was assessed using both subjective (questionnaire) and objective (observational) measures.

Questionnaire data. Parents and youth completed a shortened version of the original 90-item Family Environment Scale (FES; Moos & Moos, 1994), which is a common measure of social-environmental family characteristics. Total scores from the *family conflict* and *cohesion* subscale scores of the Relationship Domain were used in the analyses. The cohesion subscale of this measure assessed the degree of commitment, help, and support family members provided for one another. The conflict subscale evaluated the amount of openly expressed anger, aggression, and conflict between family members. Studies using the FES have reported low to adequate reliability for parents of youth with SB ages 8-11 years (α's = 0.60 & 0.70; mother and father report, respectively; Coakley, Holmbeck, Friedman, Greenley, & Thill, 2002). Alpha coefficients were adequate for mother and father report for the current study samples (.76-.86).

*Observational data***.** In Sample A, a manual-based macro-coding system developed by Holmbeck, Zebracki, Johnson, Belvedere, and Hommeyer (Family Interaction Macro-coding System Edition 2 or FIMS-II; Kaugers et al., 2011) was used to obtain observational data for family *conflict* and *cohesion*. This coding system is an adaptation of a system developed by Holmbeck, Belvedere, Gorey-Ferguson, & Schneider (1995). In Sample B, the Family Interaction Macro-coding System Edition 1 (FIMS-I; Holmbeck et al., 1995) was used to evaluate these same constructs. Both of these coding systems require trained undergraduate and graduate research assistants to view each videotaped task and rate families according to interaction style, conflict, affect, control and problem-solving using and family systems/general family atmosphere using 5-point Likert scale ratings. Although coding domains overlapped, these two coding systems differed slightly in item code content included under each domain. Generally, the FIMS-I has fewer codes per domain. For example, under the interaction system domain, the FIMS-I codes included (a) clarity of thought/idea expression, (b) listens to others, (c) confidence in stating opinion, (d) requests input from other family members, (e) comfort level during interaction, (f) involvement in the task, (g) receptive to statements made by others, and (e) provides explanations for positions. The FIMS-II included all of these codes (with the exception of "comfort level during interaction"), as well as six additional codes: (1) off-task behavior (e.g., discussing topics unrelated to the task), (2) attunement (i.e., the level which family members are "in sync," (3) mutuality (i.e., the degree of "we-ness" and reciprocity between family member dyads), (4) positive escalation (i.e., consecutive chains of positive behaviors between a dyad), (5) maturity, and (6) child is needy.

Both of these coding systems tap into five key aspects of parenting and family functioning: parental acceptance, behavioral control, psychological control, family cohesion, and family conflict. For example, a coding item included in the cohesion subscale of both coding systems assessed whether "Parents present as a united front" through verbal and non-verbal cues (5 = Always to 1 = Not at all). Utilizing these coding methods, two coders rated each of the interaction tasks, and item level means of the raters were averaged across tasks to yield a single score for each coding item across families in both samples. Coding item mean scores was computed to create the final composite cohesion and conflict subscales: the same coding items comprised the cohesion (7 items) and conflict (3 coding items) scales in both samples. Research has demonstrated adequate scale-level rater reliability and internal consistency reliability of the FIMS-I conflict and cohesion subscales in youth ages 14-15 with SB (α's = 0.78 – 0.84; Kaugers et al., 2011). The current study indicated similar internal consistency reliability in youth ages 14-18 with SB in Sample A (α's = 0.91 for cohesion scale and 0.61 for conflict scale) and Sample B (α's = 0.83 for cohesion scale and 0.73 for conflict scale). Inter-rater reliability was adequate for both the conflict and cohesion scales in both Samples (α's = .65-.85).

***Community support*.** Community support was examined using the total score of the 16-item Social and Community Support Questionnaire, which was modified from the 75-item ACCESS Needs Assessment for Parents Scale (Kennedy et al., 1998). This measure assesses parental perception of SB-specific community resources available to their child. More specifically, parents are asked to endorse items that are important to them (e.g., adequate health insurance, wheelchair accessibility), and then rate the extent to which this resource is available to the family using a 5-point likert scale (1 = Not taken care of at all to 5 = Well taken care of), with higher scores indicating better community support. In the current study, internal consistency was adequate for both samples (α's = 0.81 – 0.87).

Health-related quality of life

***Health-related quality of life*.** In *Sample A*, youths' HRQOL was assessed by self-report and mother- and father-proxy report using the Pediatric Quality of Life Scale (PedsQL™ 4.0;Generic Core Scale) which has well-established reliability and validity in children with both acute and chronic health conditions. The PedsQL yields a 15-item psychosocial total score as well as four subscale scores to assess a child's physical, emotional, social, and school functioning. The physical subscale of the PedsQL contains questions that implicate physical function, and the majority of children in the sample have physical impairments that may lead to a measured reduction in HRQOL. Thus, the psychosocial total score, which includes emotional, social and school functioning subscales, was utilized in regression analyses to capture quality of life beyond simple impairment.

Children and parents were asked how much of a problem each item has been over the past month using a 5-point Likert scale rating (0 = never a problem to 4 = almost always a problem). Raw scores were then transformed into standard scores ranging from 0 to 100, with higher scores indicating better HRQOL. In the current study, internal consistency was adequate (α's = 0.83 – 0.90) for the PedsQL subscales (physical, emotional, social, and school) as well as the psychosocial total scores at both time points.

In *Sample B,* youth were administered a health-related quality of life instrument specific to SB (HRQOL-SB; Parkin, et al., 1997). The HRQOL-SB is a 47-item measure is that taps ten domains: (a) social, (b) emotional, (c) intellectual, (d) financial, (e) medical, (f) independence, (g) environmental, (h) physical, (i) recreational, and (j) vocational quality of life. Youth were asked how much they feel (e.g., that you have a lot of pain; happy with yourself; etc.) about all of these topic areas using a 5-point Likert scale (1 = only little to 5 = a lot). The HRQOL-SB has demonstrated adequate internal consistency and construct reliability (Parkin, et al., 1997). In addition, the total score on

Quality of Life in Epilepsy scale (QOLIE; Devinsky et al., 1995; Sample B) were used to control for Time 1 HRQOL. In the current sample, internal consistency was adequate for the QOLIE and HRQOL-SB (α's = 0.89 and 0.95, respectively).

Finally, it is important to note that the social adjustment measures listed above were chosen in order to reduce item overlap in the Social Domains of the PedsQL and HRQOL-SB. Item overlap may become an issue because statistical analyses containing similar or overlapping measured independent and dependent variables can cause inflation or overestimation of study results. The social domains of these measures ask if the child has problems with 1) getting along with others, 2) other children not wanting to be their friend, 3) kids teasing them, 4) doing things other kids can do, and 5) keeping up when they play with other kids due to the severity of their condition. These items were determined to be different from items within all of the Social Adjustment independent variables. In particular, items within the CBCL Social Competence subscale pertained to participation and involvement in social activities and general social behavior (e.g., participation in clubs, behavior towards others and while alone). Items within the Social Skills Rating System (SSRS) tapped into several social skills, including appropriate reactions to and interactions with adults and peers. Finally, the Perceived Emotional Support Scale (PESP) contained items that described the child's satisfaction with and quality of their current peer support. Finally, the PedsQL is a multidimensional questionnaire, and thus any issues regarding item overlap may be not be particularly salient.

Statistical Treatment

Preliminary analyses. Prior to hypothesis testing, preliminary analyses determined the psychometric properties of all measures. Analyses also determined whether variables are skewed or contained outliers. Hierarchical regression analyses were used to determine the utility of prospective social-environmental predictor variables in explaining the variance in Time 2 total HRQOL. Assuming a power of .80, and an alpha of .05, a sample of 50 is required to detect large effect sizes ($R^2 = .35$) and a sample size of 107 is required to detect medium effect sizes ($R^2 = .15$) for analyses with 8 predictors and a single dependent variable (Cohen, 1992). Thus, the current study had enough power to detect medium to large effect sizes in Sample A, and large effect sizes in Sample B.

Given the relatively large number of potential covariates and predictors in the study model, preliminary analyses examined correlations among all covariates and predictors of youth- and parent- reported HRQOL to determine which variables would be most appropriate for inclusion in subsequent regression analyses. Only variables that were significantly ($p < .05$) related to HRQOL were included in regression analyses, and no more than eight predictors were used in each regression model. Only covariates that had p-values of .10 or more were included in regression analyses. In order to reduce the number of potential analyses, mother- and father- reports of their youths' HRQOL, social problems, social acceptance, as well as family environment and community support were combined if significantly correlated. Youth and parent report of HRQOL were analyzed separately in an effort to reduce the effects of common method variance.

***HRQOL descriptive information*.** It was expected that child and caregiver reports of HRQOL in Sample A would display low to moderate agreement (*hypothesis 1)*. Agreement between child and self-report of caregiver proxy measures was addressed using bivariate correlations and paired-sample t-tests. It was also expected that youth with SB in Sample A would display impaired HRQOL across all domains (i.e., physical, emotional, social, school, and total HRQOL) compared to healthy youth, and would display similar or lower mean scores compared to youth with chronic illnesses (Varni, Seid, & Kurtin, 2001; *hypothesis 2*). Mean HRQOL subscale and total scores were compared to normed references groups of healthy and illness populations that have been published in previous research (Varni et al., 2001) using independent samples t-tests. Additionally, standard deviations were compared to provide further information on clinically significant differences in HRQOL. Finally, it was expected that HRQOL would decrease over time in Sample A (*hypothesis 3)*. This hypothesis was tested using repeated measure ANOVAS. Specifically, youth and caregiver report of HRQOL was examined to determine whether there was a decrease in HRQOL from Time 1 (ages 8-15) to Time 2 (ages 10 to 17).

***Social-environmental predictors of HRQOL*.** For Sample A*,* it was expected that better social acceptance, peer support, family cohesion, and community support at Time 1 would predict improved HRQOL at Time 2, and increased social problems, family conflict, and family stress at Time 1 would predict reduced HRQOL at Time 2, across both informants (i.e., youth and parent report of HRQOL; *hypothesis 4*). It was also expected that social-environmental factors would explain the variance in Time 2 HRQOL beyond relevant demographic and illness-related variables, including age, gender, SES, cognitive ability, illness severity and pain frequency (*hypothesis 5*). To test these hypotheses, separate analyses were conducted for each reporter of HRQOL (youth or parent). Variables were entered in the following steps: (1) Time 1 HRQOL total score, (2) Time 1 demographics and illness-related covariates, (3) Time 1 social adjustment predictors (i.e., social problems, social acceptance, peer support), (4) Time 1 family environmental predictors (i.e., family stress, family conflict, and family cohesion), and (5) Time 1 community support. Within each step, variables were entered simultaneously. Finally, it was expected that variables within the social adjustment domain (i.e., social problems, social acceptance, and peer support) would be most predictive of HRQOL at Time 2 in this sample (*hypothesis 6*). To test this hypothesis, R^2 –change values were compared at each step in the hierarchical regression models to compare the relative contribution of social adjustment to all other domains/steps.

Finally, to provide additional support for study hypotheses, it was expected that hypotheses 4-6 delineated above would be replicated in Sample B. Specifically, in Sample B, it was expected that individual and contextual social-environmental predictors measured at Time 1 would predict Time 2 youth-reported HRQOL above and beyond demographic and illness-related covariates. Individual and contextual social-environmental predictors included social adjustment (i.e., social problems, social acceptance, peer support), family environment (i.e., family stress, observed or perceived family conflict, and family cohesion), and community support. Similar to *hypothesis 6*, it was expected that individual social adjustment variables would be most predictive of future HRQOL in this sample. To test this hypothesis, statistical procedures run on Sample A were replicated.

CHAPTER FOUR

RESULTS

Preliminary Analyses

All independent and dependent variables were tested for skewness. Results indicated that across respondents, reports of community support, family conflict, family cohesion, social competence, social skills, peer support (at Time 2) and heath-related quality of life (at Time 1 and Time 2) were not highly skewed for either sample (Skewness values = 0.85 to -0.84 Sample A and 1.68 to -1.41 in Sample B). Thus, it was not necessary to perform variable transformations prior to analyses.

Preliminary analyses included an examination of the degree of relationship across reports for variables in which there were multiple responders. These correlational analyses were used to determine whether reports could be combined to reduce the number of longitudinal analyses. Mother and father reports of community support, family conflict, family cohesion, social competence, and social skills were significantly correlated at Time 2 for both samples (r's = 0.31 - 0.63, M = 0.42, p's < .05). In addition, mother and father reports of social skills were significantly correlated in Sample A and B (r's = 0.56 and 0.39, respectively, p's < .05). Both mother and father report of social skills were also significantly correlated with teacher report of social skills in Sample A (r's = 0.21 and 0.23, respectively, p's < .05), but mother report of social skills was not significantly correlated with teacher report in Sample B, $r = 0.05$, $p > .05$. Thus, mother and father reports of community support, family conflict, family cohesion, and social competence were combined for both samples. Further, a social skills composite score of all three reporters was created for Sample A, but teacher report was not combined with parent report of social skills in Sample B. Finally, mother and father reports of HRQOL were significantly correlated at both Time 1 and Time 2 in Sample A (*r*'s = 0.54 and 0.62, *p*'s < .05 respectively*)*. Thus, mother and father report of HRQOL at Time 1 and Time 2 were combined for Sample A; this was not necessary for Sample B as only youth report of HRQOL was collected.

Descriptive Information on Health-Related Quality of Life

Hypothesis 1. Descriptive statistics on the PedsQL in Sample A are summarized in Table 2. As hypothesized, there were moderate levels of agreement between youth and caregiver reports on HRQOL in Sample A. Specifically, cross-informant correlations for the PedsQL psychosocial total score were 0.24 and 0.42 for Time 1 and Time 2, respectively; physical functioning cross-informant correlations were 0.31 and 0.41, respectively; emotional functioning cross-informant correlations were .13 and .40, respectively; and school functioning cross-informant correlations were 0.34 and 0.39, respectively. The only nonsignificant correlation was parent-proxy and child-reported emotional functioning at Time 1 ($r = .13$ $p > .05$). Further, there were no significant differences between youth and parent report of Time 1 psychosocial HRQOL [$t(120) = 0.98$, $p > .05$], and Time 1 and Time 2 emotional functioning [$t(120) = 1.10$, $p > .05$; $t(102) = 0.76$, $p > .05$, respectively], and school functioning [$t(120) = 0.53$, $p > .05$; $t(102) = 0.76$, $p > .05$]. However, there were significant differences between youth and parent report of Time 2 psychosocial HRQOL, [$t(102) = 2.15$, $p < .05$], and Time 1 and

Table 2. Scale Descriptives, Cross-Informant Correlations, and Differences on PedsQL Generic Score: Sample A

		Child	Caregiver	Cross-informant	Difference
Variable	*N* (Child/caregiver)	*M* (*SD*)	*M* (*SD*)	*r*	*t*
Total psychosocial score					
Time 1	129 / 128	62.53 (16.81)	60.89 (12.70)	.24*	0.98
Time 2	106 / 105	68.10 (15.70)	64.42 (13.60)	.42**	2.15*
Physical functioning					
Time 1	129 / 128	58.52 (21.02)	52.83 (20.12)	.31**	2.72*
Time 2	106 / 105	61.06 (20.60)	51.96 (20.07)	.41**	4.20**
Emotional functioning					
Time 1	129 / 128	64.22 (20.72)	66.15 (14.86)	.18*	1.10
Time 2	106 / 105	69.53 (19.13)	70.48 (15.49)	.30**	0.76
Social functioning					
Time 1	129 / 128	66.47 (22.16)	58.89 (15.52)	.13	3.48**
Time 2	106 / 105	72.69 (19.20)	62.62 (18.86)	.40**	4.89**
School functioning					
Time 1	129 / 128	56.90 (22.13)	57.38 (17.56)	.34**	0.53
Time 2	106 / 105	62.08 (20.56)	60.31 (16.81)	.39**	0.76

$^{*}p < .05$. $^{**}p < .01$.

Time 2 physical HRQOL [*t*(120) = 4.20, p < .01; *t*(102) = 2.15, p < .05, respectively] and social HRQOL [*t*(120) = 3.48, p < .01; *t*(102) = 4.89, p < .01, respectively]. More specifically, parent proxy scores of HRQOL were significantly lower than youth report of psychosocial HRQOL at Time 1 and physical and social HRQOL for both time points (see Table 2), such that parents reported youth to have significantly worse HRQOL compared to youth report. Thus, hypothesis 1 was supported such that there was moderate agreement between child-self report and caregiver proxy report of HRQOL In general, it appears that parents rated similar or significantly lower HRQOL compared to youth self-report.

Hypothesis 2. It was also expected that youth with SB in Sample A would display impaired HRQOL across all domains (i.e., physical, emotional, social, school, and total HRQOL) compared to mean scores of healthy populations of youth, and would display similar to lower mean scores compared to other illness groups. According to youth-report at Time 1 and Time 2 of the PedsQL, youth with SB reported significantly lower total psychosocial HRQOL, as well as physical, emotional, social, and school HRQOL compared to healthy as well as chronically ill samples as reported in the study by Varni and colleagues (2001; *p*'s < .001, see Table 3). Similar findings were found for parent-report at Time 1 and Time 2 of the PedsQL, such that parent-reported quality of life was significantly lower than total psychosocial HRQOL, as well as physical, emotional, social and school HRQOL compared to healthy and chronically ill samples as reported in Varni and colleagues (2001, *p*'s < .001, see Table 4). Thus, hypothesis 2 was

Table 3. One-Sample *t* Tests Comparing Time 1 and 2 HRQOL: Spina Bifida Versus Chronically Ill and Healthy Populations: Child Report

Scale	*N* (T1/T2)	*M* (T1/T2)	*SD* (T1/T2)	T (T1/T2)
Psychosocial total				
Spina bifida	129 / 106	62.53 / 68.10	16.81 / 15.70	
Chronically ill	367	77.10	15.84	−9.84** / −5.90**
Healthy	399	82.38	15.51	−13.40** / −9.37**
Physical				
Spina bifida	129 / 106	58.52 / 61.06	21.02 / 20.60	
vs. Chronically ill	366	77.36	20.36	−10.17** / −8.16**
vs. healthy	400	84.41	17.26	−13.98** / −11.69**
Emotional				
Spina bifida	129 / 106	64.22 / 69.53	20.72 / 19.13	
vs. Chronically ill	366	76.40	21.48	−6.67** / −3.70**
vs. healthy	400	80.86	19.64	−9.12** / −6.10**
Social				
Spina bifida	129 / 106	66.47 / 72.69	22.16 / 19.20	
vs. Chronically ill	367	81.60	20.24	−7.75** / −4.78**
vs. healthy	399	87.42	17.18	−10.74** / −7.90**
School				
Spina bifida	129 / 106	56.90 / 62.08	22.13 / 20.56	
vs. Chronically ill	362	73.43	19.57	−7.30** / −5.69**
vs. healthy	386	78.63	20.53	−9.97** / −8.29**

**$p < .00$.

Table 4. One-Sample *t* Tests Comparing Time 1 and 2 HRQOL: Spina Bifida Versus Chronically Ill and Healthy Populations: Parent Report

Scale	*N* (T1/T2)	*M* (T1/T2)	*SD* (T1/T2)	T (T1/T2)
Psychosocial total				
Spina bifida	128 / 105	60.89 / 64.42	12.70 / 13.60	
Chronically ill	367	77.10	15.84	−14.48**/ −9.55**
Healthy	399	82.38	15.51	−19.20**/ −13.50**
Physical				
Spina bifida	128 / 105	52.83 / 51.96	20.12 / 20.07	
vs. Chronically ill	366	77.36	20.36	−13.79** / −8.16**
vs. Healthy	400	84.41	17.26	−17.75** / −11.69**
Emotional				
Spina bifida	128 / 105	66.15 / 70.48	14.86 / 15.49	
vs. Chronically ill	366	76.40	21.48	−7.80**/ −3.92*
vs. Healthy	400	80.86	19.64	−11.19**/ −6.87**
Social				
Spina bifida	128 / 105	58.89 / 62.62	15.52 / 18.86	
vs. Chronically ill	367	81.60	20.24	−16.55**/ −10.31**
vs. Healthy	399	87.42	17.18	−20.79**/ −13.47**
School				
Spina bifida	128 / 105	57.38 / 60.31	17.56 / 16.81	
vs. Chronically ill	362	73.43	19.57	−10.33** / −8.00**
vs. Healthy	386	78.63	20.53	−13.68** / −11.17**

**$p < .001$.

supported, such that youth with SB have significantly impaired HRQOL compared to both healthy and chronic illness groups.

Further, according to youth-report of Time 1 HRQOL, mean scores were at least one SD lower than those found in healthy youth in Varni et al. (2001) on HRQOL scores, with the exception of emotional HRQOL. Of particular note, children were 1.31 SDs below the healthy population mean on total psychosocial HRQOL, 1.50 SDs below the population mean on physical HRQOL, 1.22 SDs below the population mean on social functioning, an 1.06 SDs below the population mean on school functioning. Youth report of emotional HRQOL was only 0.85 SDs below the sample mean as reported by Varni and colleagues (2001).

Caregiver report of HRQOL at Time 1 yielded slightly more robust findings for total, physical and social functioning; results indicated that youth with SB were 2.01 SDs below the healthy population mean on total psychosocial HRQOL, 2.23 SDs below the population mean on physical HRQOL, 2.30 SDs below the population mean on social functioning, and 1.60 SDs below the population mean on school functioning. Similar to findings for youth-report at Time 1, parent-proxy on emotional HRQOL was 0.94 SD below the mean healthy population score.

Time 2 comparison analyses yielded different findings for youth at Time 2. Youth and parent-proxy report reported the following results: child and parent reports were 0.91 and 1.73 SDs below the population mean on total psychosocial HRQOL, respectively; 1.35 and 1.73 SDs below the population mean on physical HRQOL, respectively; 0.58 and 2.29 SDs below the population mean on emotional HRQOL, respectively; 0.86 and

0.63 SDs below the population mean on social HRQOL, respectively; and 0.81 and 1.43 SDs below population mean on school HRQOL, respectively. Thus, data at Time 2 indicated that findings were less robust. One exception was parent-report of emotional HRQOL, which was 1.35 SDs higher compared to parent report at Time 1. Further, this data provide evidence that physical HRQOL was a consistently poor area of functioning in this population across informants and at both time points.

Hypothesis 3. Repeated-measures ANOVAS tested the hypothesis that total psychosocial HRQOL would decrease over time in Sample A (*hypothesis 3*). This Hypothesis was not supported. In fact, results indicated that there was a significant increase in youth-reported psychosocial HRQOL from Time 1 to Time 2 for Sample A, $F(1, 99) = 9.46$, $p < .01$. Results also indicated that there was a marginally significant increase in parent-reported psychosocial HRQOL from Time 1 to Time 2 in this same sample, $F(1, 101) = 3.11$, $p = .08$.

Longitudinal Analyses of Health-Related Quality of Life in Sample A

Hypotheses 4-6. In Sample A, it was proposed that all social-environmental factors measured when youth were ages 8-15 would prospectively predict HRQOL (in youth ages 10-17) across both informants (e.g., child and parent; *hypothesis 4*). It was also expected that social-environmental predictors of HRQOL would be significant above and beyond all demographic and illness-related variables (*hypothesis 5)*. Finally, it was expected that social adjustment variables (e.g., social problems, social acceptance, and peer support) would be the strongest prospective predictors of HRQOL in this sample (*hypothesis 6*).

First, two-tailed Pearson correlations were calculated between all covariates, independent variables, and measures of HRQOL across informants (see Table 5). Predictors that were not significantly correlated with the outcome were not entered into the regression model for that outcome. Only two variables were significantly correlated with Time 2 youth-reported psychosocial HRQOL in Sample A: child pain intensity and parent-reported social competence. In other words, child pain intensity when youth were ages 8-15 (Time 1) was negatively associated with child report of HRQOL when youth were ages 10-17 (Time 2), such that higher pain intensity at Time 1 was associated with lower HRQOL at Time 2, $r = -.29$, $p < .05$. In addition, parent-reported social competence at Time 1 was positively associated with child-reported HRQOL at Time 2, such that lower social competence was associated with reduced HRQOL, $r = .31$, $p < .05$. The following variables were not significantly correlated with Time 2 youth-reported psychosocial HRQOL in Sample A: (a) covariates: child age, socioeconomic status, gender, child IQ; (b) social-environmental predictors: parent-reported community support, family stress, family conflict, family cohesion, social skills, child-reported peer social support, as well as observed family conflict and cohesion (*p*'s > .05; see Table 5).

Only two social-environmental variables were significantly correlated with Time 2 parent-reported psychosocial HRQOL in Sample A: parent-reported community support and the composite score (i.e., mother, father, and teacher) of social skills. In other words, higher levels of community support ($r = .23$, $p < .05$) and better social skills ($r = .21$, $p < .05$) were associated with parent-proxy report of HRQOL. The following variables were not significantly correlated with Time 2 parent-reported psychosocial

Table 5. Correlation Matrix for Socio-Environmental Predictors of Time 2 Health-Related Quality of Life: Sample A

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1.Time 2 QOL- Child	—	.41*	−.02	−.01	−.02	.01	−.16	−.29*	.08	.09	−.01	−.11	−.07	.03	.31*	.17	−.16
2. Time 2 QOL- Parent		—	−.01	.08	−.12	−.02	−.18	−.04	.23*	−.05	−.14	−.09	.07	.04	.11	.21*	−.05
3. Child age			—	−.08	−.08	−.23*	.22	.05	−.01	−.09	−.01	−.06	.02	−.14	−.08	.08	.12
4. SES				—	−.10	.47*	−.14	−.11	.12	.18*	.05	−.18*	.08	.34*	.33*	.09	−.06
5. Gender					—	.05	−.06	−.10	−.11	.02	.02	.03	−.02	.00	−.05	.08	.20*
6. Child IQ						—	−.31*	−.07	−.04	.15	.10	−.15	.05	.33*	.44	.23*	.07
7. Illness severity							—	.30*	.05	−.03	−.03	−.12	−.03	.00	−.19*	−.06	.06
8. Child pain intensity								—	.05	−.13	−.15	.02	.43	−.08	−.22*	−.04	.10
9. Community support									—	−.18*	−.16	−.11	.24	.05	.14	.17	−.01
10. Family Stress										—	.32*	.13	−.30*	.04	.10	.01	−.08
11. Family Conflict-Qx											—	.10	−.60*	−.08	−.06	−.32*	−.09
12. Family Conflict-Mac												—	.09	−.47*	−.17	−.21*	−.09
13. Family Cohesion-Qx													—	.15	.03	.27	.01
14.Family Cohesion-Mac														—	.31*	.36*	.01
15. Social Competence															—	.41*	.12
16. Social Skills																—	.11
17. Peer Social Support																	—

*$p < .05$.

HRQOL in Sample A: (a) covariates: child age, socioeconomic status, gender, child IQ, illness severity, child pain intensity; (b) social-environmental predictors: parent-reported family stress, conflict, cohesion, social skills, child-reported peer social support, as well as observed family conflict and cohesion. Thus, results were similar to correlational analyses of Time 2 youth-reported HRQOL (see Table 5).

Subsequently, longitudinal hierarchical regression analyses were conducted to determine whether socio-environmental variables were related to subsequent change in HRQOL over time. Separate regression analyses were conducted for child-reported HRQOL and parent proxy-report of HRQOL. To control for previous quality of life, HRQOL at Time 1 was entered in the first step. Time 1 covariates obtained that were moderately correlated with Time 2 HRQOL (i.e., $p = .10$ or lower) were entered in the second step. Finally, socio-environmental variables were entered in the remaining steps. For the first hierarchical regression analysis predicting child-report of HRQOL at Time 2, Time 1 HRQOL was entered in the first step, illness severity ($r = -.16$, $p = .10$) and child pain intensity were entered in the second step, and parent-report of social competence was entered in the last step.

Hypotheses 4-6 were partially supported according to this analysis. Although several of the proposed covariates and social-environmental predictors were not associated with Time 2 HRQOL, results indicated that social competence predicted child report of HRQOL over time in Sample A, above and beyond illness related variables, $\beta = 0.23$, $p < .05$. However, illness severity and child pain intensity did not significantly predict HRQOL, β*'s* = -0.04 and -0.08, respectively, *p's* > .05. Social competence accounted for 4.0% of the variance in child-reported HRQOL at Time 2 above baseline levels. The final model accounted for 28% of variance in youth-reported HRQOL at Time 2, $R^2 = .28$, adjusted $R^2 = .24$, $F(4, 80) = 7.77$, $p < .05$. However, longitudinal analyses of parent-reported quality of life yielded different results, such that none of the covariates or socio-environmental factors predicted HRQOL in youth with SB (see Table 6).

Longitudinal Analyses of Health-Related Quality of Life in Sample B

Hypothesis 7. Finally, it was expected that hypotheses 4-6 delineated for Sample A regarding socio-environmental predictors of HRQOL would be replicated in Sample B. Again, two-tailed Pearson correlations were calculated between all covariates, independent variables, and measures of HRQOL across informants in this sample. Only two variables were significantly correlated with Time 2 youth-reported psychosocial HRQOL in Sample A: socioeconomic status and teacher-report of youths' social skills. Socio-economic status was positively associated with child report of HRQOL at Time 2 (youth ages 16-17), such that higher SES was associated with better HRQOL at Time 2, $r = .40$, $p < .05$. In addition, teacher-report of social skills was positively correlated with HRQOL at Time 2, such that better social skills was associated with better HRQOL, $r = .31$, $p < .05$. The following covariates and socio-environmental variables were not significantly associated with Time 2 youth-reported HRQOL: (a) covariates: child age, gender, IQ, illness severity, pain frequency (b) social-environmental variables: parent-reported community support, family stress, family conflict, family cohesion, social competence and social skills, child-reported peer social support, and observed family conflict and cohesion (see Table 7).

Table 6. Hierarchical Regressions: Time 1 Socio-Environmental Predictors of Time 2 Psychosocial HRQOL

Quality of life outcome	Covariates and predictors	*b*	*SE b*	β	*p*
Sample A					
Time 2 HRQOL- Child	Time 1 PedsQL- Child	0.44	0.10	0.46**	0.00
	Illness severity	−0.35	1.03	−0.04	0.73
	Child pain intensity	−0.86	0.50	−0.18	0.08
	T1 Social Competence (M)	0.40	0.19	0.23*	0.03
Time 2 HRQOL- Parent	Time 1 PedsQL- Parent	0.74	0.09	0.64**	0.00
	Gender	−4.17	2.20	−0.15	0.06
	Illness Severity	−0.42	0.77	−0.05	0.59
	Community Support (MF)	1.47	1.44	0.08	0.31
	Family Stress (MF)	−0.20	0.15	−0.10	0.20
	Social Skills (MF)	7.01	4.76	0.12	0.14
Sample B					
Time 2 HRQOL- Child	Time 1 HRQOL-SB – Child	0.05	0.06	0.13	0.42
	Socioeconomic Status	0.02	0.01	0.42*	0.01
	Social Skills (TR)	0.51	0.22	0.33*	0.02

Note. MF = mother and father report; TR = teacher report.

**p* < .05; ***p* < .01.

Table 7. Correlation Matrix for Socio-Environmental Variables and Time 2 Health-Related Quality of Life: Sample B

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Time 2 QOL- Child	—	−.02	.40*	.02	−.12	−.05	.02	.07	−.02	.20	.10	−.24	.02	.20	.21	.31*	.01
2. Child age		—	−.10	−.09	−.17	−.05	−.24	.11	.10	.03	.19	−.07	−.20	−.06	.01	−.18	−.07
3. SES			—	.04	.29*	.02	−.15	−.10	.07	−.17	−.16	.22	.33*	.28*	.46*	.06	.24
4. Gender				—	−.09	.02	.06	.12	.13	−.09	−.19	.01	.09	.07	.06	−.19	.29*
5. Child IQ					—	−.19	−.04	−.22	.26*	−.45*	.12	.23	.26	.37*	.23	.16	.37*
6. Illness severity						—	−.05	.45*	−.03	−.12	−.10	.10	−.10	−.13	−.06	−.18	−.20
7. Child pain frequency							—	−.05	−.15	.03	−.08	.13	.05	−.03	−.20	.03	.01
8. Community support								—	−.01	.10	−.10	.20	−.20	−.05	−.17	−.08	.07
9. Family Stress									—	.15	.12	−.32*	.00	.08	−.08	−.15	.12
10. Family Conflict -Qx										—	.42*	−.42*	−.48	−.25	−.24	.12	−.36*
11. Family Conflict-Mac											—	.04	−.49*	−.13	−.28*	.04	−.10
12. Family Cohesion-Qx												—	−.16	−2.6	−.07	−.03	.16
13. Family Cohesion-Mac													—	−.13	.27*	.30*	−.11
14. Social Competence														—	.63*	.26	.18
15. Social Skills-MF															—	.18	.16
16. Social Skills-T																—	.02
17. Peer Social Support																	—

Note. Child report. Combined mother and father report.

*$p < .05$.

Again, a longitudinal hierarchical regression analysis was conducted to determine whether teacher-report of social skills predicted subsequent change in HRQOL over time. Analysis for Sample B was similar to that which was conducted for Sample A: Time 1 HRQOL was entered in the first step, SES was entered in the second step, and teacher-report of social skills was entered in the last step. Results indicated that socioeconomic predicted HRQOL at Time 2 in this sample, $\beta = 0.33$, $p < .05$. Also, similar to results found in Sample A, analyses in Sample B indicated that social skills predicted child-report of HRQOL over time, above and beyond socioeconomic status, $\beta = 0.33$, $p < .05$. Socioeconomic status explained 15.1% of the variance in Time 2 HRQOL above baseline levels; teacher-reported social skills accounted for 10.7% of the variance in Time 2 HRQOL above baseline levels. The final model accounted for 27% of variance in youth-reported HRQOL at Time 2, $R^2 = .27$, adjusted $R^2 = .22$, $F(3, 38) = 4.78$, $p < .05$. Thus, *hypothesis 7* was partially supported, as variables within the social domain (see Figure 1) were found to be the most important prospective predictors of child-reported HRQOL across samples (i.e., social competence in Sample A; social skills in Sample B; see Table 6).

CHAPTER FIVE

DISCUSSION

The present study examined descriptive data as well as prospective predictors of overall psychosocial HRQOL in youth with SB. Consistent with previous research on several pediatric populations, such as cancer, sickle cell disease, obese and chronic pain patients (Varni, Limbers, & Burwinkle, 2007; Palermo, Schwartz, Drotar, & McGowan, 2002; Schwimmer, Burwinkle, Varni, 2003; Modi & Quittner, 2003; Hunfeld et al., 2001), results indicated that children and adolescents with SB are at-risk for poor HRQOL. At both time points, scores on HRQOL across all domains (i.e., physical, emotional, social, and school HRQOL) were significantly lower than those reported by Varni and colleages (2001) in populations of children with other chronic health conditions, and scores were also well below the normative scores for healthy children.

Several scholars have proposed that patient self-report should be considered the standard for measuring perceptions of HRQOL (Riley, 2004; Sawin & Bellin, 2010). These researchers assert that the adolescent should serve as the primary informant, because HRQOL includes subjective appraisal of life contexts, events, and experiences. When the youth is unable to report on HRQOL due to physical or cognitive limitations, seeking parent-proxy report has been supported (Haas, 1999). Although moderate cross-informant correlations of child and parent HRQOL were found in the current study, the mild to moderate cognitive limitations associated with this condition (Fletcher & Brei, 2010) may highlight the need to gather data from both child and parent perspectives.

Thus, due to potential differences in parental observations of functioning versus the child's reliance on internal cues, as well as the cognitive impairments associated with SB, future studies should follow the guidance provided by several researchers (e.g., Modi & Quittner, 2003; Palermo et al., 2008) in including both youth and caregiver proxy report of HRQOL.

Moreover, significant discrepancies were found between youth and caregiver-proxy report of HRQOL. Specifically, child and parents reported significantly different social and physical HRQOL at Time 1 and 2, such that caregivers indicated their child had lower HRQOL compared to youth self-report. There may be several explanations for this finding. First, caregivers may have relied solely on behavioral and visual cues to assess their child's functioning (Varni, Seid, & Kurtin, 2001), while the child may have relied on internal emotional cues to assess of their level of functioning relative to other youth (Gold, Mahrer, Yee & Palermo, 2009). Second, the cognitive limitations associated with spina bifida may result in youths' lowered awareness of the physical and social consequences of their illness, and again caregivers may have a more complete understanding of the functioning of their child as it is understood by behavioral observation. Finally, youth with SB may have adapted to and accepted their chronic condition while their caregivers may have not (Berrin, Malcarne, Varni, et al). Overall, research on cross-informant discrepancies is inconsistent. Some research has indicated that children report more physical complaints and problems with motor functioning (Theunissen et al., 1998) as well as greater emotional distress (Modi & Quittner, 2003; Verrips, Vogels, den Ouden, Paneth, & Verloove-Vanhorick, 2000). However, in line with the current study, other studies have indicated that youth report better HRQOL compared to parent-proxy report (e.g., cerebal palsy, cystic fibrosis & chronic pain; Berrin, Malcarne, Varni, et al., Britto, Kotagal, & Chenier et al., Gold, Mahrer, Yee & Palermo, 2009).

Although contrary to previous research and study hypotheses, the current study's results indicated that youth-report of HRQOL significantly increased over time, while caregiver-report of HRQOL remained stable. Such findings may be explained by several factors. First, HRQOL data were based on group means, yet individual trajectories may vary; some patients may improve while others decline over time. Individual HRQOL can yield patient-specific and clinically-relevant information for healthcare providers. Second, this finding may point to a resiliency factor in families of youth with SB as indicated in previous research (Holmbeck et al., 2002), such that youth with SB may be better able to adapt to and accept their condition compared to other illness populations. Despite this resiliency, it should be noted that HRQOL was significantly lower than population means for chronically ill and healthy youth at both time points. Thus, although HRQOL may increase over time, youth with SB still had relatively low HRQOL scores across time. The stability in parent report of HRQOL can be supported by some longitudinal studies that have also found this trend in pediatric illness groups. For example, a study of parents of 124 children with newly diagnosed epilepsy found that HRQOL remained relatively stable across most scales, and only detected a statistical trend for improvements in emotional functioning over time (Modi, Ingerski, Rausch, & Glauser). Finally, as some data suggest that young adults with SB may be at a heightened risk for psychological distress (Bellin et al., 2009), it will be important for studies to investigate trajectories of HRQOL in this population from childhood to adulthood. In particular, future research should determine whether trajectories of HRQOL continue to increase, or have a bell-shaped curve due to the difficulties with an individual securing employment and gaining independence as well as the continued deterioration of their condition.

To date, this study is the first to provide multi-informant, multi-method longitudinal data on the impact of social-environmental factors on HRQOL in two independent samples of youth with SB. Results of this study indicated that few social-environmental factors predicted decreased future HRQOL. Specifically, only one illness variable and one social-environmental variable were significantly associated with youth-reported HRQOL at Time 2: Pain intensity and parent-reported social competence. In other words, two-tailed Pearson correlations indicated that higher child pain intensity when youth were ages 8-15 (Time 1) was associated with lower HRQOL when youth were ages 10-17 (Time 2). However, the following social-environmental factors were associated with decreased HRQOL: lower parent-reported social competence, lower parent-reported community support, and a composite score (i.e., teacher, father, and teacher) of social skills at Time 1. No other demographic, illness-related, or social-environmental factors were related to Time 2 youth-report of HRQOL in Sample A. Similar correlational results were found in Sample B, such that only two variables were significantly associated with Time 2 youth-reported HRQOL. In particular, decreased SES and youth social skills (as reported by teachers) were related to lower HRQOL.

Finally, hierarchical linear regression analyses determined that decreased social competence (in Sample A) and social skills (in Sample B) predicted reduced HRQOL. Although study findings did not support the expectation that variables from the community and family environment domains would significantly predict HRQOL in both samples, the hypothesis that variables within the social adjustment domain of the study model (see Figure 1) would have the greatest impact on future youth HRQOL was supported.

Few studies have investigated the impact of poor social adjustment in youth with SB, thus poor social adjustment and acceptance by peers in this population should receive increased attention. Historically, research on SB has focused on physical and neuropsychological domains, with less attention paid to psychological and social variables (Devine & Holmbeck, 2010). Researchers have found that youth with SB are at risk for having fewer friendships, social immaturity, and may have poor quality friendships (Blum, Resnick, Nelson, & St. Germaine, 1991; Ellerton, Stewart, Ritchie & Hirth, 1996; Devine, Holmbeck, Gayes, & Purnell, 2012). Showcasing the importance of the social domain in this population, a camp-based intervention originally designed to increase independence in this population incorporated additional modules aimed to increase social-related goals, such as greeting others appropriately, contributing to conversation, speaking clearly and audibly, and asserting self appropriately (Holbein et al., in press). Results from this intervention of 119 individuals aged 7 to 41 with SB indicated improvement in campers' independence, social goal attainment, and social functioning (Holbein et al., in press). To my knowledge, no interventions in youth and young adults with SB have incorporated measures of HRQOL as an outcome measure, which may provide critical information related to youths' overall improvement. Indeed, researchers have recently begun to recognize the important role of HRQOL in evaluating the effectiveness of medical and psychosocial interventions (Sawyer et al., 2006; Seid, Varni, Segall, & Kurtin, 2004; Varni, Limbers, & Burwinkle, 2007). Further, future studies may benefit from investigating the impact of several aspects of social competence in dyadic and general friendships (e.g. social adjustment, social performance, social skills; Devine, Holmbeck, Gayes, Purnell et al., 2012) on HRQOL, using multiple methods (e.g. observational coding of peer intervention). Such research may provide important information for interventions in this population that aim to improve youths' social competence and HRQOL.

Given the considerable influence of the family on psychosocial adjustment in youth with chronic illnesses, the finding that none of the family environment variables predicted HRQOL was surprising. Despite methodological limitations, some studies have found associations between family and parent variables in youth with SB (e.g., parental hope, parental overprotection, maternal psychological distress; Sawin et al., 2002; Abad, 2007 unpublished manuscript) as well as other pediatric illness groups (e.g. diabetes, asthma, obesity, organ transplant recipients; Pereira, Berg-Cross, Almeida, & Machado, 2008; Sawyer, Spurrier, Whaites, Kennedy, Martin, & Baghurst, 2001; Janicke et al., 2007; Devine et al., 2011). Regardless, it is possible that individual psychological and behavioral variables may have more predictive utility than family and contextual domains. For one, future studies could utilize measures of SB-related stress and family conflict, which may have more important implications on a youths' HRQOL compared to the broad measures of family environment used in the current study. For example, a longitudinal study of 124 children ages 2-18 with newly diagnosed Type 1 diabetes measured both general and disease-specific parent-child behaviors and HRQOL, and found that diabetes-specific family conflict and negative diabetes-specific family communication were associated with lower HRQOL (Weissberg-Benchell et al., 2009).

In addition, behavioral factors such as poor sleep quality and insomnia have been implicated in impaired HRQOL in patients with chronic illnesses (Katz & McHorney, 2002; Palermo & Kiska, 2005). In children and adolescents with SB, studies have revealed the presence of insomnia symptoms (e.g., difficulty initiating and maintaining sleep; Quine, 1991) and central and obstructive sleep disordered breathing (SDB; 16-20%; Waters, Forbes, Morielli, et al., 1997). High rates of SDB and other sleep disturbances in this population may be due to central nervous system malformations and pulmonary function abnormalities (Waters, Forbes, Morielli, et al., 1997). Thus, examination of associations between sleep disturbances and HRQOL may be an important consideration for future research.

Although HRQOL represents an important area of study, it is a complex construct. The measurement of HRQOL involves several challenges. For one, HRQOL is a multidimensional construct. A HRQOL psychosocial total score was utilized in hierarchical analyses, which may have obscured domain differences. For example, it is possible that increased family stress and conflict may predict decreased emotional and social HRQOL in youth with SB, but may not predict role-related (i.e., school) HRQOL.

In addition, given the complex medical profiles of youth with SB, HRQOL in this population may have different predictors than those found for other pediatric populations. Every pediatric condition has a complex array of symptomatology, as well as a prognosis and course that may differentially impact a youth's HRQOL (Kazak, Rourke, & Crump, 2003). While many chronic illnesses share common features, such as family conflict, fatigue, pain and/or discomfort in the child, stigmatization by peers, and financial burden, there are also striking differences in the nature and course of every chronic illness. Some conditions are highly visible, such as SB, whereas other illnesses have no external physical manifestations except when the child becomes severely ill (e.g., epilepsy, diabetes). In addition, SB is a congenital disorder with a chronic and stable course, unlike conditions such as cancer or children with organ transplants. Thus, youth with SB may not face the increased and unpredictable stress of conditions such as cancer. Instead, youth with SB may experience a chronic type of stress due to daily struggles that a complex medical regimen, ambulation needs, and urologic difficulties require. In summary, while the social-environmental predictors used in this study were based on previous research of HRQOL in pediatric populations, the broad differences across numerous diagnoses may account for this study's unique results.

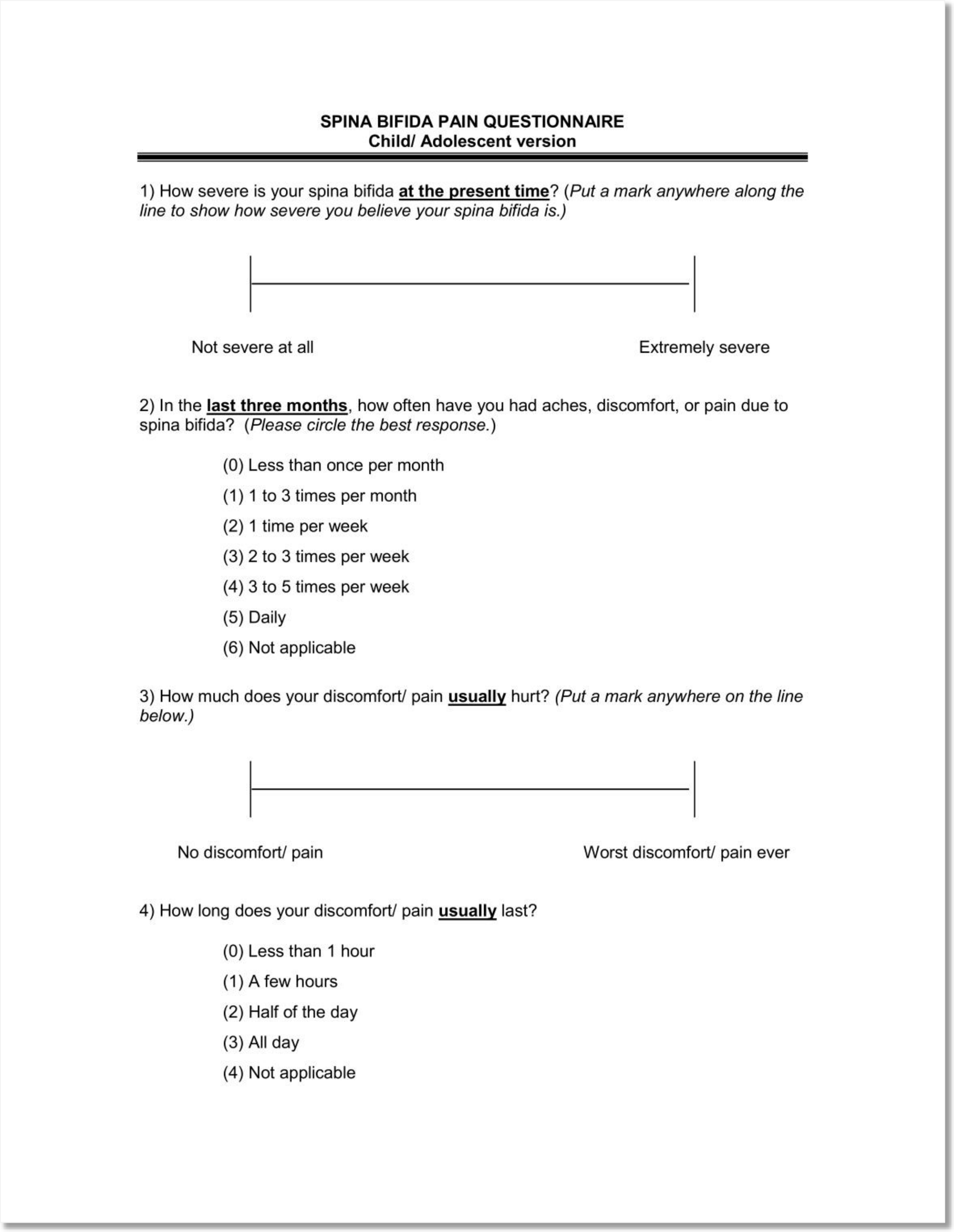
Beyond conceptual and theoretical issues influencing the modest findings of the current study, statistical factors may also account for study findings. The analyses conducted in this study were fairly conservative. First, HRQOL was controlled at earlier time points, thus eliminating some of the variance in the dependent variable. Thus, the change in HRQOL may not have been large enough to yield significant variability in the residuals that remained after controlling for previous levels of HRQOL. Analyses were also conservative given the utilization of multiple reporters in the dependent and independent measures, which addressed common method variance in findings. Specifically, mother and father reports were combined for several predictor variables as well as the main outcome variable of HRQOL.

This study represents an important step in identifying that youth with SB are at-risk for poor HRQOL, and detecting modifiable individual social characteristics that predict future HRQOL; however, several limitations should be considered. First, because there was a significant difference in Time 1 parent-reported HRQOL in Sample A, such that parent non-responders reported lower levels of HRQOL (N of non-responders = 27; $t(127) = -2.45$, $p < .05$), our results may not be representative of youth with particularly poor quality of life, as these families may have dropped out of the study. Second, Sample B was relatively small, and statistical power would be enhanced in future studies that use a larger sample size. Third, Sample A and B were not matched according to number of participants, age, ethnicity, and several other important demographic variables, which may have limited our ability to compare results between these two samples. In fact, Sample B had a relatively small sample size compared to Sample A, and was primarily composed of Caucasian participants. On the other hand, because similar findings were found across both independent samples, one may argue that the external validity of the study was expanded and results may be applicable to heterogeneous populations of youth with this condition. Fourth, the HRQOL measure used in Sample B has not been well-established in literature, compared to the psychometrically sound and frequently used measure of HRQOL used in Sample A (the PedsQL). In sum, although similar results were found in both samples, more definitive conclusions could be drawn if researchers were to compare two samples with similar demographics using the same well-established outcome measure. Although the use of the PedsQL in Sample A allowed for normed comparison data analysis on chronically ill and healthy youth populations, future studies should use a matched comparison sample to provide methodologically sound and sensitive HRQOL comparison analyses. Future research should also investigate a broader range of individual behavioral and psychosocial predictors of HRQOL, such as SB-related family conflict, SB-related stress, anxiety, coping, and sleep disturbances. Mediation models could be tested to identify temporal associations among the factors. Finally, as noted above, continuing to follow youth and measure HRQOL into adulthood may elucidate important linear and curvilinear trajectories of individual functioning.

In conclusion, the results of this study suggested that youth with SB are at-risk for poor HRQOL, and poor social adjustment at Time 1 predicted decreased HRQOL two years later across two distinct samples. Clinics should routinely examine risk factors of poor HRQOL in this population. In particular, youth with lower social competence and poor social skills may represent a subgroup that is particularly vulnerable to poor HRQOL outcomes. Interventions aimed to improve social competence may help to improve long-term HRQOL in this population. Currently, clinical and hospital settings often use ambulation status and bladder/bowel function to determine a child's HRQOL, despite the lack of evidence of the predictive utility of these variables (Sawin & Bellin, 2010; Kirpalani, et al., 2002; Sawin, Brei, Buran, & Fastenau, 2002). Clinicians could benefit from the use of standard self-administered questionnaires to assess social adjustment routinely in clinics. Further, it may be useful for interdisciplinary teams to include a psychologist or social worker to assist in identifying and treating youth with social adjustment risk factors in order to promote optimal HRQOL. Further research is required to better understand the role of social adjustment in youth with SB in order to identify strategies to reduce its impact on broader domains of functioning.

APPENDIX A

QUESTIONNAIRE MEASURES



SPINA BIFIDA PAIN QUESTIONNAIRE
Child/ Adolescent version

1) How severe is your spina bifida **at the present time**? (*Put a mark anywhere along the line to show how severe you believe your spina bifida is.)*

Not severe at all — Extremely severe

2) In the **last three months**, how often have you had aches, discomfort, or pain due to spina bifida? (*Please circle the best response.*)

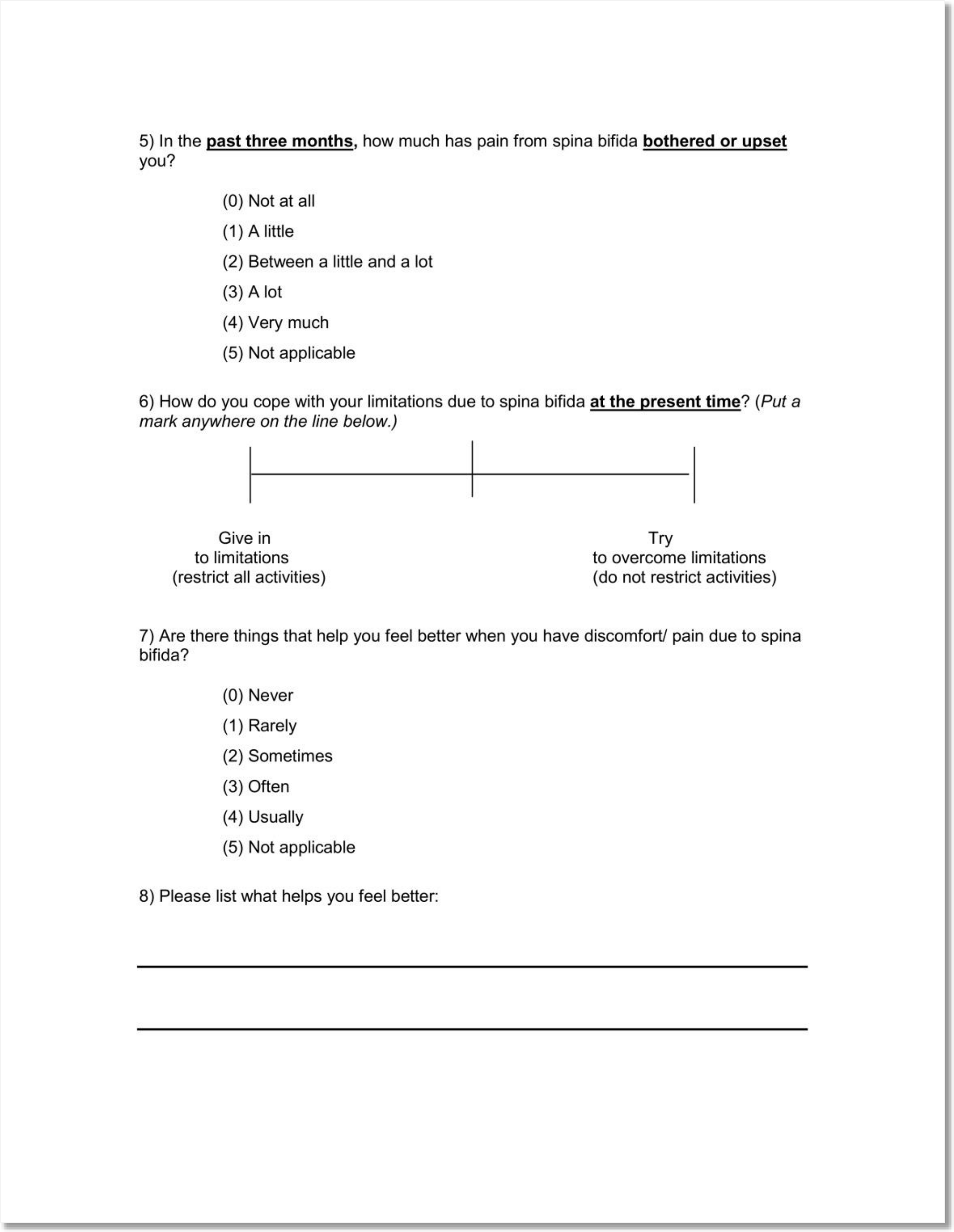
(0) Less than once per month
(1) 1 to 3 times per month
(2) 1 time per week
(3) 2 to 3 times per week
(4) 3 to 5 times per week
(5) Daily
(6) Not applicable

3) How much does your discomfort/ pain **usually** hurt? *(Put a mark anywhere on the line below.)*

No discomfort/ pain — Worst discomfort/ pain ever

4) How long does your discomfort/ pain **usually** last?

(0) Less than 1 hour
(1) A few hours
(2) Half of the day
(3) All day
(4) Not applicable



5) In the **past three months,** how much has pain from spina bifida **bothered or upset** you?

(0) Not at all
(1) A little
(2) Between a little and a lot
(3) A lot
(4) Very much
(5) Not applicable

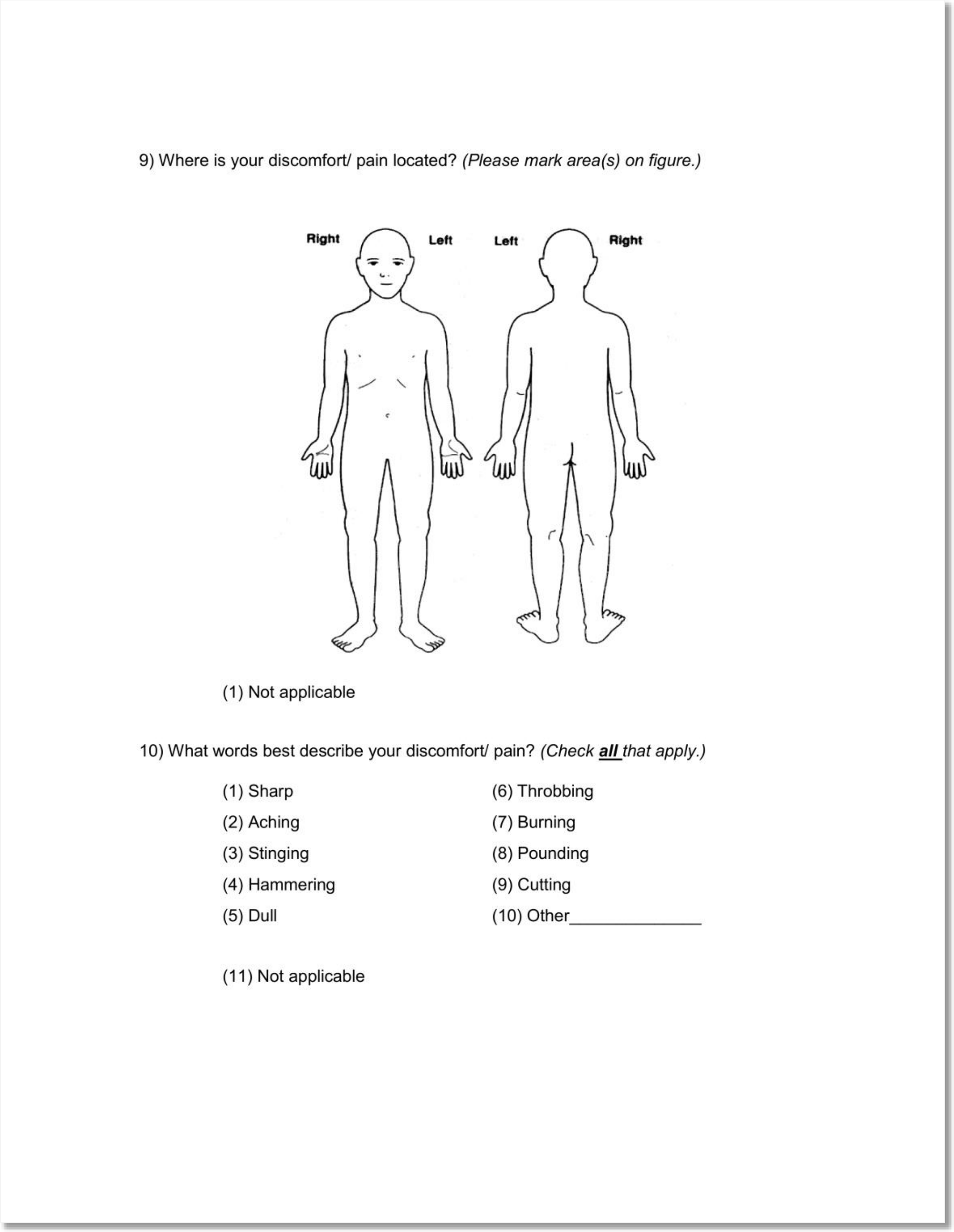
6) How do you cope with your limitations due to spina bifida **at the present time**? (*Put a mark anywhere on the line below.)*

Give in to limitations (restrict all activities)	Try to overcome limitations (do not restrict activities)

7) Are there things that help you feel better when you have discomfort/ pain due to spina bifida?

(0) Never
(1) Rarely
(2) Sometimes
(3) Often
(4) Usually
(5) Not applicable

8) Please list what helps you feel better:



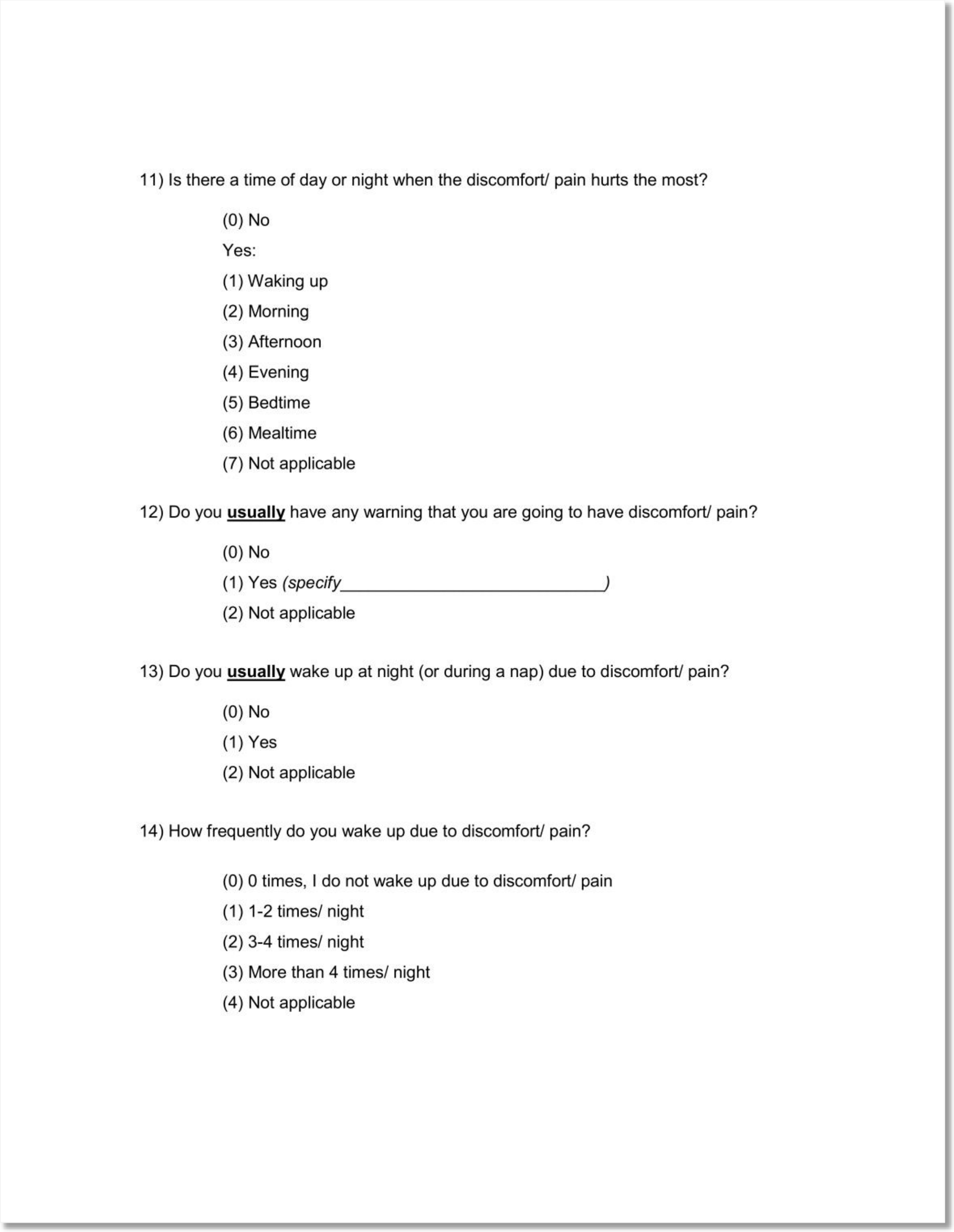
9) Where is your discomfort/ pain located? *(Please mark area(s) on figure.)*

(1) Not applicable

10) What words best describe your discomfort/ pain? *(Check* ***all*** *that apply.)*

(1) Sharp
(2) Aching
(3) Stinging
(4) Hammering
(5) Dull
(6) Throbbing
(7) Burning
(8) Pounding
(9) Cutting
(10) Other______________

(11) Not applicable



11) Is there a time of day or night when the discomfort/ pain hurts the most?

(0) No
Yes:
(1) Waking up
(2) Morning
(3) Afternoon
(4) Evening
(5) Bedtime
(6) Mealtime
(7) Not applicable

12) Do you **usually** have any warning that you are going to have discomfort/ pain?

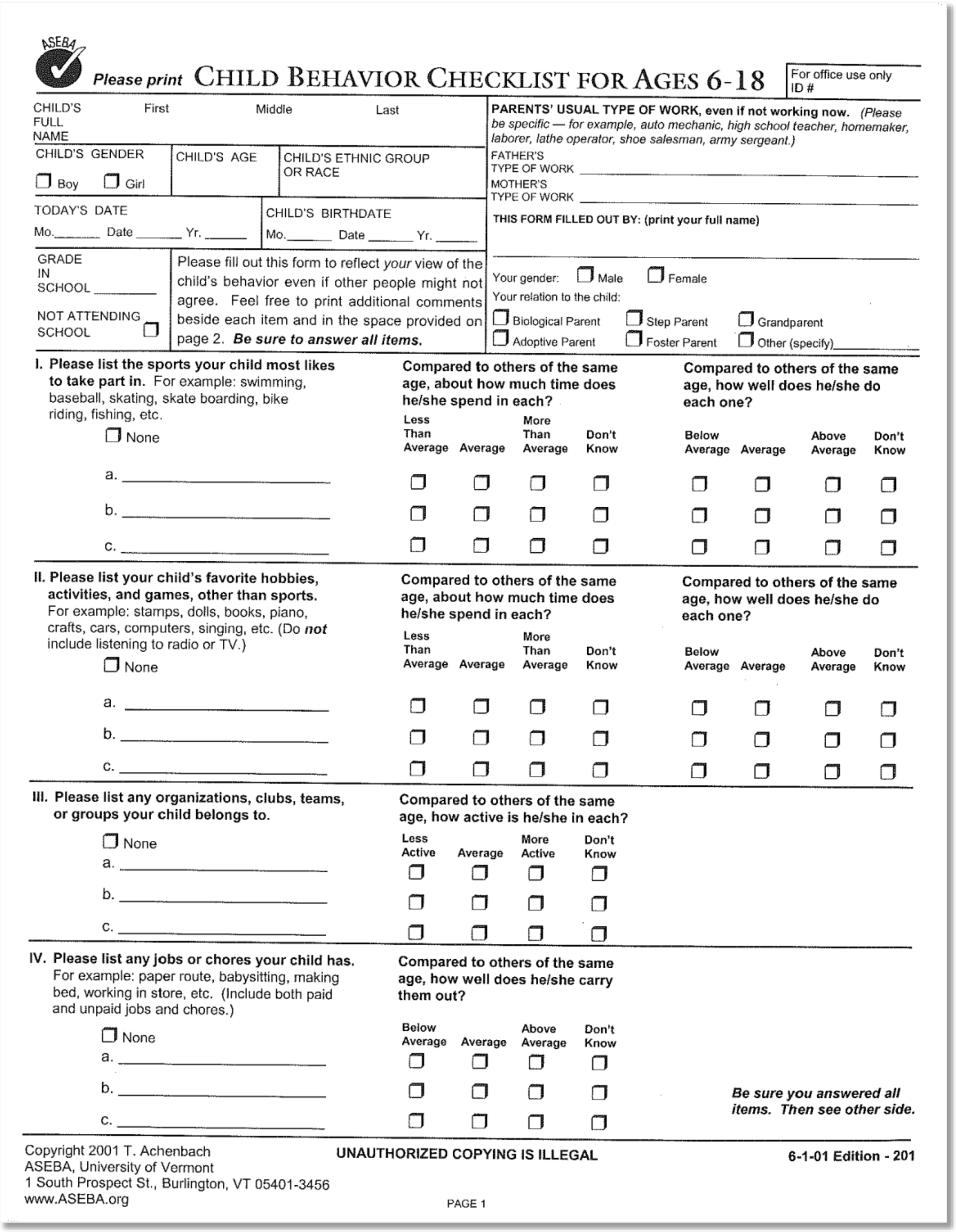
(0) No
(1) Yes *(specify___________________________)*
(2) Not applicable

13) Do you **usually** wake up at night (or during a nap) due to discomfort/ pain?

(0) No
(1) Yes
(2) Not applicable

14) How frequently do you wake up due to discomfort/ pain?

(0) 0 times, I do not wake up due to discomfort/ pain
(1) 1-2 times/ night
(2) 3-4 times/ night
(3) More than 4 times/ night
(4) Not applicable



ASEBA

Please print **CHILD BEHAVIOR CHECKLIST FOR AGES 6-18**

For office use only
ID #

CHILD'S FULL NAME First Middle Last

CHILD'S GENDER ☐ Boy ☐ Girl

CHILD'S AGE

CHILD'S ETHNIC GROUP OR RACE

TODAY'S DATE Mo.______ Date ______ Yr. ______

CHILD'S BIRTHDATE Mo.______ Date ______ Yr. ______

GRADE IN SCHOOL ________

NOT ATTENDING SCHOOL ☐

Please fill out this form to reflect *your* view of the child's behavior even if other people might not agree. Feel free to print additional comments beside each item and in the space provided on page 2. ***Be sure to answer all items.***

PARENTS' USUAL TYPE OF WORK, even if not working now. *(Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.)*

FATHER'S TYPE OF WORK ____________________

MOTHER'S TYPE OF WORK ____________________

THIS FORM FILLED OUT BY: (print your full name)

____

Your gender: ☐ Male ☐ Female

Your relation to the child:

☐ Biological Parent ☐ Step Parent ☐ Grandparent

☐ Adoptive Parent ☐ Foster Parent ☐ Other (specify)__________

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				**Compared to others of the same age, how well does he/she do each one?**			
	Less Than Average	**Average**	**More Than Average**	**Don't Know**	**Below Average**	**Average**	**Above Average**	**Don't Know**
a. ____________	☐	☐	☐	☐	☐	☐	☐	☐
b. ____________	☐	☐	☐	☐	☐	☐	☐	☐
c. ____________	☐	☐	☐	☐	☐	☐	☐	☐

II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, cars, computers, singing, etc. (Do ***not*** include listening to radio or TV.)

☐ None

	Compared to others of the same age, about how much time does he/she spend in each?				**Compared to others of the same age, how well does he/she do each one?**			
	Less Than Average	**Average**	**More Than Average**	**Don't Know**	**Below Average**	**Average**	**Above Average**	**Don't Know**
a. ____________	☐	☐	☐	☐	☐	☐	☐	☐
b. ____________	☐	☐	☐	☐	☐	☐	☐	☐
c. ____________	☐	☐	☐	☐	☐	☐	☐	☐

III. Please list any organizations, clubs, teams, or groups your child belongs to.

☐ None

	Compared to others of the same age, how active is he/she in each?			
	Less Active	**Average**	**More Active**	**Don't Know**
a. ____________	☐	☐	☐	☐
b. ____________	☐	☐	☐	☐
c. ____________	☐	☐	☐	☐

IV. Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, working in store, etc. (Include both paid and unpaid jobs and chores.)

☐ None

	Compared to others of the same age, how well does he/she carry them out?			
	Below Average	**Average**	**Above Average**	**Don't Know**
a. ____________	☐	☐	☐	☐
b. ____________	☐	☐	☐	☐
c. ____________	☐	☐	☐	☐

Be sure you answered all items. Then see other side.

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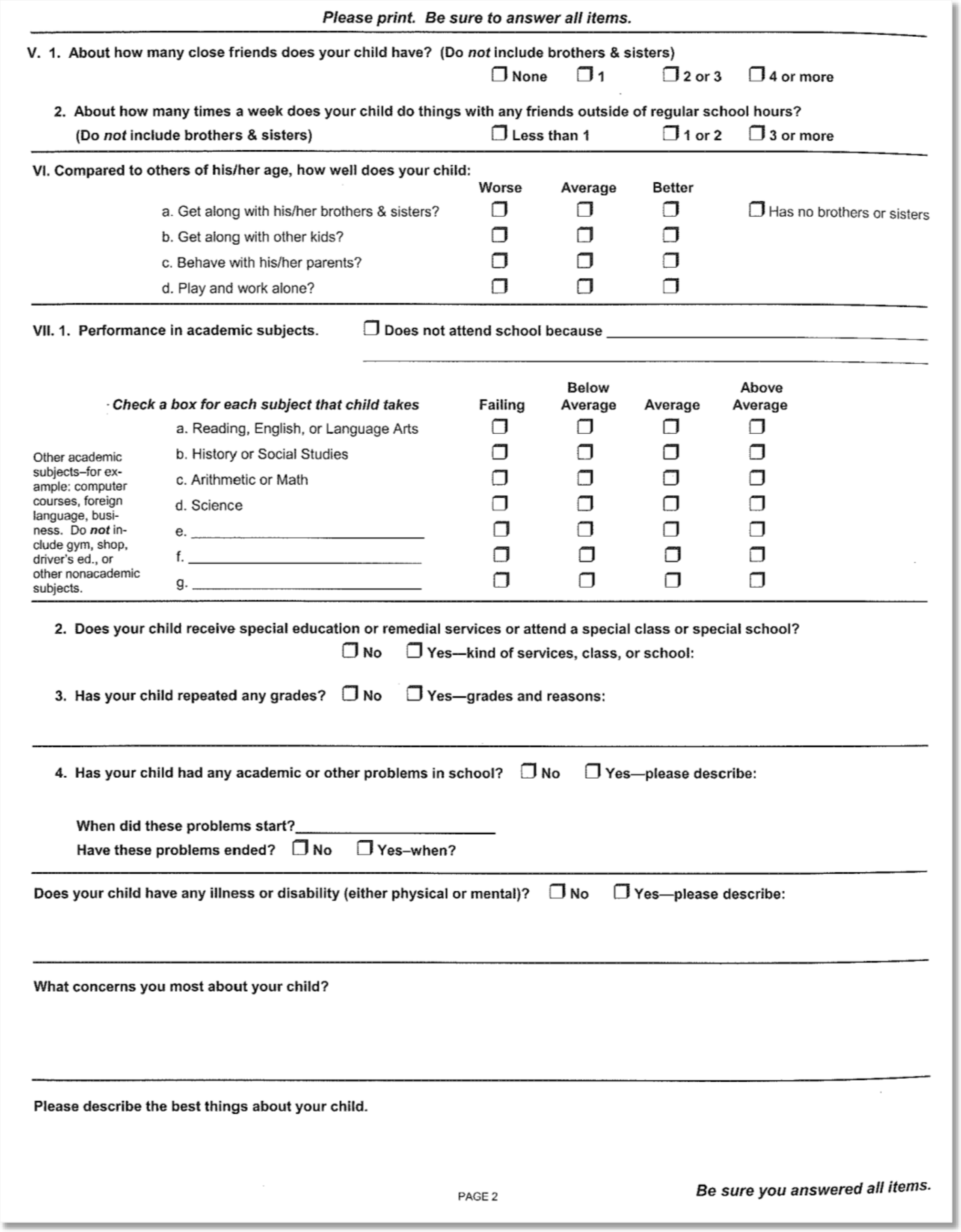
PAGE 1



Please print. Be sure to answer all items.

V. 1. About how many close friends does your child have? (Do *not* include brothers & sisters)
☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

2. About how many times a week does your child do things with any friends outside of regular school hours? (Do *not* include brothers & sisters) **☐ Less than 1 ☐ 1 or 2 ☐ 3 or more**

VI. Compared to others of his/her age, how well does your child:

	Worse	Average	Better	
a. Get along with his/her brothers & sisters?	☐	☐	☐	☐ Has no brothers or sisters
b. Get along with other kids?	☐	☐	☐	
c. Behave with his/her parents?	☐	☐	☐	
d. Play and work alone?	☐	☐	☐	

VII. 1. Performance in academic subjects. **☐ Does not attend school because** ______________________

____

Check a box for each subject that child takes

	Failing	Below Average	Average	Above Average
a. Reading, English, or Language Arts	☐	☐	☐	☐
b. History or Social Studies	☐	☐	☐	☐
c. Arithmetic or Math	☐	☐	☐	☐
d. Science	☐	☐	☐	☐
e. ______________	☐	☐	☐	☐
f. ______________	☐	☐	☐	☐
g. ______________	☐	☐	☐	☐

Other academic subjects–for example: computer courses, foreign language, business. Do ***not*** include gym, shop, driver's ed., or other nonacademic subjects.

2. Does your child receive special education or remedial services or attend a special class or special school?
☐ No ☐ Yes—kind of services, class, or school:

3. Has your child repeated any grades? ☐ No ☐ Yes—grades and reasons:

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?

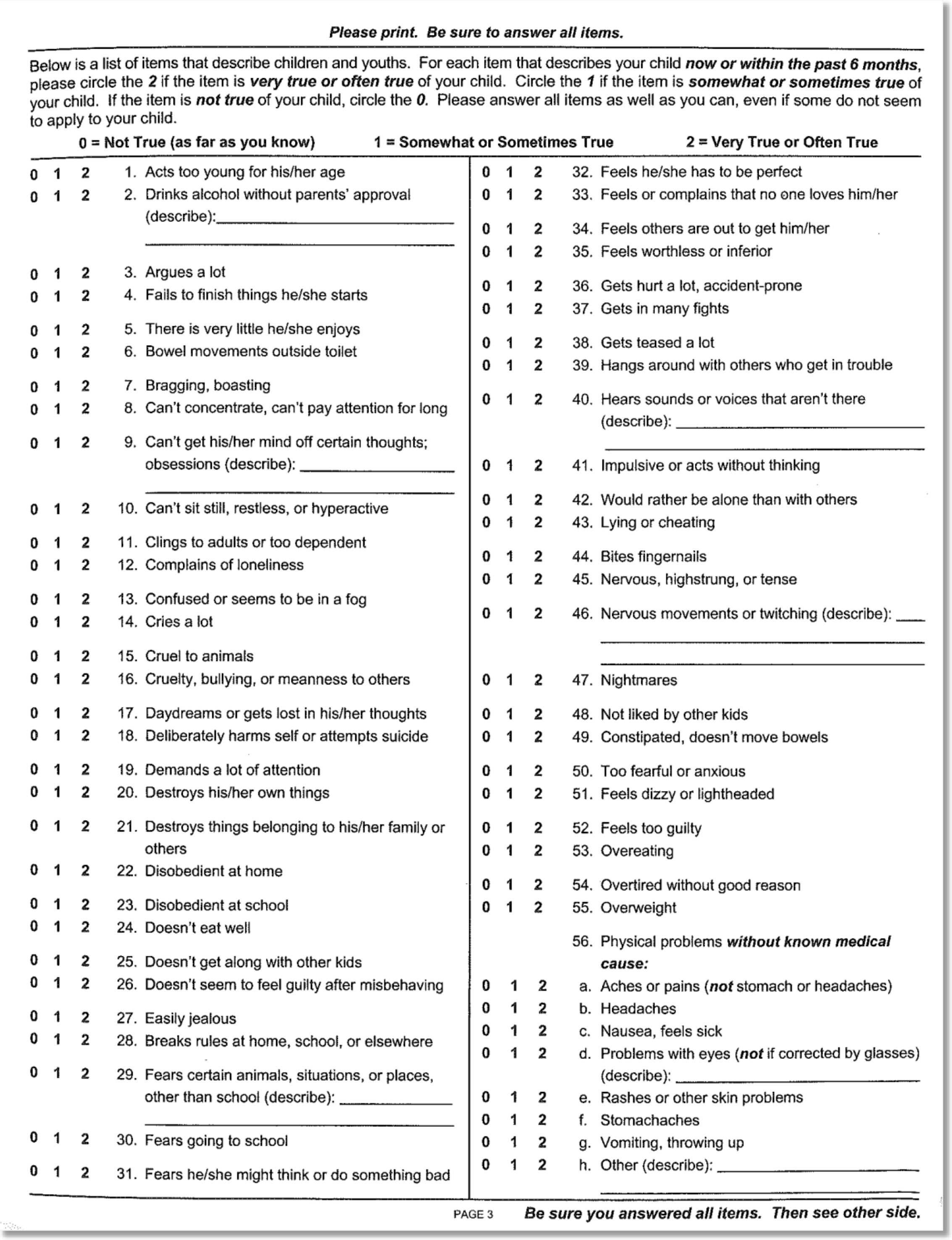
Does your child have any illness or disability (either physical or mental)? ☐ No ☐ Yes—please describe:

What concerns you most about your child?

Please describe the best things about your child.

PAGE 2

Be sure you answered all items.



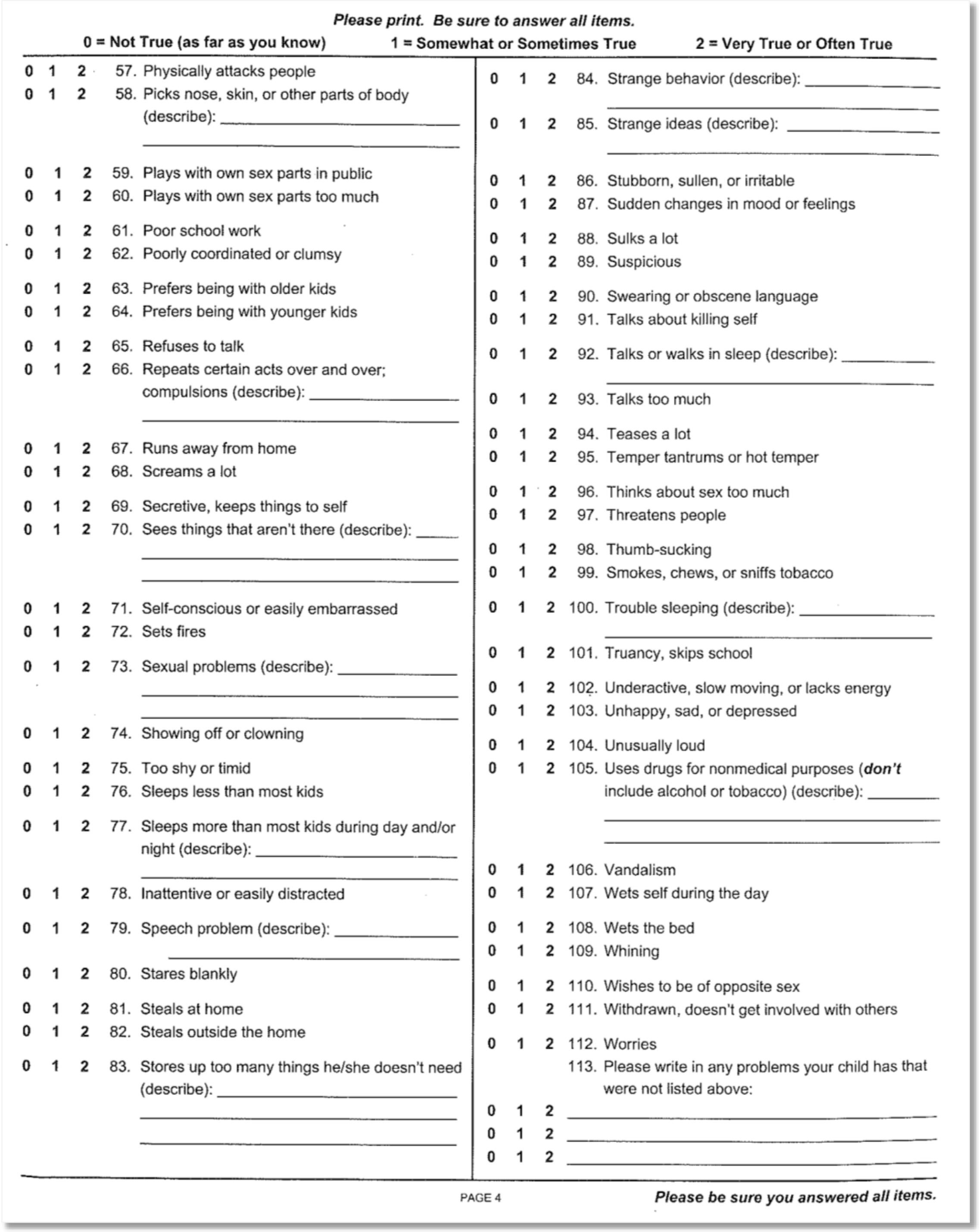
Please print. Be sure to answer all items.

Below is a list of items that describe children and youths. For each item that describes your child ***now or within the past 6 months***, please circle the ***2*** if the item is ***very true or often true*** of your child. Circle the ***1*** if the item is ***somewhat or sometimes true*** of your child. If the item is ***not true*** of your child, circle the ***0***. Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 1. Acts too young for his/her age
0 1 2 2. Drinks alcohol without parents' approval (describe): ____________
0 1 2 3. Argues a lot
0 1 2 4. Fails to finish things he/she starts
0 1 2 5. There is very little he/she enjoys
0 1 2 6. Bowel movements outside toilet
0 1 2 7. Bragging, boasting
0 1 2 8. Can't concentrate, can't pay attention for long
0 1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): ____________
0 1 2 10. Can't sit still, restless, or hyperactive
0 1 2 11. Clings to adults or too dependent
0 1 2 12. Complains of loneliness
0 1 2 13. Confused or seems to be in a fog
0 1 2 14. Cries a lot
0 1 2 15. Cruel to animals
0 1 2 16. Cruelty, bullying, or meanness to others
0 1 2 17. Daydreams or gets lost in his/her thoughts
0 1 2 18. Deliberately harms self or attempts suicide
0 1 2 19. Demands a lot of attention
0 1 2 20. Destroys his/her own things
0 1 2 21. Destroys things belonging to his/her family or others
0 1 2 22. Disobedient at home
0 1 2 23. Disobedient at school
0 1 2 24. Doesn't eat well
0 1 2 25. Doesn't get along with other kids
0 1 2 26. Doesn't seem to feel guilty after misbehaving
0 1 2 27. Easily jealous
0 1 2 28. Breaks rules at home, school, or elsewhere
0 1 2 29. Fears certain animals, situations, or places, other than school (describe): ____________
0 1 2 30. Fears going to school
0 1 2 31. Fears he/she might think or do something bad
0 1 2 32. Feels he/she has to be perfect
0 1 2 33. Feels or complains that no one loves him/her
0 1 2 34. Feels others are out to get him/her
0 1 2 35. Feels worthless or inferior
0 1 2 36. Gets hurt a lot, accident-prone
0 1 2 37. Gets in many fights
0 1 2 38. Gets teased a lot
0 1 2 39. Hangs around with others who get in trouble
0 1 2 40. Hears sounds or voices that aren't there (describe): ____________
0 1 2 41. Impulsive or acts without thinking
0 1 2 42. Would rather be alone than with others
0 1 2 43. Lying or cheating
0 1 2 44. Bites fingernails
0 1 2 45. Nervous, highstrung, or tense
0 1 2 46. Nervous movements or twitching (describe): ____________
0 1 2 47. Nightmares
0 1 2 48. Not liked by other kids
0 1 2 49. Constipated, doesn't move bowels
0 1 2 50. Too fearful or anxious
0 1 2 51. Feels dizzy or lightheaded
0 1 2 52. Feels too guilty
0 1 2 53. Overeating
0 1 2 54. Overtired without good reason
0 1 2 55. Overweight
56. Physical problems ***without known medical cause:***
0 1 2 a. Aches or pains (***not*** stomach or headaches)
0 1 2 b. Headaches
0 1 2 c. Nausea, feels sick
0 1 2 d. Problems with eyes (***not*** if corrected by glasses) (describe): ____________
0 1 2 e. Rashes or other skin problems
0 1 2 f. Stomachaches
0 1 2 g. Vomiting, throwing up
0 1 2 h. Other (describe): ____________

PAGE 3 ***Be sure you answered all items. Then see other side.***



Please print. Be sure to answer all items.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 57. Physically attacks people
0 1 2 58. Picks nose, skin, or other parts of body (describe): ____________________
____

0 1 2 59. Plays with own sex parts in public
0 1 2 60. Plays with own sex parts too much

0 1 2 61. Poor school work
0 1 2 62. Poorly coordinated or clumsy

0 1 2 63. Prefers being with older kids
0 1 2 64. Prefers being with younger kids

0 1 2 65. Refuses to talk
0 1 2 66. Repeats certain acts over and over; compulsions (describe): ____________
____

0 1 2 67. Runs away from home
0 1 2 68. Screams a lot

0 1 2 69. Secretive, keeps things to self
0 1 2 70. Sees things that aren't there (describe): _____
____
____

0 1 2 71. Self-conscious or easily embarrassed
0 1 2 72. Sets fires

0 1 2 73. Sexual problems (describe): __________
____
____

0 1 2 74. Showing off or clowning

0 1 2 75. Too shy or timid
0 1 2 76. Sleeps less than most kids

0 1 2 77. Sleeps more than most kids during day and/or night (describe): ________________
____

0 1 2 78. Inattentive or easily distracted

0 1 2 79. Speech problem (describe): __________
____

0 1 2 80. Stares blankly

0 1 2 81. Steals at home
0 1 2 82. Steals outside the home

0 1 2 83. Stores up too many things he/she doesn't need (describe): ____________________
____
____

0 1 2 84. Strange behavior (describe): ____________
____

0 1 2 85. Strange ideas (describe): ____________
____

0 1 2 86. Stubborn, sullen, or irritable
0 1 2 87. Sudden changes in mood or feelings

0 1 2 88. Sulks a lot
0 1 2 89. Suspicious

0 1 2 90. Swearing or obscene language
0 1 2 91. Talks about killing self

0 1 2 92. Talks or walks in sleep (describe): ________
____

0 1 2 93. Talks too much

0 1 2 94. Teases a lot
0 1 2 95. Temper tantrums or hot temper

0 1 2 96. Thinks about sex too much
0 1 2 97. Threatens people

0 1 2 98. Thumb-sucking
0 1 2 99. Smokes, chews, or sniffs tobacco

0 1 2 100. Trouble sleeping (describe): ____________
____

0 1 2 101. Truancy, skips school

0 1 2 102. Underactive, slow moving, or lacks energy
0 1 2 103. Unhappy, sad, or depressed

0 1 2 104. Unusually loud
0 1 2 105. Uses drugs for nonmedical purposes (***don't*** include alcohol or tobacco) (describe): ________
____
____

0 1 2 106. Vandalism
0 1 2 107. Wets self during the day

0 1 2 108. Wets the bed
0 1 2 109. Whining

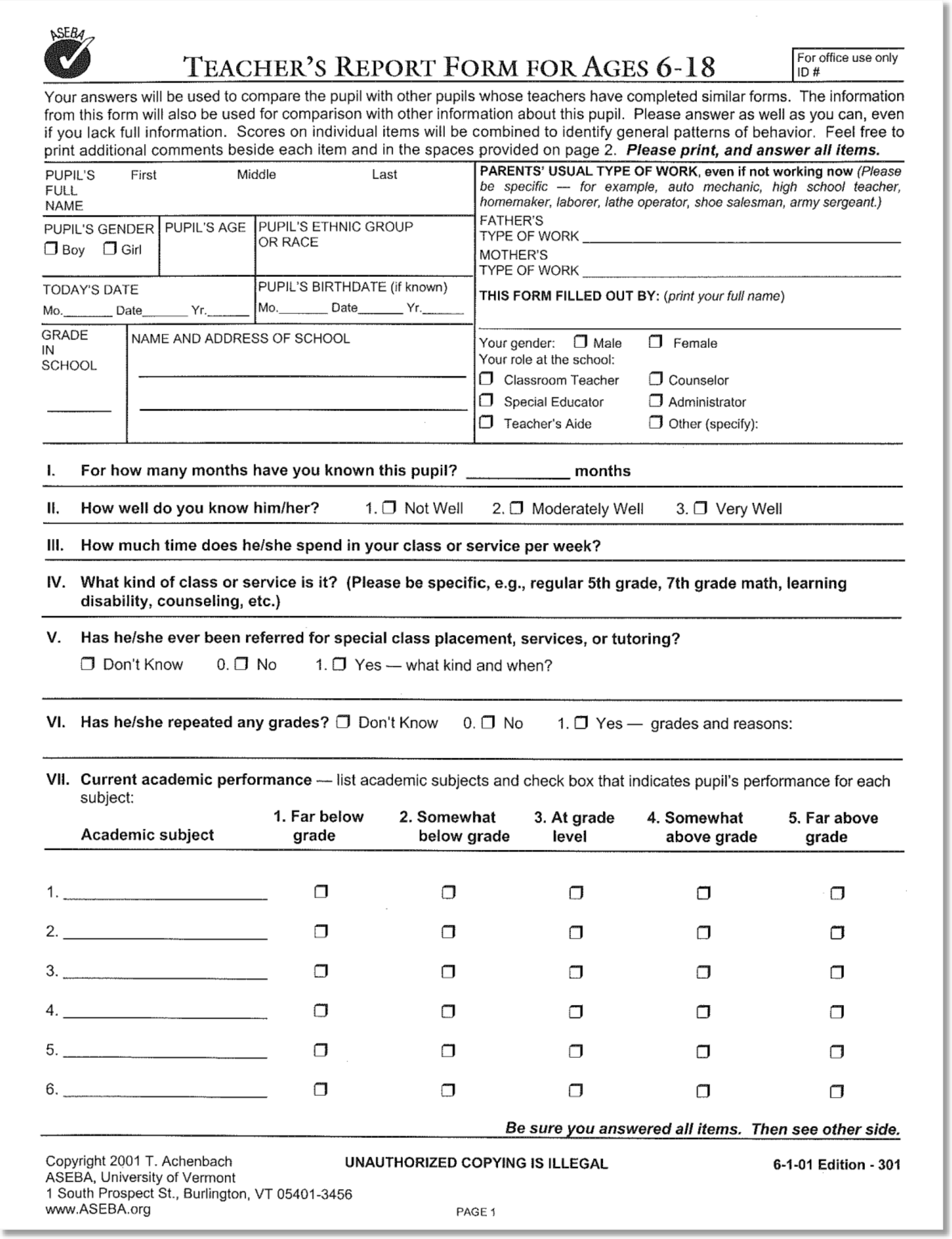
0 1 2 110. Wishes to be of opposite sex
0 1 2 111. Withdrawn, doesn't get involved with others

0 1 2 112. Worries

113. Please write in any problems your child has that were not listed above:
0 1 2 ____________________
0 1 2 ____________________
0 1 2 ____________________

PAGE 4

Please be sure you answered all items.



ASEBA

TEACHER'S REPORT FORM FOR AGES 6-18

For office use only
ID #

Your answers will be used to compare the pupil with other pupils whose teachers have completed similar forms. The information from this form will also be used for comparison with other information about this pupil. Please answer as well as you can, even if you lack full information. Scores on individual items will be combined to identify general patterns of behavior. Feel free to print additional comments beside each item and in the spaces provided on page 2. ***Please print, and answer all items.***

PUPIL'S FULL NAME First Middle Last

PUPIL'S GENDER ☐ Boy ☐ Girl

PUPIL'S AGE

PUPIL'S ETHNIC GROUP OR RACE

TODAY'S DATE Mo.______ Date______ Yr.______

PUPIL'S BIRTHDATE (if known) Mo.______ Date______ Yr.______

GRADE IN SCHOOL ________

NAME AND ADDRESS OF SCHOOL

____

____

PARENTS' USUAL TYPE OF WORK, even if not working now *(Please be specific — for example, auto mechanic, high school teacher, homemaker, laborer, lathe operator, shoe salesman, army sergeant.)*

FATHER'S TYPE OF WORK ________________________________

MOTHER'S TYPE OF WORK ________________________________

THIS FORM FILLED OUT BY: (*print your full name*)

____

Your gender: ☐ Male ☐ Female

Your role at the school:

☐ Classroom Teacher ☐ Counselor

☐ Special Educator ☐ Administrator

☐ Teacher's Aide ☐ Other (specify):

I. For how many months have you known this pupil? __________ months

II. How well do you know him/her? 1. ☐ Not Well 2. ☐ Moderately Well 3. ☐ Very Well

III. How much time does he/she spend in your class or service per week?

IV. What kind of class or service is it? (Please be specific, e.g., regular 5th grade, 7th grade math, learning disability, counseling, etc.)

V. Has he/she ever been referred for special class placement, services, or tutoring?

☐ Don't Know 0. ☐ No 1. ☐ Yes — what kind and when?

VI. Has he/she repeated any grades? ☐ Don't Know 0. ☐ No 1. ☐ Yes — grades and reasons:

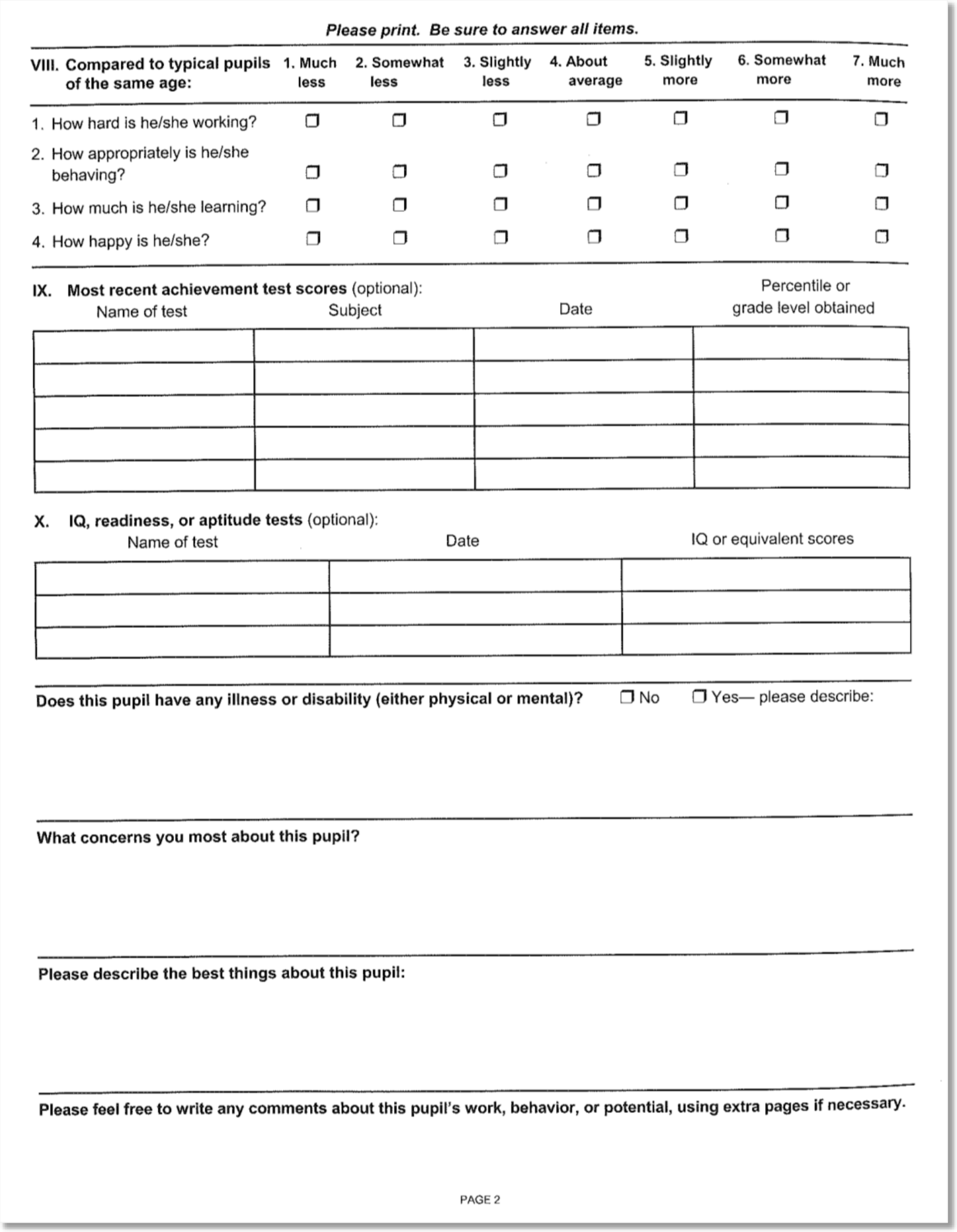
VII. Current academic performance — list academic subjects and check box that indicates pupil's performance for each subject:

Academic subject	**1. Far below grade**	**2. Somewhat below grade**	**3. At grade level**	**4. Somewhat above grade**	**5. Far above grade**
1. ____________	☐	☐	☐	☐	☐
2. ____________	☐	☐	☐	☐	☐
3. ____________	☐	☐	☐	☐	☐
4. ____________	☐	☐	☐	☐	☐
5. ____________	☐	☐	☐	☐	☐
6. ____________	☐	☐	☐	☐	☐

Be sure you answered all items. Then see other side.

6-1-01 Edition - 301

PAGE 1



Please print. Be sure to answer all items.

VIII. Compared to typical pupils of the same age:	**1. Much less**	**2. Somewhat less**	**3. Slightly less**	**4. About average**	**5. Slightly more**	**6. Somewhat more**	**7. Much more**
1. How hard is he/she working?	☐	☐	☐	☐	☐	☐	☐
2. How appropriately is he/she behaving?	☐	☐	☐	☐	☐	☐	☐
3. How much is he/she learning?	☐	☐	☐	☐	☐	☐	☐
4. How happy is he/she?	☐	☐	☐	☐	☐	☐	☐

IX. Most recent achievement test scores (optional):

Name of test	Subject	Date	Percentile or grade level obtained

X. IQ, readiness, or aptitude tests (optional):

Name of test	Date	IQ or equivalent scores

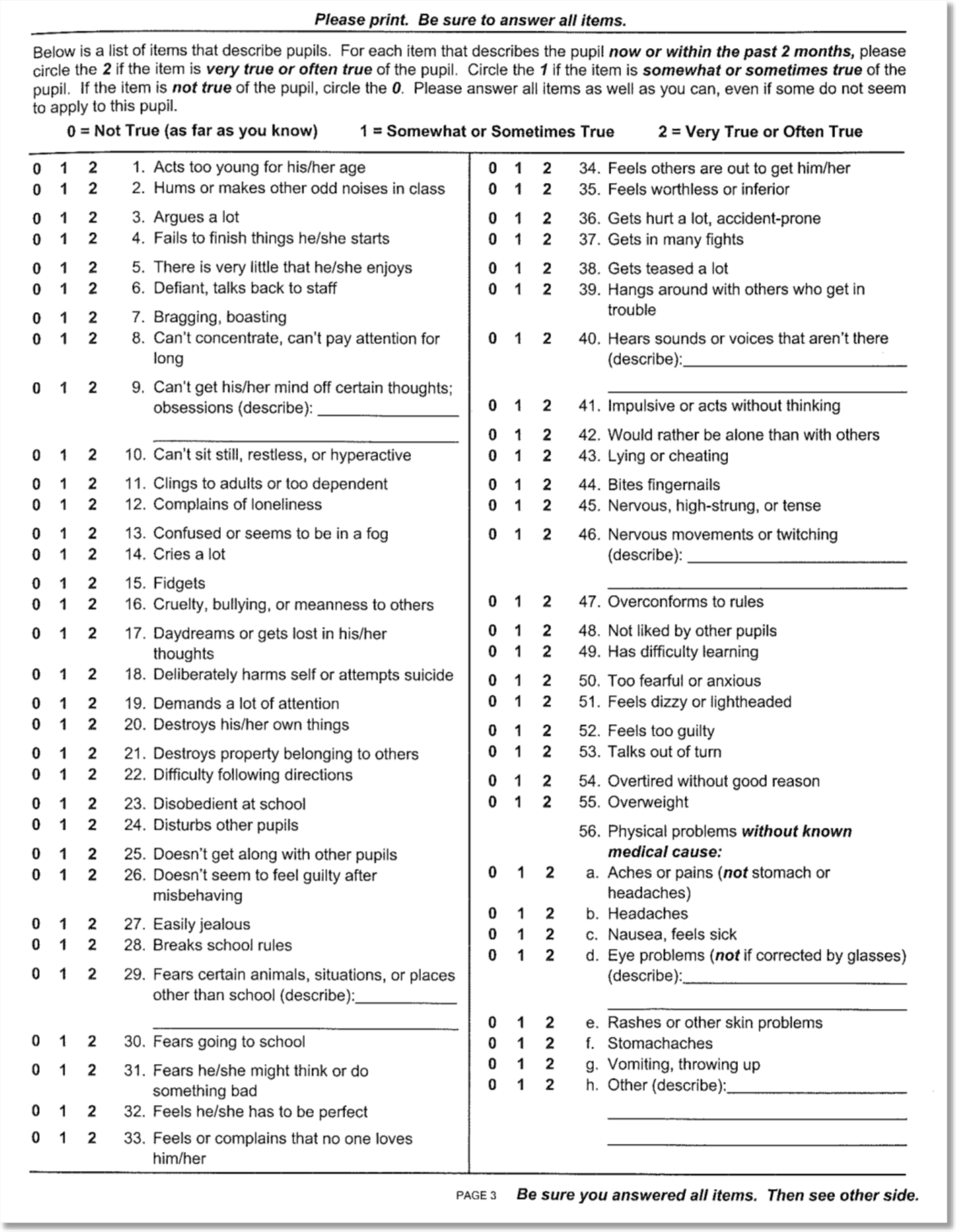
Does this pupil have any illness or disability (either physical or mental)? ☐ No ☐ Yes— please describe:

What concerns you most about this pupil?

Please describe the best things about this pupil:

Please feel free to write any comments about this pupil's work, behavior, or potential, using extra pages if necessary.

PAGE 2



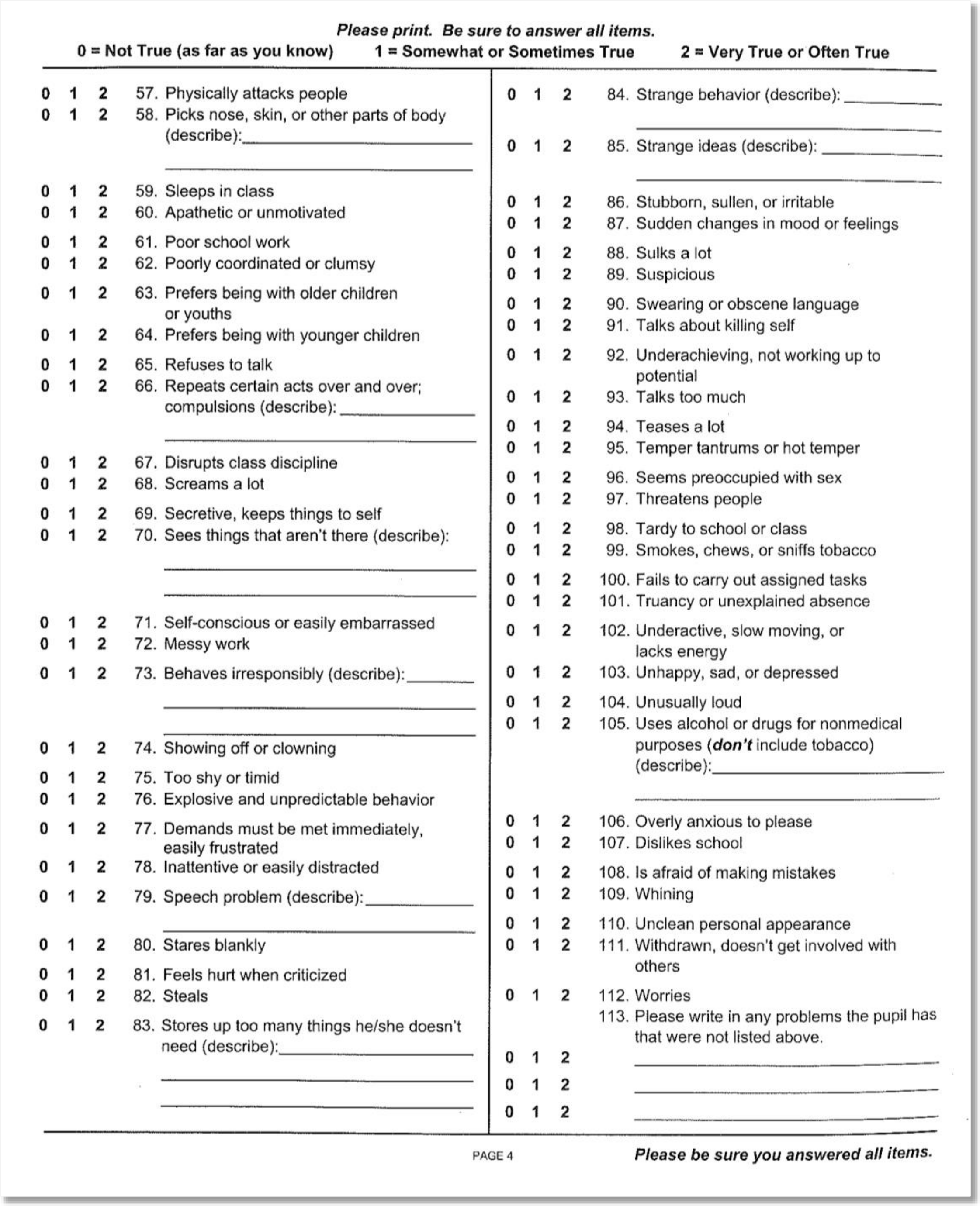
Please print. Be sure to answer all items.

Below is a list of items that describe pupils. For each item that describes the pupil ***now or within the past 2 months,*** please circle the ***2*** if the item is ***very true or often true*** of the pupil. Circle the ***1*** if the item is ***somewhat or sometimes true*** of the pupil. If the item is ***not true*** of the pupil, circle the ***0***. Please answer all items as well as you can, even if some do not seem to apply to this pupil.

0 = Not True (as far as you know) **1 = Somewhat or Sometimes True** **2 = Very True or Often True**

0 1 2 1. Acts too young for his/her age
0 1 2 2. Hums or makes other odd noises in class
0 1 2 3. Argues a lot
0 1 2 4. Fails to finish things he/she starts
0 1 2 5. There is very little that he/she enjoys
0 1 2 6. Defiant, talks back to staff
0 1 2 7. Bragging, boasting
0 1 2 8. Can't concentrate, can't pay attention for long
0 1 2 9. Can't get his/her mind off certain thoughts; obsessions (describe): ________________
____
0 1 2 10. Can't sit still, restless, or hyperactive
0 1 2 11. Clings to adults or too dependent
0 1 2 12. Complains of loneliness
0 1 2 13. Confused or seems to be in a fog
0 1 2 14. Cries a lot
0 1 2 15. Fidgets
0 1 2 16. Cruelty, bullying, or meanness to others
0 1 2 17. Daydreams or gets lost in his/her thoughts
0 1 2 18. Deliberately harms self or attempts suicide
0 1 2 19. Demands a lot of attention
0 1 2 20. Destroys his/her own things
0 1 2 21. Destroys property belonging to others
0 1 2 22. Difficulty following directions
0 1 2 23. Disobedient at school
0 1 2 24. Disturbs other pupils
0 1 2 25. Doesn't get along with other pupils
0 1 2 26. Doesn't seem to feel guilty after misbehaving
0 1 2 27. Easily jealous
0 1 2 28. Breaks school rules
0 1 2 29. Fears certain animals, situations, or places other than school (describe): ____________
____
0 1 2 30. Fears going to school
0 1 2 31. Fears he/she might think or do something bad
0 1 2 32. Feels he/she has to be perfect
0 1 2 33. Feels or complains that no one loves him/her
0 1 2 34. Feels others are out to get him/her
0 1 2 35. Feels worthless or inferior
0 1 2 36. Gets hurt a lot, accident-prone
0 1 2 37. Gets in many fights
0 1 2 38. Gets teased a lot
0 1 2 39. Hangs around with others who get in trouble
0 1 2 40. Hears sounds or voices that aren't there (describe): ________________
____
0 1 2 41. Impulsive or acts without thinking
0 1 2 42. Would rather be alone than with others
0 1 2 43. Lying or cheating
0 1 2 44. Bites fingernails
0 1 2 45. Nervous, high-strung, or tense
0 1 2 46. Nervous movements or twitching (describe): ________________
____
0 1 2 47. Overconforms to rules
0 1 2 48. Not liked by other pupils
0 1 2 49. Has difficulty learning
0 1 2 50. Too fearful or anxious
0 1 2 51. Feels dizzy or lightheaded
0 1 2 52. Feels too guilty
0 1 2 53. Talks out of turn
0 1 2 54. Overtired without good reason
0 1 2 55. Overweight
56. Physical problems ***without known medical cause:***
- **0 1 2** a. Aches or pains (***not*** stomach or headaches)
- **0 1 2** b. Headaches
- **0 1 2** c. Nausea, feels sick
- **0 1 2** d. Eye problems (***not*** if corrected by glasses) (describe): ________________
  ____
- **0 1 2** e. Rashes or other skin problems
- **0 1 2** f. Stomachaches
- **0 1 2** g. Vomiting, throwing up
- **0 1 2** h. Other (describe): ________________
  ____
  ____

PAGE 3 ***Be sure you answered all items. Then see other side.***



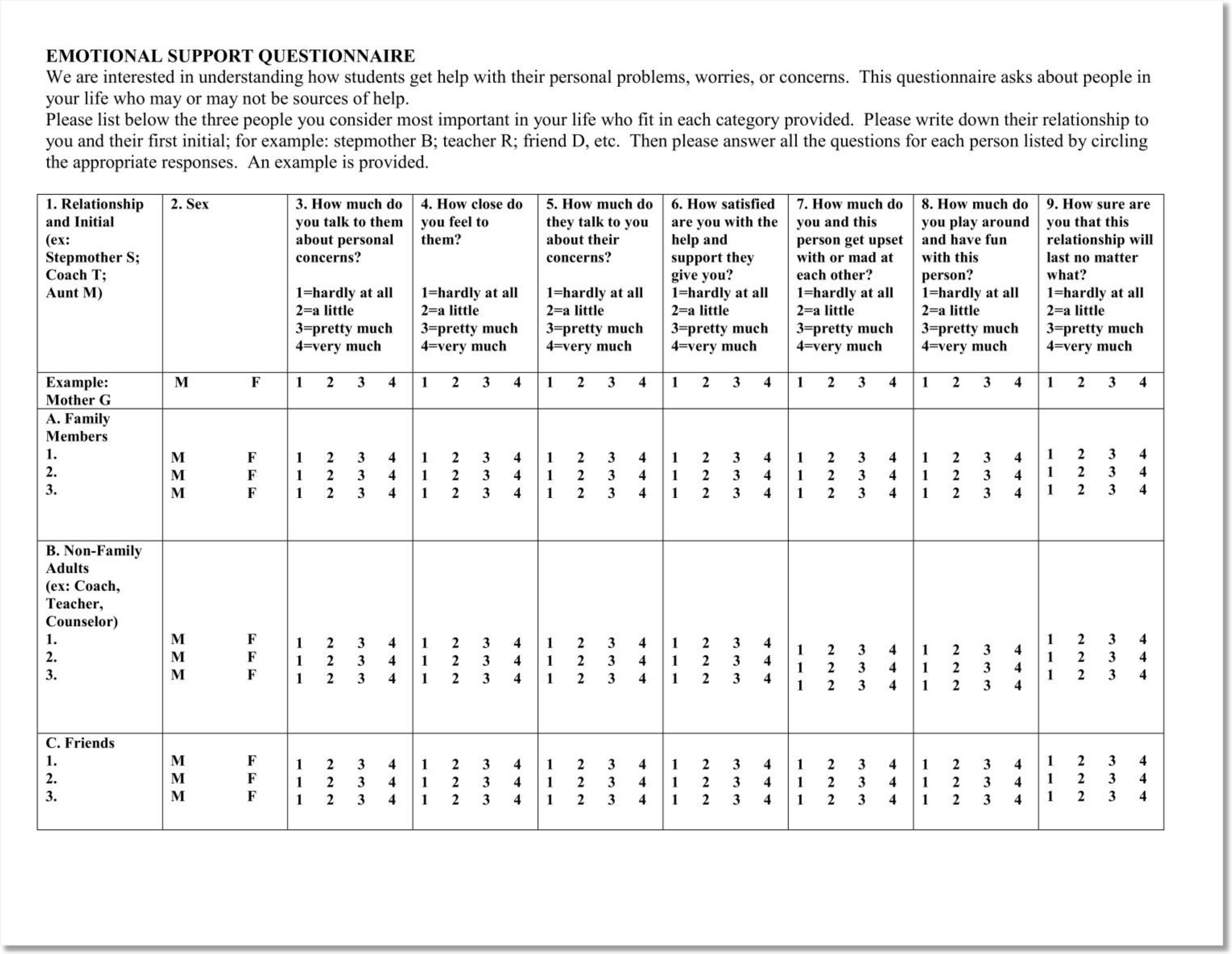
Please print. Be sure to answer all items.

0 = Not True (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

0 1 2 57. Physically attacks people
0 1 2 58. Picks nose, skin, or other parts of body (describe): ______
0 1 2 59. Sleeps in class
0 1 2 60. Apathetic or unmotivated
0 1 2 61. Poor school work
0 1 2 62. Poorly coordinated or clumsy
0 1 2 63. Prefers being with older children or youths
0 1 2 64. Prefers being with younger children
0 1 2 65. Refuses to talk
0 1 2 66. Repeats certain acts over and over; compulsions (describe): ______
0 1 2 67. Disrupts class discipline
0 1 2 68. Screams a lot
0 1 2 69. Secretive, keeps things to self
0 1 2 70. Sees things that aren't there (describe): ______
0 1 2 71. Self-conscious or easily embarrassed
0 1 2 72. Messy work
0 1 2 73. Behaves irresponsibly (describe): ______
0 1 2 74. Showing off or clowning
0 1 2 75. Too shy or timid
0 1 2 76. Explosive and unpredictable behavior
0 1 2 77. Demands must be met immediately, easily frustrated
0 1 2 78. Inattentive or easily distracted
0 1 2 79. Speech problem (describe): ______
0 1 2 80. Stares blankly
0 1 2 81. Feels hurt when criticized
0 1 2 82. Steals
0 1 2 83. Stores up too many things he/she doesn't need (describe): ______
0 1 2 84. Strange behavior (describe): ______
0 1 2 85. Strange ideas (describe): ______
0 1 2 86. Stubborn, sullen, or irritable
0 1 2 87. Sudden changes in mood or feelings
0 1 2 88. Sulks a lot
0 1 2 89. Suspicious
0 1 2 90. Swearing or obscene language
0 1 2 91. Talks about killing self
0 1 2 92. Underachieving, not working up to potential
0 1 2 93. Talks too much
0 1 2 94. Teases a lot
0 1 2 95. Temper tantrums or hot temper
0 1 2 96. Seems preoccupied with sex
0 1 2 97. Threatens people
0 1 2 98. Tardy to school or class
0 1 2 99. Smokes, chews, or sniffs tobacco
0 1 2 100. Fails to carry out assigned tasks
0 1 2 101. Truancy or unexplained absence
0 1 2 102. Underactive, slow moving, or lacks energy
0 1 2 103. Unhappy, sad, or depressed
0 1 2 104. Unusually loud
0 1 2 105. Uses alcohol or drugs for nonmedical purposes (***don't*** include tobacco) (describe): ______
0 1 2 106. Overly anxious to please
0 1 2 107. Dislikes school
0 1 2 108. Is afraid of making mistakes
0 1 2 109. Whining
0 1 2 110. Unclean personal appearance
0 1 2 111. Withdrawn, doesn't get involved with others
0 1 2 112. Worries
113. Please write in any problems the pupil has that were not listed above.
0 1 2 ______
0 1 2 ______
0 1 2 ______

PAGE 4

Please be sure you answered all items.

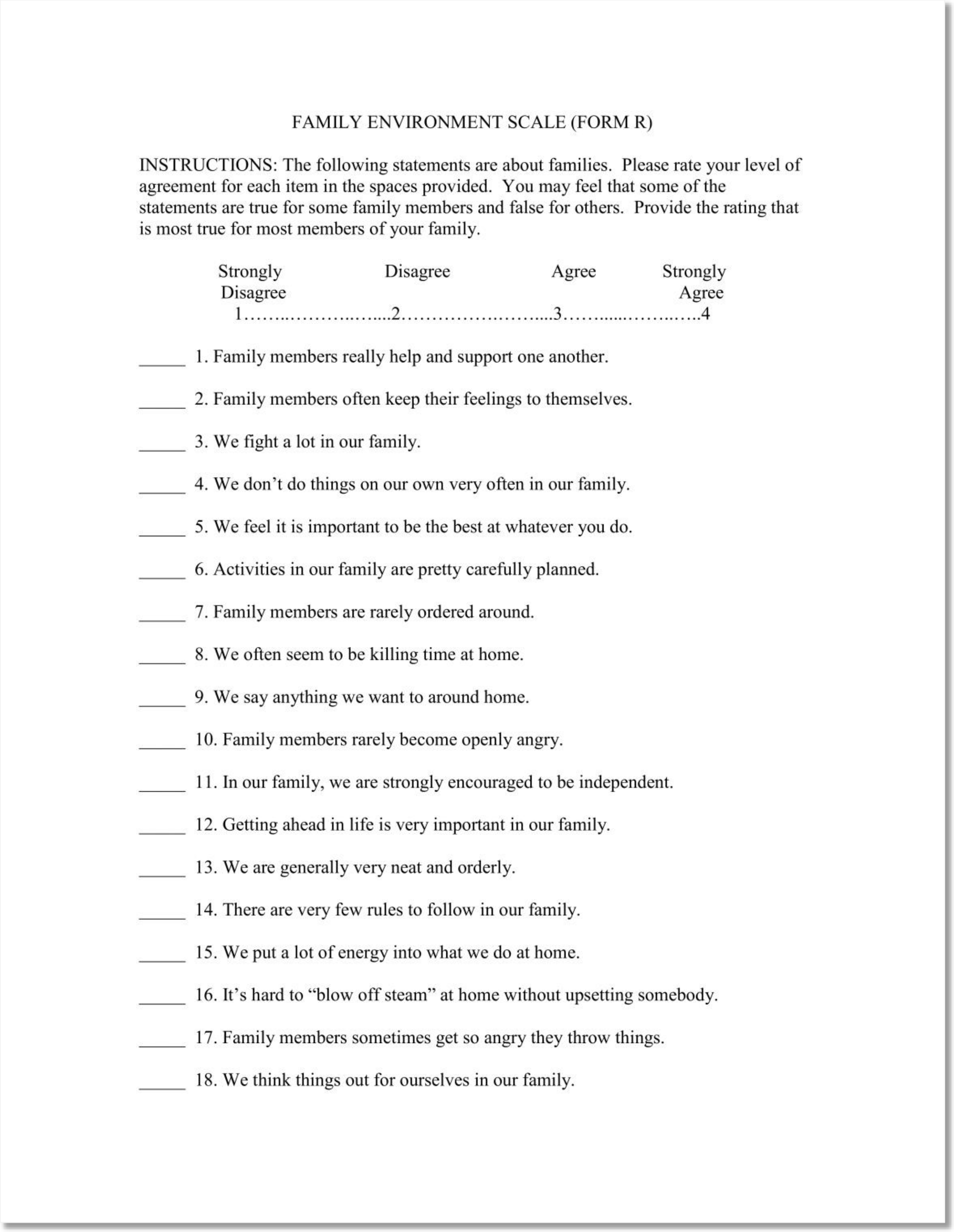


EMOTIONAL SUPPORT QUESTIONNAIRE

We are interested in understanding how students get help with their personal problems, worries, or concerns. This questionnaire asks about people in your life who may or may not be sources of help.

Please list below the three people you consider most important in your life who fit in each category provided. Please write down their relationship to you and their first initial; for example: stepmother B; teacher R; friend D, etc. Then please answer all the questions for each person listed by circling the appropriate responses. An example is provided.

1. Relationship and Initial (ex: Stepmother S; Coach T; Aunt M)	2. Sex	3. How much do you talk to them about personal concerns? 1=hardly at all 2=a little 3=pretty much 4=very much	4. How close do you feel to them? 1=hardly at all 2=a little 3=pretty much 4=very much	5. How much do they talk to you about their concerns? 1=hardly at all 2=a little 3=pretty much 4=very much	6. How satisfied are you with the help and support they give you? 1=hardly at all 2=a little 3=pretty much 4=very much	7. How much do you and this person get upset with or mad at each other? 1=hardly at all 2=a little 3=pretty much 4=very much	8. How much do you play around and have fun with this person? 1=hardly at all 2=a little 3=pretty much 4=very much	9. How sure are you that this relationship will last no matter what? 1=hardly at all 2=a little 3=pretty much 4=very much
Example: Mother G	M F	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
A. Family Members								
1.	M F	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
2.	M F	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
3.	M F	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
B. Non-Family Adults (ex: Coach, Teacher, Counselor)								
1.	M F	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
2.	M F	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
3.	M F	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
C. Friends								
1.	M F	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
2.	M F	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4
3.	M F	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4	1 2 3 4



FAMILY ENVIRONMENT SCALE (FORM R)

INSTRUCTIONS: The following statements are about families. Please rate your level of agreement for each item in the spaces provided. You may feel that some of the statements are true for some family members and false for others. Provide the rating that is most true for most members of your family.

Strongly Disagree   Disagree   Agree   Strongly Agree
1……..………..…....2…………….……....3……......……..…..4

_____ 1. Family members really help and support one another.

_____ 2. Family members often keep their feelings to themselves.

_____ 3. We fight a lot in our family.

_____ 4. We don’t do things on our own very often in our family.

_____ 5. We feel it is important to be the best at whatever you do.

_____ 6. Activities in our family are pretty carefully planned.

_____ 7. Family members are rarely ordered around.

_____ 8. We often seem to be killing time at home.

_____ 9. We say anything we want to around home.

_____ 10. Family members rarely become openly angry.

_____ 11. In our family, we are strongly encouraged to be independent.

_____ 12. Getting ahead in life is very important in our family.

_____ 13. We are generally very neat and orderly.

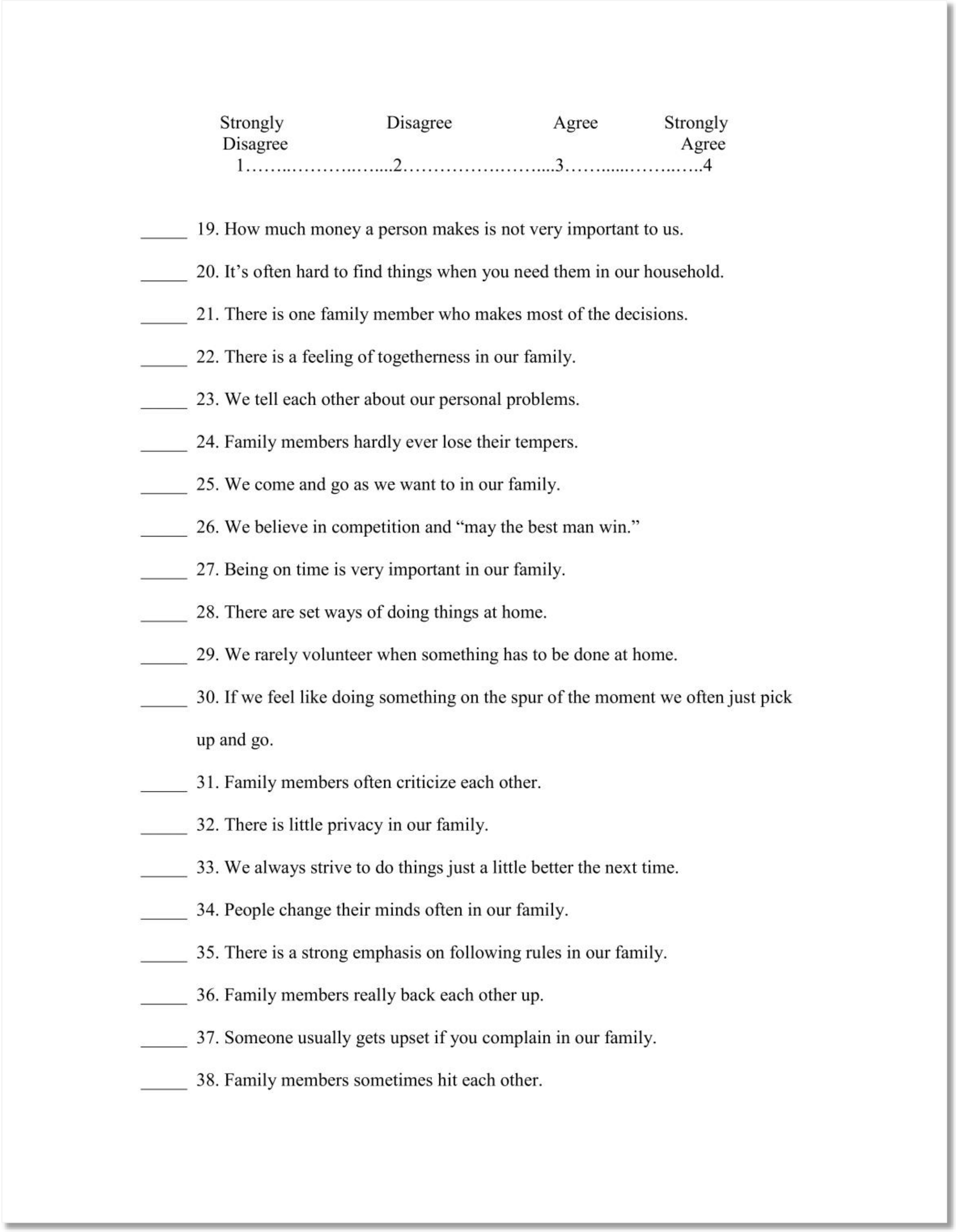
_____ 14. There are very few rules to follow in our family.

_____ 15. We put a lot of energy into what we do at home.

_____ 16. It’s hard to “blow off steam” at home without upsetting somebody.

_____ 17. Family members sometimes get so angry they throw things.

_____ 18. We think things out for ourselves in our family.



Strongly Disagree   Disagree   Agree   Strongly Agree
1……..………..…....2……………..……....3……......……..…..4

_____ 19. How much money a person makes is not very important to us.

_____ 20. It’s often hard to find things when you need them in our household.

_____ 21. There is one family member who makes most of the decisions.

_____ 22. There is a feeling of togetherness in our family.

_____ 23. We tell each other about our personal problems.

_____ 24. Family members hardly ever lose their tempers.

_____ 25. We come and go as we want to in our family.

_____ 26. We believe in competition and “may the best man win.”

_____ 27. Being on time is very important in our family.

_____ 28. There are set ways of doing things at home.

_____ 29. We rarely volunteer when something has to be done at home.

_____ 30. If we feel like doing something on the spur of the moment we often just pick up and go.

_____ 31. Family members often criticize each other.

_____ 32. There is little privacy in our family.

_____ 33. We always strive to do things just a little better the next time.

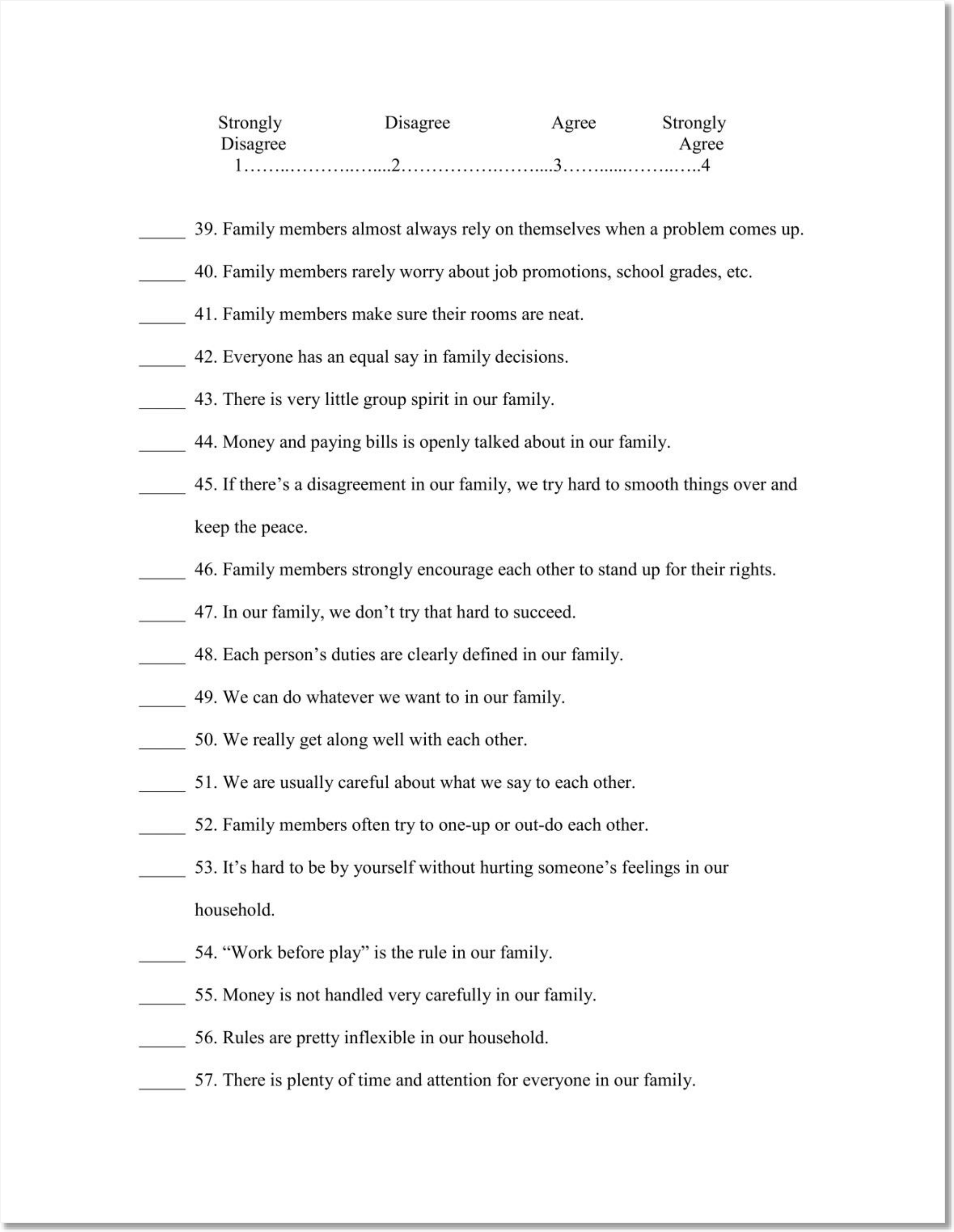
_____ 34. People change their minds often in our family.

_____ 35. There is a strong emphasis on following rules in our family.

_____ 36. Family members really back each other up.

_____ 37. Someone usually gets upset if you complain in our family.

_____ 38. Family members sometimes hit each other.



Strongly Disagree Agree Strongly
Disagree Agree
1……..………..…....2…………….……....3……......……..…..4

_____ 39. Family members almost always rely on themselves when a problem comes up.

_____ 40. Family members rarely worry about job promotions, school grades, etc.

_____ 41. Family members make sure their rooms are neat.

_____ 42. Everyone has an equal say in family decisions.

_____ 43. There is very little group spirit in our family.

_____ 44. Money and paying bills is openly talked about in our family.

_____ 45. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.

_____ 46. Family members strongly encourage each other to stand up for their rights.

_____ 47. In our family, we don't try that hard to succeed.

_____ 48. Each person's duties are clearly defined in our family.

_____ 49. We can do whatever we want to in our family.

_____ 50. We really get along well with each other.

_____ 51. We are usually careful about what we say to each other.

_____ 52. Family members often try to one-up or out-do each other.

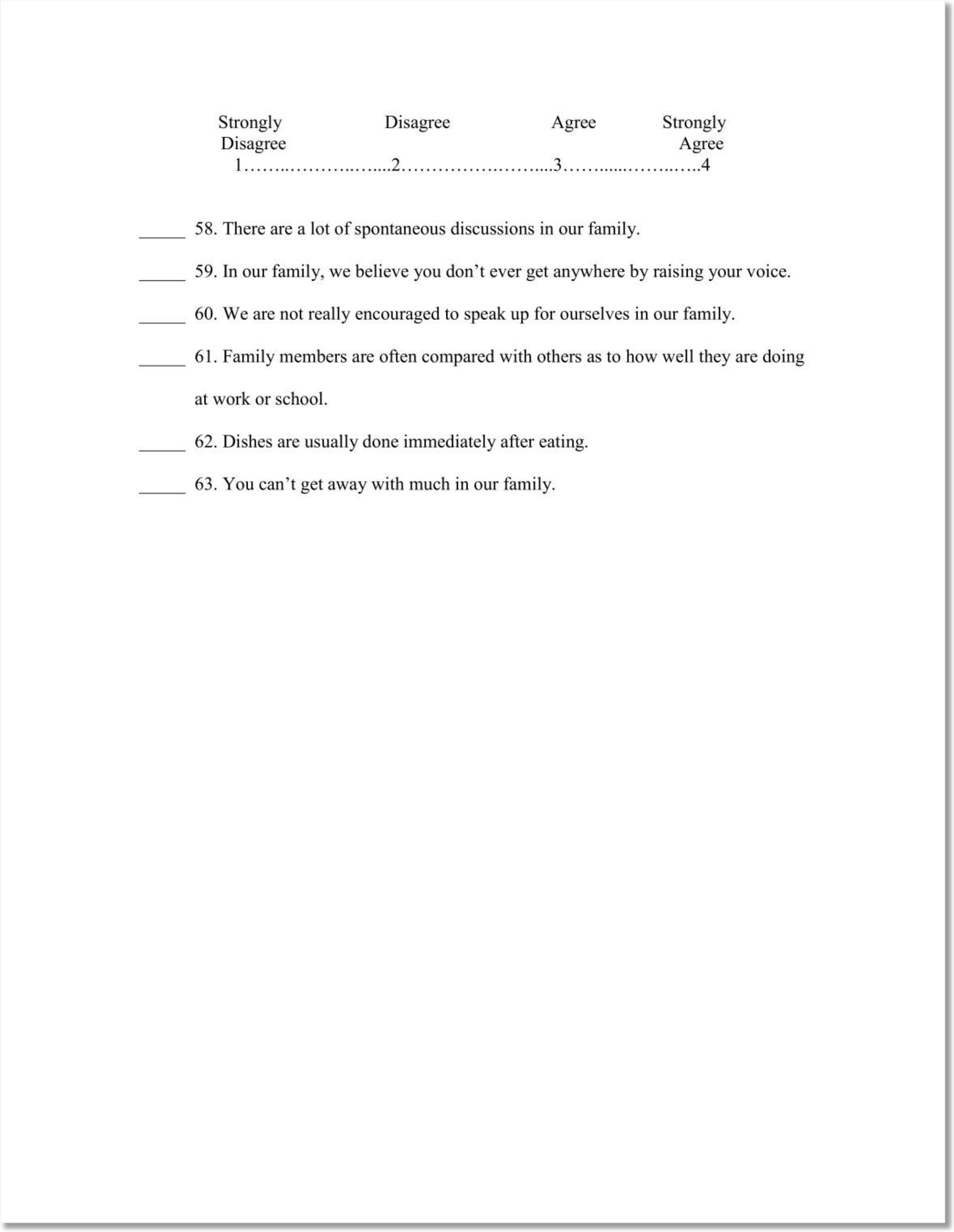
_____ 53. It's hard to be by yourself without hurting someone's feelings in our household.

_____ 54. "Work before play" is the rule in our family.

_____ 55. Money is not handled very carefully in our family.

_____ 56. Rules are pretty inflexible in our household.

_____ 57. There is plenty of time and attention for everyone in our family.



Strongly Disagree	Disagree	Agree	Strongly Agree

1……..……...…....2……………..……....3……......……..…..4

_____ 58. There are a lot of spontaneous discussions in our family.

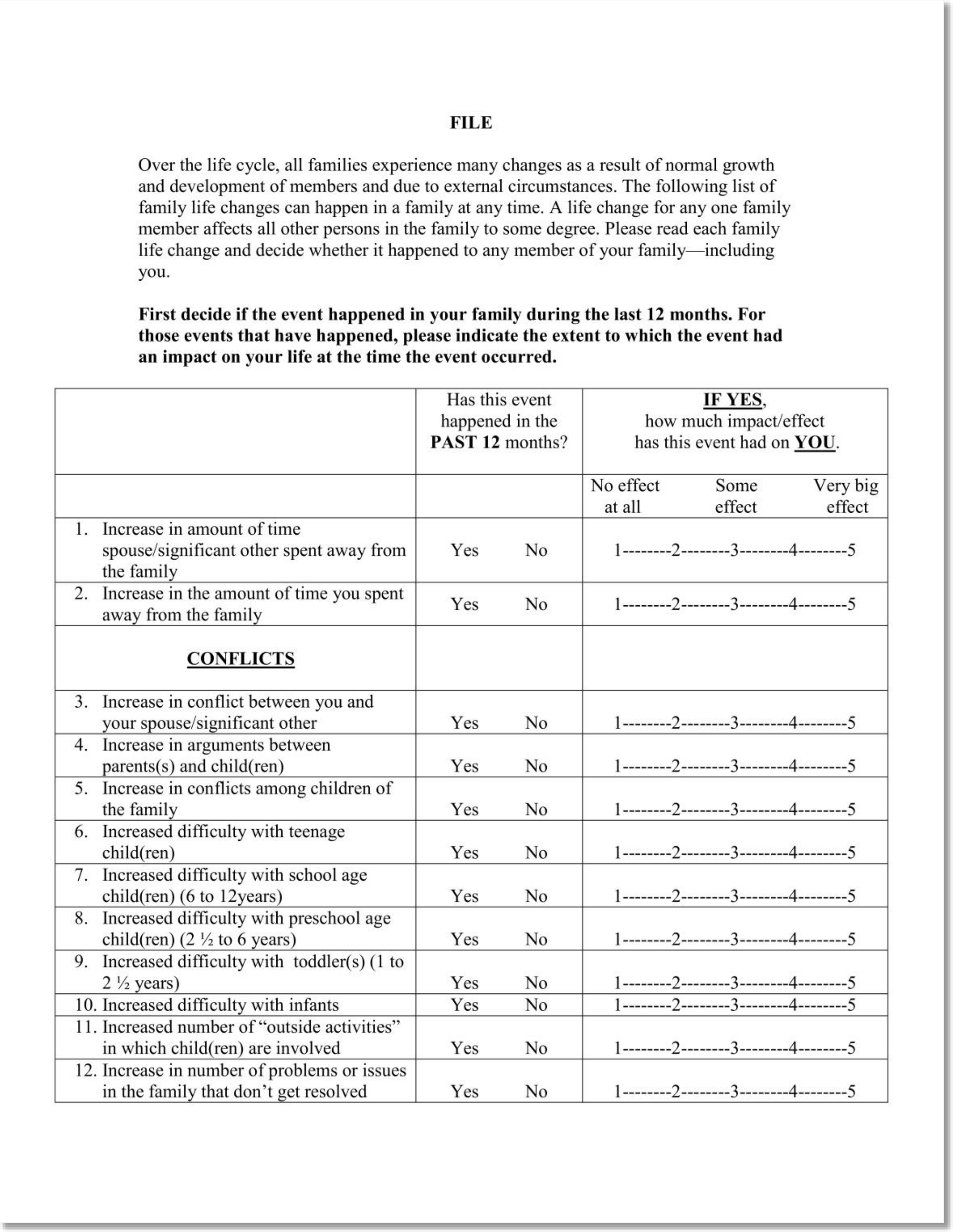
_____ 59. In our family, we believe you don't ever get anywhere by raising your voice.

_____ 60. We are not really encouraged to speak up for ourselves in our family.

_____ 61. Family members are often compared with others as to how well they are doing at work or school.

_____ 62. Dishes are usually done immediately after eating.

_____ 63. You can't get away with much in our family.

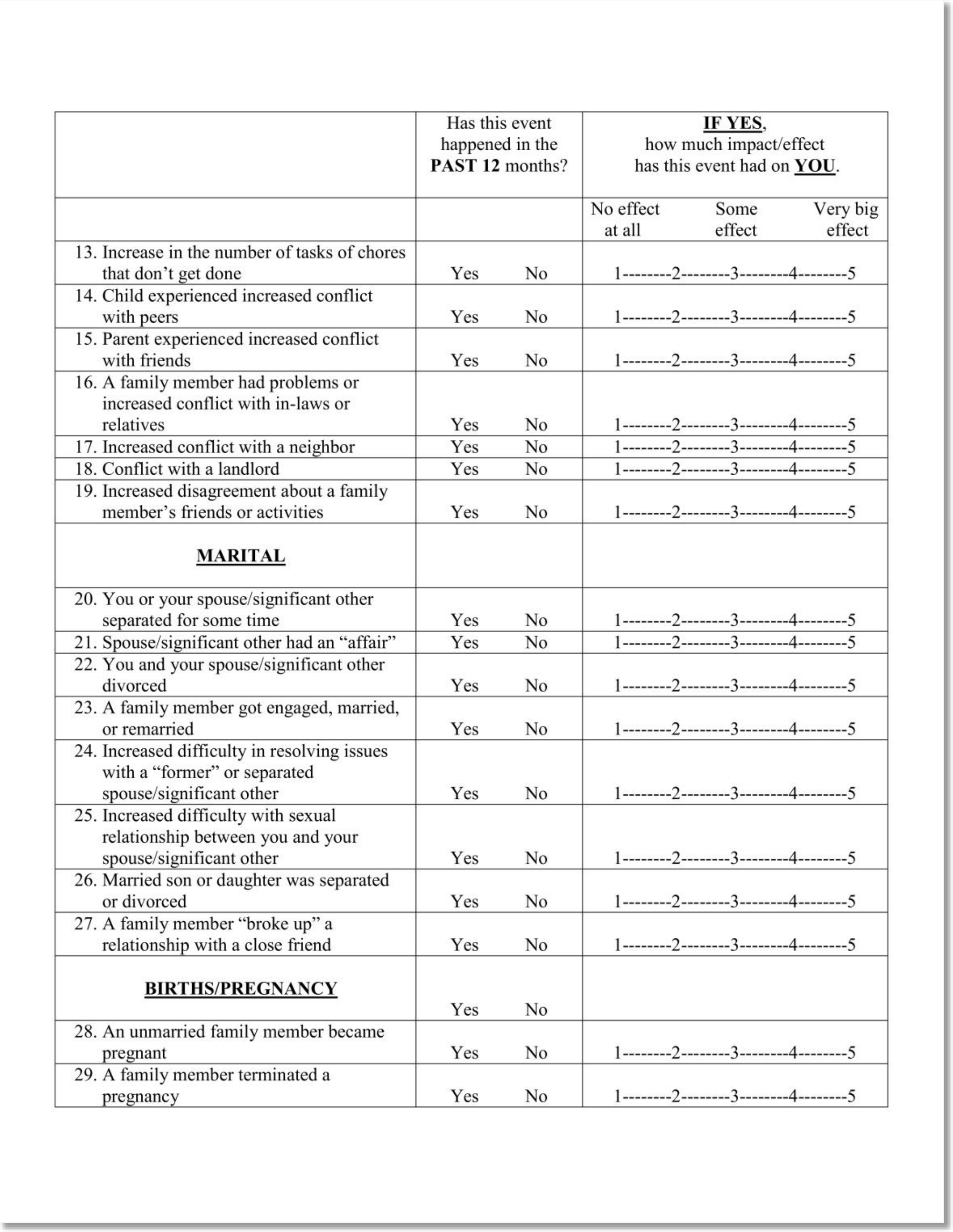


FILE

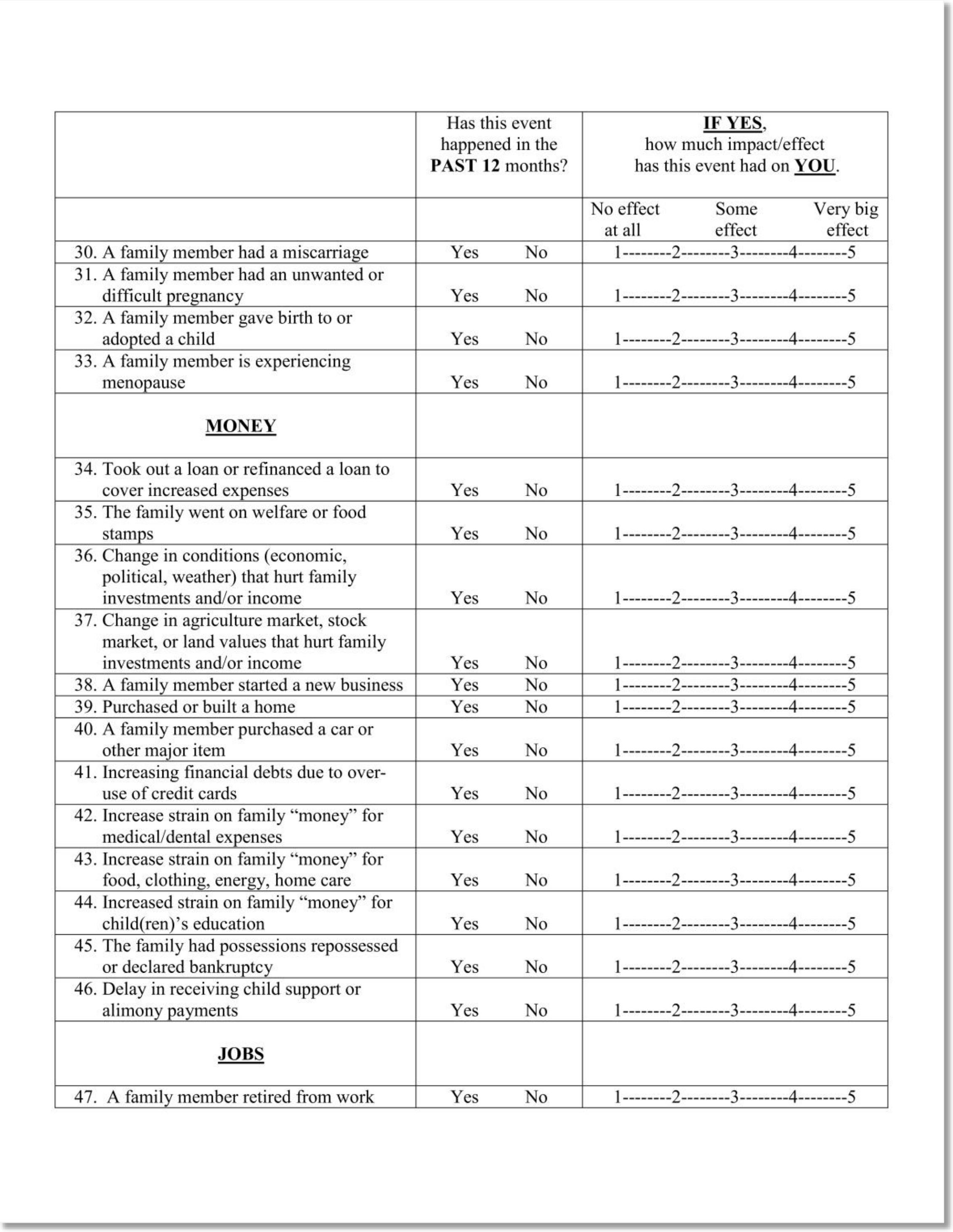
Over the life cycle, all families experience many changes as a result of normal growth and development of members and due to external circumstances. The following list of family life changes can happen in a family at any time. A life change for any one family member affects all other persons in the family to some degree. Please read each family life change and decide whether it happened to any member of your family—including you.

First decide if the event happened in your family during the last 12 months. For those events that have happened, please indicate the extent to which the event had an impact on your life at the time the event occurred.

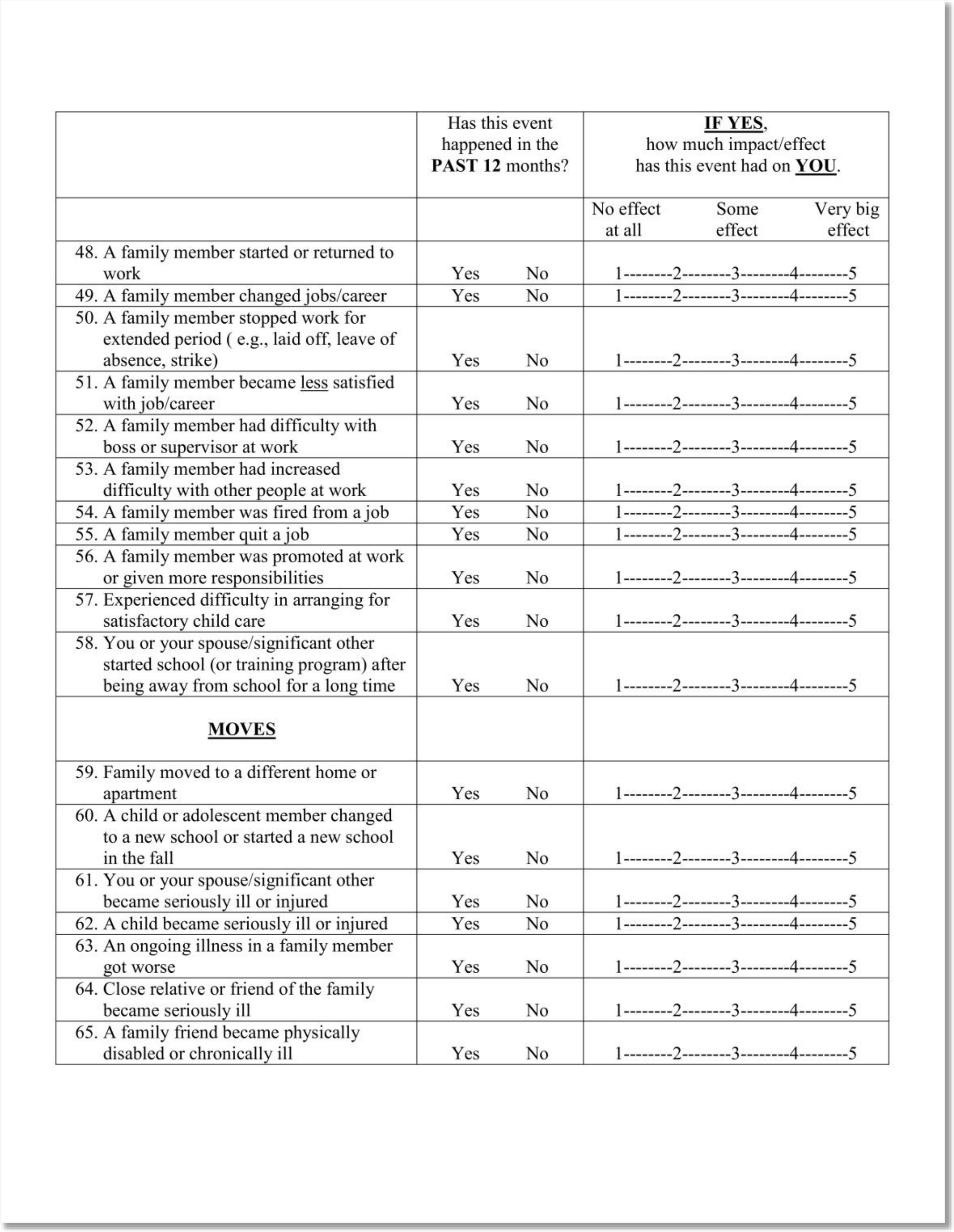
	Has this event happened in the **PAST 12** months?	**IF YES**, how much impact/effect has this event had on **YOU**.
		No effect at all Some effect Very big effect
1. Increase in amount of time spouse/significant other spent away from the family	Yes No	1--------2--------3--------4--------5
2. Increase in the amount of time you spent away from the family	Yes No	1--------2--------3--------4--------5
CONFLICTS		
3. Increase in conflict between you and your spouse/significant other	Yes No	1--------2--------3--------4--------5
4. Increase in arguments between parents(s) and child(ren)	Yes No	1--------2--------3--------4--------5
5. Increase in conflicts among children of the family	Yes No	1--------2--------3--------4--------5
6. Increased difficulty with teenage child(ren)	Yes No	1--------2--------3--------4--------5
7. Increased difficulty with school age child(ren) (6 to 12years)	Yes No	1--------2--------3--------4--------5
8. Increased difficulty with preschool age child(ren) (2 ½ to 6 years)	Yes No	1--------2--------3--------4--------5
9. Increased difficulty with toddler(s) (1 to 2 ½ years)	Yes No	1--------2--------3--------4--------5
10. Increased difficulty with infants	Yes No	1--------2--------3--------4--------5
11. Increased number of "outside activities" in which child(ren) are involved	Yes No	1--------2--------3--------4--------5
12. Increase in number of problems or issues in the family that don't get resolved	Yes No	1--------2--------3--------4--------5



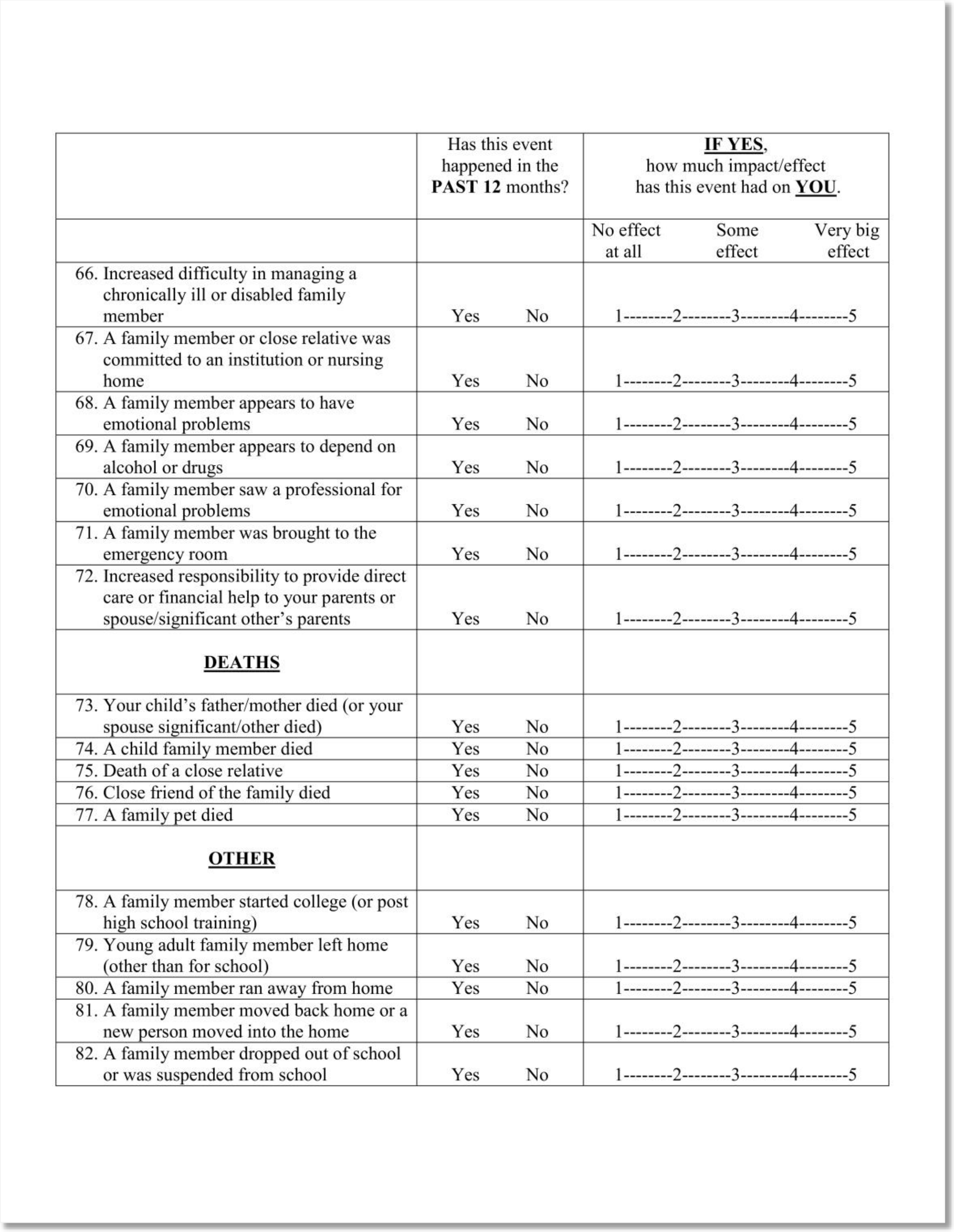
	Has this event happened in the **PAST 12** months?	**IF YES**, how much impact/effect has this event had on **YOU**.
		No effect at all Some effect Very big effect
13. Increase in the number of tasks of chores that don't get done	Yes No	1--------2--------3--------4--------5
14. Child experienced increased conflict with peers	Yes No	1--------2--------3--------4--------5
15. Parent experienced increased conflict with friends	Yes No	1--------2--------3--------4--------5
16. A family member had problems or increased conflict with in-laws or relatives	Yes No	1--------2--------3--------4--------5
17. Increased conflict with a neighbor	Yes No	1--------2--------3--------4--------5
18. Conflict with a landlord	Yes No	1--------2--------3--------4--------5
19. Increased disagreement about a family member's friends or activities	Yes No	1--------2--------3--------4--------5
MARITAL		
20. You or your spouse/significant other separated for some time	Yes No	1--------2--------3--------4--------5
21. Spouse/significant other had an "affair"	Yes No	1--------2--------3--------4--------5
22. You and your spouse/significant other divorced	Yes No	1--------2--------3--------4--------5
23. A family member got engaged, married, or remarried	Yes No	1--------2--------3--------4--------5
24. Increased difficulty in resolving issues with a "former" or separated spouse/significant other	Yes No	1--------2--------3--------4--------5
25. Increased difficulty with sexual relationship between you and your spouse/significant other	Yes No	1--------2--------3--------4--------5
26. Married son or daughter was separated or divorced	Yes No	1--------2--------3--------4--------5
27. A family member "broke up" a relationship with a close friend	Yes No	1--------2--------3--------4--------5
BIRTHS/PREGNANCY	Yes No	
28. An unmarried family member became pregnant	Yes No	1--------2--------3--------4--------5
29. A family member terminated a pregnancy	Yes No	1--------2--------3--------4--------5



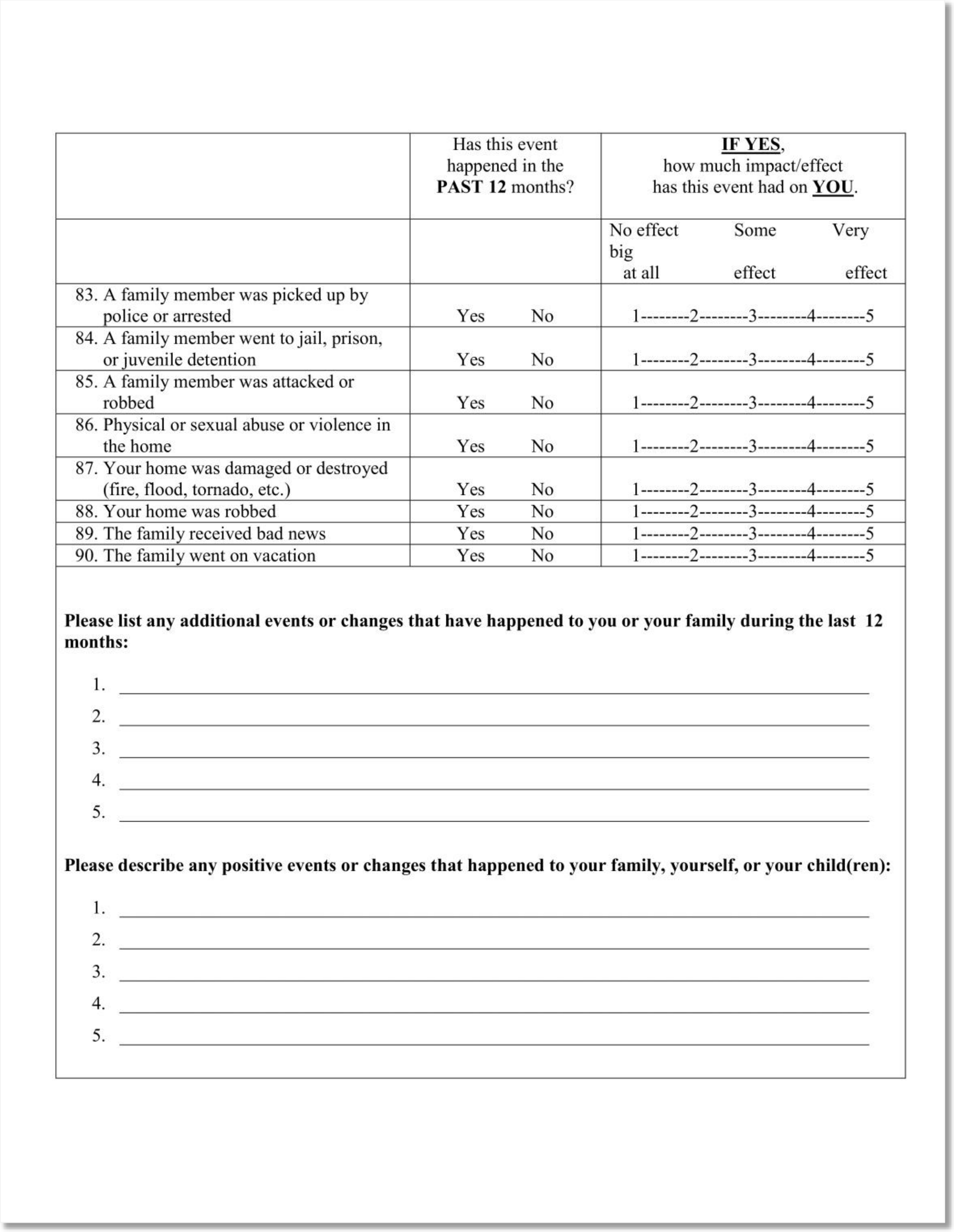
	Has this event happened in the **PAST 12** months?	**IF YES**, how much impact/effect has this event had on **YOU**.
		No effect at all Some effect Very big effect
30. A family member had a miscarriage	Yes No	1--------2--------3--------4--------5
31. A family member had an unwanted or difficult pregnancy	Yes No	1--------2--------3--------4--------5
32. A family member gave birth to or adopted a child	Yes No	1--------2--------3--------4--------5
33. A family member is experiencing menopause	Yes No	1--------2--------3--------4--------5
MONEY		
34. Took out a loan or refinanced a loan to cover increased expenses	Yes No	1--------2--------3--------4--------5
35. The family went on welfare or food stamps	Yes No	1--------2--------3--------4--------5
36. Change in conditions (economic, political, weather) that hurt family investments and/or income	Yes No	1--------2--------3--------4--------5
37. Change in agriculture market, stock market, or land values that hurt family investments and/or income	Yes No	1--------2--------3--------4--------5
38. A family member started a new business	Yes No	1--------2--------3--------4--------5
39. Purchased or built a home	Yes No	1--------2--------3--------4--------5
40. A family member purchased a car or other major item	Yes No	1--------2--------3--------4--------5
41. Increasing financial debts due to over-use of credit cards	Yes No	1--------2--------3--------4--------5
42. Increase strain on family "money" for medical/dental expenses	Yes No	1--------2--------3--------4--------5
43. Increase strain on family "money" for food, clothing, energy, home care	Yes No	1--------2--------3--------4--------5
44. Increased strain on family "money" for child(ren)'s education	Yes No	1--------2--------3--------4--------5
45. The family had possessions repossessed or declared bankruptcy	Yes No	1--------2--------3--------4--------5
46. Delay in receiving child support or alimony payments	Yes No	1--------2--------3--------4--------5
JOBS		
47. A family member retired from work	Yes No	1--------2--------3--------4--------5



	Has this event happened in the **PAST 12** months?		**IF YES**, how much impact/effect has this event had on **YOU**.
			No effect at all Some effect Very big effect
48. A family member started or returned to work	Yes	No	1--------2--------3--------4--------5
49. A family member changed jobs/career	Yes	No	1--------2--------3--------4--------5
50. A family member stopped work for extended period (e.g., laid off, leave of absence, strike)	Yes	No	1--------2--------3--------4--------5
51. A family member became less satisfied with job/career	Yes	No	1--------2--------3--------4--------5
52. A family member had difficulty with boss or supervisor at work	Yes	No	1--------2--------3--------4--------5
53. A family member had increased difficulty with other people at work	Yes	No	1--------2--------3--------4--------5
54. A family member was fired from a job	Yes	No	1--------2--------3--------4--------5
55. A family member quit a job	Yes	No	1--------2--------3--------4--------5
56. A family member was promoted at work or given more responsibilities	Yes	No	1--------2--------3--------4--------5
57. Experienced difficulty in arranging for satisfactory child care	Yes	No	1--------2--------3--------4--------5
58. You or your spouse/significant other started school (or training program) after being away from school for a long time	Yes	No	1--------2--------3--------4--------5
MOVES			
59. Family moved to a different home or apartment	Yes	No	1--------2--------3--------4--------5
60. A child or adolescent member changed to a new school or started a new school in the fall	Yes	No	1--------2--------3--------4--------5
61. You or your spouse/significant other became seriously ill or injured	Yes	No	1--------2--------3--------4--------5
62. A child became seriously ill or injured	Yes	No	1--------2--------3--------4--------5
63. An ongoing illness in a family member got worse	Yes	No	1--------2--------3--------4--------5
64. Close relative or friend of the family became seriously ill	Yes	No	1--------2--------3--------4--------5
65. A family friend became physically disabled or chronically ill	Yes	No	1--------2--------3--------4--------5



	Has this event happened in the **PAST 12** months?		**IF YES**, how much impact/effect has this event had on **YOU**.
			No effect at all — Some effect — Very big effect
66. Increased difficulty in managing a chronically ill or disabled family member	Yes	No	1--------2--------3--------4--------5
67. A family member or close relative was committed to an institution or nursing home	Yes	No	1--------2--------3--------4--------5
68. A family member appears to have emotional problems	Yes	No	1--------2--------3--------4--------5
69. A family member appears to depend on alcohol or drugs	Yes	No	1--------2--------3--------4--------5
70. A family member saw a professional for emotional problems	Yes	No	1--------2--------3--------4--------5
71. A family member was brought to the emergency room	Yes	No	1--------2--------3--------4--------5
72. Increased responsibility to provide direct care or financial help to your parents or spouse/significant other's parents	Yes	No	1--------2--------3--------4--------5
DEATHS			
73. Your child's father/mother died (or your spouse significant/other died)	Yes	No	1--------2--------3--------4--------5
74. A child family member died	Yes	No	1--------2--------3--------4--------5
75. Death of a close relative	Yes	No	1--------2--------3--------4--------5
76. Close friend of the family died	Yes	No	1--------2--------3--------4--------5
77. A family pet died	Yes	No	1--------2--------3--------4--------5
OTHER			
78. A family member started college (or post high school training)	Yes	No	1--------2--------3--------4--------5
79. Young adult family member left home (other than for school)	Yes	No	1--------2--------3--------4--------5
80. A family member ran away from home	Yes	No	1--------2--------3--------4--------5
81. A family member moved back home or a new person moved into the home	Yes	No	1--------2--------3--------4--------5
82. A family member dropped out of school or was suspended from school	Yes	No	1--------2--------3--------4--------5



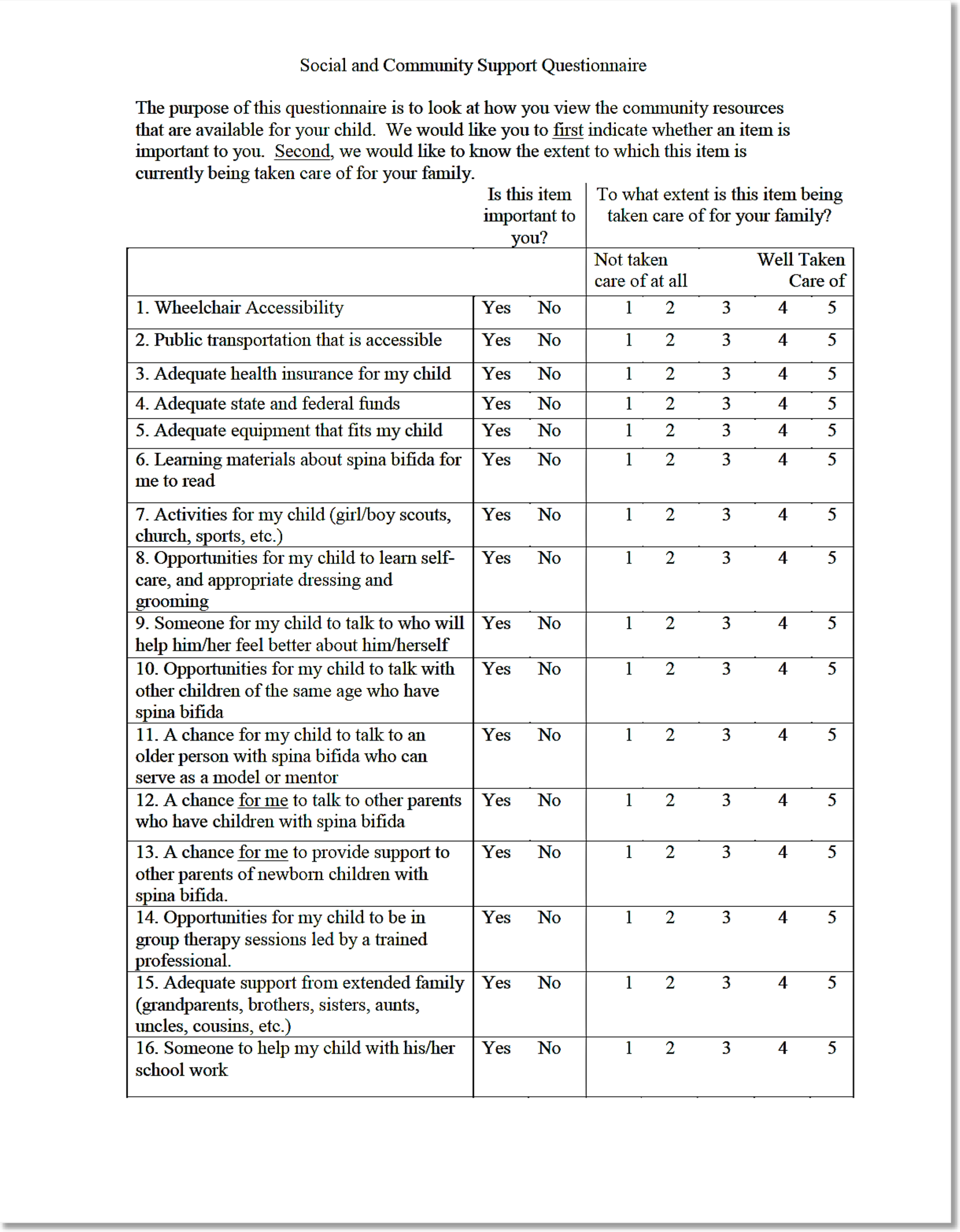
	Has this event happened in the **PAST 12** months?	**IF YES**, how much impact/effect has this event had on **YOU**.
		No effect Some Very big at all effect effect
83. A family member was picked up by police or arrested	Yes No	1--------2--------3--------4--------5
84. A family member went to jail, prison, or juvenile detention	Yes No	1--------2--------3--------4--------5
85. A family member was attacked or robbed	Yes No	1--------2--------3--------4--------5
86. Physical or sexual abuse or violence in the home	Yes No	1--------2--------3--------4--------5
87. Your home was damaged or destroyed (fire, flood, tornado, etc.)	Yes No	1--------2--------3--------4--------5
88. Your home was robbed	Yes No	1--------2--------3--------4--------5
89. The family received bad news	Yes No	1--------2--------3--------4--------5
90. The family went on vacation	Yes No	1--------2--------3--------4--------5

Please list any additional events or changes that have happened to you or your family during the last 12 months:

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________

Please describe any positive events or changes that happened to your family, yourself, or your child(ren):

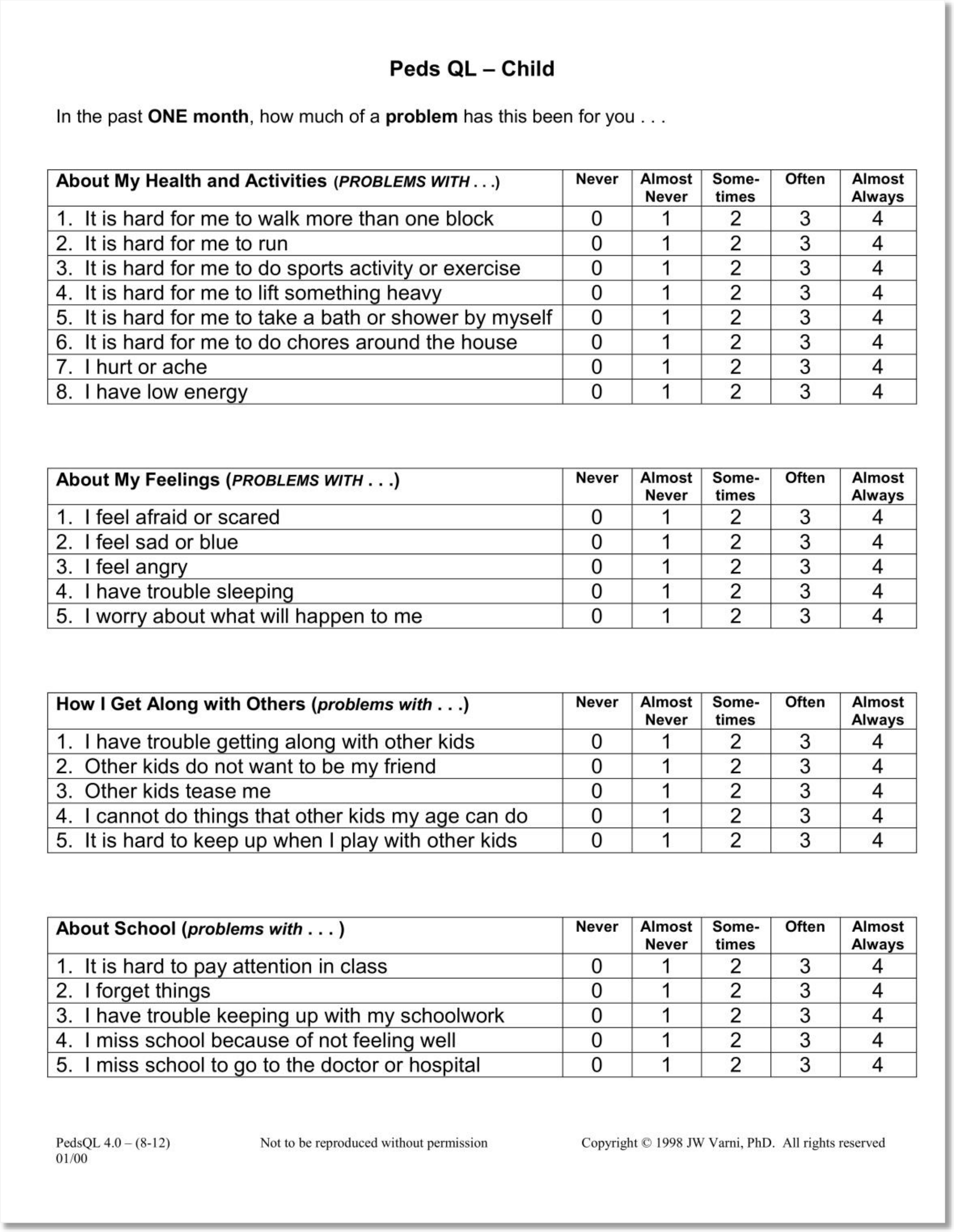
1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________



Social and Community Support Questionnaire

The purpose of this questionnaire is to look at how you view the community resources that are available for your child. We would like you to first indicate whether an item is important to you. Second, we would like to know the extent to which this item is currently being taken care of for your family.

	Is this item important to you?		To what extent is this item being taken care of for your family?				
			Not taken care of at all				Well Taken Care of
1. Wheelchair Accessibility	Yes	No	1	2	3	4	5
2. Public transportation that is accessible	Yes	No	1	2	3	4	5
3. Adequate health insurance for my child	Yes	No	1	2	3	4	5
4. Adequate state and federal funds	Yes	No	1	2	3	4	5
5. Adequate equipment that fits my child	Yes	No	1	2	3	4	5
6. Learning materials about spina bifida for me to read	Yes	No	1	2	3	4	5
7. Activities for my child (girl/boy scouts, church, sports, etc.)	Yes	No	1	2	3	4	5
8. Opportunities for my child to learn self-care, and appropriate dressing and grooming	Yes	No	1	2	3	4	5
9. Someone for my child to talk to who will help him/her feel better about him/herself	Yes	No	1	2	3	4	5
10. Opportunities for my child to talk with other children of the same age who have spina bifida	Yes	No	1	2	3	4	5
11. A chance for my child to talk to an older person with spina bifida who can serve as a model or mentor	Yes	No	1	2	3	4	5
12. A chance for me to talk to other parents who have children with spina bifida	Yes	No	1	2	3	4	5
13. A chance for me to provide support to other parents of newborn children with spina bifida.	Yes	No	1	2	3	4	5
14. Opportunities for my child to be in group therapy sessions led by a trained professional.	Yes	No	1	2	3	4	5
15. Adequate support from extended family (grandparents, brothers, sisters, aunts, uncles, cousins, etc.)	Yes	No	1	2	3	4	5
16. Someone to help my child with his/her school work	Yes	No	1	2	3	4	5



Peds QL – Child

In the past **ONE month**, how much of a **problem** has this been for you . . .

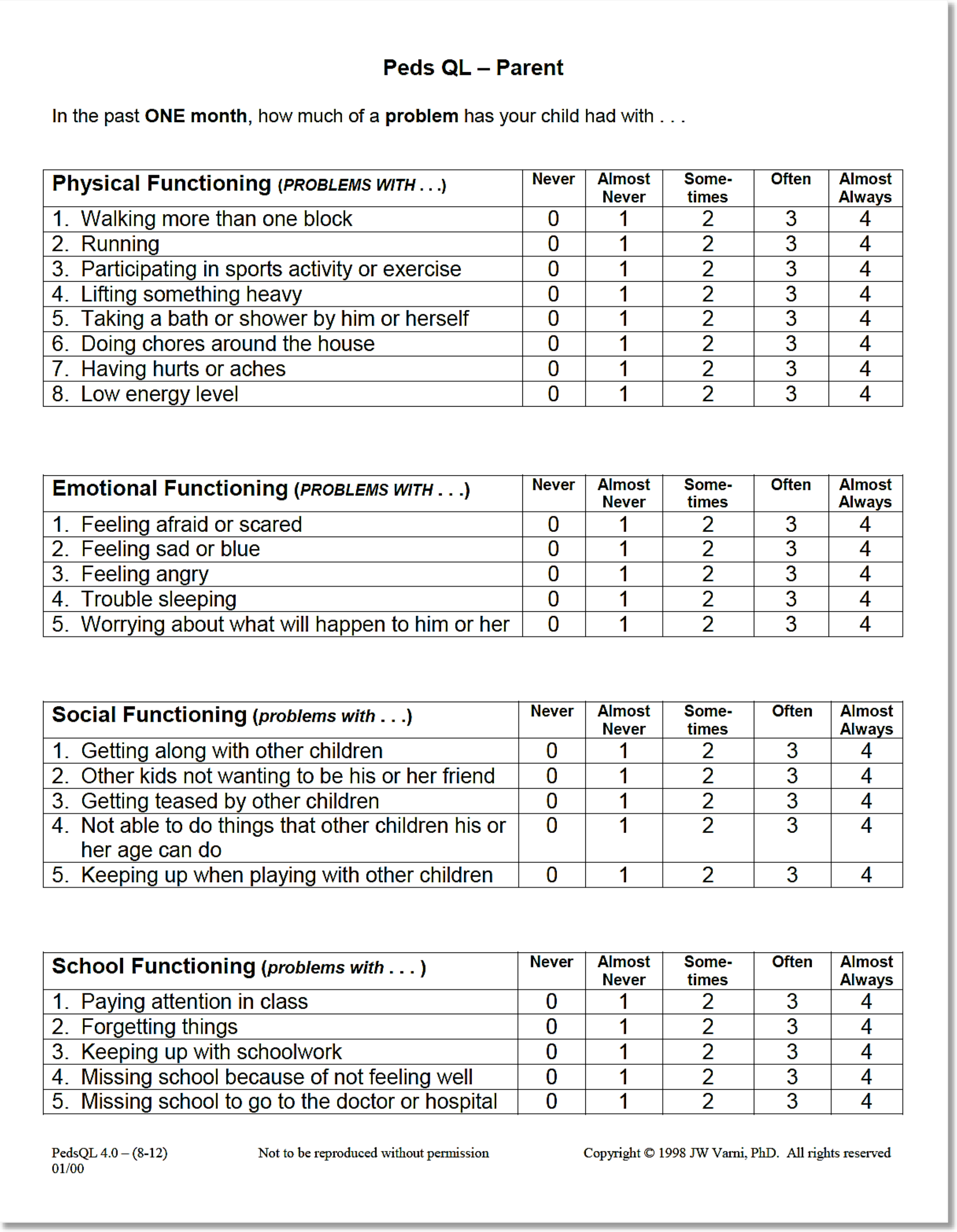
About My Health and Activities (*PROBLEMS WITH . . .*)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

About My Feelings (*PROBLEMS WITH . . .*)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

How I Get Along with Others (*problems with . . .*)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. I have trouble getting along with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

About School (*problems with . . .*)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

PedsQL 4.0 – (8-12)
01/00



Peds QL – Parent

In the past **ONE month**, how much of a **problem** has your child had with . . .

Physical Functioning (***PROBLEMS WITH . . .***)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Walking more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores around the house	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

Emotional Functioning (***PROBLEMS WITH . . .***)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

Social Functioning (***problems with . . .***)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

School Functioning (***problems with . . .***)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with schoolwork	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

PedsQL 4.0 – (8-12)
01/00

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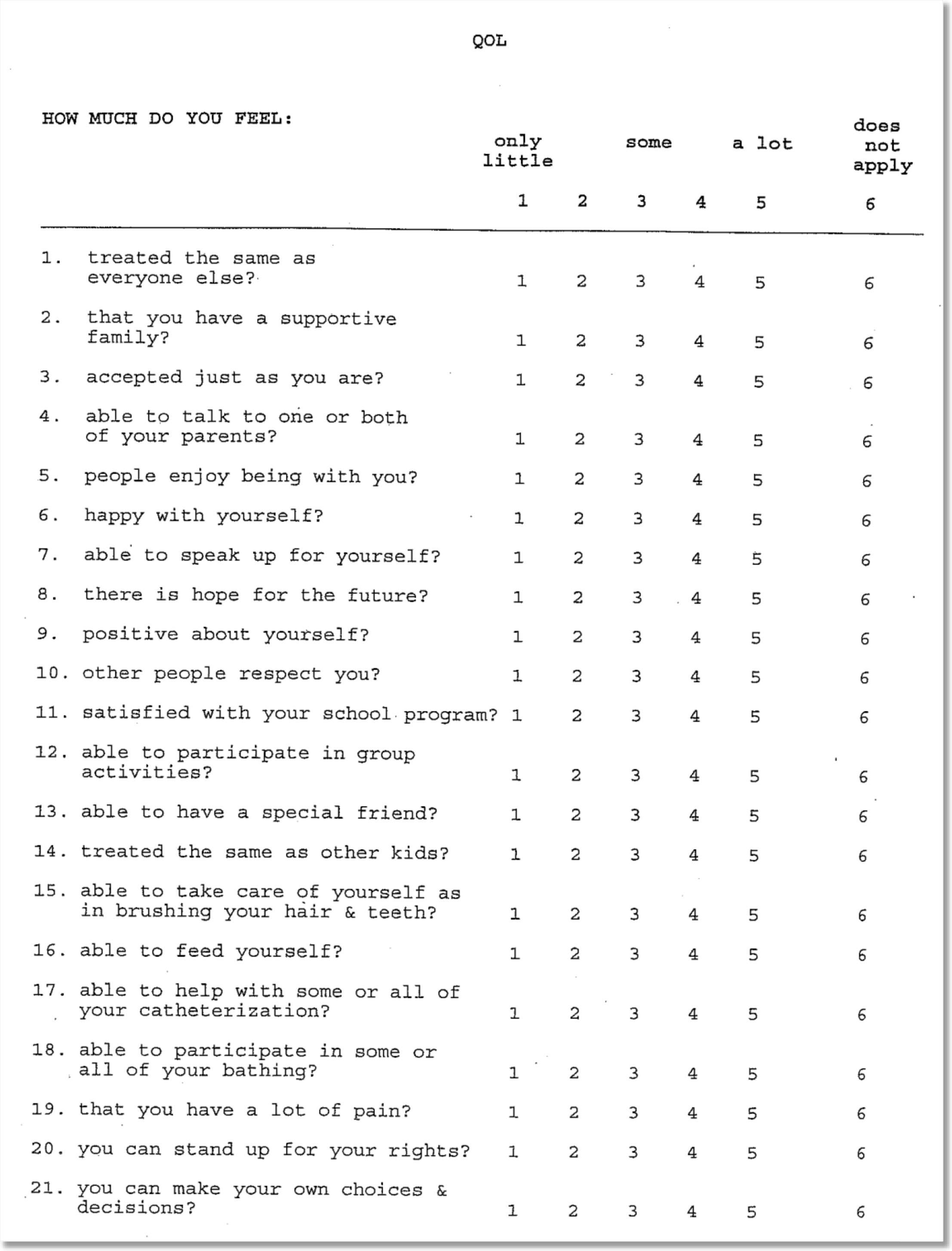
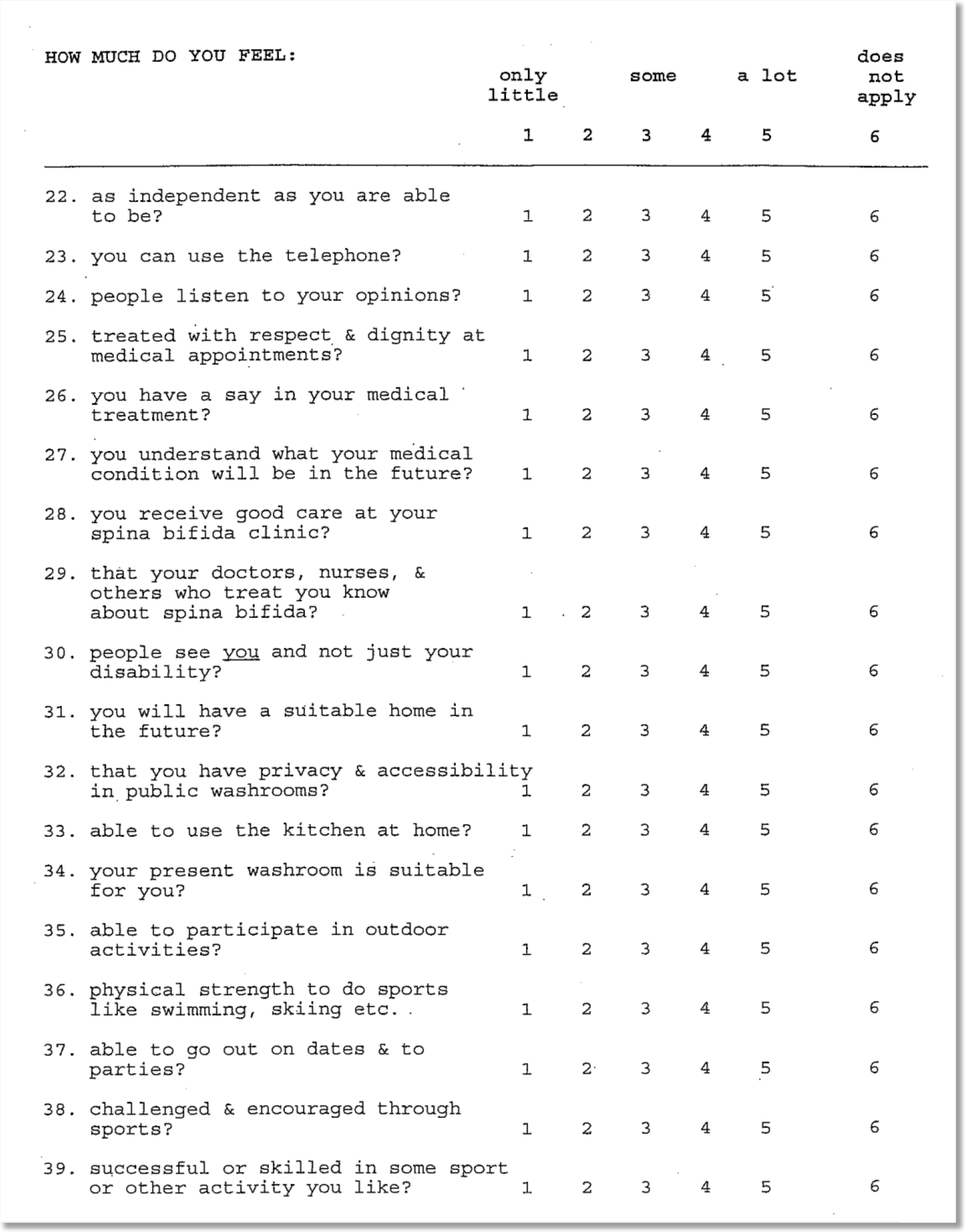
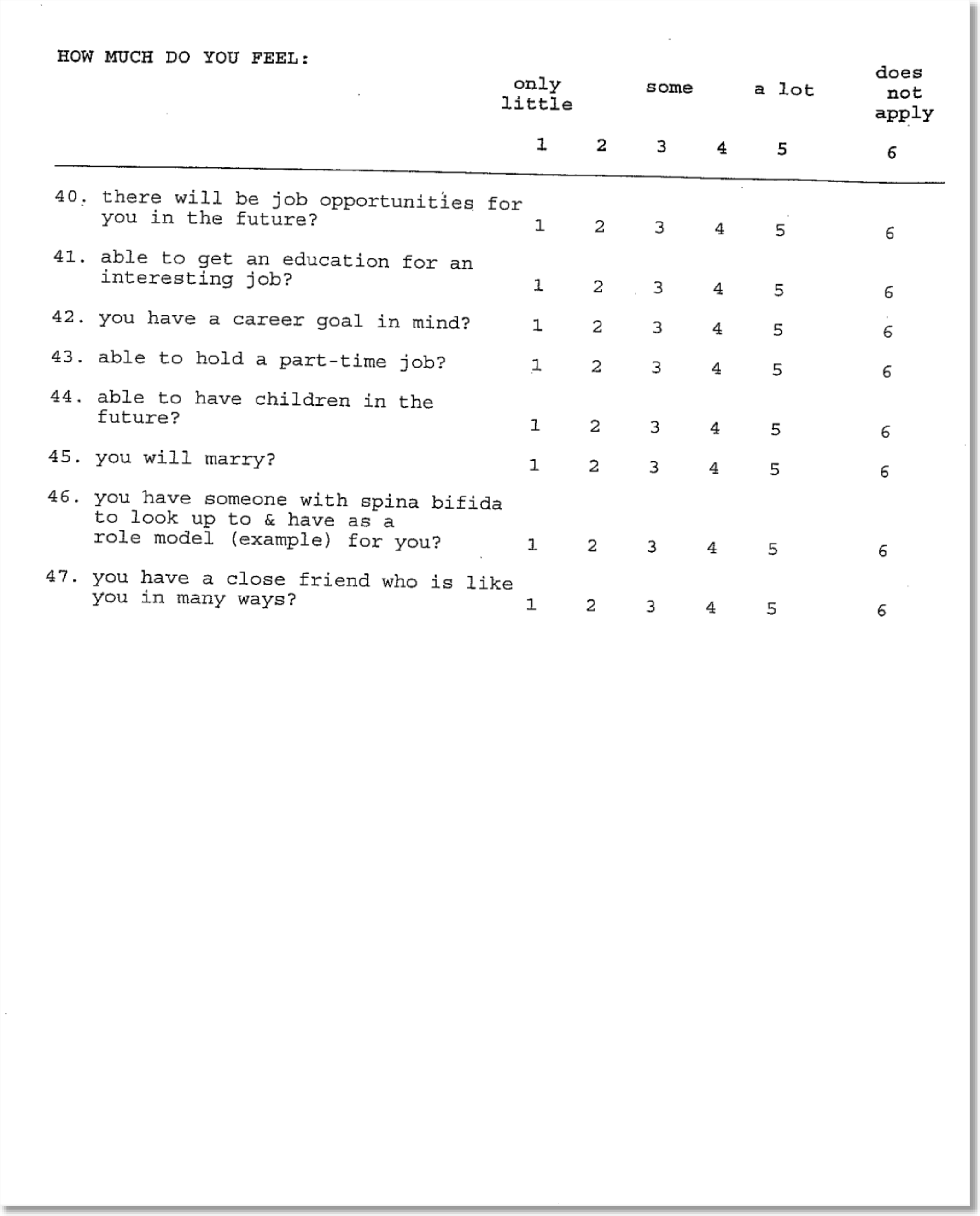


QOL

HOW MUCH DO YOU FEEL:	only little		some		a lot	does not apply
	1	2	3	4	5	6
1. treated the same as everyone else?	1	2	3	4	5	6
2. that you have a supportive family?	1	2	3	4	5	6
3. accepted just as you are?	1	2	3	4	5	6
4. able to talk to one or both of your parents?	1	2	3	4	5	6
5. people enjoy being with you?	1	2	3	4	5	6
6. happy with yourself?	1	2	3	4	5	6
7. able to speak up for yourself?	1	2	3	4	5	6
8. there is hope for the future?	1	2	3	4	5	6
9. positive about yourself?	1	2	3	4	5	6
10. other people respect you?	1	2	3	4	5	6
11. satisfied with your school program?	1	2	3	4	5	6
12. able to participate in group activities?	1	2	3	4	5	6
13. able to have a special friend?	1	2	3	4	5	6
14. treated the same as other kids?	1	2	3	4	5	6
15. able to take care of yourself as in brushing your hair & teeth?	1	2	3	4	5	6
16. able to feed yourself?	1	2	3	4	5	6
17. able to help with some or all of your catheterization?	1	2	3	4	5	6
18. able to participate in some or all of your bathing?	1	2	3	4	5	6
19. that you have a lot of pain?	1	2	3	4	5	6
20. you can stand up for your rights?	1	2	3	4	5	6
21. you can make your own choices & decisions?	1	2	3	4	5	6

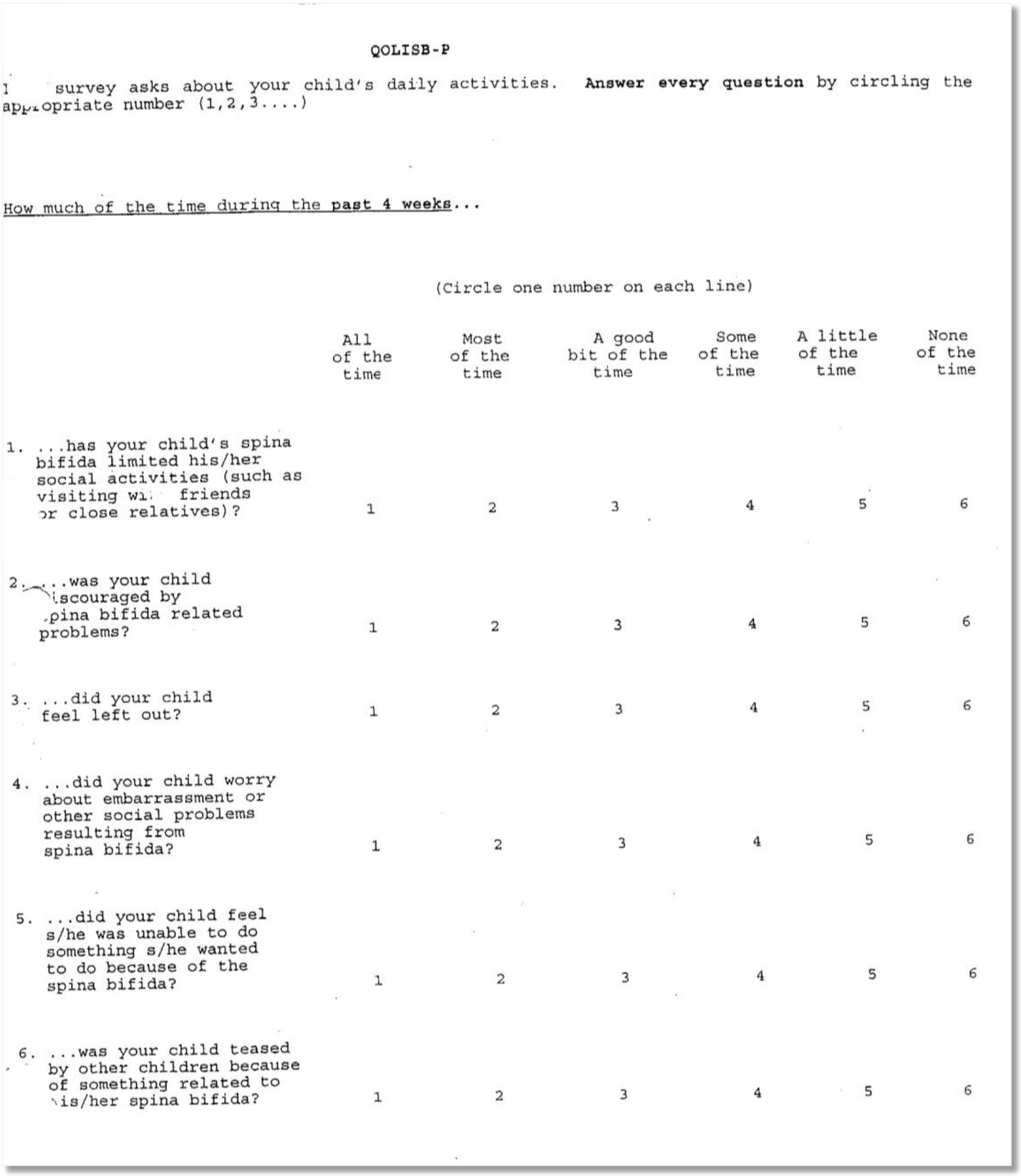


HOW MUCH DO YOU FEEL:	only little **1**	**2**	some **3**	**4**	a lot **5**	does not apply **6**
22. as independent as you are able to be?	1	2	3	4	5	6
23. you can use the telephone?	1	2	3	4	5	6
24. people listen to your opinions?	1	2	3	4	5	6
25. treated with respect & dignity at medical appointments?	1	2	3	4	5	6
26. you have a say in your medical treatment?	1	2	3	4	5	6
27. you understand what your medical condition will be in the future?	1	2	3	4	5	6
28. you receive good care at your spina bifida clinic?	1	2	3	4	5	6
29. that your doctors, nurses, & others who treat you know about spina bifida?	1	2	3	4	5	6
30. people see <u>you</u> and not just your disability?	1	2	3	4	5	6
31. you will have a suitable home in the future?	1	2	3	4	5	6
32. that you have privacy & accessibility in public washrooms?	1	2	3	4	5	6
33. able to use the kitchen at home?	1	2	3	4	5	6
34. your present washroom is suitable for you?	1	2	3	4	5	6
35. able to participate in outdoor activities?	1	2	3	4	5	6
36. physical strength to do sports like swimming, skiing etc.	1	2	3	4	5	6
37. able to go out on dates & to parties?	1	2	3	4	5	6
38. challenged & encouraged through sports?	1	2	3	4	5	6
39. successful or skilled in some sport or other activity you like?	1	2	3	4	5	6



HOW MUCH DO YOU FEEL:

	only little		some		a lot	does not apply
	1	2	3	4	5	6
40. there will be job opportunities for you in the future?	1	2	3	4	5	6
41. able to get an education for an interesting job?	1	2	3	4	5	6
42. you have a career goal in mind?	1	2	3	4	5	6
43. able to hold a part-time job?	1	2	3	4	5	6
44. able to have children in the future?	1	2	3	4	5	6
45. you will marry?	1	2	3	4	5	6
46. you have someone with spina bifida to look up to & have as a role model (example) for you?	1	2	3	4	5	6
47. you have a close friend who is like you in many ways?	1	2	3	4	5	6



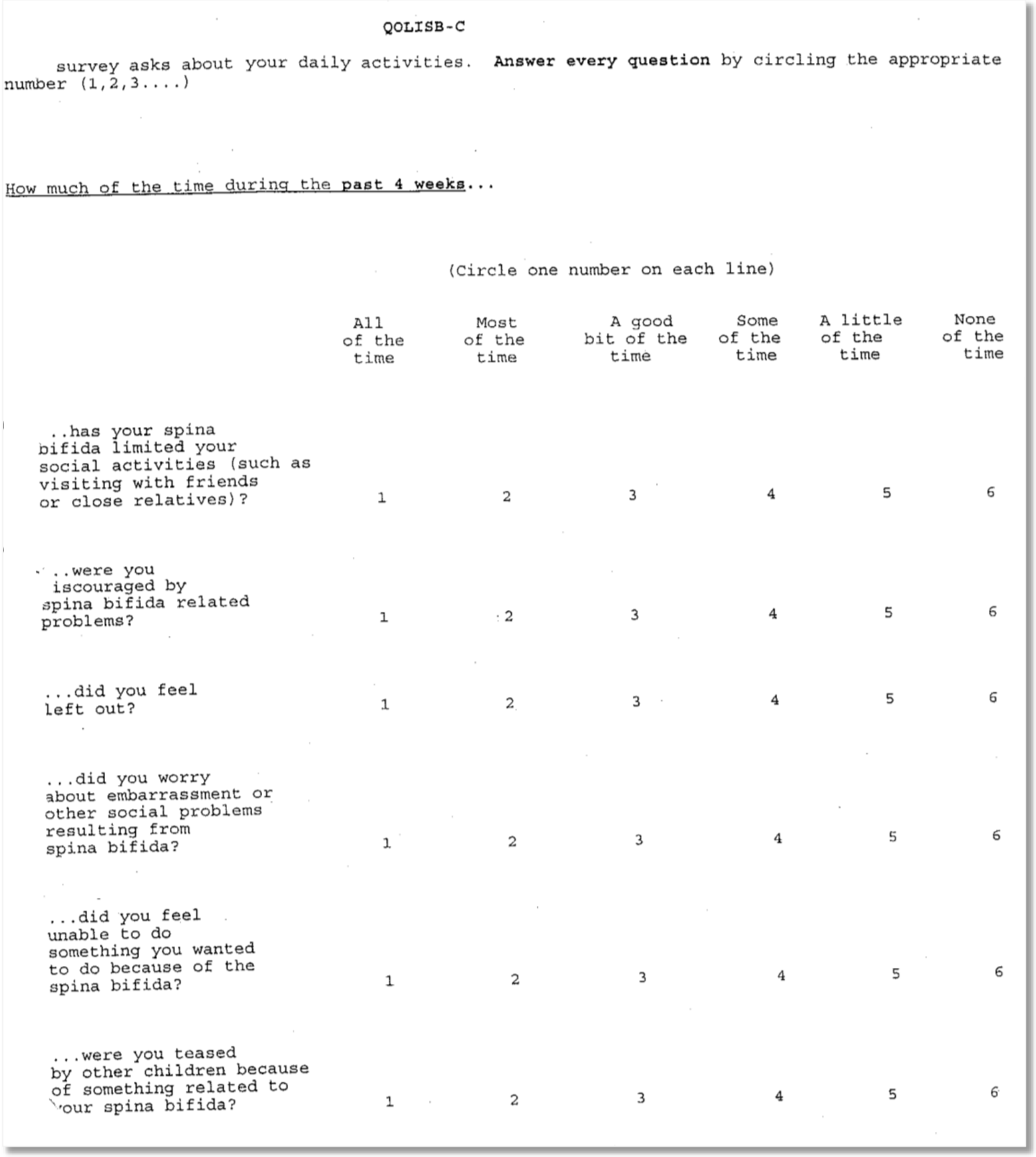
QOLISB-P

This survey asks about your child's daily activities. **Answer every question** by circling the appropriate number (1,2,3....)

How much of the time during the **past 4 weeks**...

(Circle one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
1. ...has your child's spina bifida limited his/her social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6
2. ...was your child discouraged by spina bifida related problems?	1	2	3	4	5	6
3. ...did your child feel left out?	1	2	3	4	5	6
4. ...did your child worry about embarrassment or other social problems resulting from spina bifida?	1	2	3	4	5	6
5. ...did your child feel s/he was unable to do something s/he wanted to do because of the spina bifida?	1	2	3	4	5	6
6. ...was your child teased by other children because of something related to his/her spina bifida?	1	2	3	4	5	6



QOLISB-C

survey asks about your daily activities. **Answer every question** by circling the appropriate number (1,2,3....)

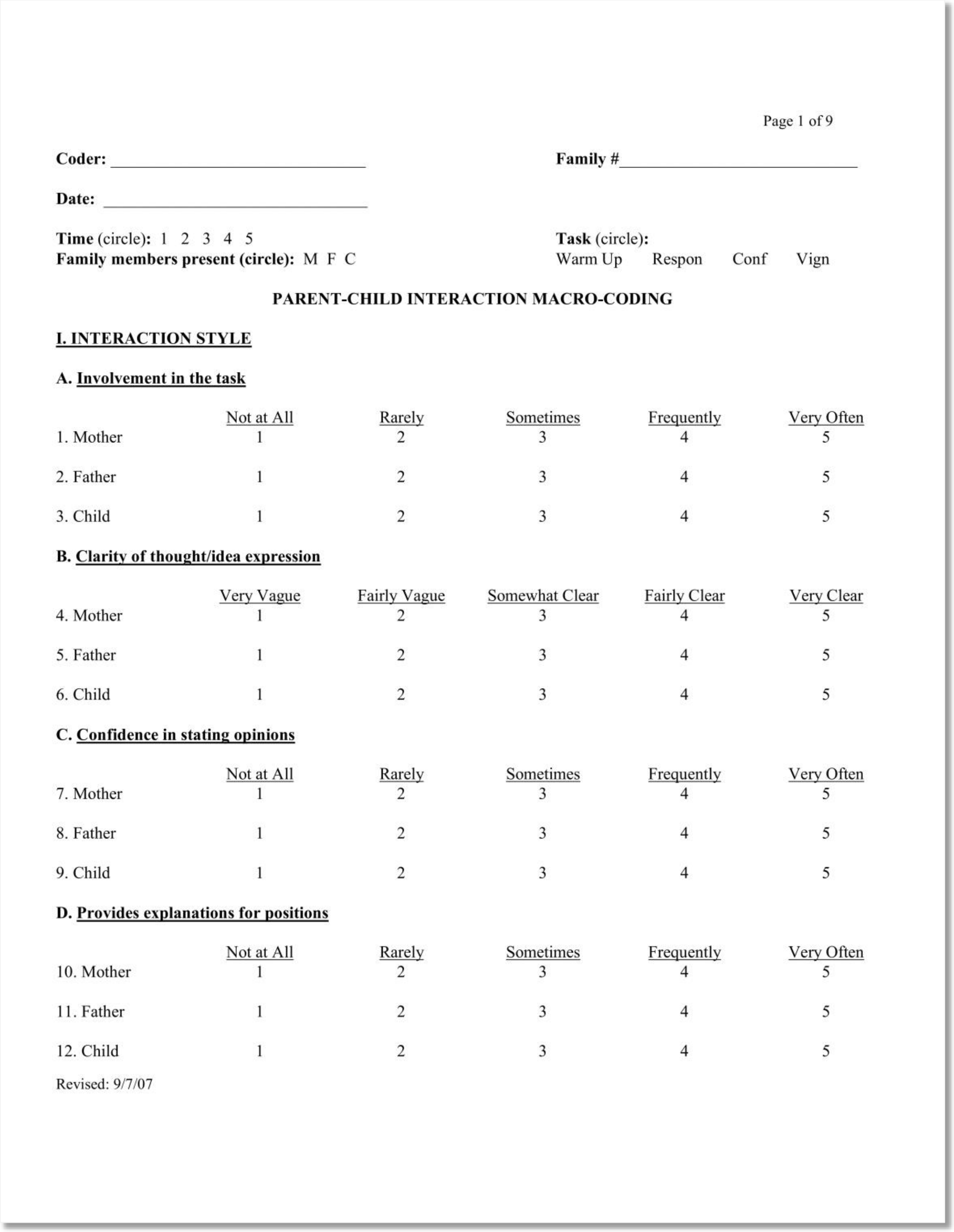
How much of the time during the **past 4 weeks**...

(Circle one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
..has your spina bifida limited your social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6
..were you iscouraged by spina bifida related problems?	1	2	3	4	5	6
...did you feel left out?	1	2	3	4	5	6
...did you worry about embarrassment or other social problems resulting from spina bifida?	1	2	3	4	5	6
...did you feel unable to do something you wanted to do because of the spina bifida?	1	2	3	4	5	6
...were you teased by other children because of something related to your spina bifida?	1	2	3	4	5	6

APPENDIX B

OBSERVATIONAL CODING MANUAL



Page 1 of 9

Coder: ______________________________ **Family #**____________________________

Date: _______________________________

Time (circle)**:** 1 2 3 4 5

Family members present (circle): M F C

Task (circle)**:**
Warm Up Respon Conf Vign

PARENT-CHILD INTERACTION MACRO-CODING

I. INTERACTION STYLE

A. Involvement in the task

	Not at All	Rarely	Sometimes	Frequently	Very Often
1. Mother	1	2	3	4	5
2. Father	1	2	3	4	5
3. Child	1	2	3	4	5

B. Clarity of thought/idea expression

	Very Vague	Fairly Vague	Somewhat Clear	Fairly Clear	Very Clear
4. Mother	1	2	3	4	5
5. Father	1	2	3	4	5
6. Child	1	2	3	4	5

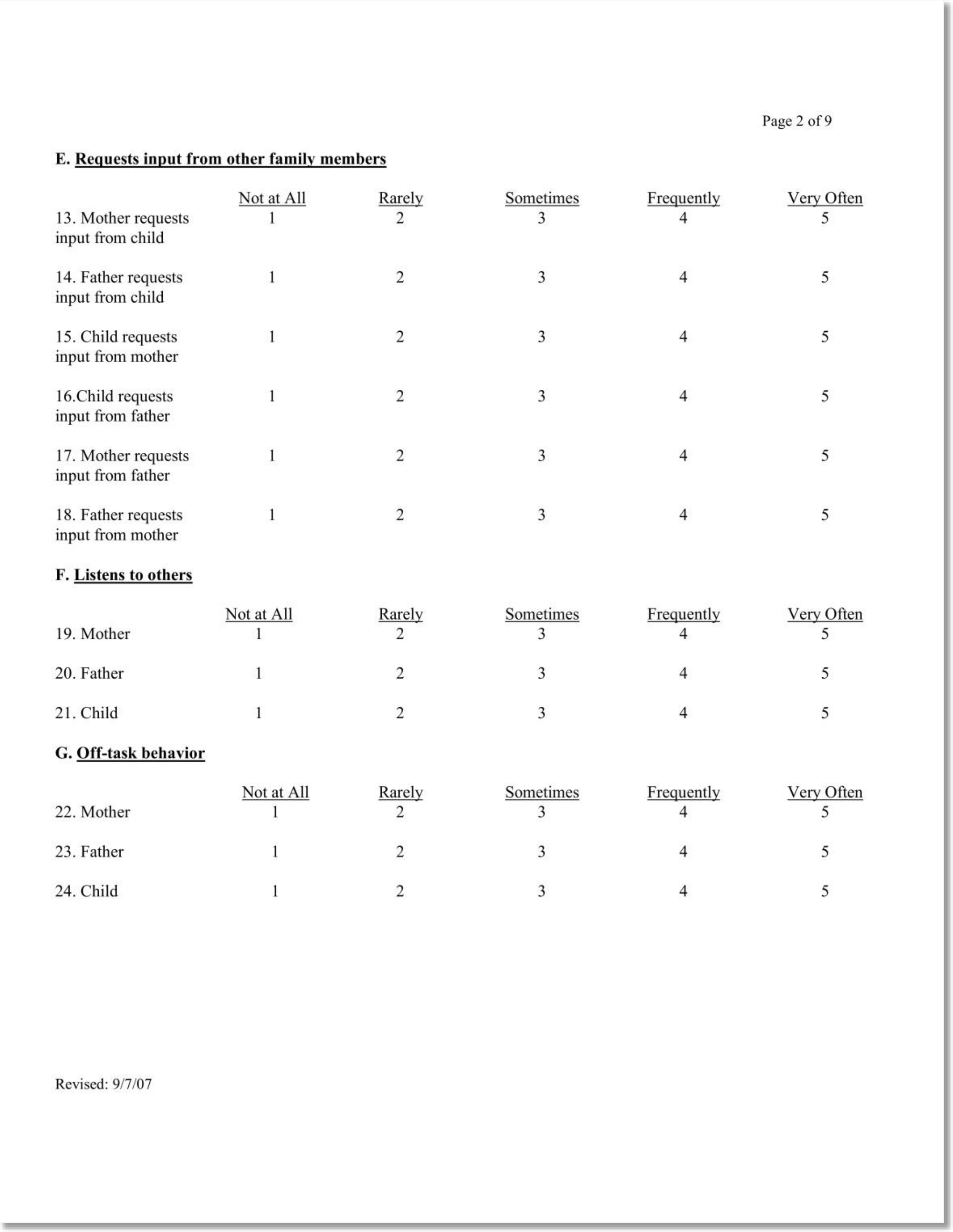
C. Confidence in stating opinions

	Not at All	Rarely	Sometimes	Frequently	Very Often
7. Mother	1	2	3	4	5
8. Father	1	2	3	4	5
9. Child	1	2	3	4	5

D. Provides explanations for positions

	Not at All	Rarely	Sometimes	Frequently	Very Often
10. Mother	1	2	3	4	5
11. Father	1	2	3	4	5
12. Child	1	2	3	4	5

Revised: 9/7/07



E. Requests input from other family members

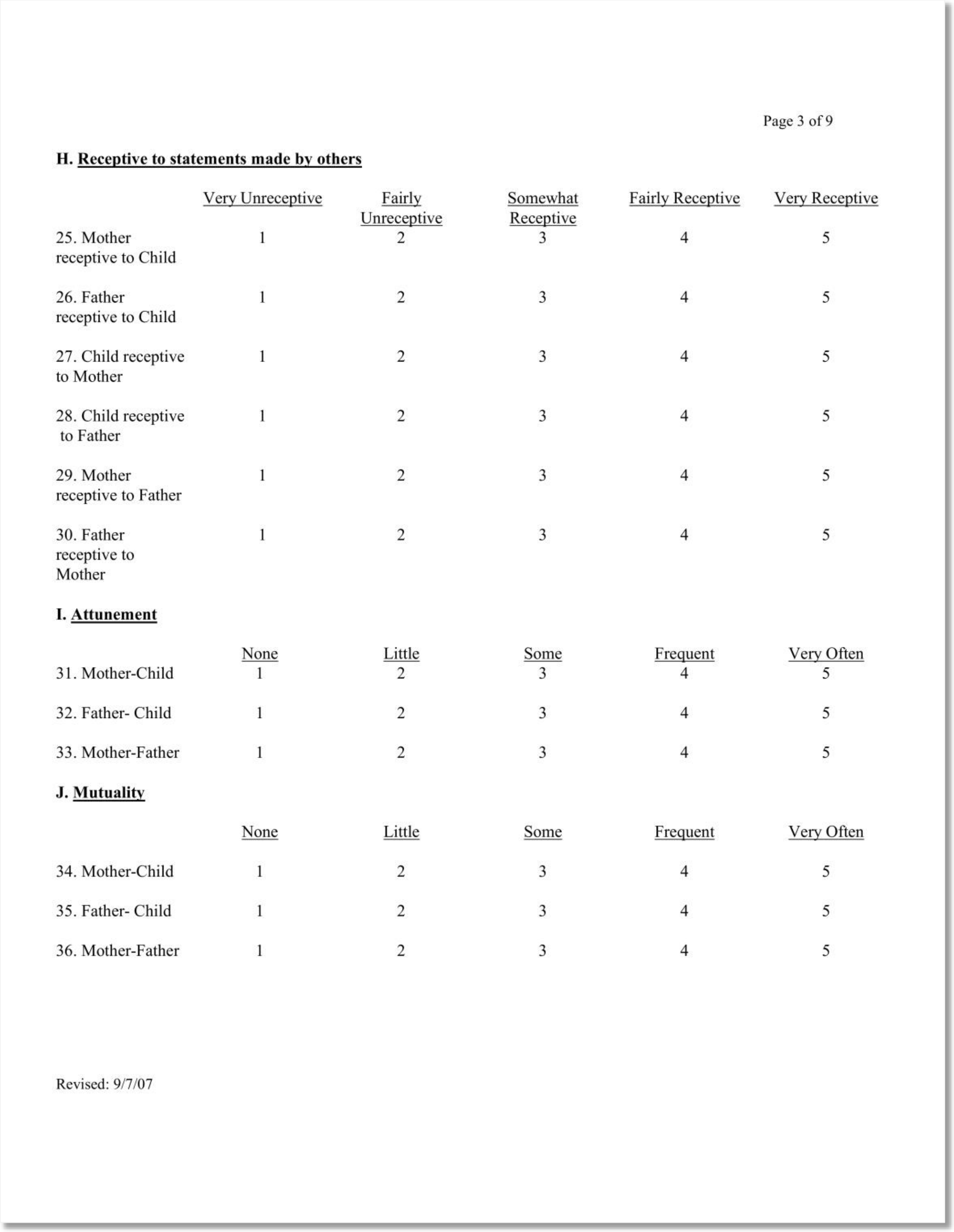
	Not at All	Rarely	Sometimes	Frequently	Very Often
13. Mother requests input from child	1	2	3	4	5
14. Father requests input from child	1	2	3	4	5
15. Child requests input from mother	1	2	3	4	5
16.Child requests input from father	1	2	3	4	5
17. Mother requests input from father	1	2	3	4	5
18. Father requests input from mother	1	2	3	4	5

F. Listens to others

	Not at All	Rarely	Sometimes	Frequently	Very Often
19. Mother	1	2	3	4	5
20. Father	1	2	3	4	5
21. Child	1	2	3	4	5

G. Off-task behavior

	Not at All	Rarely	Sometimes	Frequently	Very Often
22. Mother	1	2	3	4	5
23. Father	1	2	3	4	5
24. Child	1	2	3	4	5



H. Receptive to statements made by others

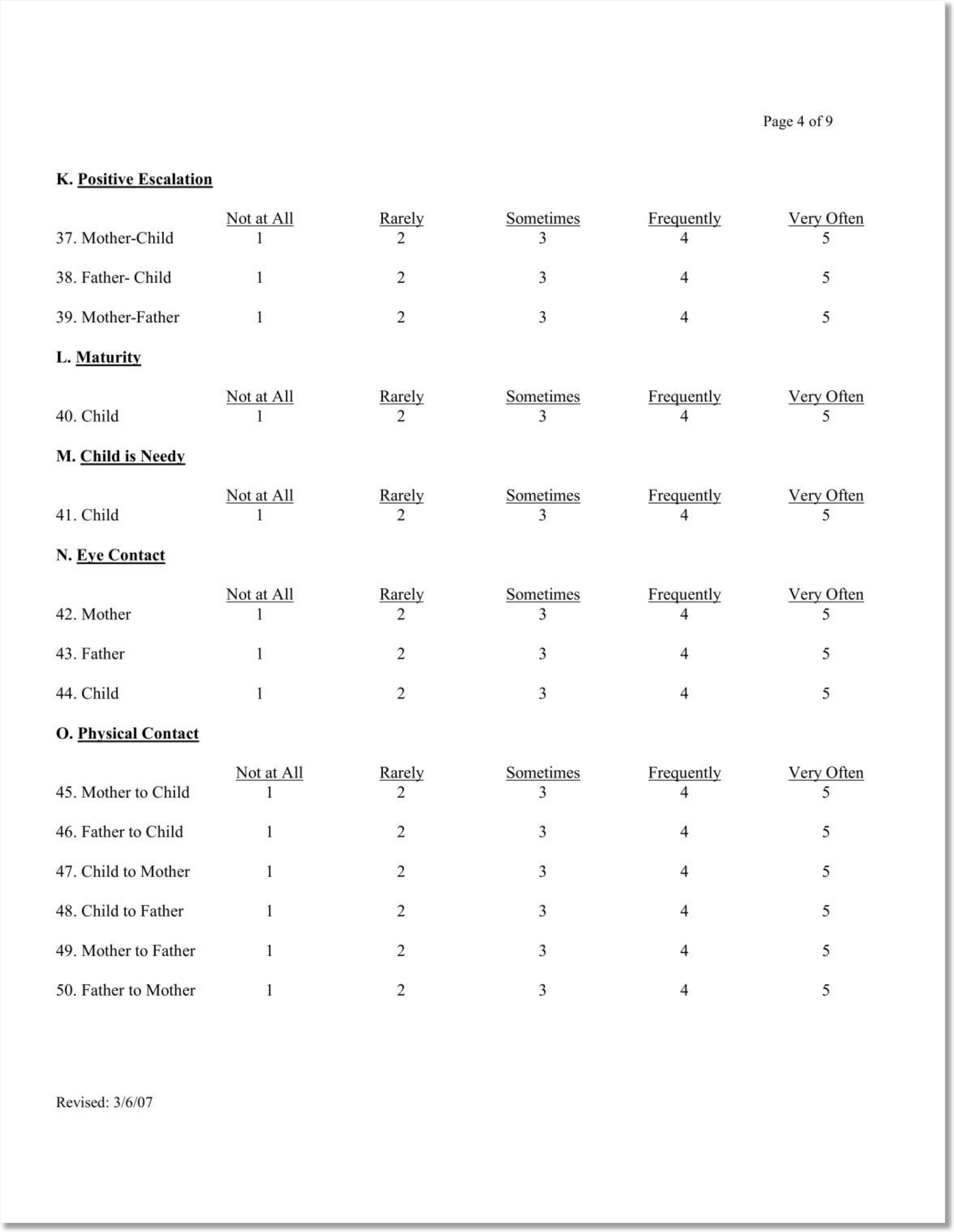
	Very Unreceptive	Fairly Unreceptive	Somewhat Receptive	Fairly Receptive	Very Receptive
25. Mother receptive to Child	1	2	3	4	5
26. Father receptive to Child	1	2	3	4	5
27. Child receptive to Mother	1	2	3	4	5
28. Child receptive to Father	1	2	3	4	5
29. Mother receptive to Father	1	2	3	4	5
30. Father receptive to Mother	1	2	3	4	5

I. Attunement

	None	Little	Some	Frequent	Very Often
31. Mother-Child	1	2	3	4	5
32. Father- Child	1	2	3	4	5
33. Mother-Father	1	2	3	4	5

J. Mutuality

	None	Little	Some	Frequent	Very Often
34. Mother-Child	1	2	3	4	5
35. Father- Child	1	2	3	4	5
36. Mother-Father	1	2	3	4	5



K. Positive Escalation

	Not at All	Rarely	Sometimes	Frequently	Very Often
37. Mother-Child	1	2	3	4	5
38. Father- Child	1	2	3	4	5
39. Mother-Father	1	2	3	4	5

L. Maturity

	Not at All	Rarely	Sometimes	Frequently	Very Often
40. Child	1	2	3	4	5

M. Child is Needy

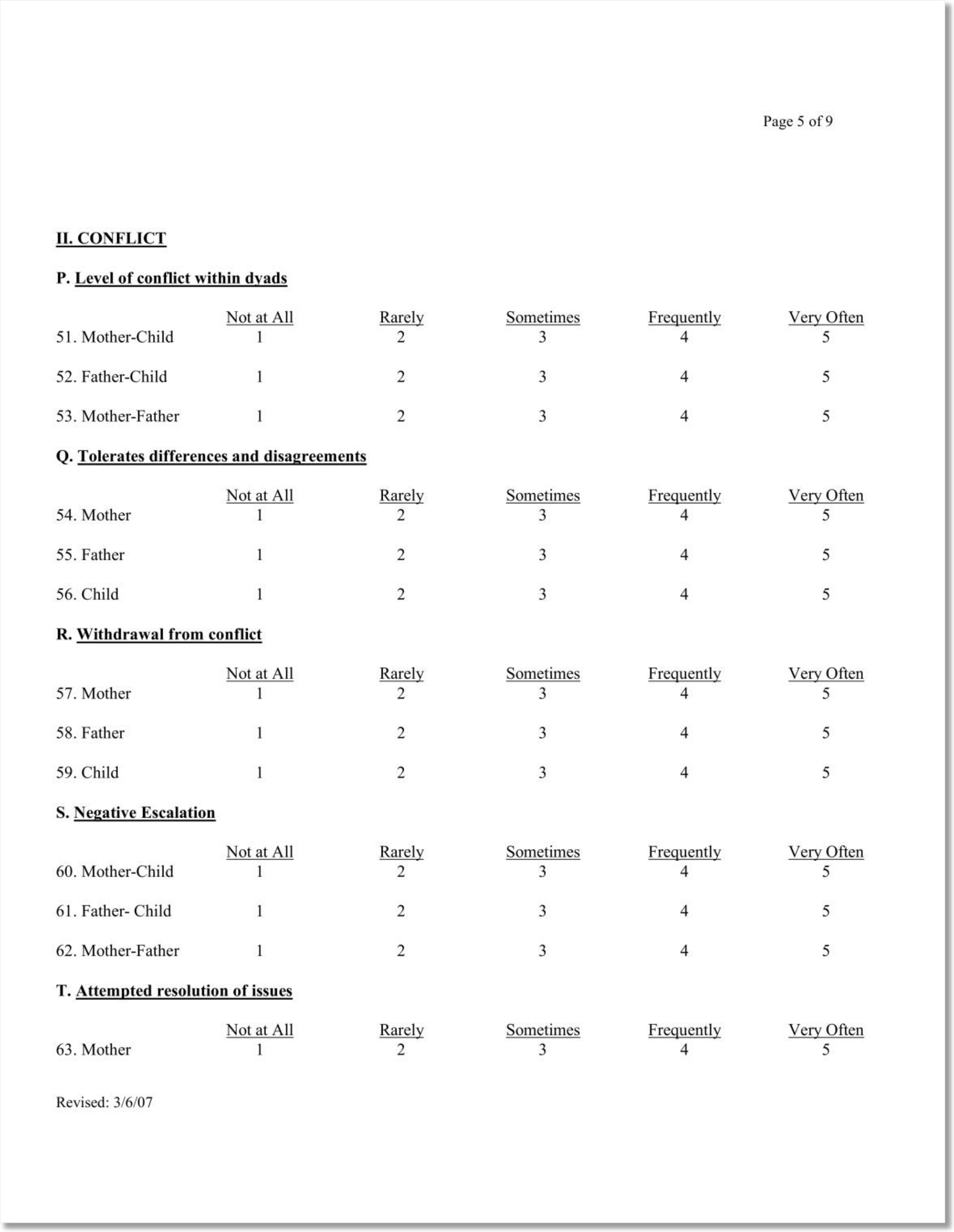
	Not at All	Rarely	Sometimes	Frequently	Very Often
41. Child	1	2	3	4	5

N. Eye Contact

	Not at All	Rarely	Sometimes	Frequently	Very Often
42. Mother	1	2	3	4	5
43. Father	1	2	3	4	5
44. Child	1	2	3	4	5

O. Physical Contact

	Not at All	Rarely	Sometimes	Frequently	Very Often
45. Mother to Child	1	2	3	4	5
46. Father to Child	1	2	3	4	5
47. Child to Mother	1	2	3	4	5
48. Child to Father	1	2	3	4	5
49. Mother to Father	1	2	3	4	5
50. Father to Mother	1	2	3	4	5



II. CONFLICT

P. Level of conflict within dyads

	Not at All	Rarely	Sometimes	Frequently	Very Often
51. Mother-Child	1	2	3	4	5
52. Father-Child	1	2	3	4	5
53. Mother-Father	1	2	3	4	5

Q. Tolerates differences and disagreements

	Not at All	Rarely	Sometimes	Frequently	Very Often
54. Mother	1	2	3	4	5
55. Father	1	2	3	4	5
56. Child	1	2	3	4	5

R. Withdrawal from conflict

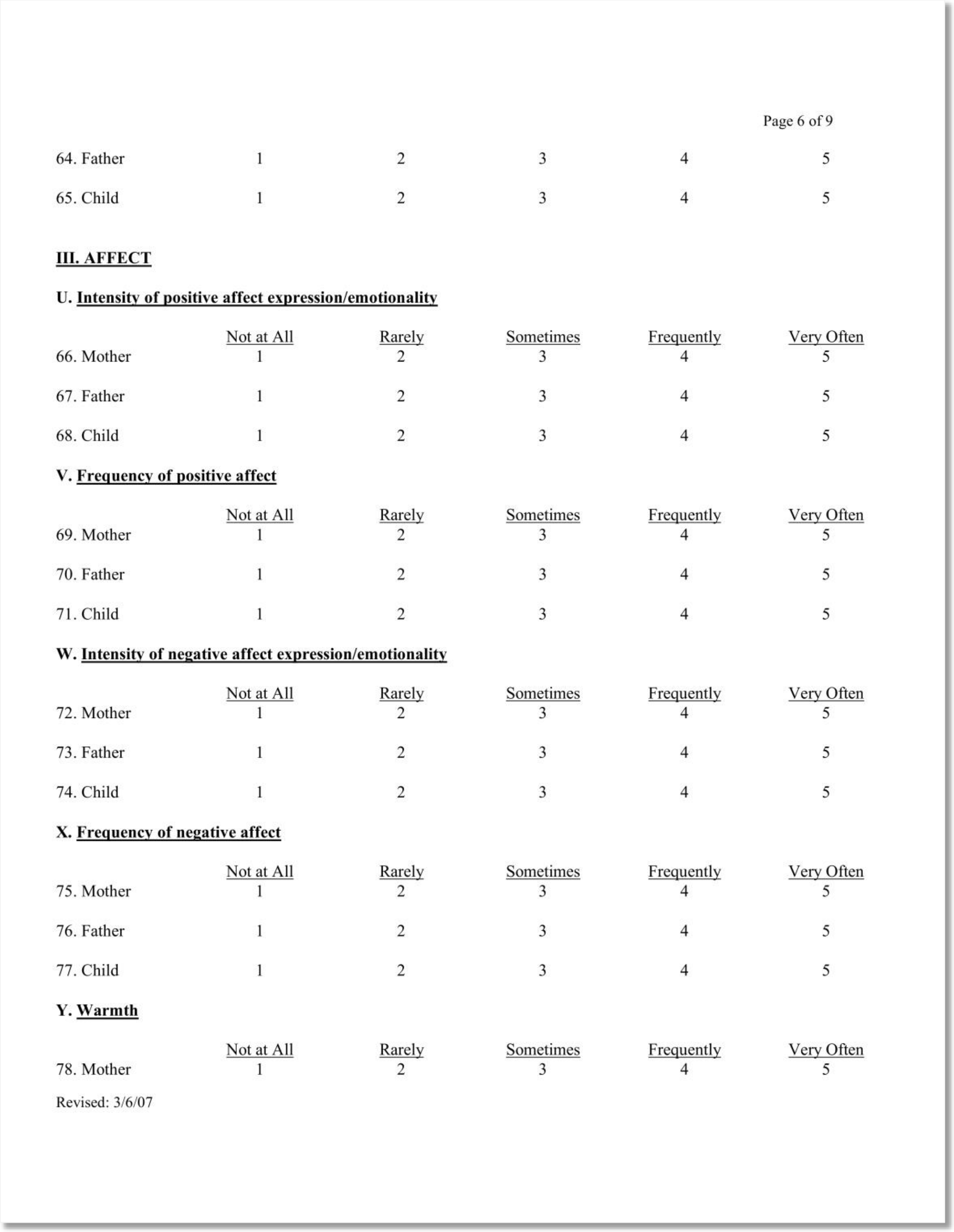
	Not at All	Rarely	Sometimes	Frequently	Very Often
57. Mother	1	2	3	4	5
58. Father	1	2	3	4	5
59. Child	1	2	3	4	5

S. Negative Escalation

	Not at All	Rarely	Sometimes	Frequently	Very Often
60. Mother-Child	1	2	3	4	5
61. Father- Child	1	2	3	4	5
62. Mother-Father	1	2	3	4	5

T. Attempted resolution of issues

	Not at All	Rarely	Sometimes	Frequently	Very Often
63. Mother	1	2	3	4	5



64. Father	1	2	3	4	5
65. Child	1	2	3	4	5

III. AFFECT

U. Intensity of positive affect expression/emotionality

	Not at All	Rarely	Sometimes	Frequently	Very Often
66. Mother	1	2	3	4	5
67. Father	1	2	3	4	5
68. Child	1	2	3	4	5

V. Frequency of positive affect

	Not at All	Rarely	Sometimes	Frequently	Very Often
69. Mother	1	2	3	4	5
70. Father	1	2	3	4	5
71. Child	1	2	3	4	5

W. Intensity of negative affect expression/emotionality

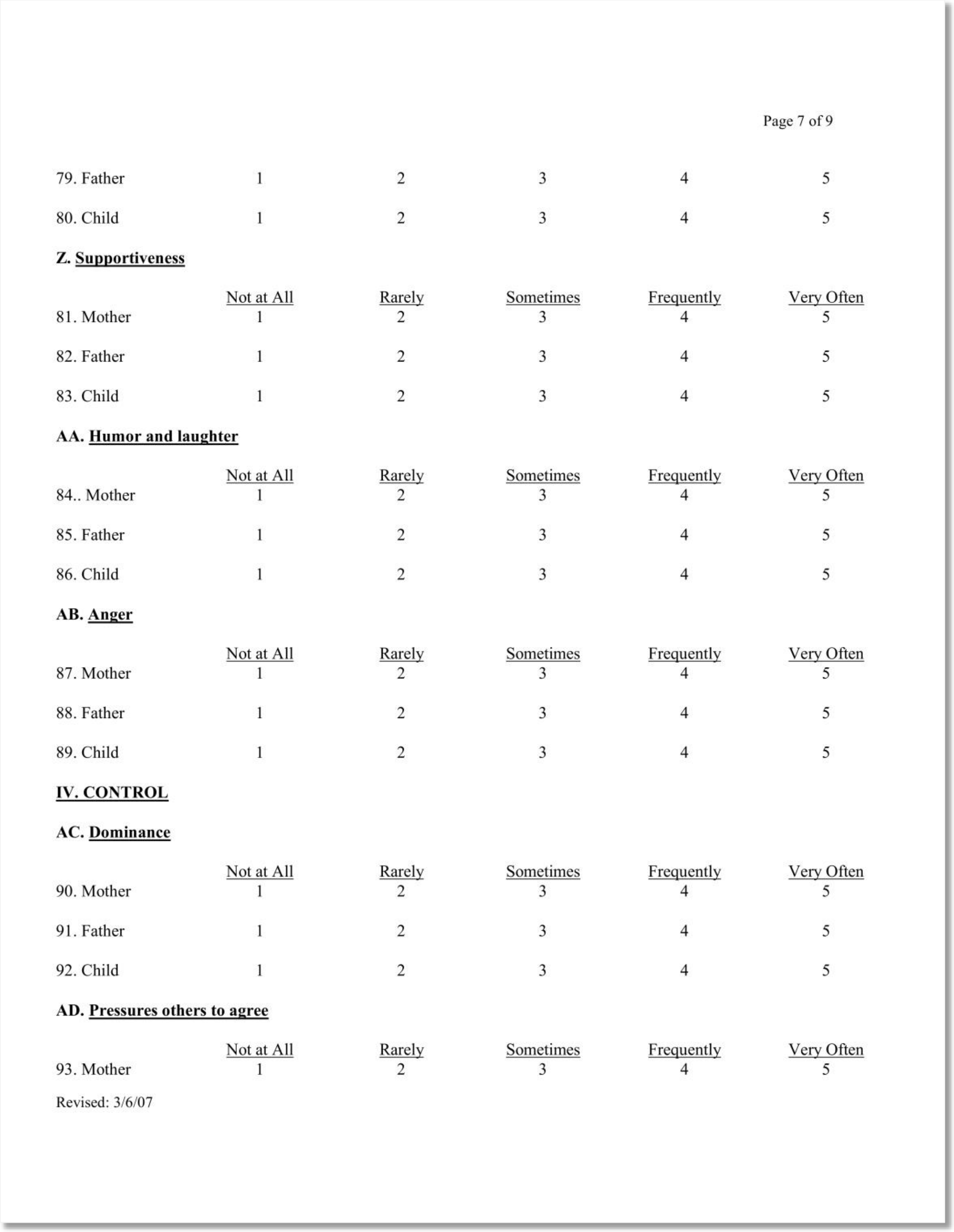
	Not at All	Rarely	Sometimes	Frequently	Very Often
72. Mother	1	2	3	4	5
73. Father	1	2	3	4	5
74. Child	1	2	3	4	5

X. Frequency of negative affect

	Not at All	Rarely	Sometimes	Frequently	Very Often
75. Mother	1	2	3	4	5
76. Father	1	2	3	4	5
77. Child	1	2	3	4	5

Y. Warmth

	Not at All	Rarely	Sometimes	Frequently	Very Often
78. Mother	1	2	3	4	5



79. Father	1	2	3	4	5
80. Child	1	2	3	4	5

Z. Supportiveness

	Not at All	Rarely	Sometimes	Frequently	Very Often
81. Mother	1	2	3	4	5
82. Father	1	2	3	4	5
83. Child	1	2	3	4	5

AA. Humor and laughter

	Not at All	Rarely	Sometimes	Frequently	Very Often
84.. Mother	1	2	3	4	5
85. Father	1	2	3	4	5
86. Child	1	2	3	4	5

AB. Anger

	Not at All	Rarely	Sometimes	Frequently	Very Often
87. Mother	1	2	3	4	5
88. Father	1	2	3	4	5
89. Child	1	2	3	4	5

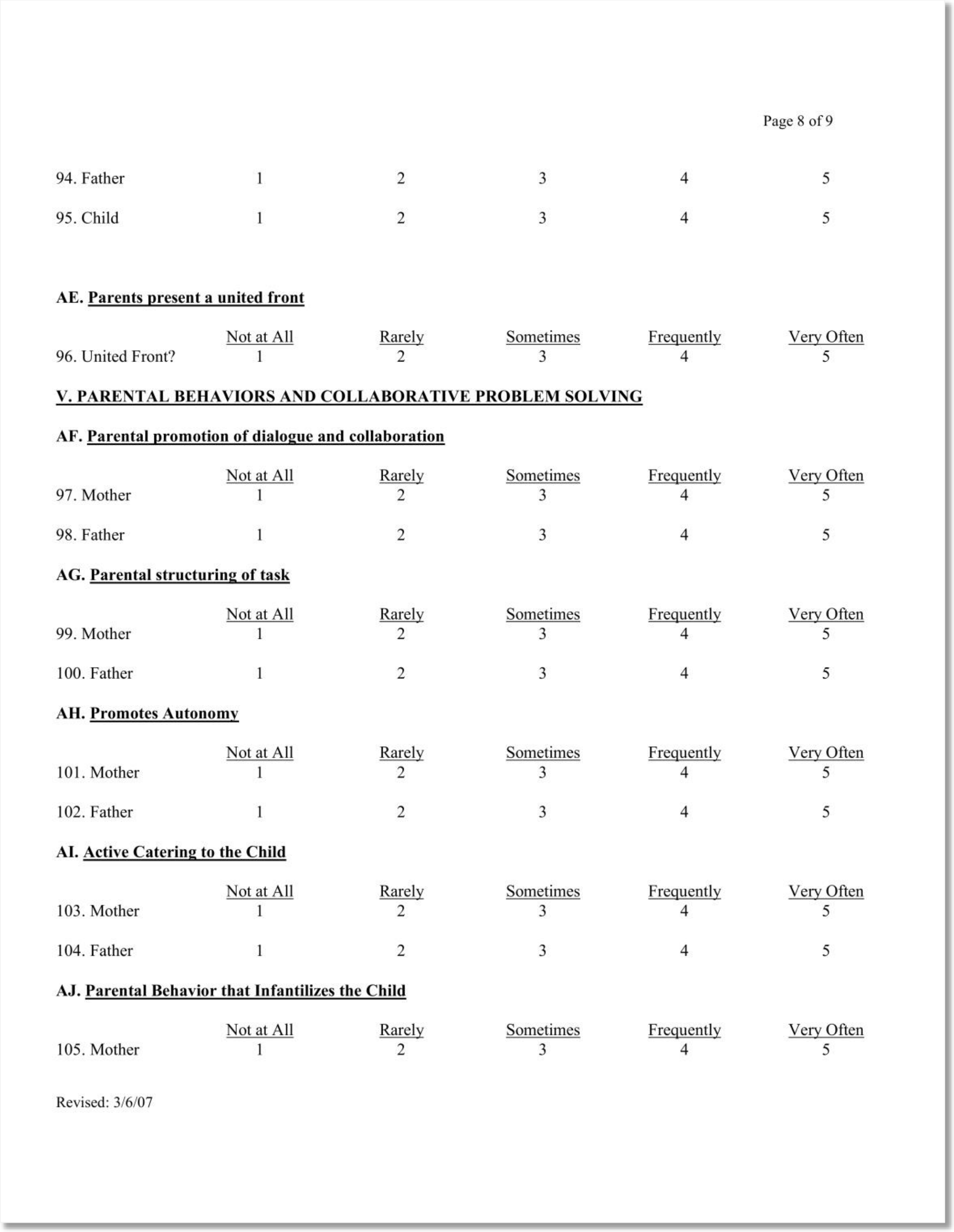
IV. CONTROL

AC. Dominance

	Not at All	Rarely	Sometimes	Frequently	Very Often
90. Mother	1	2	3	4	5
91. Father	1	2	3	4	5
92. Child	1	2	3	4	5

AD. Pressures others to agree

	Not at All	Rarely	Sometimes	Frequently	Very Often
93. Mother	1	2	3	4	5



94. Father	1	2	3	4	5
95. Child	1	2	3	4	5

AE. Parents present a united front

	Not at All	Rarely	Sometimes	Frequently	Very Often
96. United Front?	1	2	3	4	5

V. PARENTAL BEHAVIORS AND COLLABORATIVE PROBLEM SOLVING

AF. Parental promotion of dialogue and collaboration

	Not at All	Rarely	Sometimes	Frequently	Very Often
97. Mother	1	2	3	4	5
98. Father	1	2	3	4	5

AG. Parental structuring of task

	Not at All	Rarely	Sometimes	Frequently	Very Often
99. Mother	1	2	3	4	5
100. Father	1	2	3	4	5

AH. Promotes Autonomy

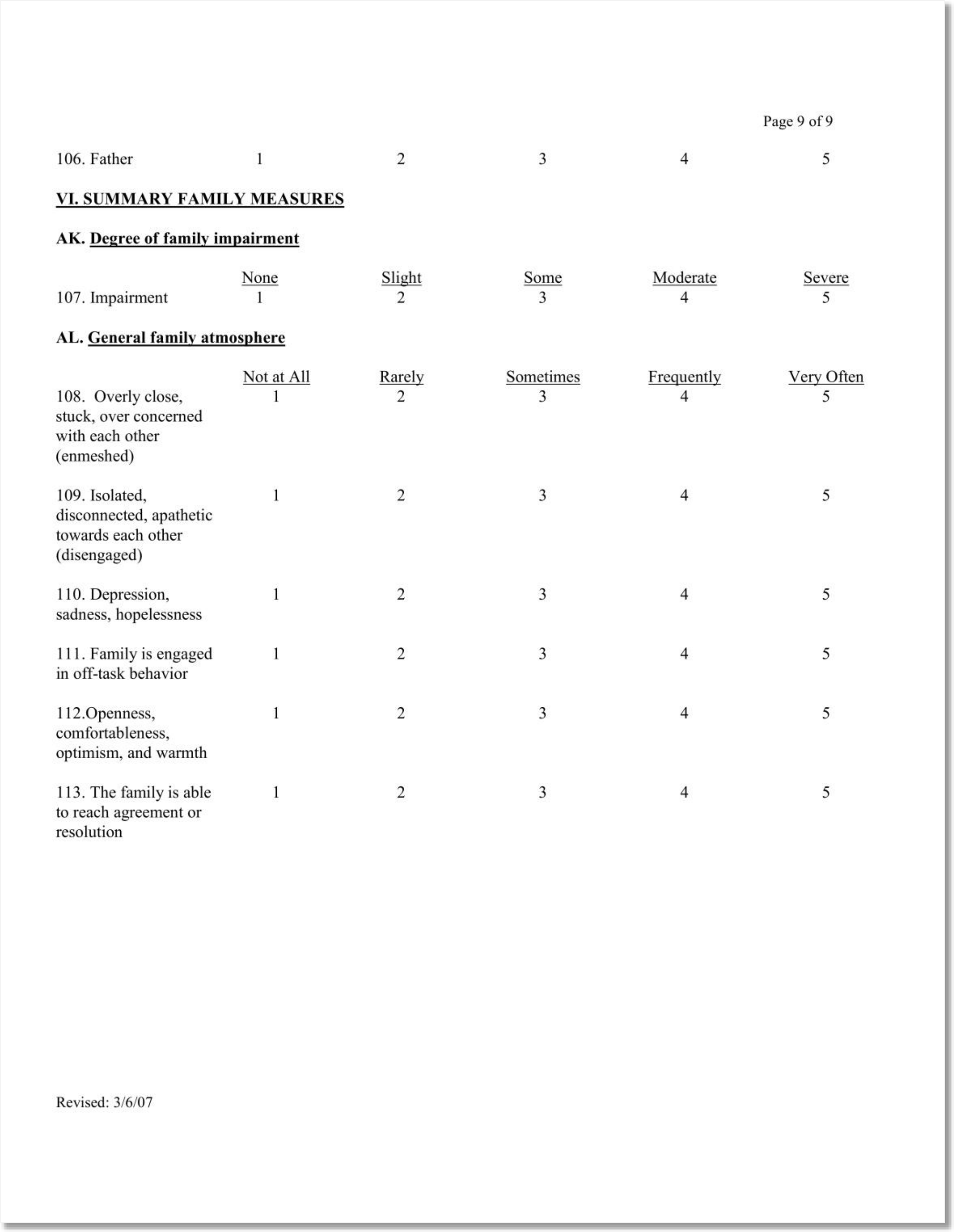
	Not at All	Rarely	Sometimes	Frequently	Very Often
101. Mother	1	2	3	4	5
102. Father	1	2	3	4	5

AI. Active Catering to the Child

	Not at All	Rarely	Sometimes	Frequently	Very Often
103. Mother	1	2	3	4	5
104. Father	1	2	3	4	5

AJ. Parental Behavior that Infantilizes the Child

	Not at All	Rarely	Sometimes	Frequently	Very Often
105. Mother	1	2	3	4	5



106. Father	1	2	3	4	5

VI. SUMMARY FAMILY MEASURES

AK. Degree of family impairment

	None	Slight	Some	Moderate	Severe
107. Impairment	1	2	3	4	5

AL. General family atmosphere

	Not at All	Rarely	Sometimes	Frequently	Very Often
108. Overly close, stuck, over concerned with each other (enmeshed)	1	2	3	4	5
109. Isolated, disconnected, apathetic towards each other (disengaged)	1	2	3	4	5
110. Depression, sadness, hopelessness	1	2	3	4	5
111. Family is engaged in off-task behavior	1	2	3	4	5
112.Openness, comfortableness, optimism, and warmth	1	2	3	4	5
113. The family is able to reach agreement or resolution	1	2	3	4	5

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