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The public health of disabilities : functional independence, health-related quality of life, and parental stress in adolescents with disabilities

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The Public Health of Disabilities:

Functional Independence, Health-Related Quality of Life, and Parental Stress
in Adolescents with Disabilities

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B.A., Dartmouth College

A Thesis

Submitted in Partial Fulfillment of the

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Master of Arts Thesis

The Public Health of Disabilities: Functional Independence, Health-Related Quality of Life, and
Parental Stress in Adolescents with Disabilities

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ABSTRACT

Background/Objectives: *To investigate the null hypotheses that no correlation exists between functional independence, health related quality of life, and parental stress*

Design: *Baseline cross-sectional analysis of a population*

Participants and Setting: *Participants were recruited from camps, wheelchair sports, and disability-related meetings. They are 10-21 years old with disabilities, in school for the prior year, understand English, and demonstrate necessary cognitive comprehension. We enrolled 72 youths, with 39 completing all components. There were 39 males and 33 females. Fifty six subjects self-identified as Caucasian. Six were African American, 5 were Hispanic, 2 were Asian, and 3 self-identified as "other." The range of diagnoses included cerebral palsy, spina bifida, orthopedic or neuromuscular conditions, and developmental or cognitive conditions.*

Materials/Methods: *The Functional Independence Measure (FIM) was given by structured interview. Dr. Leger trained and observed interviewers for inter-rater reliability. Adolescent health-related quality of life (HRQOL) was determined by a modified version of Parkin's (1997) instrument for spina bifida. Parental stress was evaluated by the Stress Index for Parents of Adolescents by Sheras, Abidin, & Konold. Results include Adolescent Domain, Parent Domain, and Adolescent-Parent Relationship Domain score. Data was analyzed with SPSS 13.0. Central tendencies and bi-variate correlations were conducted using two-tailed Spearman's rank correlation with a significance value of $\alpha \leq 0.05$. Small correlations had a coefficient of 0.10 to 0.29, medium was 0.30 to 0.49, and large was 0.50 to 1.00.*

Results: *Statistical power was not fully reached, yet a near significant correlation exists between FIM score and either the Parental Domain of the SIPA ($r = -0.243$, $N = 52$, $p = 0.082$) or the Adolescent Domain ($r = 0.256$, $N = 52$, $p = 0.067$). These correlations are stronger for the physical components of the FIM ($r = -0.320$, $N = 52$, $p = 0.021$; and $r = 0.377$, $N = 52$, $p = 0.006$ respectively). The motor FIM correlates with HRQOL ($r = 0.358$, $N = 48$, $p = 0.012$). HRQOL correlates with the Adolescent-Parent Relationship Domain ($r = -0.295$, $N = 41$, $p = 0.061$).*

Conclusions/Significance: *As physical independence increases, an adolescent has higher health-related quality of life, and parents have less stress from the parenting role. This is associated with more parental stress due to the child's behavior, though. With less stress in the adolescent-parent relationship, there is a trend towards increased quality of life. (UCHC IRB # 05-028)*

INTRODUCTION

The field of public health and disabilities is maturing. At earlier points in time, people with disabilities were often eliminated, through practices such as eugenics, or isolated or concealed. But with evolving knowledge and attitudes, these have given way to increased focus on enhancing the lived experiences and quality of life of those affected. The entire perception of disability “is in transition. With the recognition that disability is not an illness, we increasingly emphasize continuity of care and the relationship between a person with a disability and the environment at the physical, emotional and environmental levels...”¹ This attitude opens new doors and creates previously unimagined opportunities for public health to maximize quality of life for individuals with disabilities.

There is an opportunity for public health research to explore the issues facing this previously-neglected population. Research traditionally focused on the health condition itself, including pathology and prevention. However, an emerging body of research looks beyond this limited focus. It understands disability as a state at the interface of patient and environment, influenced by expectations and the larger psychosocial context, parents and family, and modified by adaptive equipment or environmental barriers. This evolving research embraces the idea of systems, and incorporates a broad and dynamic understanding of health issues and the role of public health.

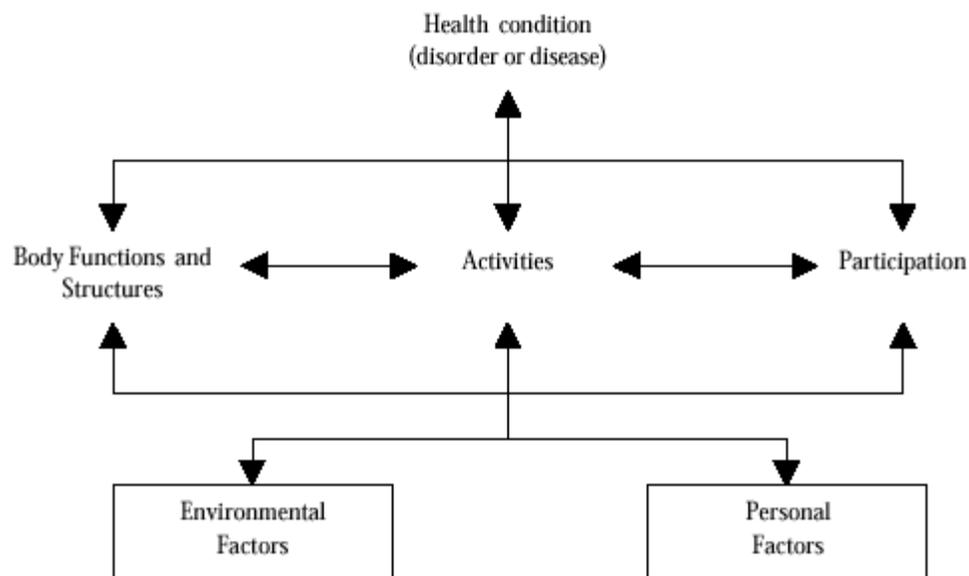
The purpose of this thesis is to understand the influences on the public health of the population with disabilities, specifically focusing on adolescents. The objective of this thesis is to determine the significance of functional independence, parental stress, and health-related quality of life during the transition through adolescence.

Life Span Approach

A holistic approach to health – and therefore to disability - is espoused by the World Health Organization definition of health as “a state of complete physical, mental and social well-

being and not merely the absence of disease or infirmity." Health is a system at the interface of numerous factors, including interpersonal relationships, individual characteristics, societal values and expectations, and environmental barriers and facilitators. The *International Classification of Functioning, Disability and Health*, or ICF, defines components of well-being "as *health domains* and *health-related domains*. These domains are described from the perspective of the body, the individual and society through: (1) Body Functions and Structures; and (2) Activities and Participation (Figure 1)." ² Public health benefits from appreciating this system of relationships, and the opportunities for interventions represented by each.

Figure 1: *Interactions between the components of the International Classification of Functioning, Disability and Health (ICF)* ²



The dynamic nature of these interactions reinforces the significance of changes over time. A lifespan approach to health recognizes that the individual's conditions and developmental needs are not static. Each life stage is associated with unique constellations of relationships and

sequellae, issues and opportunities, which must be addressed to successfully negotiate the challenges and further develop.³

Erikson’s theory of development identifies changes over the lifespan for the general population (Figure 2). The period prior to adolescence is marked by friendship, skill learning, self-evaluation, and team play. In adolescence, appearance to others becomes significant, and the adolescent must negotiate identity and role confusion. The transition to early adulthood is challenged by the development of intimate relationships and commitments to others.⁴ Through adolescence, the struggles between independence, boundaries, defining personality, and assuming new roles may strain existing relationships. Each stage’s internal developmental challenges interact with the multifactorial external influences on health and well-being.

Figure 2: Erikson’s stages of development ⁴

Steinberg, Adolescence, 7e. Copyright © 1998. McGraw-Hill Companies, Inc. All Rights Reserved.

Eight Stages of Development

I Infancy	Trust vs. mistrust							
II Early childhood		Autonomy vs. shame, doubt						
III Play age			Initiative vs. guilt					
IV School age				Industry vs. inferiority				
V Adolescence					Identity vs. identity diffusion			
VI Young adult						Intimacy vs. isolation		
VII Adulthood							Generativity vs. self- absorption	
VIII Mature age								Integrity vs. disgust, dispair

A lifespan approach to disability recognizes the uniqueness adolescence (and all developmental stages). But it is unclear if the relationships and stages described by Erikson are

influenced - and perhaps complicated - by disability. While this intuitively seems likely, objective evidence is lacking. Public health research must recognize the dynamic nature of disability and, as this thesis examines adolescence, the larger research agenda must explore unique issues across the lifespan.

Parental Stress

For adolescents with disabilities, a holistic lifespan approach incorporates both the nature of the disability and the nature of adolescence. Parents may be pivotal in the transition through adolescence generally, and for those with disabilities specifically. But in response to early puberty, parent-adolescent relationships for those with disabilities may be more resistant to change compared to their non-disabled peers.⁵ A holistic approach understands these complex psychosocial dynamics, influenced in some ways by the disability, while independent of it in others.

Mothers of children with special needs often serve as primary care givers, taking responsibility for a child's disability, physical needs, psychological and social development through this transition. At the same time, parents of adolescents with disabilities report additional demands related to their own needs, family roles or relationships, and activities outside the home. These demands create challenges in their interactions with the children, health professionals, or partners.⁶ In children, conflict between parents has been linked to parent-child hostility. This in turn is linked to children's emotional development.⁷

Distressed parents with harsh coping strategies have children who express emotion more intensely⁸, while maternal depression is associated with children having problems with externalizing emotion.⁹ The parent-child relationship is pivotal for the development of mature emotional responses and social skills in the adolescent.¹⁰ An adolescent's self-concept and emotional health are directly related to perceived parental warmth, although not to their level of restrictiveness.¹¹ In contrast, parenting style and authority do contribute to the adolescent's

autonomy and reactions to conflict, both with the parent and generally.^{12, 13} These parenting factors and the adolescent's temperament together predict adjustment during the transition to adolescence.¹⁴ Successful coping skills depend on both parent and child.

Adolescents are not just shaped by their parents and family environment, but seem to influence the characteristics and wellbeing of their family as well, both directly and indirectly. A parent's wellbeing correlates to their child's self-regulatory processes – notably behavioral problems and mastery motivation – and to the dynamic created by the mother-child interaction.¹⁰ In younger children, maternal (but not paternal) stress is predicted by the type of disability, which is also associated with the child's functional abilities.¹³ The health of caregivers for children with cerebral palsy is strongly linked to the child's behavior and care giving demands.¹⁵ As a whole, parents of children with disabilities tend to have more physical and psychological health problems, consistent with a stress model.¹⁶ But much remains unclear about the reciprocal relationship between adolescent and parent wellbeing.

But parental stress is not simply due to the child. Stress derives from multiple sources, including parent-related stress in addition to child-related stress.¹⁷ In muscular dystrophy, for example, caregiver characteristics such as poor social skills or anxiety influence the perceived burden.¹⁸ Assets including social support and problem-focused coping lessen maternal and paternal stress respectively.¹⁰ Positive affective and emotional responses by parents predict better parent psychological health, and a higher sense of mastery with less guilt or incompetence.¹⁵ Wellbeing in caregivers of children with cerebral palsy is optimized not just by child-targeted interventions, but also through stress management and self-efficacy techniques for parents. Better stress management is in turn associated with fewer child behavior problems.

Interventions and quality of life improvements must embrace the entire milieu around an adolescent, particularly the primary caregiver. “These data support clinical pathways that require biopsychosocial frameworks that are family centered, not simply technical and short-term

rehabilitation interventions that are focused primarily on the child.”¹⁵ The current thesis attempts to understand this better, especially for adolescents with disabilities.

Functional Independence

Disability may be analyzed and understood through its limitations in physical and/or cognitive independence in daily activities. First developed for rehabilitation, the concept of functional independence can be applied to individuals with disabilities across the lifespan. An overall level of independence in key tasks can be determined and followed over time by using a standardized measure. Although specific formulations arguably undervalue function in personal care, occupation, or leisure domains,¹⁹ the concept has nonetheless proven valuable for research.

Research in disability shows that the functional status of children with cerebral palsy is correlated to prematurity, level of gross motor impairment, and epilepsy.²⁰ In individuals with spina bifida, good muscle strength, mental ability and mobility are significant for day-to-day function.²¹ They are often limited by bowel and bladder incontinence, the inability to traverse stairs, and select memory deficits.²² Physical factors including hydrocephalus and a lesion at L2 or above are associated with more impairment, whereas those less affected by these physical factors were generally functionally independent in all domains except sphincter control.²³ Comparing populations with spina bifida and cerebral palsy using functional independence shows that both groups may need assistance in basic and instrumental activities of daily living. However subjects with spina bifida are more likely to report dependence for eating, bladder and bowel functions. Limitations of mobility in this group influences instrumental tasks to a greater degree.¹⁹ Research in muscular dystrophy has found that eating and bowel management are easier, whereas transfers and stair climbing are more difficult. Independence correlates with muscle strength and, controlling for this, cognitive function is also significant.²⁴ In contrast, conditions such as Down syndrome may rarely have severe functional limitations for school-aged

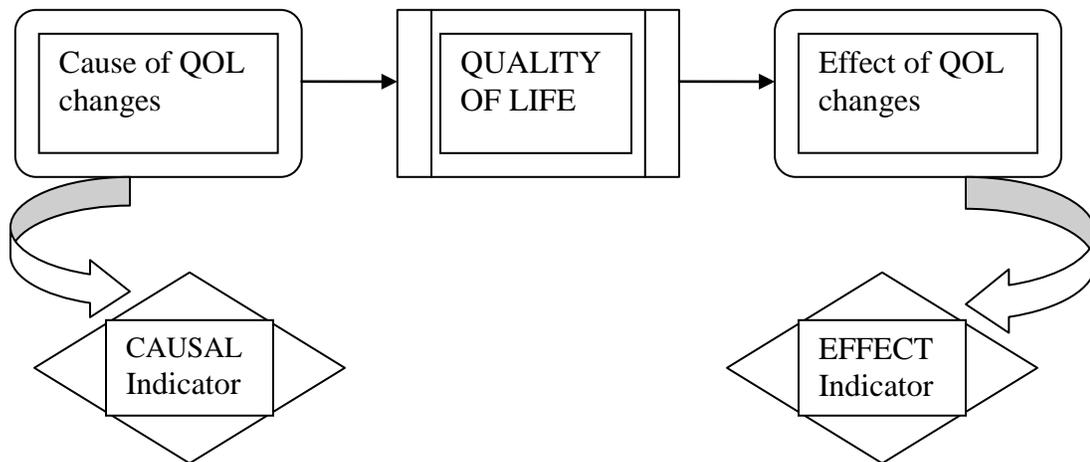
children. In this case, functional independence is only limited by the need for support and supervision for complex self-care, communication and social skill tasks.²⁵

For all disability, maximizing function and reducing dependence on caregiver assistance are considered among the pivotal “points of performance” for environmental modification and adaptation.²⁶ Measures of functional independence, then, can allow for comparisons between and within different disabilities. There is an astounding breadth of disabilities, and breadth of functional abilities in the affected population. Engaging this range through the perspective of functional independence allows for comparisons that are not limited by a diagnostic label.

Quality of Life

Quality of life (QOL) has emerged as a significant outcome measure – or even a defining purpose - for medicine or public health in individuals with disabilities. The concept can be understood as a complex and intensely personal phenomenon composed of the interplay of objective and subjective indicators across a broad range of life domains. Six key areas have been identified: physical, material, social, productive, emotional and civic well-being.²⁷

Figure 3: *The position of causal and effect indicators in relation to Quality of Life*

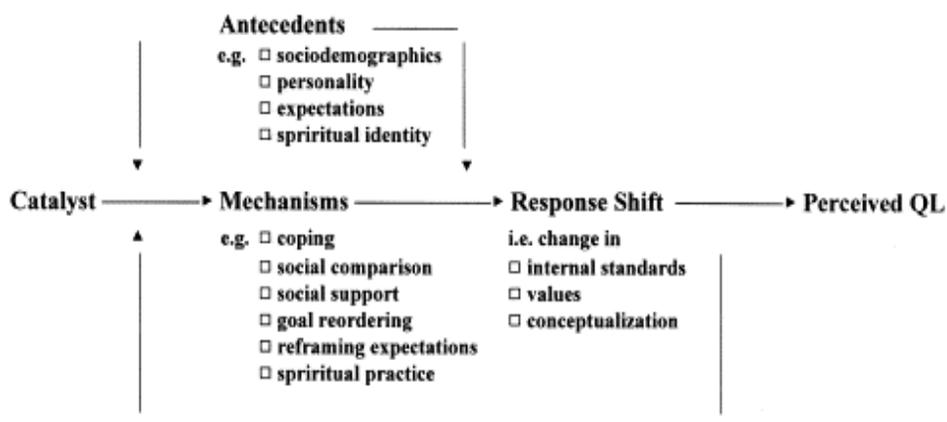


Within each area, QOL incorporates causal and effect indicators (Figure 3). Causal indicators are those factors that can change an individual's QOL, such as financial burdens or significant disease symptoms. These causal indicators do not in themselves, however, take into account the personal reaction to the issue. They therefore have a less predictable relationship with QOL on a case-by-case basis. Effect indicators measure variables that are manifestations of and are changed by QOL. This might include outcomes such as anxiety and depression. Unlike causal indicators, which merely trigger a change in QOL, effect indicators are a consequence of personal responses to those situations and triggers. A poor QOL is likely to have more evenly and uniformly low scores on a broad array of effect indicators. Identifying the range of these indicators, both causal and effect, is crucial in capturing the nature of quality of life.²⁸

The attempts to organize these indicators and conceptualize "quality of life" are broadly divided into²⁹ either single or multi-domain. Some argue that QOL is a single domain: "a global personal assessment of a single dimension which may be causally responsive to a variety of other distinct dimensions: it is a unidimensional concept with multiple causes."³⁰ QOL may be its own complete entity, instead of just a sum of its components. But a multi-domain QOL incorporates overall QOL as the sum of quality in multiple distinct domains – including physical, psychological, and social.³¹ Each domain is a part of the overall quality of life picture, but may also be understood as an entity unto itself.

In this context, health may either be a component of QOL, or a dimension to which QOL is responsive. Multi-domain models for QOL regularly incorporate the more specific concept of health-related quality of life (HRQOL).^{32, 33, 34} HRQOL is not just a surrogate for one's medical condition. HRQOL is an individual's health status and functioning combined with the emotional evaluation and affective responses, capturing the meaning and lived experience of the condition for the individual. Like overall QOL, HRQOL is complex, individualized, and multifactorial, shaped by individual and cultural influences through the construction of internal standards.³⁵

Figure 4: A theoretical model of response shift and quality of life ⁴⁸



For those with disabilities, HRQOL may be a product of more than just health status and the nature of the disability. Other factors include functional abilities and accommodations, comorbidities, and the expectations, attitudes, and values shaped by life experiences and family. These others factors may be influenced by the nature of the disability in some ways, although independent of it in others. Much remains to be clarified about these phenomena.

Interaction of variables

There has been some prior effort to clarify the multiple variables – such as affective responses, or the physical and cognitive attributes which shape functional independence – that interact to create HRQOL in adolescents with disabilities. Despite this intricate conceptualization, though, some research indicates that HRQOL is primarily determined by objective measures of health and function, not subjective or psychosocial influences. In cerebral palsy, the reduction in quality of life is proportional to the severity of the cerebral palsy, and children with quadriplegia report lower HRQOL than those affected by diplegia or hemiplegia.³⁶

³⁷ Adolescents with spina bifida show that conventional neurologic-neurophysiologic measurements and perceived QOL are highly correlated.³⁸ Incontinence or decreased function of

proximal lower limb muscles is closely related to greater disability and reductions in the physical aspects of QOL.³⁹ For muscular dystrophy, the objectively measured factors "walk and move" and "finger function" are associated with QOL.⁴⁰ In contrast, individuals with developmental disabilities show that substantial dependence in mobility may be related to *enhanced* overall life satisfaction.⁴¹

The association may be weaker for cognitive aspects of quality of life,³⁸ or cognition and quality of life may show no significant association at all.⁴² The psychosocial well-being of children with cerebral palsy does not directly correlate to their cognitive abilities and, in fact, well-being is more impaired in mild cerebral palsy than would be predicted by the mild functional disability alone.⁴³

Ultimately, we can not presume that those with greater functional impairments have a lower quality of life. Research shows these to be flawed surrogates. The complex and dynamic relationship merits further study in order to understand and serve individuals with disabilities. A comparison of Swedish and Australian spinal cord patients showed that the most important predictors of QOL are shared, and these cover the spectrum from mood, to physical and social functioning, to problems regarding injury.⁴⁴ In cerebral palsy, HRQOL and function might not be directly inferable from each other,⁴⁵ and individuals with spina bifida, too, can attain a high HRQOL despite experiencing anxiety from multiple secondary health conditions.²² For muscular dystrophy, the relationship is not robust - even severely disabled individuals show perhaps surprisingly high QOL.⁴⁶ Nonetheless, progression of the condition over time is accompanied by increased dependency and an associated deterioration of HRQOL. Thus for those with muscular dystrophy, coping skills impact HRQOL too.⁴⁷

Appreciating this psychological resilience is essential, and HRQOL might not be a direct correlate of disability alone. An important mediator of this adaptation process is *response shift*, modifying internal standards and values, and hence the perceived quality of life.⁴⁸ Given the intimate role of parents in the development of internal standards and attitudes, the impact of their

perceptions and relationship on HRQOL may be significant.^{49, 50} Erikson's stages define typical adolescence as a period of defining oneself, with changing relationships and opportunities to modify the internal standards or emotional evaluations that can shape affective responses to health. At the same time, alterations in the normal developmental processes would fundamentally alter the parent-child relationship, and the adolescence experience. As a consequence, adolescents with disabilities may have different relationships with family and peers, and different responses to challenges impacting on HRQOL.

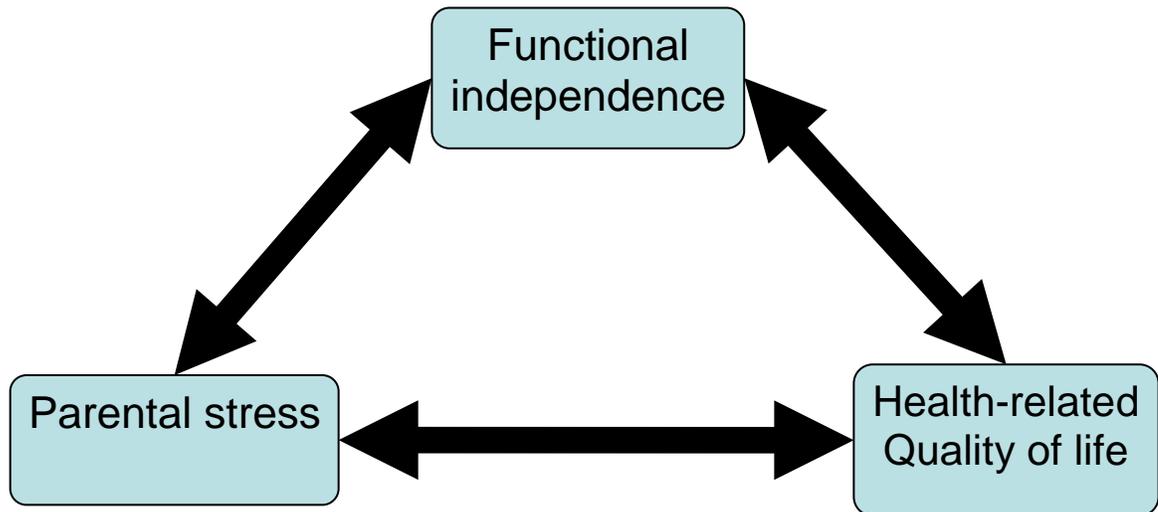
Although there is a significant body of research in the areas of functional independence, health-related quality of life, and the parental response to children, much still is unknown. The interaction between these domains and their components may provide insights relevant to a more complete understanding of the "lived experience" of growing into adulthood with a disability.

MATERIALS AND METHODS

Research Design

This study is a cross-sectional descriptive study that explores quality of life issues in adolescents with disabilities. It focuses on the relationship between quality of life, functional independence, and parental stress. Participants were recruited from two recreational summer camps serving individuals with disabilities, one in central New York, and the other located in Connecticut and drawing participants from throughout lower New England. Subjects were also recruited at a wheelchair track meet and a tennis day camp for children or young adults in wheelchairs, both located in Connecticut. A Spina Bifida Association of Connecticut parents meeting was another source for participants.

Figure 5: *Simple model of possible bivariate correlations for major variables of interest*



Inclusion criteria were that subjects be adolescents with diagnosed disabilities between the ages of 10 and 21 years old in school for the previous school year, able to understand English language or ASL, and able to demonstrate necessary cognitive comprehension through appropriateness in responses and questions as judged by the researcher. Subjects were excluded

if they spoke languages other than English as their primary language. Subjects were also excluded if they had been to college or had lived away from home for the school year. If subjects showed poor cognitive comprehension of the Likert scale or an inability to communicate their responses to the questions, they were excluded from completing the self-report quality of life questionnaire, although the other portions of the study might still be completed. When needed, assistance was available to read the questions and to mark responses.

The study was IRB # 05-028 approved by the University of Connecticut Health Center. Informed consent was obtained from all participants age 18 and older. Parental consent was obtained for these subjects as well when the parents participated in the parental stress questionnaire. For participants younger than 18 years old, parental consent was attained, with the child completing an informed assent process.

Data Collection Measures

Functional Independence Measure

The Functional Independence Measure (FIM™) was developed by a national task force of the American Congress of Rehabilitation Medicine and the American Academy of Physical Medicine and Rehabilitation.⁵¹ The 18-item FIM is a widely used and validated measure of disability and independence in daily functions including self-care, sphincter control, transfers, locomotion, communication, and social cognition. The first four are considered the motor components of the FIM, while the last two represent cognitive elements. Data is collected by semi-structured interview. A one-to-seven scale quantifies major gradations as follows:

Two levels of independence:

(7) Complete Independence

(6) Modified Independence

Three levels of modified dependence:

(5) Supervision or Setup

(4) Minimal Contact Assistance

(3) Moderate Assistance

Two levels of complete dependence:

(2) Maximal Assistance

(1) Total Assistance

Greater dependence translates to time and energy that is expended by the individual or their caregivers in order to maintain quality of life. Assistance may be from a caregiver (considered to be more dependent) or a device (considered to be more independent). In the context of physical and developmental disability, an objective measure of functional independence can identify differences between individuals with the same diagnosis, as has been done for spinal cord injury and stroke.⁵² It may also compare those with different diagnoses on a uniform scale.

The FIM is the most commonly used functional assessment in rehabilitation medicine to quantify disability and to document changes in functioning.⁵³ It has been shown useful for tracking an individual's changes in function over time.⁵² The statistical properties of the FIM have been explored extensively.^{52, 53, 54, 55} High overall internal consistency (discharge FIM alpha = .93) and adequate discriminative capability have been demonstrated.⁵² These characteristics are reflected in the clinically-appropriate validity, test-retest reliability, and interrater agreement.^{54, 55} Reliability of FIM motor items was higher than for the cognitive or communication subscales. Median reliability for the six FIM subscales ranged from .95 for Self-Care to .78 for Social Cognition.⁵⁵

Some challenges remain unresolved with the FIM. While the FIM may be able to detect meaningful change in level of function during rehabilitation⁵⁶ and demonstrates some responsiveness, others question its capacity to measure change over time.⁵² Some note that repeated interview over time by different raters shows less than stable agreement for transfers, locomotion and social-cognition. FIM assessments showed high inter-rater agreement for the same interview setting for motor areas more than cognitive.⁵⁷ Additionally, adjustments may be needed for cultural factors in cross-cultural samples.⁵⁸ Rasch analysis of the FIM defines two separate domains: a motor domain with thirteen items and a cognitive domain consisting of five items.⁵⁹ In spinal cord injury, for example, cognitive independence is not informative for detecting change over time, and may only serve as a crude screening assessment. Motor items, in contrast, reflect the functional status of these individuals, although high correlations among several motor items suggest redundancy.⁶⁰ This indicates that these separate domains may be of more value than the total score. The multidimensional nature of functional independence may make the FIM total score too broad and may obscure significant results within subscores.⁶¹ Analysis using individual domains may be more useful.

Previously the FIM has been applied to understanding quality of life in patients and parents affected by disability. The results tend to show a linear inverse correlation between

disability and the physical aspects of QOL only. Conversely, disability much better parallels the emotional aspects of the parent's QOL.⁶² The FIM has been used to predict quality of life after traumatic injury⁶³, stability of transition to adulthood in pediatric spinal cord injuries⁶⁴, motor recovery and quality of life in patients with complete spinal cord injuries⁶⁵, and functional status and muscle strength in Duchenne's muscular dystrophy.²⁴ Prior research has also applied the FIM to predict survival after cardiopulmonary resuscitation in pediatric trauma⁶⁶, rehabilitation outcomes in encephalitis⁶⁷ and Guillain-Barre syndrome.⁶⁸ The FIM has evaluated the effectiveness of interventions, including the effects of botulinum toxin upper extremity function of hemiparetic patients⁶⁹, electronic aids to daily living⁷⁰, and comparisons of functional electrical stimulation versus long leg braces for upright mobility in spinal cord injuries.⁷¹ The widespread acceptance and use of the FIM has created a substantial body of existing literature on which to base further studies.

Stress Index for Parents of Adolescents

The Stress Index for Parents of Adolescents (SIPA) was conceived as a developmentally-sensitive upward extension of the Parenting Stress Index (PSI)⁷², and contains items that reflect issues and stressors faced by parents of adolescents. This instrument understands "parental stress" as the interplay of the parents' characteristics with the adolescent's characteristics through the parent-adolescent relationship. Four subscales measure parent characteristics (Life Restrictions, Relationship with Spouse/Partner, Social Alienation, and Incompetence/Guilt), and four measure adolescent characteristics (Moodiness/Emotional Lability, Social Isolation/Withdrawal, Delinquency/Antisocial, and Failure to Achieve or Persevere). These factors both influence and are influenced by the parent-adolescent relationship, and are colored by the context of overall life stressors. The SIPA is a 112-item questionnaire with a 1 to 5 ordinal scale for 90 items, plus nominal data for 22 items which count external stressors. The SIPA was initially designed for the parents and caregivers of adolescents age 11 to 19, although ages 10 to

21 were included in the current study. Whenever possible, a parent who was present when the adolescent was recruited would independently complete the SIPA questionnaire.¹⁷

The SIPA is highly reliable. Internal consistency for the each subscale exceeds .80, with most subscales even higher. Alpha coefficients for the Adolescent Domain, Parent Domain, and Adolescent-Parent Relationship Domain exceed .90, as does the Index of Total Parenting Stress. The test-retest reliability coefficients for the subscales range from .74-.91, suggesting stability over time. Confidence intervals are provided in the SIPA Professional Manual.¹⁷

Adolescence is a period of rapid shifts in familial roles and in parent-adolescent conflicts. The SIPA was used to measure such social and interpersonal influences on the adolescent with a disability, specifically those influences derived from the parent. In adolescents without disabilities, parental stress can have an impact. Parents' responses to traumatic events influence how they assess the child's symptoms of acute stress disorder.⁷³ Similarly, the adolescent may influence the parent, and a bidirectional relationship has been shown between conflict in the parent-child relationship and a child's externalizing behaviors. Parent-child conflict is in part a result of the parent's responses to their child's behavior, while at the same time such conflict contributes to externalizing behavior by the adolescent.⁷⁴ Stress for both parent and adolescent may result from dysfunctional parent-adolescent relationships. The SIPA recognizes the spectrum of parental stress, both in quantity and quality. This stress might be confined to specific domains (such as stress only in specific aspects of the parenting role) or may be more generalized.¹⁷ Interventions and therapeutic priorities can be specifically targeted to the type of stress and its underlying causes. This, in turn, can benefit both parent and adolescent.

This is not, however, an indication that all stress is dysfunctional. As adolescents generally develop autonomy and the capability for more complex and multidimensional relationships, the changes can be expected to challenge the adolescent and the family system too. Parents might be coping with a change in family structure, perhaps a loss of control, and often times their own midlife issues. While change can provide some stress for all involved, it may be

crucial in preparing the adolescent for adulthood, and the parent for their own future as well. The instrument may also not distinguish stress that is “normal” from pathologic, except insofar as there are comparisons with normative data.¹⁷

In adolescents with disabilities, the Adolescent-Parent Relationship Domain (APRD) may be particularly informative. The APRD may provide insight into the nature of the home environment and interpersonal relationships, which can have a major effect on quality of life.⁷⁵ The SIPA has previously been used to explore adolescent-parent relationships in families of adolescents with chronic pain (reporting less adolescent-parent relationship distress compared to normative data)⁷⁶, and to explore the support systems available to parents of youths with intellectual disabilities.⁷⁵

Health-related Quality of Life

Parkin, Kirpalani, and colleagues have designed a health-related quality of life questionnaire (HRQOL) for self-report by adolescents with spina bifida ages 13 to 20 years old. It consists of forty-seven questions covering several domains, and is derived from open-ended interviews that were then validated. A 1-to-5 Likert-type score was used, and summed for cumulative HRQOL. This instrument was used for this study while extending it (with minor changes approved by Parkin and Kirpalani) to cover the ages and range of disabilities in this study.⁷⁷ Adolescents would independently complete the HRQOL survey, but assistance reading questions or circling responses was provided as by the research team as needed.

Maximum likelihood factor analysis on a sample of sixty subjects ages 15-25 years old with spina bifida revealed three factors: 1) self/peer concept, 2) skills at activities of daily living, employment, and recreational activities, and 3) thoughts and hopes for the future. In this sample, high mean scores for HRQOL and the negative skewness reflected fairly positive feelings about quality of life.^{22, 78} Parkin and Kirpalani’s HRQOL results are reproducible using intra-class

correlation coefficients, and valid using both a global question concerning the child's well-being, and the Piers-Harris Children's Self-Concept Scale. The construct validity correlation was 0.37.⁵⁰

This instrument has previously evaluated the influence of parental hope on quality of life in spina bifida. A significant relationship was found between quality of life and parental hope, exceeding any association with neonatal or current physical deficits.⁷⁵

Methods

Data was recorded and analyzed using the SPSS 13.0 for Windows Integrated Student Version. This included simple calculations of means, standard deviations, and ranges.

Correlations were analyzed using two-tailed Spearman's rank correlation coefficient. Unlike the Pearson product-moment correlation coefficient, the Spearman's rank correlation coefficient does not assume a linear relationship between variables or the normality of variables, nor does it require internal data. Instead, it can be used to analyze Likert-like ordinal data. For Spearman's correlations, a significance value was set at $\alpha \leq 0.05$. "Near significant" was used to describe correlations in which $\alpha \leq 0.10$, and were noted as possible relationships since statistical power was not reached. The size of correlations was considered small for a coefficient of 0.10 to 0.29, medium for 0.30 to 0.49, and large for 0.50 to 1.00. The same criteria applied for negative correlations.

The analysis of variance model (or "ANOVA model") examines the association between nominal predictor variables, such as gender or race, and a continuous outcome variable, such as quality of life. The ANOVA model is a univariate model, assessing how the predictors affect a single outcome variable. One way ANOVA was performed to look at differences in HRQOL by race, age, diagnosis group, or gender. Differences in total FIM, or its physical or cognitive component, were also determined. The one-way ANOVA was also used to assess differences in total SIPA score, the Adolescent Domain, the Parent Domain, and the Adolescent-Parent Relationship Domain based on the demographic variables.

Following ANOVA, a two sample t-test was used for those nominal predictors found to influence outcome variables outcomes. Specifically, the different groupings for the nominal predictor would be compared head-to-head to determine the specific nature of the differences based on age, race, gender, or diagnosis. In this way, if a difference was found by ANOVA for race, for example, t-test would be used to compare various pairs of races to determine which races statistically differed from each other in that outcome of interest.

In order to properly apply the two sample t-test for analysis of equality of means, the variances of the two samples were assessed to determine whether equal variance would be assumed for each comparison. The variance of a sample is a measure of dispersion, and the Levene's test assesses the equality of variance in different samples. For Levene's test results with a p-value of less than $\alpha = 0.05$, the differences in variances are unlikely a product of random sampling. Thus, for these t-tests, unequal variance was assumed.⁷⁹

RESULTS

Power analysis revealed that a sample size of 50 subjects would give adequate power to detect a 0.4 correlation coefficient, 85 subjects for a 0.3 correlation, and 194 subjects for a 0.2 correlation. A target sample of 100 was chosen, for a 0.28 correlation coefficient.

Sixty six participants completed the FIM, 51 completed the HRQOL, and 55 parents completed SIPAs. The SIPA was frequently completed by the mother, and in one instance, both parents completed separate SIPAs. Analysis of the data produced 41 comparisons of HRQOL with SIPA, 48 comparisons of HRQOL with FIM, and 52 comparisons of FIM with SIPA.

Correlations with $\alpha \leq 0.05$ were “significant.” An $\alpha \leq 0.10$ was “near significant”. Since the sample size did not reach the goal of $N=100$, “near significant” correlation were considered worth consideration insofar as statistical power was not fully reached. Given the inadequate powering of these analyses, some near significant correlations might be expected to emerge as significant. However, at present, the true implication of the “near significant” group can not be definitively known.

Among the three primary outcome measures, the only noteworthy relationships was a near significant positive correlation between the FIM score and the HRQOL ($r = 0.270$, $N = 48$, $p = 0.063$). There is not a significant correlation between the total SIPA score and either the FIM score or the adolescent’s HRQOL. The score for the FIM was not correlated with age or gender. Similarly, the score for the SIPA or for the HRQOL was independent of both age and gender.

Demographic Characteristics

During the data collection period, 72 youth who met inclusion criteria were enrolled in the study. Sixty seven individuals completed the FIM, and 55 parents of 54 adolescents completed the SIPA. A total of 52 HRQOL surveys were completed. Thirty nine participants completed all components.

The participants consisted of 39 males and 33 females. A total of 77.8% (56 participants) self-identified as Caucasian/White. Six participants (8.3%) self-identified as Black/African American, five (6.9%) were Hispanic/Latin American, two (2.8%) were Asian, and three participants (4.2%) self-identified as “other.”

Primary diagnoses were provided by participant or parent. The participants were affected by a range of diagnoses. For data analysis, the diagnoses were divided into four groups (Table 1).

Table 1: *Classification of participant primary diagnoses*

Category	Group	Diagnoses Included
1	Cerebral conditions (N= 20)	CP [CP/TBI/DD, CP/mild MR, CP/epilepsy or, CP/DD]
2	Spinal cord conditions (N= 14)	SB, [SB/epilepsy or] hydrocephalus
3	Orthopedic/ neuromuscular conditions (N= 20)	Muscular dystrophy [DMD] progressive degeneration Spinal Muscular Atrophy Charcot-Marie Tooth arthrogryposis osteogenesis imperfecta RSD amputations polio ataxia telangiectasia Freeman-Sheldon cord injury [cord injury/par]
4	Developmental/cognitive conditions (N= 18)	Developmental Delay [Fetal Alcohol Syndrome/DD, Autism/DD, ADHD/DD, DD/seizure d.o.] Maternal PKU MR [mild MR] neurological impairment epilepsy/seizure Prader Willi syndrome Down syndrome

Table 2: Distribution by age

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	10	2	2.8	2.8	2.8
	11	8	11.1	11.3	14.1
	12	8	11.1	11.3	25.4
	13	6	8.3	8.5	33.8
	14	9	12.5	12.7	46.5
	15	8	11.1	11.3	57.7
	16	7	9.7	9.9	67.6
	17	5	6.9	7.0	74.6
	18	10	13.9	14.1	88.7
	19	5	6.9	7.0	95.8
	20	3	4.2	4.2	100.0
	Total	71	98.6	100.0	
Missing	System	1	1.4		
Total		72	100.0		

Figure 6: Distribution of participants by age

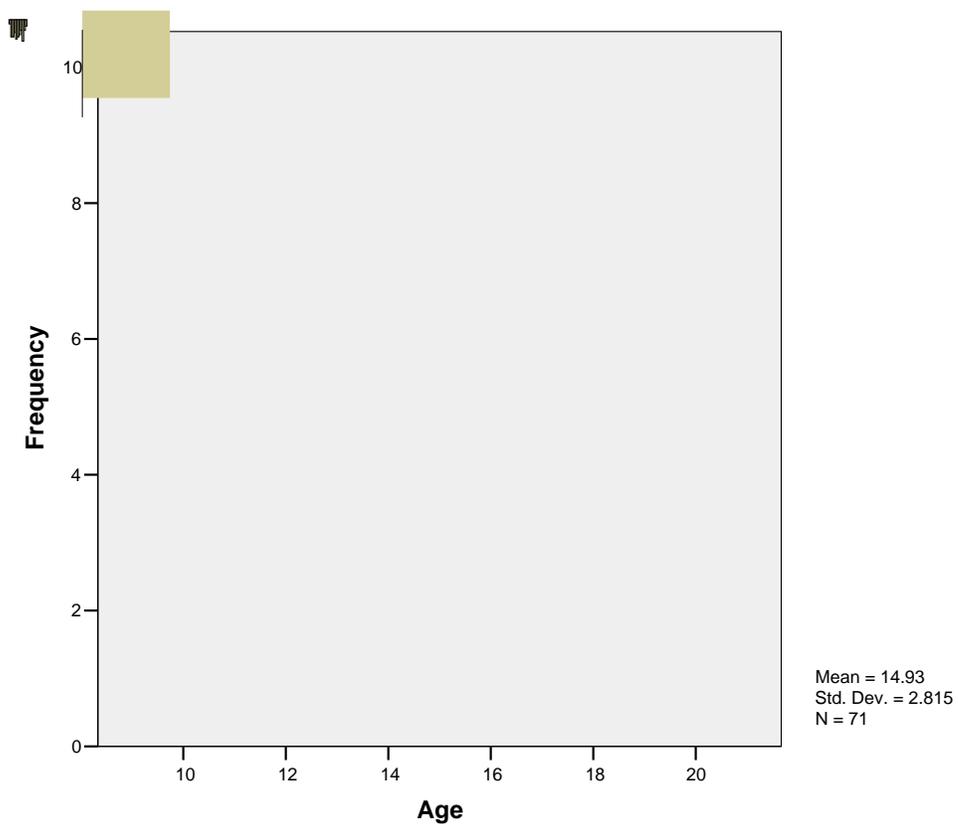


Figure 7: Participants by gender



Gender
 ■ Male (N=39)
 ■ Female (N=33)

	Frequency	%
Male	39	54.2
Female	33	45.8
Total	72	100.0

Figure 8: Participants by race



Ethnicity
 ■ White/Caucasian
 ■ Black/African American
 ■ Hispanic/Latino
 ■ Asian
 ■ Other

	Frequency	%
White/Caucasian	56	77.8
Black/African Am.	6	8.3
Hispanic/Latin Am.	5	6.9
Asian	2	2.8
Other	3	4.2
Total	72	100.0

Descriptive Statistics

The sample had a mean HRQOL score of 196.09 (SD = 24.80, range = 116.79 - 231).

The mean Functional Independence Measure score was 101.66 (SD = 19.33, range = 41 - 125). The motor portion of the FIM had a mean of 72.26 (SD = 18.03, range = 23 - 91). The cognitive portion of the FIM had a mean of 29.40 (SD = 5.48, range = 14 - 35).

This sample had a mean Stress Index for Parents of Adolescents score of 193.12 (SD = 33.78, range = 108 - 295). The Adolescent Domain had a mean of 86.32 (SD = 20.20, range = 44 - 137), while the Parent Domain had a mean of 77.33 (SD = 19.62, range = 41 - 119). The Adolescent-Parent Domain score had a mean of 29.47 (SD = 6.62, range = 16 - 48).

Table 3: Descriptive Statistics (N = 72)

VARIABLE	MEAN	SD	MIN	MAX	POSSIBLE RANGE
HRQOL (n = 52)	196.09	24.80	116.79	231	47-235
FIM (n = 67)	101.66	19.33	41	125	18-126
Motor FIM	72.26	18.03	23	91	13-91
Self Care	33.17	9.54	10	42	6-42
Sphincter	11.39	2.99	2	14	2-14
Transfer	16.79	6.07	3	21	3-21
Locomotion	10.92	2.89	2	14	2-14
Cognitive FIM	29.40	5.48	14	35	5-35
Communication	12.44	1.87	7	14	2-14
Social Cognition	16.95	4.13	7	21	3-21
SIPA (n = 55)	193.12	33.78	108	295	90-450
Adolescent Domain	86.32	20.20	44	137	40-200
MEL	25.12	7.97	10	46	10-50
ISO	23.46	6.32	10	38	10-50
DEL	14.43	4.81	13	31	10-50
ACH	23.31	8.26	10	43	10-50
Parent Domain	77.33	19.62	41	119	34-170
LFR	25.09	8.00	13	43.35	10-50
SOC	13.43	4.06	7	23	7-35
REL	20.99	8.01	9	44	9-45
INC	17.82	4.36	9	29	8-40
APRD	29.47	6.62	16	48	16-80

Variables: MEL = Moodiness/Emotional Liability, ISO = Social Isolation/Withdrawal, DEL = Delinquency/Antisocial, ACH = Failure to Achieve or Persevere, LFR = Life Restrictions, SOC = Social Alienation, REL = Relationship with Partner/Spouse, INC = Incompetence/Guilt, APRD = Adolescent-Parent Relationship Domain

Comparison of Means between Groups

No significant difference was found based on age, gender, or race for the HRQOL, the FIM or its physical and cognitive components. There was also no difference in the SIPA, or its Adolescent, Parent, or Adolescent-Parent Relationship Domains.

For total FIM score showed a near significant difference based on diagnosis ($F = 2.741, p = 0.051$). For the group with cerebral conditions, mean total FIM score was lowest ($x = 93.5, SD = 22.7, n = 19$), followed by orthopedic/neuromuscular diseases ($x = 99.1, SD = 19.6, n = 17$), and then developmental/cognitive disabilities ($x = 106.4, SD = 13.2, n = 18$). Spinal cord conditions had the highest FIM score ($x = 111.1, SD = 16.8, n = 12$). This difference was significant for cerebral palsy and related cerebral diseases when compared to spinal conditions such as spina bifida ($p = 0.028$, 2-tailed, equal variance). Orthopedic/neuromuscular diseases also had nearly significantly lower FIM than the spina bifida group ($p = 0.095$, 2-tailed, equal variance). There is a significant difference in FIM score between developmental/cognitive disabilities and cerebral disabilities, as well ($p = 0.044$, 2-tailed, equal variance).

The differences were more pronounced when considering just the physical components of functional independence. A statistically significant difference existed in for the four diagnostic groups ($F = 4.336, p = 0.008$). For the group with cerebral conditions, the mean motor FIM score was 64.6 ($SD = 20.7, n = 19$), and the orthopedic/neuromuscular group was 66.6 ($SD = 19.0, n = 17$). Spina bifida and other spinal conditions had a higher mean ($x = 78.3, SD = 15.1, n = 12$), but developmental and cognitive disabilities had the highest motor FIM score ($x = 81.6, SD = 9.5, n = 18$). The difference between those with cerebral disabilities and those with spinal disabilities was statistically significant ($p = 0.058$, 2-tailed, equal variance). Adolescents with spinal conditions were also nearly significantly more physically independent than those with orthopedic/neuromuscular conditions ($p = 0.088$). The group with developmental or cognitive disabilities had a statistically significantly higher physical independence than the group with

cerebral palsy ($p=0.003$, 2-tailed, unequal variance), and the group with orthopedic or neuromuscular diseases ($p=0.007$, 2-tailed, unequal variance).

Considering the cognitive aspects of functional independence, the differences between the diagnostic categories were significant ($F=11.452$, $p<0.001$). The group with developmental/cognitive disabilities had the lowest cognitive FIM ($x=24.7$, $SD=4.9$, $n=18$). For the group with cerebral disabilities such as cerebral palsy, the mean score was 29.0 ($SD=5.8$, $n=19$). The groups with spinal conditions and orthopedic/neuromuscular diseases showed higher cognitive independence ($x=32.8$, $SD=3.4$, $n=12$; and $x=32.5$, $SD=2.7$, $n=17$ respectively). The differences were significant when comparing the group with spinal disabilities with those having orthopedic/neuromuscular diseases or cerebral palsy and related conditions ($p=0.041$, 2-tailed, equal variance and $p=0.023$, 2-tailed, unequal variance). The group with developmental/cognitive disabilities had significantly less cognitive independence than the group with cerebral disabilities ($p=0.025$, 2-tailed, equal variance), the group with spina bifida ($p<0.001$, 2-tailed, equal variance), or the group with orthopedic or neuromuscular diseases ($p<0.001$, 2-tailed, unequal variance).

Regarding total parental stress, there was no statistically significant difference in the SIPA score or its Parent Domain when comparing the four diagnostic groups ($F=1.243$, $p=0.304$ and $F=1.551$, $p=0.213$ respectively). However, a near-significant difference in the Adolescent Domain of the SIPA did exist based on diagnosis ($F=2.494$, $p=0.070$). The mean for Adolescent Domain was lowest in orthopedic/neuromuscular diseases ($x=77.1$, $SD=20.9$, $n=17$) and highest in developmental/cognitive disabilities ($x=95.2$, $SD=23.6$, $n=15$). The mean Adolescent Domain score for the group with cerebral disabilities was 89.7 ($SD=15.1$, $n=13$), and was 84.4 for subjects with spina bifida and related conditions ($SD=13.8$, $n=10$). There was a trend towards less adolescent-related parental stress in orthopedic/neuromuscular disabilities compared with cerebral conditions ($p=0.077$, 2-tailed, equal variance), and

significantly less stress than for developmental/cognitive disabilities ($p= 0.028$, 2-tailed, equal variance).

The Adolescent-Parent Relationship Domain also differed significantly between diagnoses ($F = 3.003$, $p = 0.030$). The means were comparable for the group with cerebral disorders ($x = 31.4$, $SD = 6.1$, $n = 13$), those with spina bifida and other spinal cord conditions ($x = 31.1$, $SD = 6.6$, $n = 10$), and developmental/cognitive disabilities ($x = 31.0$, $SD = 6.5$, $n = 15$). In contrast, the lowest mean score was for parents of adolescents with orthopedic/neuromuscular disability ($x = 25.7$, $SD = 5.9$, $n = 17$). This APRD score was significantly lower than the three other groups ($p= 0.016$, 2-tailed, equal variance for cerebral conditions; $p= 0.037$, 2-tailed, equal variance for spinal conditions; and $p= 0.021$, 2-tailed, equal variance for developmental/cognitive conditions).

Health-related quality of life differed significantly based on diagnosis ($F=2.910$, $p= 0.044$). HRQOL was lowest for spinal cord conditions ($x = 187.4$, $SD = 30.5$, $n = 14$). The group with cerebral conditions or orthopedic/neuromuscular conditions showed intermediate scores ($x = 191.5$, $SD = 26.2$, $n = 13$; and $x = 198.2$, $SD = 17.8$, $n = 18$ respectively). The highest score was reported by those with developmental/cognitive conditions ($x = 219.9$, $SD = 7.2$, $n = 6$). This was a significantly higher HRQOL than subjects with cerebral conditions ($p= 0.002$, 2-tailed, unequal variance) or spinal cord conditions ($p= 0.002$, 2-tailed, unequal variance). It was also statistically significantly higher than the developmental/cognitive group ($p= 0.009$, 2-tailed, equal variance).

Table 4: ANOVA Comparing Diagnostic Groups

		Sum of Squares	df	Mean Square	F	Sig.
Total FIM score	Between Groups	2843.965	3	947.988	2.741	0.051*
	Within Groups	21440.576	62	345.816		
	Total	24284.541	65			
Motor FIM	Between Groups	3665.697	3	1221.899	4.336	0.008**
	Within Groups	17473.060	62	281.824		
	Total	21138.757	65			
Cognitive FIM	Between Groups	697.063	3	232.354	11.452	<0.001**
	Within Groups	1257.993	62	20.290		
	Total	1955.056	65			
HRQOL	Between Groups	4816.345	3	1605.448	2.910	0.044**
	Within Groups	25926.900	47	551.636		
	Total	30743.244	50			
Parent Domain	Between Groups	1738.500	3	579.500	1.551	0.213
	Within Groups	19050.308	51	373.535		
	Total	20788.808	54			
Adolescent Domain	Between Groups	2818.632	3	939.544	2.494	0.070*
	Within Groups	19214.514	51	376.755		
	Total	22033.146	54			
APRD	Between Groups	354.965	3	118.322	3.003	0.039**
	Within Groups	2009.216	51	39.396		
	Total	2364.181	54			
Total SIPA	Between Groups	4199.306	3	1399.769	1.243	0.304
	Within Groups	57429.426	51	1126.067		
	Total	61628.732	54			

Table 5: *Results based on diagnosis*

Test	Diagnosis Group	Mean	N	St. Dev.
Total FIM score	Cerebral	93.5263	19	22.67798
	Spinal	111.1174	12	16.75270
	Ortho/NM	99.0882	17	19.55300
	Cognitive/Dev	106.3813	18	13.23773
Motor FIM	Cerebral	64.6316	19	20.66118
	Spinal	78.2841	12	15.11312
	Ortho/NM	66.6176	17	18.96010
	Cognitive/Dev	81.6389	18	9.47102
Cognitive FIM	Cerebral	28.8947	19	5.76286
	Spinal	32.8333	12	3.40677
	Ortho/NM	32.4706	17	2.74130
	Cognitive/Dev	24.7424	18	4.92474
HRQOL	Cerebral	191.4810	13	26.21690
	Spinal	187.4408	14	30.46298
	Ortho/NM	198.1932	18	17.75251
	Cognitive/Dev	219.9410	6	7.17634
Parent Domain	Cerebral	84.7597	13	20.00169
	Spinal	74.1985	10	14.42140
	Ortho/NM	79.9496	17	17.37497
	Cognitive/Dev	69.9990	15	23.21864
Adolescent Domain	Cerebral	89.6624	13	15.11949
	Spinal	84.4000	10	13.84197
	Ortho/NM	77.0654	17	20.85040
	Cognitive/Dev	95.1914	15	23.59040
APRD	Cerebral	31.3741	13	6.14464
	Spinal	31.1000	10	6.64078
	Ortho/NM	25.6757	17	5.91443
	Cognitive/Dev	31.0302	15	6.54408

Table 6: 2 Sample T-test for total FIM, two-tailed

			<i>Levene's test</i>		
Variable 1	Variable 2	<i>P value</i>	Variance	F	<i>P value</i>
Cerebral	Spinal	0.028 **	equal	1.154	0.292
Cerebral	Ortho/NM	0.439	equal	0.002	0.965
Cerebral	Cognitive/Developmental	0.044**	equal	3.688	0.063
Spinal	Ortho/NM	0.095*	equal	2.116	0.157
Spinal	Cognitive/Developmental	0.395	equal	0.410	0.527
Ortho/NM	Cognitive/Developmental	0.209	unequal	7.428	0.010

Table 7: 2 Sample T-test for motor FIM, two-tailed

			<i>Levene's test</i>		
Variable 1	Variable 2	<i>P value</i>	Variance	F	<i>P value</i>
Cerebral	Spinal	0.058*	equal	2.202	0.149
Cerebral	Ortho/NM	0.767	equal	0.019	0.892
Cerebral	Cognitive/Developmental	0.003 **	unequal	9.573	0.004
Spinal	Ortho/NM	0.088*	unequal	4.329	0.047
Spinal	Cognitive/Developmental	0.460	equal	1.252	0.273
Ortho/NM	Cognitive/Developmental	0.007 **	unequal	23.499	< 0.001

Table 8: 2 Sample T-test for cognitive FIM, two-tailed

			<i>Levene's test</i>		
Variable 1	Variable 2	<i>P value</i>	Variance	F	<i>P value</i>
Cerebral	Spinal	0.041**	equal	3.501	0.071
Cerebral	Ortho/NM	0.023**	unequal	5.693	0.023
Cerebral	Cognitive/Developmental	0.025**	equal	0.108	0.745
Spinal	Ortho/NM	0.753	equal	0.000	0.991
Spinal	Cognitive/Developmental	< 0.001**	equal	3.957	0.057
Ortho/NM	Cognitive/Developmental	< 0.001**	unequal	7.051	0.012

Table 9: 2 Sample T-test for total SIPA, two-tailed

			<i>Levene's test</i>		
Variable 1	Variable 2	P value	Variance	F	P value
Cerebral	Spinal	0.123	equal	0.000	0.987
Cerebral	Ortho/NM	0.062*	equal	1.598	0.217
Cerebral	Cognitive/Developmental	0.462	equal	3.041	0.093
Spinal	Ortho/NM	0.602	equal	1.246	0.275
Spinal	Cognitive/Developmental	0.653	equal	2.393	0.136
Ortho/NM	Cognitive/Developmental	0.335	equal	0.192	0.664

Table 10: 2 Sample T-test for Adolescent Domain of SIPA, two-tailed

			<i>Levene's test</i>		
Variable 1	Variable 2	P value	Variance	F	P value
Cerebral	Spinal	0.401	equal	0.118	0.735
Cerebral	Ortho/NM	0.077*	equal	0.609	0.442
Cerebral	Cognitive/Developmental	0.475	equal	1.719	0.201
Spinal	Ortho/NM	0.333	equal	0.960	0.337
Spinal	Cognitive/Developmental	0.207	equal	2.098	0.161
Ortho/NM	Cognitive/Developmental	0.028**	equal	0.289	0.595

Table 11: 2 Sample T-test for Parent Domain of SIPA, two-tailed

			<i>Levene's test</i>		
Variable 1	Variable 2	P value	Variance	F	P value
Cerebral	Spinal	0.174	equal	1.703	0.206
Cerebral	Ortho/NM	0.487	equal	0.354	0.556
Cerebral	Cognitive/Developmental	0.086*	equal	0.806	0.378
Spinal	Ortho/NM	0.387	equal	0.730	0.401
Spinal	Cognitive/Developmental	0.583	unequal	4.980	0.036
Ortho/NM	Cognitive/Developmental	0.177	equal	2.619	0.116

Table 12: 2 Sample T-test for Adolescent-Parent Relationship Domain of SIPA, two-tailed

			<i>Levene's test</i>		
Variable 1	Variable 2	<i>P value</i>	Variance	F	<i>P value</i>
Cerebral	Spinal	0.919	equal	0.042	0.839
Cerebral	Ortho/NM	0.016**	equal	0.062	0.805
Cerebral	Cognitive/Developmental	0.888	equal	0.062	0.806
Spinal	Ortho/NM	0.037**	equal	0.203	0.656
Spinal	Cognitive/Developmental	0.979	equal	0.171	0.683
Ortho/NM	Cognitive/Developmental	0.021**	equal	0.002	0.961

Table 13: 2 Sample T-test for HRQOL, two-tailed

			<i>Levene's test</i>		
Variable 1	Variable 2	<i>P value</i>	Variance	F	<i>P value</i>
Cerebral	Spinal	0.716	equal	0.056	0.814
Cerebral	Ortho/NM	0.402	equal	4.062	0.053
Cerebral	Cognitive/Developmental	0.002**	unequal	8.009	0.012
Spinal	Ortho/NM	0.220	equal	3.905	0.057
Spinal	Cognitive/Developmental	0.002**	unequal	4.923	0.040
Ortho/NM	Cognitive/Developmental	0.009**	equal	1.514	0.232

Correlations

Total FIM

There was a near significant positive correlation between the FIM score and the HRQOL ($r = 0.270$, $N = 48$, $p = 0.063$).

The FIM was not correlated with total SIPA score, nor with the Adolescent-Parent Relationship Domain of total parent stress. However, a near-significant, weakly positive correlation existed between total FIM score and the Adolescent Domain of the SIPA ($r = 0.256$, $N = 52$, $p = 0.067$). This relationship appeared to primarily be due to the near significant correlation between the FIM score and Failure to Achieve or Persevere ($r = 0.249$, $N = 52$, $p = 0.074$). However, the FIM score was not related to Moodiness/Emotional Lability, Social Isolation/Withdrawal, or Delinquency/Antisocial.

A near significant correlation existed between total FIM score and the Parental Domain as well, but this was weakly negative ($r = -0.243$, $N = 52$, $p = 0.082$). This appeared to be based on a significant but small correlation between the adolescent's FIM and the parent's Relationship with Partner/Spouse ($r = -0.277$, $N = 52$, $p = 0.046$), and a near significant correlation with parental Life Restriction ($r = -0.262$, $N = 52$, $p = 0.061$). The FIM score did not appear to be associated with Social Alienation or Incompetence/Guilt.

The correlations with the FIM score were stronger when only the physical component was considered. For example, the physical component of the FIM was correlated with the adolescent's HRQOL ($r = 0.358$, $N = 48$, $p = 0.012$).

There was a significant medium sized negative correlation of the motor FIM with the Parent Domain of the SIPA ($r = -0.320$, $N = 52$, $p = 0.021$). Among the components of the Parent Domain, the motor FIM showed a significant medium size correlation with Life Restrictions, and a significant medium size correlation with Relationship with Partner/Spouse ($r = -0.364$, $N = 52$, $p = 0.008$ and $r = -0.307$, $N = 52$, $p = 0.027$ respectively) but no correlation with parental Social Alienation or Incompetence/Guilt. In contrast, there was a significant medium-sized positive

correlation between the motor FIM and the Adolescent Domain ($r = 0.377$, $N = 52$, $p = 0.006$). This was a consequence of a medium sized correlation with Failure to Achieve/Persevere ($r = 0.333$, $N = 52$, $p = 0.016$). No correlation existed between motor functional independence and Moodiness/Emotional Lability, Social Isolation/Withdrawal, or Delinquency/Antisocial. There was no correlation between the motor FIM and the Adolescent/Parent Relationship Domain. Similarly, there was no correlation between motor FIM and cognitive FIM.

The cognitive aspect of functional independence was not correlated with HRQOL, and neither were its contributing variables (Communication or Social Cognition). The cognitive aspect of the FIM was not correlated with the total SIPA score, the Adolescent-Parent Relationship Domain, the Parent Domain, or the Adolescent Domain, but did show a significant negative correlation with the Delinquency/Antisocial sub-domain ($r = -0.317$, $N = 52$, $p = 0.002$).

SIPA

The total Stress Index for Parents of Adolescents score showed no correlation with the adolescent's Health-Related Quality of Life. The Parent Domain of the SIPA and each of its components showed no correlation with the adolescent's HRQOL. Similarly, the Adolescent Domain of the SIPA and each of its components showed no correlation with the HRQOL. The Adolescent-Parent Relationship Domain did have a near significant small negative correlation with the adolescent's HRQOL ($r = -0.295$, $N = 41$, $p = 0.061$).

The SIPA score was not correlated with the total FIM score, nor with the motor FIM score or the cognitive FIM score. It was also not correlated with any specific component of the FIM, either physical or cognitive.

The Parent Domain of the SIPA had a near significant small negative correlation with the total FIM ($r = -0.243$, $N = 52$, $p = 0.082$), with a significant medium-sized negative correlation with the physical aspects of the FIM ($r = -0.320$, $N = 52$, $p = 0.021$) but no correlation with the cognitive aspects. Among the physical components of functional independence, the Parent

Domain of the SIPA was significantly correlated with Transfers, and significantly correlated with Self-Care ($r = -0.349$, $N = 52$, $p = 0.011$ and $r = -0.368$, $N = 52$, $p = 0.007$ respectively). There was no correlation with the Parent Domain of the SIPA and the score for either Sphincter Control or Locomotion. There was also no correlation with the Parent Domain and either Communication or Social Cognition, which comprise the cognitive aspect of the FIM.

The Adolescent Domain had a near significant correlation with the total FIM ($r = 0.173$, $N = 52$, $p = .074$), with a significant correlation with the physical aspects of the FIM ($r = 0.358$, $N = 52$, $p = .0012$) but no correlation with the cognitive aspects. Among the physical components, there was a significant positive correlation with the Adolescent Domain of the SIPA and the score for Locomotion ($r = 0.382$, $N = 52$, $p = 0.005$). The Adolescent Domain of the SIPA also significantly correlated with Transfers ($r = 0.342$, $N = 52$, $p = 0.013$), and Self Care ($r = 0.275$, $N = 52$, $p = 0.049$). There was a near significant correlation with independence in Sphincter Control ($r = 0.262$, $N = 52$, $p = 0.060$). Similar to the Parent Domain, though, there was no correlation with the Adolescent Domain of the SIPA and either Communication or Social Cognition, which comprise the cognitive aspect of the FIM.

However, there was no correlation between the APRD and total FIM score. The APRD was also not correlated with any specific component of the FIM, either physical or cognitive.

Health-Related Quality of Life

The correlation between HRQOL and the total FIM score reached near significance with a small positive relationship ($r = 0.270$, $N = 48$, $p = 0.063$). This appears to be related to the physical components of the FIM specifically ($r = 0.358$, $N = 48$, $p = 0.012$). Of the motor FIM, HRQOL score was correlated with independence in Transfers and Locomotion ($r = 0.357$, $N = 48$, $p = 0.013$ and $r = 0.321$, $N = 48$, $p = 0.026$ respectively). HRQOL was nearly correlated with Self Care ($r = 0.252$, $N = 48$, $p = 0.084$), but not correlated with Sphincter Control. Cognitive aspects of the FIM, and its components, do not appear to be correlated with HRQOL.

Regarding parental stress, there was no correlation between total SIPA score and the adolescent's reported HRQOL. Among the components of the total SIPA, there was neither a correlation with the Parent Domain, nor any of its sub-domains. The adolescent's HRQOL also did not appear to be correlated with the Adolescent Domain, nor any of its sub-domains. However, there was a near significant medium negative correlation between the Adolescent-Parent Relationship Domain and HRQOL ($r = -0.295$, $N = 41$, $p = 0.061$).

Table 14: Significant Correlations

Variable 1	Variable 2	Correlation	Significance
HRQoL	Motor FIM	0.358	0.012
HRQoL	Transfers (FIM)	0.357	0.013
HRQoL	Locomotion (FIM)	0.321	0.026
FIM	REL (SIPA)	-0.277	0.046
Motor FIM	Parent Domain (SIPA)	-0.320	0.021
Motor FIM	Adolescent Domain (SIPA)	0.377	0.006
Motor FIM	ACH (SIPA)	0.333	0.016
Motor FIM	REL (SIPA)	-0.307	0.027
Motor FIM	LFR (SIPA)	-0.364	0.008
Self Care (FIM)	Parent Domain	-0.368	0.007
Self Care (FIM)	Adolescent Domain (SIPA)	0.275	0.049
Self Care (FIM)	ACH (SIPA)	0.355	0.010
Self Care (FIM)	REL (SIPA)	-0.356	0.010
Self Care (FIM)	LFR (SIPA)	-0.391	0.004
Locomotion (FIM)	Adolescent Domain (SIPA)	0.382	0.005
Transfers (FIM)	Parent Domain (SIPA)	-0.349	0.011
Transfers (FIM)	Adolescent Domain (SIPA)	0.342	0.013
Transfers (FIM)	ACH (SIPA)	0.396	0.004
Transfers(FIM)	REL (SIPA)	-0.369	0.007
Transfers (FIM)	LFR (SIPA)	-0.390	0.004
Cognitive Domain (FIM)	DEL (SIPA)	-0.451	0.001
Communication (FIM)	DEL (SIPA)	-0.383	0.005
Social Cognition (FIM)	DEL (SIPA)	-0.430	0.001

** Bold signifies those correlations involving two substantial domains.

Table 15: Near Significant Correlations

Variable 1	Variable 2	Correlation	Significance
HRQoL	Self Care (FIM)	0.252	0.084
HRQoL	Total FIM	0.270	0.063
HRQoL	APRD (SIPA)	-0.295	0.061
FIM	Parent Domain (SIPA)	-0.243	0.082
FIM	Adolescent Domain (SIPA)	0.173	0.074
FIM	ACH (SIPA)	0.249	0.074
FIM	LFR (SIPA)	-0.262	0.061
Adolescent Domain (SIPA)	Sphincter (FIM)	0.262	0.060
ISO (SIPA)	Locomotion (FIM)	0.248	0.076
DEL (SIPA)	Locomotion (FIM)	0.272	0.051

** Bold signifies those correlations involving two substantial variables.

INTERPRETATION

Outcome measures that guide public health interventions may be categorized as either objective, such as functional abilities and health status, or as subjective, such as perceived quality of life and stress levels. For disabled populations, variables such as functional independence and quality of life are often assumed to be correlated. Functional characteristics are even considered in many quality of life assessments.^{80, 81} Although likely related, objective and subjective are not interchangeable. Properly assessing the impact of these factors – and the impact of interventions which target these factors – requires a mindfulness of this dichotomy of outcomes. So too, the biopsychosocial milieu may influence variables and outcomes, including the impact of demographic variables or parental influences on those with disabilities. This thesis explores such issues to better understand their relationship in adolescents with disabilities. This may guide care and appropriate public health interventions for this underserved population.

Interpretations based on Demographics

At slightly less than \$40,000, families of individuals with disabilities have a median income more than 15% lower than the median of \$46,326 for the general population in 2005.⁸² At the same time, out-of-pocket medical expenses are greater⁸³, constituting 11.2% of family income compared to 4.1% for families without a disabled member.⁸⁴ Families of those with disabilities are doubly burdened, then, both with less income and with greater expenses. Yet research shows that enhanced socioeconomic status leads to better clinical outcomes for those affected by disabilities.^{85, 86} This could be mediated by access to personal care attendants, recreational programs, and other services. Enhanced socioeconomic status may also afford the parents greater flexibility with work demands and schedules. This facilitates caring for their child and adapting to the demands of parenting. With parents often acting as primary care givers for those with disabilities, flexibility is particularly important. Independence from socioeconomic burdens benefits the adolescent and the family as a whole.

Almost all participants in the study (66.2% of respondents, 9 with no response) indicated they had a family income of “greater than \$40,000.” This data is limited because it is not possible to precisely determine the income distribution of the sample. The preponderance of participants above the expected median income of families with children with disabilities (which is slightly less than \$40,000) might indicate that the study sites, such as summer camps and sporting groups, were utilized by families with higher incomes. There remains a need, then, to increase opportunities for individuals who are challenged by socioeconomic burdens in addition to a disability. This mandates financial and social supports for participation, principally in the dramatically underrepresented half of individuals falling below the median.

For adolescents, though, socioeconomic factors may shape outcomes less than for disabled individuals in general. Schools are instrumental in this buffering. The study population (ages 10-20) almost universally participates in the school system. This acts as a primary provider of services and resources, independent of a student’s personal finances. In contrast, once outside of the school system, there is no organized infrastructure.⁸⁷ After adolescence, when one’s own awareness, proactive efforts, and individual or family funds are required, socioeconomic constraints may profoundly limit the ability to access needed services and obtain optimal outcomes.

There was a predominance of participants who identify as “White/Caucasian” in this study. While reflective of the racial constitution of the study sites, this did not yield adequate numbers for inter-race comparisons. The reason for poor representation of minorities is unclear, but merits exploration. Interventions for adolescents with disabilities, such as camps or sports, must adequately reach the full cross section of those affected, and transcend racial barriers.

In this study, gender, age, and race did not significantly shape variations in quality of life, functional independence, or the components of parental stress. If these results are valid, this indicates the stability of the disability experience with less influence by these variables. Alternatively, this may reflect a limitation of the sampling method or sample size, the

instruments, or the influence of other variables which could more significantly drive variations seen in quality of life, functional independence, or parental stress.

Interpretations based on Diagnosis

Categorical studies explore participants that are affected by a single disability, and downplay the within-diagnosis variation. The current study, in contrast, recruited participants with various diagnoses. As a collective population, this yields results that may not be informative of a single condition. Instead, it elucidates aspects of the shared experience of disability, and the general relationships between disability and other aspect of one's life.

However, significant differences based on diagnosis can be compared. The current study identified four groups: cerebral conditions, spinal cord conditions, orthopedic/neuromuscular conditions, and developmental/cognitive conditions. These categories were established based on current understanding of disability, and the similarities in manifestations and pathophysiology. Such categories validate the idea that not all disability is experienced the same.

The difference in functional independence for the four groups is near significant. While not fully reaching statistical significance, this might still imply that different types of disabilities have different effects on daily life, and necessitate different magnitudes or types of supports to sustain independence. However, while conditions such as cerebral palsy or spina bifida may have more generalized impairments encompassing both motor and cognitive function, others such as developmental conditions demonstrate more specific limitations.

Specifically considering physical independence, those with cerebral conditions have significantly less physical independence than seen in orthopedic/neuromuscular diagnoses, or with spinal conditions such as spina bifida. The spina bifida group trends towards more independence than those with orthopedic/neuromuscular disorders, but developmental/cognitive disabilities show more physical independence than any of the other groups. Distinctions in

physical independence (transfers, self-care, etc) are more pronounced than differences in overall functional independence, and may be particularly influenced by upper body functional status.

At the same time, those diagnoses associated with increased physical assistance may not need cognitive assistance, and vice versa. Those with primarily developmental/cognitive disabilities have the least cognitive independence. Those with spina bifida or orthopedic/neuromuscular diagnoses show more cognitive independence than seen in individuals with conditions related to cerebral palsy. As cerebral palsy illustrates, cognitive dependence may coexist with physical dependence to a variable degree. However, it is important that services address the cognitive needs of consumers, even in the face of apparent physical needs. While public health must not mistakenly equate physical disability with cognitive disability, it also must not ignore the potential dually disability, both physical and cognitive.

In general, the concept of functional independence can be useful in quantifying the level of support a person needs to carry out certain activities. Adaptive equipment or personal care attendants (PCAs) may attenuate limited independence, and maximize the assessed functions, perhaps in a modified form. But parents by default often fill the caregiver role in place of a PCA, and therefore they may also be instrumental maximizing function. This caregiver role is in addition to other aspects of being a parent, and as with children in general, the relationship between parent and child faces unique challenges and stresses in adolescence.

This thesis found that the stress for parents of adolescents with disabilities was generally comparable to the stress for parents of adolescents without disabilities¹⁷, and that the cumulative magnitude of stress for parents of adolescents with disabilities was comparable across diagnoses. There was also no difference in the portion of stress derived from the parenting role specifically. Yet the diagnosis groups did trend towards differences in the stress experienced by a parent due to an adolescent's behavior. In particular, parents of an adolescent with an orthopedic/neuromuscular conditions trended towards less stress than those with cerebral conditions, and showed significantly less stress than parents of children with

cognitive/developmental disorders. Appreciating variations and alleviating the burdens of parental stress, whether due to parental duties or the child's behaviors, may benefit both parties and thus promote better outcomes. School programs and recreational opportunities, particularly for adolescents, may be powerful avenues for these goals.

Strengthening the adolescent-parent relationship may also facilitate these goals. Parents of adolescents with disabilities play a particularly potent role in that they not only often serve as primary caregiver, but are also a key element in the interpersonal networks that help negotiate the challenges of this transition. A thorough understanding of the relationship must consider the varying impacts of different diagnoses. Of note, this thesis found that the group with orthopedic/neuromuscular diagnoses had significantly less stress in this relationship than parents of adolescents in any of the other three groups. Orthopedic/neuromuscular conditions might be associated with less adolescent-parent relationship stress (and also less adolescent-related parent stress) due to the prognosis and its effects on adolescent transitions. Compared to more stable disabilities, perhaps the progressive nature of conditions such as the muscular dystrophies reinforces the significance of the parent-child relationship while lessening stress due to the behaviors of the adolescent. Alternatively, the high cognitive function of these adolescents relative to the other diagnoses may attenuate stress.

Understanding quality of life will help target interventions for these and other factors. Health-related quality of life varied significantly based on disability. Individuals with cognitive or developmental disabilities attained significantly higher health-related quality of life than the three other diagnosis groups. This may indicate fewer obstacles to a high health-related quality of life, or less emphasis on them. Some have theorized that individuals with physical disabilities - particularly with higher cognitive functioning and less apparent physical deficits - might compare themselves with able-bodied peers. This "upward comparison" leads to a more negative self-assessment and lower subjective quality of life. Those with cognitive or developmental conditions could be less prone to such upward comparisons. Finally, twenty one participants did

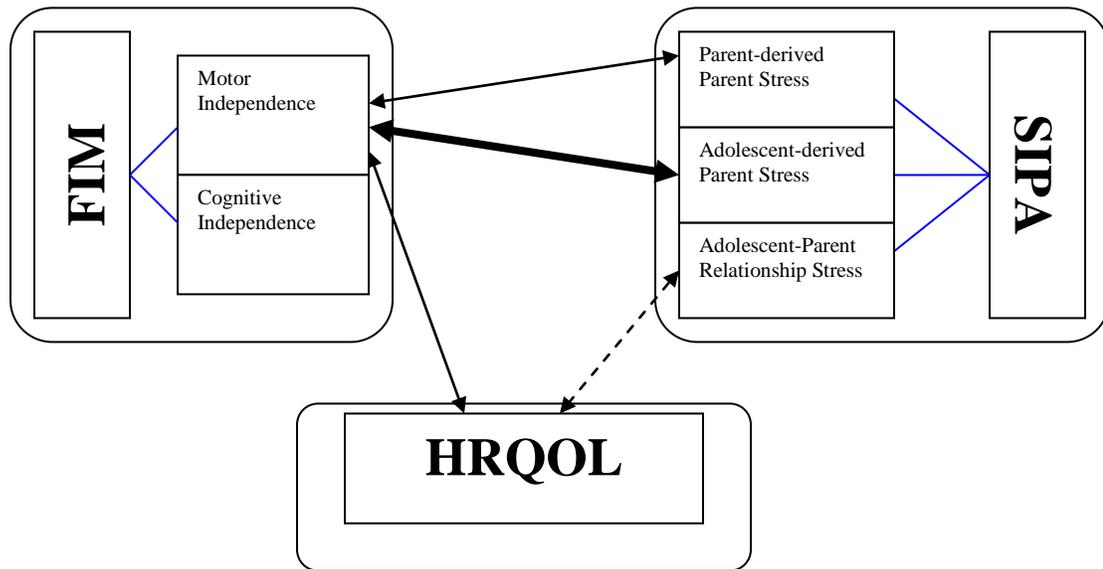
not complete the HRQOL instrument. Failure to complete this questionnaire was primarily due to inadequate comprehension, and therefore selected against participants with the most severe cognitive impairments. Individuals from this group with more severe disability may not have a quality of life as high as the individuals with a milder disability.

Regardless, cumulative results showd a high HRQOL score with a left skew and narrow range, indicating a generally high quality of life for adolescents with disabilities. This is consistent with research on individuals with spina bifida.²² But results may still be lower than a nondisabled cohort, as has been reported in comparisons of individuals with cerebral palsy relative to healthy peers.³⁷

Major relationships

In the collective group of adolescents with disabilities, some noteworthy relationships exist. Notably, adolescents with high functional independence had parents who feel significantly greater stress due to the adolescent's behavior, and concurrently felt significantly less stress due to the parenting role itself. Increases in motor independence, specifically, were also associated with significant increases in health-related quality of life. However, the relationship between higher health-related quality of life and less stressful adolescent-parent relationships only reached near significance.

Figure 9: *Diagram of pertinent relationships*



The motor aspects of functional independence seemed to particularly contribute to the near significant relationship between total functional independence and the adolescent-derived aspect of parental stress. With greater physical independence, parents derived more stress from the child’s character and behavior. Of note, individuals with enhanced motor independence were more likely to have parents who identify failures to achieve or persevere. These concerns were seen with independence in locomotion, self-care, or transfers, and trend towards an association with sphincter control. Such a finding is perhaps counter-intuitive since there is no reason to assume that adolescents who need less motor assistance tend to underachieve as a whole. Instead, this may reflect upward comparison by the parents, whereby the expectations of higher functioning adolescents are disproportionately higher. Even in higher functioning adolescents, then, stress for parents of those with disabilities can be problematic. Interventions to alleviate

parental stress should not be predicated on the functioning of the adolescent alone, and in fact should appreciate the distinct nature of stress in the face of less severe limitations.

While adolescent-related parental stress was not related to cognitive independence as a whole, there was a correlation between cognitive functional independence and parental perceptions of delinquency or antisocial behavior. Adolescents with cognitive disability – or a cognitive component to their disability – are isolated by difficulties communicating or navigating the social milieu. In turn, they are labeled “antisocial” or “delinquent,” perhaps as a consequence of society’s responses. Public health must identify ways to support the cognitive and social needs of these adolescents to enhance socialization and lessen the associated parental stress.

In contrast to adolescent-related parental stress, there was an associated near significant *reduction* in the contribution of the parenting role to parental stress as total functional independence increases. Again the relationship appeared to stem largely from the motor aspects of independence. Thus, while parents of a more dependent child were less likely to identify the adolescent as a source of stress, they derived more stress from the parenting role and responsibilities. Similar findings have been found in parents of younger children with cerebral palsy, where child behavior and care giving demands correlate with parental health and well-being.¹⁵ The conclusion argues for interventions and adaptive equipment to increase independence. This would not only benefit the child directly, but could benefit the parent through lessening the burden of the parenting role. Specifically, higher motor independence was correlated with less perceived life restrictions for the parent, and less stress in the parent’s relationship with a spouse (or partner). These correlations were strongest with self-care and transfers, which may be particularly potent targets for intervention. Alternatively, the correlation might argue that less stress of parenting promotes more independence for the adolescent, perhaps because the parent is better able to engage the adolescent and foster these behaviors. Regardless of the direction of this relationship, though, it is in public health’s interest to provide parents with support and resources to lessen the stress of parenting.

There was a near-significant but small correlation between total functional independence and an adolescent's health related quality of life. Adolescents with more independence trended towards a better quality of life. If causation can be assumed, either more independence produces a better quality of life, or else perhaps a better quality of life can foster more independent behaviors. This better quality of life was significantly correlated with the physical aspects of functional independence, rather than with the cognitive, although both are important and worth addressing. Other research has found similar relationships. Participation in regular physical activity could improve both functional status and quality of life. These relative increases in physical independence may be more significant for quality of life than absolute levels of independence.^{88, 89} Adaptive equipment could play a comparable role, while also providing safety and stability in the face of poor balance, decreased strength or movement, or decreased cognitive awareness. Lifts, wheelchairs, shower chairs, communication boards, commodes and medications which enhance bowel or bladder control are available options. Public health should also encourage "least restrictive environments" with wheelchair ramps, lower counters, and accessible bathrooms with adequate size, grab bars, and other physical modifications, for example. These extensive options are an important opportunities for the health community to improve independence and quality of life.

The correlation may also indicate that higher quality of life empowers an adolescent to challenge - and lessen - their own functional limitations. If this causation is valid, even interventions that do not directly target an adolescent's functional independence might lead to improvements indirectly via an enhanced quality of life. This would require a redoubled effort by the public health community to enhance quality of life in order to reap wide-ranging benefits.

The relationship between function and quality of life is contested by some research. Some have found a high quality of life despite what external observers might label an "undesirable daily existence" with significant limitations in function. This seeming contradiction has been labeled the "disability paradox."⁹⁰ Even in the current study group, the overall high

HRQOL scores indicate that poor quality of life can not be inferred based on impaired function alone.

The association between an adolescent's health-related quality of life and the stress in the adolescent-parent relationship is nearly significant. Enhancing this relationship could benefit the adolescent's quality of life, and prior research shows that a positive relationship with a parent acts as a psychological buffer.^{91, 92} Alternatively, public health interventions to enhance quality of life might promote more fulfilling relationships with parents. Regardless, an adolescent's quality of life and the quality of the adolescent-parent relationship for the parent appear to be related.

In sum, relationships between independence, parental stress, and quality of life highlight the challenges for adolescents with disabilities, and potential interventions for public health.

Pertinent negatives

Some of the relationships which were not validated are also noteworthy. Specifically, cognitive independence was not related to any other outcome, the adolescent-parent relationship stress was independent of the adolescent's functional independence, and adolescent-derived parental stress was not correlated with the adolescent's quality of life.

This study found that cognitive independence did not correlate with self-reported quality of life, despite a significantly higher quality of life for adolescents with cognitive and/or developmental disabilities relative to the other diagnostic groups. The result surprisingly argues that social or communicative dependence does not impair (or enhance) the individual's outlook on their health and quality of life. Perhaps cognitive needs are less apparent initially to others, or more easily adapted to than physical ones. Alternatively the HRQOL questionnaire might not adequately focus on factors that are impacted by cognitive function. This would indicate that outcome measures should be encouraged to embrace a broader definition of health.

The adolescent-parent relationship did not appear to be related to variations in cognitive independence. It similarly was not influenced by the adolescent's level of physical independence.

The adolescent's level of disability did not affect the stressfulness of the relationship with a parent, though it might have affected a parent's own feelings of stress more generally.

The adolescent's quality of life was unrelated to parental stress, due either to the responsibilities of the parenting role or the adolescent's behaviors directly. Even when parents identified stress-inducing adolescent behavior, this did not seem to correlate with the adolescent's reported quality of life. This lack of correlation may contribute to the disconnect between the perceptions of adolescents and parents. For adolescents with disabilities, in particular, the information provided by parents (as "substituted reporters") on the adolescent's attitudes, stressors, and quality of life is imperfect. The results in this thesis indicate that parent's own stress could shape their reports, and do so independent of the adolescent's quality of life. This is not to say that a parent's stress is entirely unrelated to the adolescent's quality of life. Research on adolescents with epilepsy found correlations between an adolescent's quality of life and parental anxiety or depression, for example.⁹³ However, if the relationship does exist in the general population of adolescents with disabilities, it is either not strong enough or not direct enough to be statistically significant in the current study.

The lack of relationships between these key variables is in some ways quite surprising. These are noteworthy and merit of further exploration.

Key Conclusions

- Adolescents with higher independence report higher Quality of Life.
- Less independent adolescents have parents who trend towards more stress from the impact of parenting and caregiver burden
- More independent adolescents have parents who trend towards more stress from the child's characteristics and comparison with the adolescent's peers.
- When parents report less stress due to the adolescent-parent relationship, adolescents trend towards higher Quality of Life

Specific Recommendations

- Health outcome measures should embrace a broader definition of health.
- Enhancing quality of life should be a primary goal of public health interventions, and might lead to unanticipated outcomes such as more fulfilling relationships with parents.
- Maximizing functional independence is a goal that may facilitate enhanced quality of life. This can be done via adaptive equipment. Lifts, wheelchairs, shower chairs, commodes, communication boards, and medications to enhance bowel/bladder control are options.
- To maximize functional independence, “least restrictive environments” should be encouraged, with wheelchair ramps, lower counters, and accessible bathrooms with adequate size, grab bars, and other physical modifications.
- Public health should provide support or resources for parents to lessen parenting stress.
- Public health must identify ways to support the cognitive and social needs of these adolescents to enhance socialization and lessen the associated parental stress.
- Appreciating variations and alleviating the burdens of parental stress may benefit both parties and promote better outcomes.
 - For more dependent adolescents, parent supports should reduce caregiver burden. This includes respite care, reducing isolation through support groups, and similar interventions.
 - For adolescents with more independence, supports should be designed to decrease the stress parents feel due to the adolescent’s behaviors. These may be informational resources, interventions to facilitate the adolescent’s development, and disabilities-related groups which can shape their expectations of their child’s behaviors.
- Interventions for adolescents with disabilities, such as camps or sports, must adequately reach the full cross section of those affected.
 - This mandates financial and social supports for participation, principally for minorities and those with fewer financial resources.

Limitations

The thesis provides some powerful and interesting results. However, significant limitations exist, relating both to the research design and the instruments used.

One identified limitation is the breadth of diagnoses. The thesis explores relationships affecting disabilities in general, and the more universal aspects of the disability experience. However, variations between diagnoses can not be denied. Combining a broad array of diagnoses may obscure relationships specific to some subgroups. There was some attempt to compensate for this by comparing four diagnosis groups. Yet these are likely imperfect, and based on clinical similarities which might not reflect similarities in the lived experience.

The study population did not reach full statistical power, which was a target of 100 participants. Had participation reached statistical power, interpretation of near significant correlations would be more certain. But with the relative rarity of disability, and the precautions to protect the privacy of a dually vulnerable population (disabled and minors), recruitment was restricted to disability-dense settings. Summer camps, sports groups, and other meetings may not be representative of the entire population of adolescents with disabilities, but these sites were selected in order to overcome the barriers inherent in identifying and recruiting individuals with disabilities in other ways. This might limit the ability to generalize conclusions. For example, participants in these settings may be buffered relative to other adolescents with disabilities, leading to generally better functional independence, parental stress, and quality of life. Involvement in disability-oriented sports and recreation requires a level of initiative, awareness of opportunities, and access to resources which may not be shared by all adolescents with disabilities and their families. These characteristics of the study group may translate to other resources and social supports. Through disability-oriented recreation, the adolescent and their family may be linked to peers who act as informal resources and connections. Careful consideration should be applied before presuming that conclusions of this thesis apply to all adolescents with disabilities.

The number of participants was also not adequate for analysis of a single diagnosis. Thus, the sample may not represent the true range for each diagnosis – or even for the diagnosis groups created. Similarly, conclusions based on variation by age were limited by numbers. For a given age, the mean number of participants was just 6.45 (range = 2-10). Of course, the complexity of the disability experience may also produce more variation within age, gender, race, or even diagnosis groups than between the groups. Ultimately, other variables could more significantly drive variations seen in quality of life, functional independence, or parental stress.

The limitations of the measures used also merit consideration. The instruments may lack adequate sensitivity to variations, limited by the nature of the instrument itself or by inadequate statistical power. The SIPA is designed for adolescents in general. It presumes, therefore, that the stress of parents of disabled adolescents can be adequately assessed by this measure. It may be that stress for parents of adolescents with disabilities is distinct from general parental stress, and is therefore unable to be assessed in the same way. And in quantifying stress, the SIPA domain scores may overlook differences in the qualities and nature of this stress.

Although it has been used across disabilities in rehabilitation settings, perhaps the FIM as well does not fully capture issues of function, and what matters to adolescents. Furthermore, the FIM is subject to a degree of interrater variability, although this was minimized in this thesis by the small number of researchers involved.

While the other instruments were designed for a more general population, the HRQOL questionnaire was originally designed specifically for spina bifida, but extended to all disabilities with permission of its authors.⁷⁷ Spina bifida is distinguished from other diagnostic groups by a unique blend of characteristic cognitive impairments, plus motor impairments primarily restricted to the lower extremity.^{5,6} Various diagnoses reflect distinct arrays of impairments. The HRQOL instrument created for spina bifida specifically may not capture the broad influences shaping health-related quality of life in disabilities marked by different strengths and impairments.

These and other limitations must be considered in interpreting this thesis.

Future Directions

This thesis is a foundation for further exploration. Future studies might further explore the changes over time through adolescence. Longitudinal analysis may effectively tease out changes over time in the individual's experience which were missed in the current analysis. Interracial comparisons of the disability experience, too, merit further study and would require greater more minority representation. Research might also help identify the reason for this poor representation. Even those variables studied merit further inquiry. It remains unclear why certain relationships did not hold, such as the lack of a correlation between the parent's stress and the adolescent's quality of life. Alternative instruments and means of exploration should be considered to validate and explore these results. Further characterization of parental stress still seems warranted, perhaps through a case-control style methodology or other approaches. Qualitative research would be valuable to effectively understand these processes and more.

Future directions also include applying the results of this research. Appropriate public health interventions based on these results would include efforts to facilitate motor independence, since it is associated with less caregiver stress for the parent and greater health related quality of life for the adolescent. Due to the association of motor independence with increased adolescent-related parental stress, however, there should be efforts to identify and ameliorate such stress early. Overall, this research indicates that key outcomes, such as parental stress or quality of life, are truly meaningful in shaping the life experience of adolescents with disabilities. Future efforts to explore the effect of various public health programs, approaches, or interventions should consider changes in these outcomes in order to determine the effectiveness. Ultimately, public health should ensure that its efforts on behalf of adolescents with disabilities are effective.

CONCLUSION

This thesis recognizes that all disabilities are not experienced the same, and that each disability requires an appreciation of the unique constellation of factors – both internal and external – which influence the lived experience. It supports public health efforts to improve functional independence through adaptive equipment, training, personal care attendants, and other resources tailored to the specific disability and the specific experience. It supports a greater awareness of the unique stressors experienced by parents and dynamic nature of this stress. It supports a broader holistic understanding of health, social networks, and other influences on well-being in adolescents with disabilities. And it supports the value of health-related quality of life and interventions to improve this outcome. In particular, sports, camps, and other groups can play a significant role for the adolescents by not only serving as recreation opportunities, but also by providing a source of social support and role models, facilitating parent-child interaction, or serving as sites for skills training.

A holistic understanding of the disability experience, bolstered by research, empowers medicine and public health. While these professions currently have the ability to care for individuals with disabilities, they remain unable to reverse these conditions. But if disability is not simply a biological condition to be prevented or avoided, then the objective of medicine and public health is more than simply the control of a medical condition. With a holistic approach to disabilities, there is the potential for medicine to engage new roles. At the public health level, this perspective “can lead to legislative programs for health, new policies for the health care system, and possibly new attitudes in the courts.”⁹⁴ This altered conception may require new perspectives on assessing success in interventions or programs targeting those with disabilities.

Adolescents with disabilities represent a uniquely challenging population. The adolescent transition process itself can often be difficult. But there are opportunities to facilitate the process, enhance functioning and quality of life, and improve social supports and family relationships. Recognizing the relationship between higher functional independence and

improved quality of life encourages interventions to address each of these variables. At the same time, the differences in parental stress that accompany this greater independence (less caregiver stress with more stress from the adolescent's behaviors) indicate an opportunity to adapt interventions to meet specific needs. Similarly, the relationship between higher quality of life for the adolescent and stress in the adolescent-parent relationship argues that parents should be supported. Ultimately, public health and healthcare professionals must identify relationships such as these and must understand the adolescent experience, the disability experience, and their interplay. In doing so, we embrace our mandate to serve this neglected population, and the opportunities to facilitate better outcomes prove limitless.

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