

The “Quality of Life” Study

The Impact of Personal, Interpersonal, and Environmental Factors on Changes in Quality of Life for Youth with Chronic Conditions



Baseline Data Report to Families and Stakeholders

October 2014

Study Research Partners



Funded by the
Canadian Institutes of Health Research



Collaborating Ontario Association for Children's Rehabilitation Services (OACRS) Centres





Welcome to the “Quality of Life” Study Baseline Data Report!

This report provides participating families and other stakeholders with the initial baseline (Time 1) findings of the longitudinal study examining the “The Impact of Personal, Interpersonal, and Environmental Factors on Changes in Quality of Life for Youth with Chronic Conditions.”

The longitudinal study is being conducted by Thames Valley Children’s Centre, in partnership with Bloorview Research Institute and Western University. The Canadian Institutes of Health Research has provided funding for the study. Four hundred and thirty-nine youth (and one of their parents) receiving services from eight Ontario Children’s Treatment Centres completed the study baseline survey.

What this baseline data report offers is a first look at youth and their parents’ perceptions of:

- youth physical, emotional, behavioural, social, spiritual, and educational well-being;
- the supportiveness of the home, school, and community environments for youth;
- youth satisfaction with specific aspects of their lives and quality of life overall, from the perspectives of both youth and their parents; as well as
- the initial relationships between youth personal, interpersonal, and environmental factors and youths’ overall perceived quality of life.

Readers should remember that the purpose of this report is descriptive. Based on cross-sectional data, it does not provide information that can be used to address cause and effect questions. The descriptions given are based on the self-reported perceptions of youth and their parents. Objective assessments by professionals or of the environment were not the focus of this study. The specific findings of this report should not be generalized to youth beyond those in the study.

The information presented in this report is important to share since it represents the perceptions of a significant number of youth and their families receiving pediatric rehabilitation services about important aspects of their lives at one point in time. It can be useful as one source of information or “piece of the puzzle” that families, service providers, and decision makers can refer to when considering the strengths and needs of youth and families, the supportiveness of the environment for youth, and the course of future service delivery to ensure youths’ quality of life.

Enjoy reading about our findings thus far, and do not hesitate to contact us for more information about the study. Megan Nichols, Project Coordinator can be contacted at 519-685-8700, ext. 53787 or at megan.nichols@tvcc.on.ca.

Sincerely,

Two handwritten signatures in black ink. The first signature is 'Janette M. Dougall' and the second is 'Virginia Wright'.

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1. INTRODUCTION

Study Overview

Enhancing quality of life for children and youth is a key goal of the Ontario Association of Children's Rehabilitation Services (OACRS) treatment centres. Many supports and interventions are directed toward this goal. It is important for clients, families, service providers, and policy makers to understand the key factors that predict changes in life quality for children and youth with chronic conditions so that these can be considered in the planning of services and implementation of interventions. These factors may include personal (e.g., children's emotional and behavioural functioning), interpersonal (e.g., children's social participation), or environmental factors (e.g., supportive community environments).

This longitudinal study is examining two unexplored research areas: 1) the changing nature of quality of life for youth with chronic conditions over a three-year period, and 2) the factors that predict change in quality of life for these youth. Quality of life is measured in this study from the personal perspectives of both youth and their parents. More specifically, it is measured as youth life satisfaction in several domains as well as youth overall perceived quality of life. Perspectives of both youth and parents regarding youth perceived quality of life were gathered because both are important for making intervention-related and policy decisions, since each is likely to provide unique insight into the factors important to youth perceived quality of life.

Four hundred and thirty-nine youth aged 11 to 17 years (and one of their parents) who receive services from eight OACRS centres are participating in the study. Individuals in this age span are expected to experience key life transitions during the course of the study (e.g., changes in school, independence expectations, health and mobility, role within the family and community). To be eligible to participate in the study, youth needed to be able to respond to items in the study questionnaire, with support from a study interviewer (i.e., trained health professional).

The eight OACRS centres participating in the study include: Thames Valley Children's Centre (London), Holland Bloorview Kids Rehabilitation Hospital (Toronto), Children's Treatment Centre of Chatham-Kent, Health Sciences North/Horizon Santé-Nord (Sudbury), John McGivney Children's Centre (Windsor), Ottawa Children's Treatment Centre, Child Development Centre, Hotel Dieu Hospital (Kingston), and Children's Treatment Network of Simcoe York.

Participants have been completing questionnaires at four time points spaced a year apart. All youth and parents have now completed a baseline questionnaire that includes the two validated measures of perceived quality of life, in addition to a set of measures of factors thought to predict changes in life quality. The initial baseline findings of the longitudinal study are presented in this report.

Study Participants

Families were randomly selected from initial lists of potential participants compiled at each centre using a computerized randomization method. The overall initial list across centres consisted of 3,188 families. Of those 3,188, 393 families could not be contacted. Of those contacted, 1,372 were deemed ineligible (see criteria above) and 984 chose not to participate (no interest, busy, youth acutely ill, other), leaving the 439 who agreed to participate. Those families who declined to participate did not differ significantly on a number of socio-demographic characteristics from those who agreed to participate, with the exception of age (parents who chose not to participate were, on average, two years younger than those who decided to take part).

The average age of youth at baseline was 13 years. There were more males (246) than females (see Table 1). Eighty-three percent of parent respondents were birth mothers to youth, 11% were birth fathers, 4% were adoptive mothers, and 2% were another type of relationship (e.g., grandmother, aunt).

Table 1: Description of Participant Socio-Demographic Characteristics

Characteristics	Number	(%)	Mean (Average)	Standard Deviation	Minimum-Maximum
Youth sex					
• female	193	44.0	---	---	---
• male	246	56.0	---	---	---
Youth age (years)		---	13.8	2.2	11-17
Parent sex					
• female	386	87.9	---	---	---
• male	53	12.1	---	---	---
Parent age (years)		---	44.8	6.5	29-71

Characteristics	Number	(%)	Mean (Average)	Standard Deviation	Minimum-Maximum
Parent marital status					
• married	294	67.0	---	---	---
• living common law/partner	38	8.7	---	---	---
• separated/divorced	61	13.9	---	---	---
• single (never married)	27	6.2	---	---	---
• widowed	15	3.4	---	---	---
Parent education					
• secondary school or less	28	6.4	---	---	---
• completed secondary school	65	14.8	---	---	---
• some college or university	85	19.4	---	---	---
• completed college or university	257	58.5	---	---	---
Family income					
• under \$25,000	62	14.1	---	---	---
• \$25,000 to \$34,999	32	7.3	---	---	---
• \$35,000 to \$44,999	32	7.3	---	---	---
• \$45,000 to \$54,999	29	6.6	---	---	---
• \$55,000 to \$64,999	28	6.4	---	---	---
• \$65,000 to \$74,999	42	9.6	---	---	---
• \$75,000 or more	161	36.7	---	---	---
Language spoken at home					
• English	393	89.5	---	---	---
• Other	46	10.5	---	---	---
Number of children in home		---	2.6	1.2	1-9
Population Density					
• rural (less than 3,000)	62	14.1	---	---	---
• town (3,000 to 19,999)	68	15.5	---	---	---
• small city (20,000 to 49,999)	33	7.5	---	---	---
• medium city (50,000 to 99,999)	39	8.9	---	---	---
• large city (100,000 or more)	231	52.6	---	---	---

Note: Percentages may not total to 100 due to missing data

Organization of the Report

The report describes how youth are doing in aspects of life that are thought to contribute to their perceived quality of life, and then provides findings regarding both youth and parent assessments of youth perceived quality of life. It then presents the baseline relationships among these aspects of life and overall perceived quality of life.

Findings related to youth physical well-being are presented in Chapter 2. Youth emotional and behavioural well-being are described in Chapter 3. Chapter 4 provides a description of youth social well-being, and Chapters 5 and 6 present findings about youth spiritual and educational well-being, respectively. The supportiveness of home, school, and community environments for youth is described in Chapter 7. Youth quality of life from the perspectives of both youth and parents is presented in Chapter 8. Chapter 9 describes the initial relationships found among the various personal, interpersonal, and environmental factors and perceived quality of life at baseline. Finally, findings are summarized and future work using the longitudinal data is discussed in Chapter 10.

2. YOUTH PHYSICAL WELL-BEING

Chronic Conditions

Parents reported the primary chronic health condition of youth. The majority of youth in the study were reported to have cerebral palsy (153). Table 2 provides a breakdown of the number and percent of study participants by type of chronic condition.

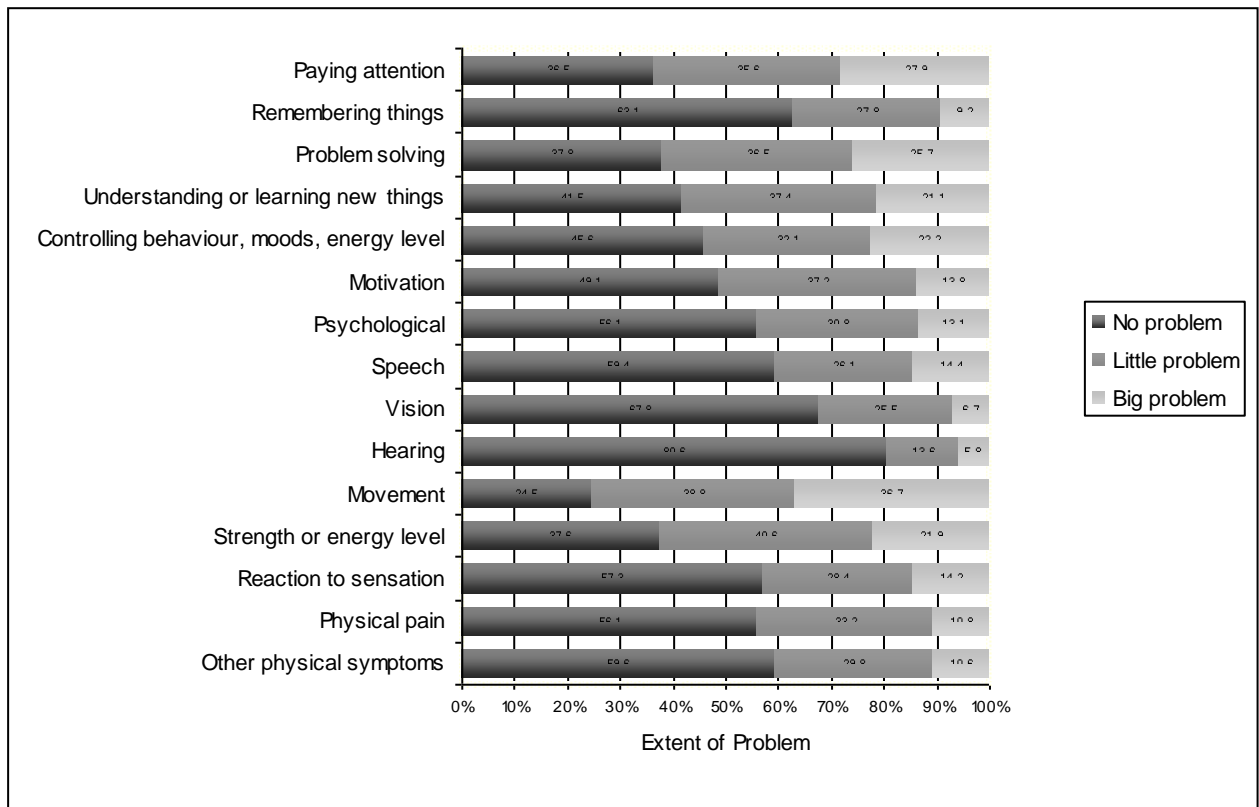
Table 2: Primary Chronic Condition of Youth Reported by Parents

Characteristics	Number	Percent
Youth primary chronic health condition		
• cerebral palsy	153	34.9
• spina bifida	36	8.2
• autism spectrum disorder	38	8.6
• brain injury	59	13.4
• communication disorder	10	2.3
• cleft lip and/or palate	31	7.1
• amputee	18	4.1
• developmental delay	29	6.6
• Down syndrome	7	1.6
• other condition (i.e., other central nervous system, musculoskeletal, or neuromuscular disorders)	58	13.2

Impairments

Movement was reported by parents to be the impairment that most youth (76%) had either a 'little' or a 'big problem' with, followed by cognitive issues such as paying attention (64%) and problem solving (63%), and strength or energy level (63%) (Figure 1). Hearing and vision were impairments that most youth had 'no problem' with (80% and 67%).

Figure 1: Impairments of Youth Reported by Parents



Activity Limitations

Both youth and parents reported on the extent that health-related problems limited youths' daily activities (Figures 2, 3 and 4). At home and school, almost half of youth and parents said health-related problems limited youths' daily activities 'a little', while in the community setting, the greatest percentage of youth said health-related problems did not limit their activities at all (43%).

Figure 2: Activity Limitations of Youth at Home Reported by Parents and Youth

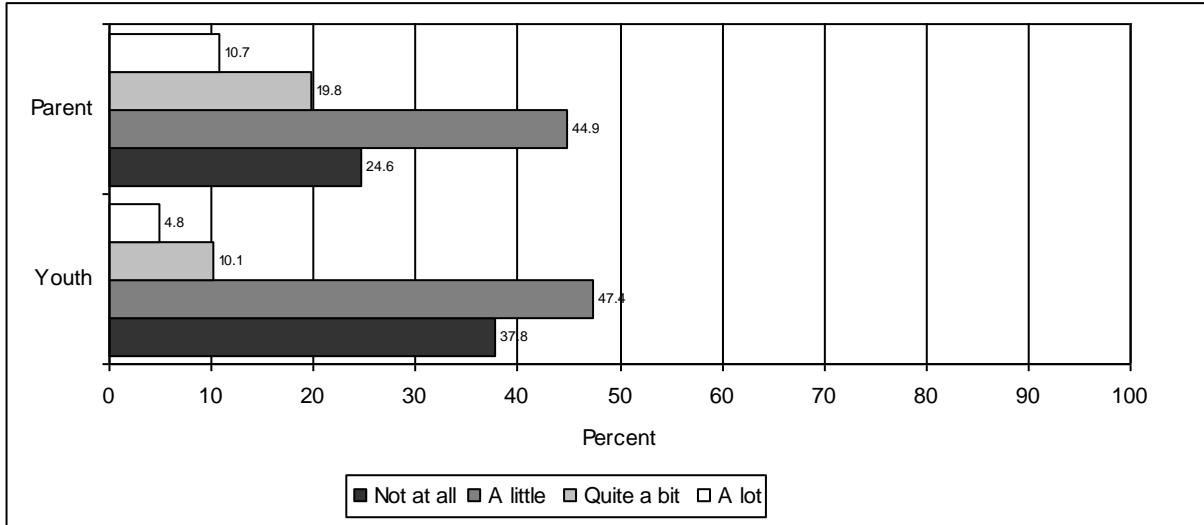


Figure 3: Activity Limitations of Youth at School Reported by Parents and Youth

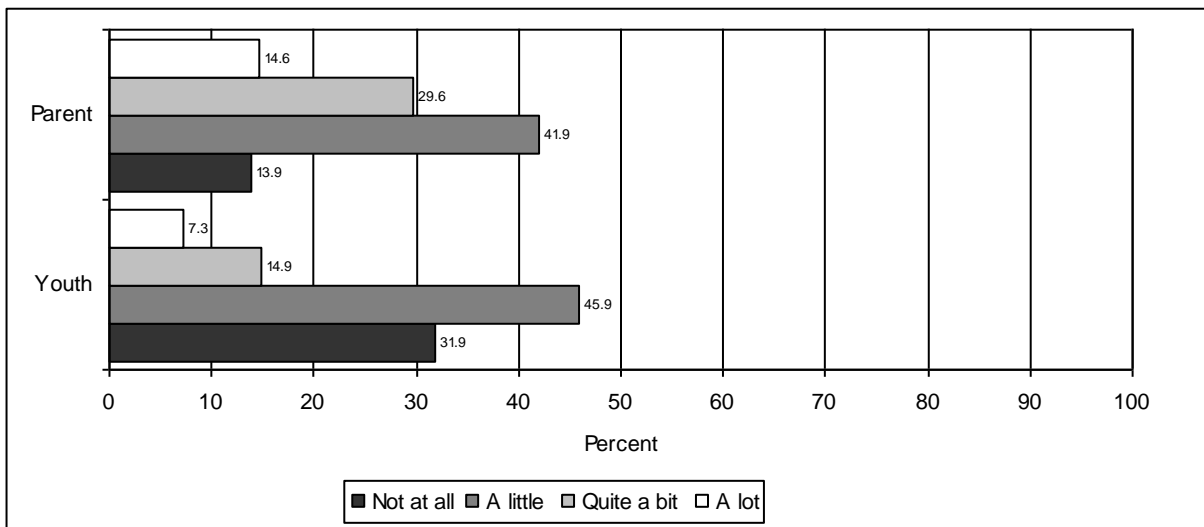
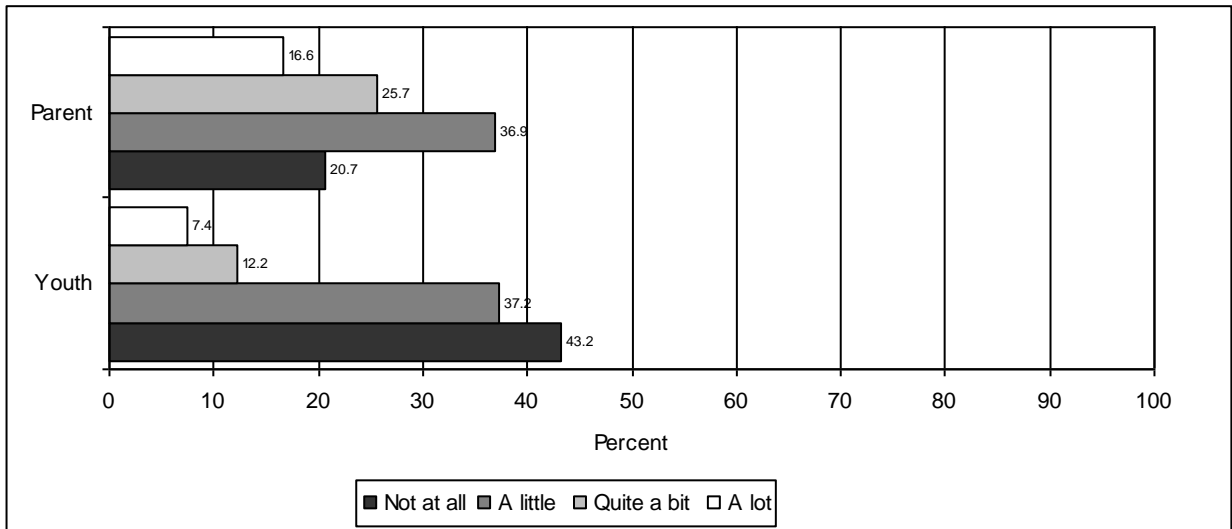


Figure 4: Activity Limitations of Youth in Community Reported by Parents and Youth



Physical Activity

Youth reported how many hours per week they took part in physical activity (see Table 3). About 30% of youth reported taking part for two hours or less per week. Close to another third of youth reported taking part between three to five hours per week. The remaining third indicated six or more hours per week of physical activity.

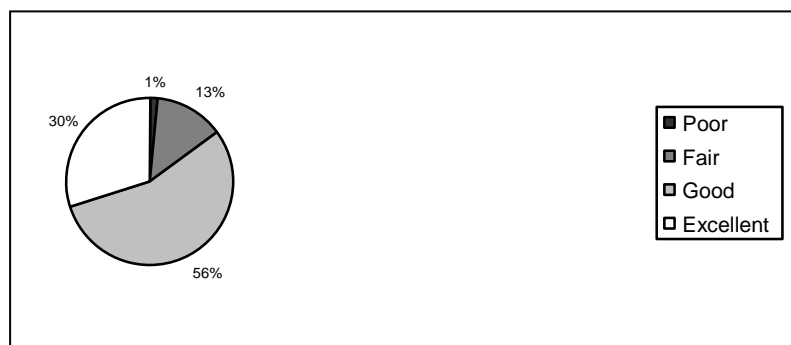
Table 3: Hours of Physical Activity per Week Reported by Youth

Hours per week of physical activity	Number	Percent
None at all	19	4.3
About ½ hour	27	6.2
About 1 hour	41	9.3
About 2 hours	56	12.8
About 3 hours	67	15.3
About 4 hours	49	11.2
About 5 hours	57	13.0
About 6 or more hours	120	27.3
Missing cases	3	0.6

Overall Health

Youth were asked, “Overall, how would you best describe your health?” Figure 5 shows that over half reported their overall health to be ‘good’. Just 1% reported it to be ‘poor’, while 13% reported it to be ‘fair’. Thirty percent thought that their overall health was ‘excellent’.

Figure 5: Overall Health of Youth Reported by Youth



3. YOUTH EMOTIONAL AND BEHAVIOURAL WELL-BEING

Emotional Symptoms

Both youth and parents were asked questions about any emotional symptoms the youth may have (Figures 6 and 7). Anxiety symptoms were reported more often than symptoms of depression by both youth and parents. More youth than parents reported as 'somewhat' to 'certainly true' that they (the youth) get a lot of headaches, stomachaches, or sickness (67% vs. 44%). More youth than parents reported as 'certainly true' that they worry a lot (67% vs. 58%).

Figure 6: Youth Report Emotional Symptoms

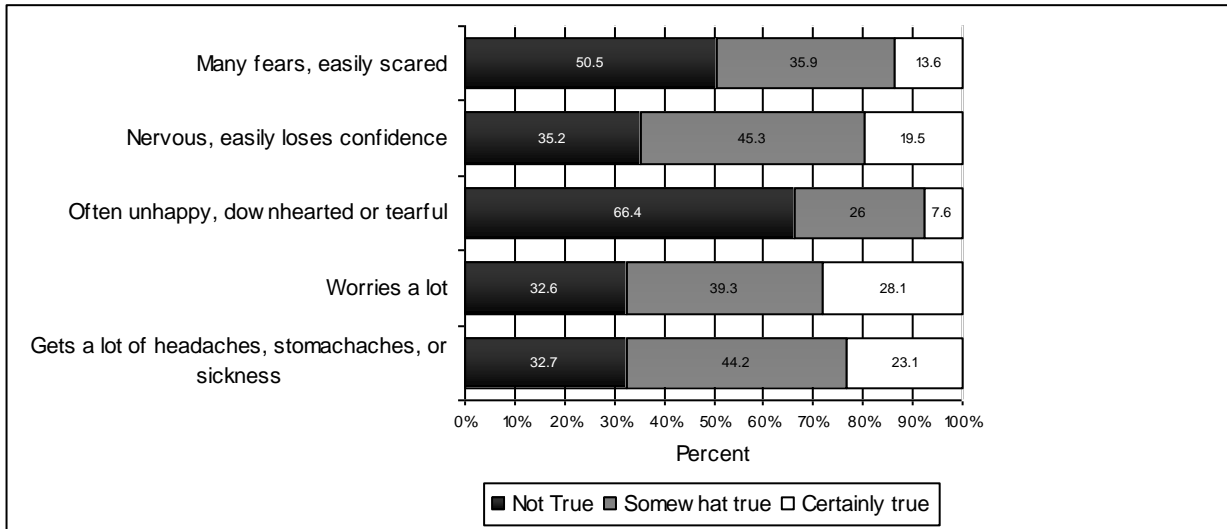
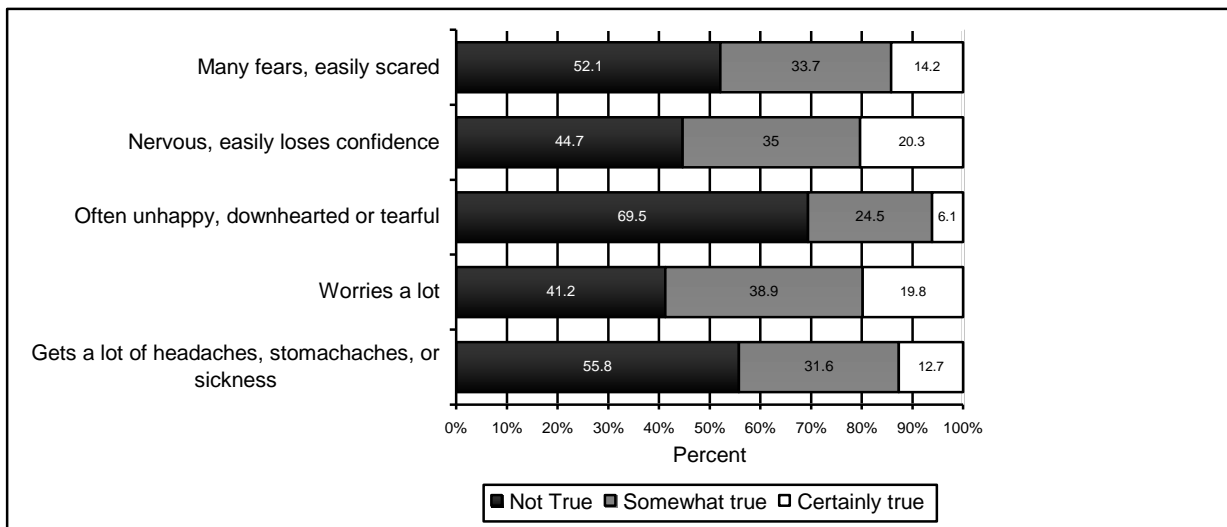


Figure 7: Parent Report Emotional Symptoms



Behaviour Problems

Both youth and parents were asked questions about any behaviour problems the youth may have (Figures 8 and 9). For most questions, the majority of youth and parents reported it to be 'not true' that youth have symptoms of behaviour problems. Slightly more youth than parents reported as 'somewhat' to 'certainly true' that they were often accused of lying or cheating (29% vs. 20%), of fighting a lot (24% vs. 11%), and of not usually doing as told (53% vs. 41%).

Figure 8: Youth Report Behaviour Problems

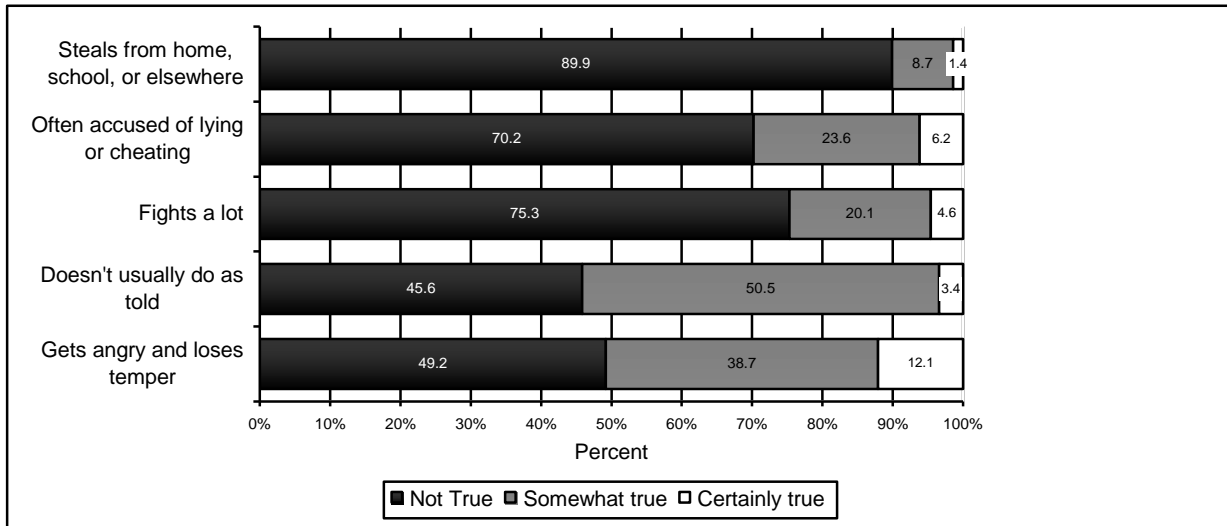
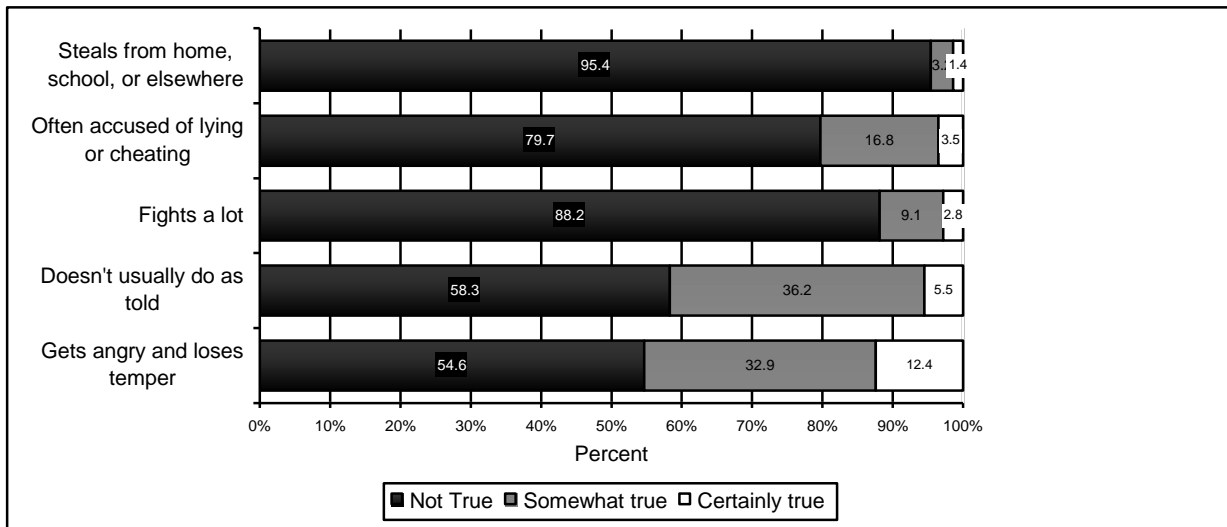


Figure 9: Parent Report Behaviour Problems



Hyperactivity/Inattention

Both youth and parents were asked questions about youth hyperactivity/inattention (Figures 10 and 11). For most questions, the majority of youth and parents reported it to be 'somewhat' to 'certainly true' that the youth have symptoms of hyperactivity/inattention. More youth than parents reported as 'somewhat' to 'certainly true' that they are constantly fidgeting (56% vs. 39%), restless, and can't keep still (67% vs. 37%) (hyperactivity). More parents than youth reported as 'somewhat' to 'certainly true' that youth have poor attention (72% vs. 56%), and don't think before doing things (73% vs. 58%) (inattention).

Figure 10: Youth Report Hyperactivity/Inattention

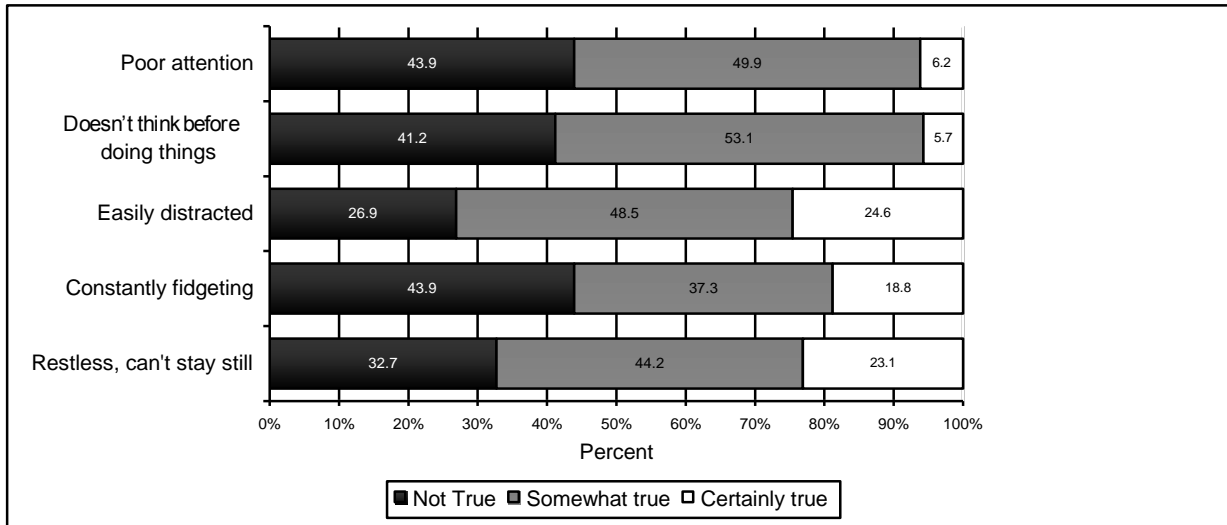
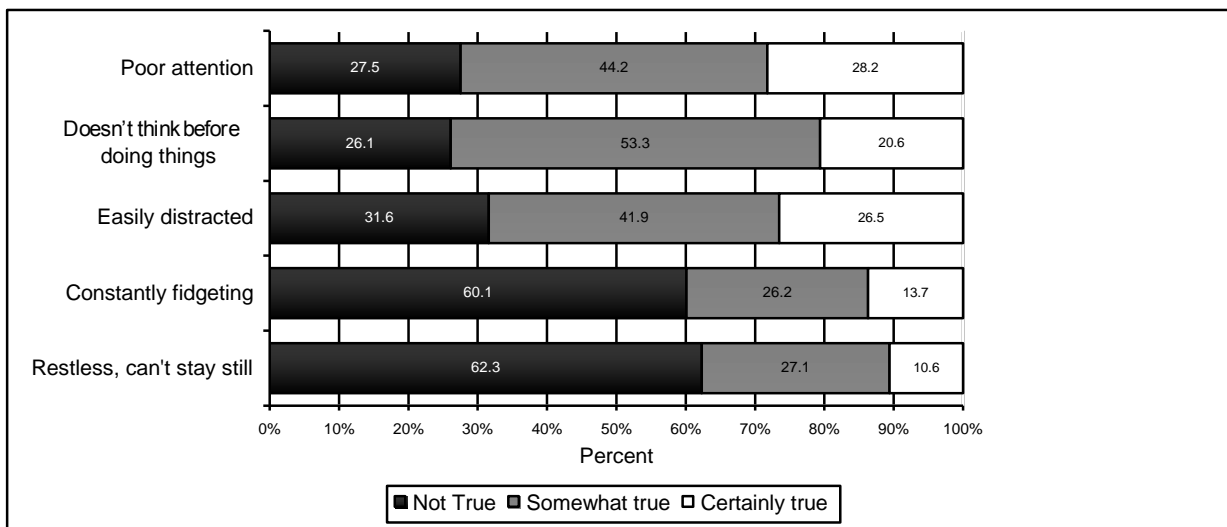


Figure 11: Parent Report Hyperactivity/Inattention



Peer Problems

Both youth and parents were asked questions about any problems the youth may have with peers (Figures 12 and 13). Overall, youth and parents generally reported similar peer problems for the youth. More parents than youth reported it to be 'somewhat' to 'certainly true' that youth haven't got a good friend (33% vs. 11%) and are bullied or picked on by other kids (48% vs. 34%).

Figure 12: Youth Report Peer Problems

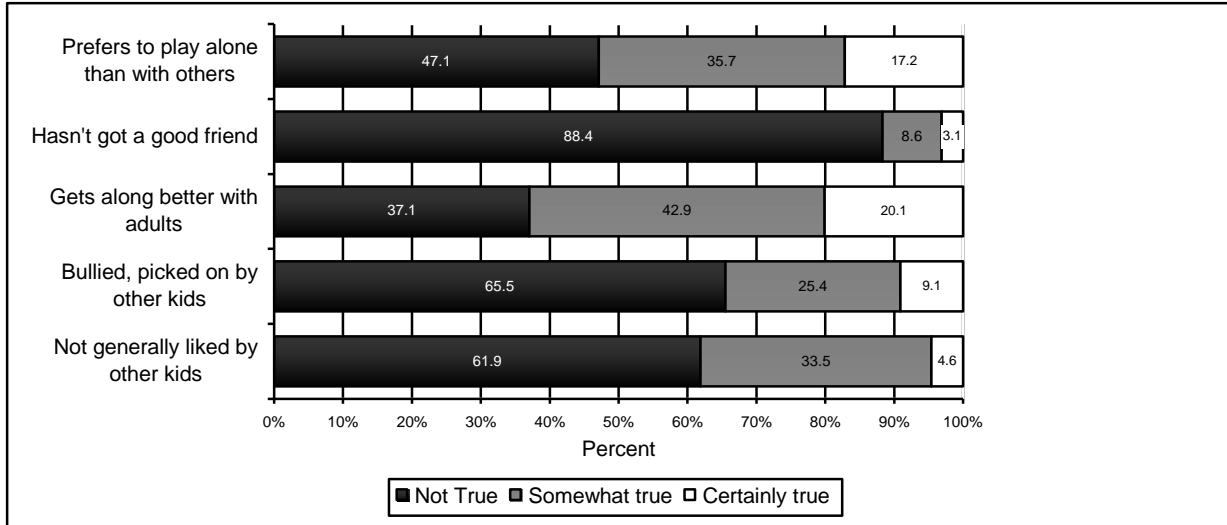
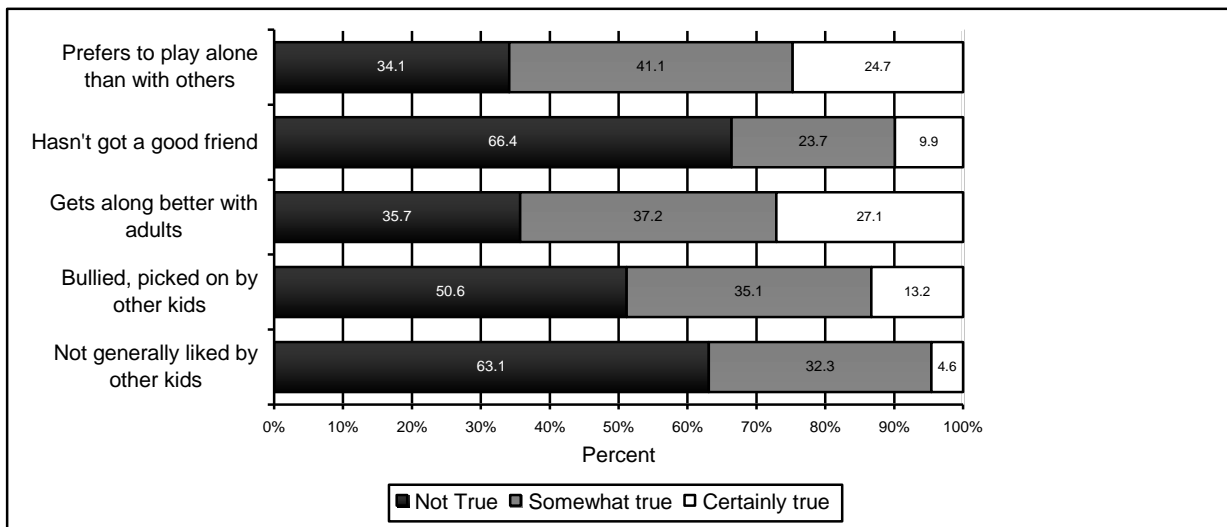


Figure 13: Parent Report Peer Problems



Pro-social Behaviour

Pro-social behaviour is considered to be any action intended to help others. Both youth and parents were asked questions about the pro-social behaviour of youth (Figures 14 and 15). Pro-social behaviour was reported to be 'certainly true' for the majority of youth by both youth and parents. A slightly greater percentage of youth than parents reported it to be 'certainly true' that youth were considerate of others' feelings (75% vs. 68%).

Figure 14: Youth Report Pro-social Behaviour

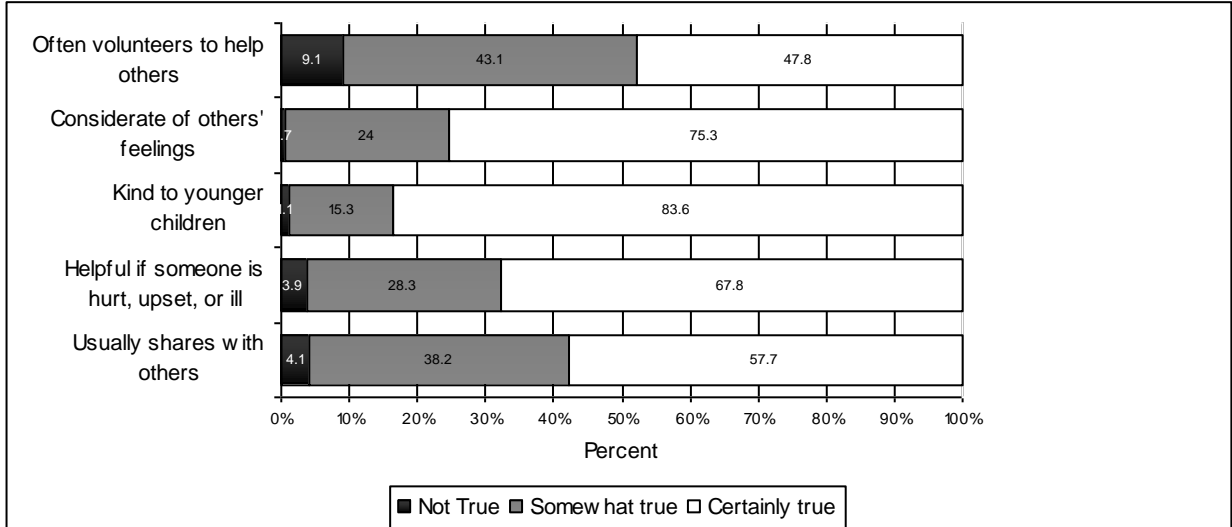
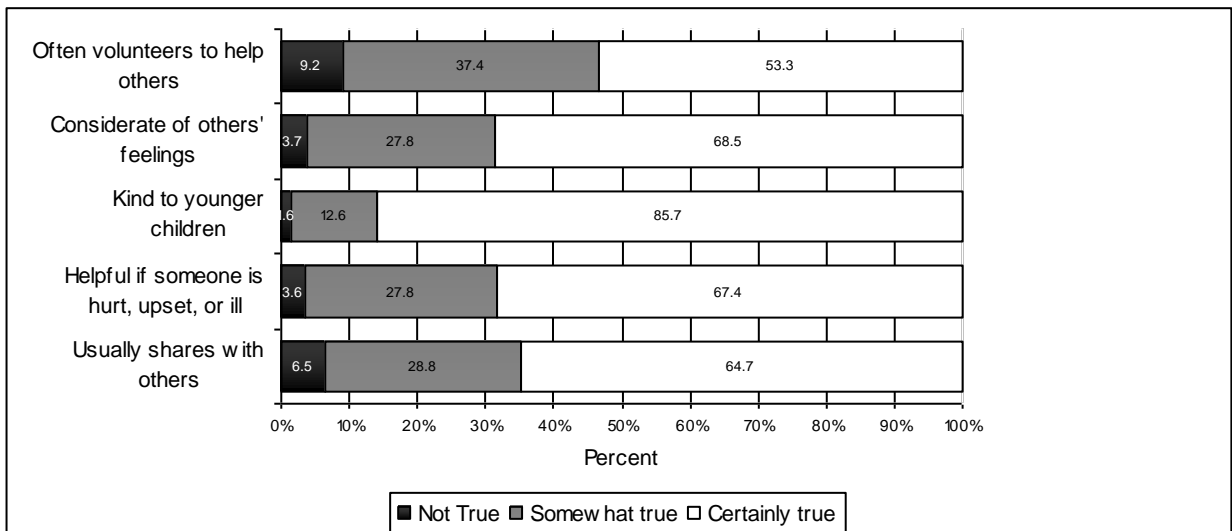


Figure 15: Parent Report Pro-social Behaviour



Social Anxiety

Social anxiety disorder is characterized by extreme fear in social situations. Both youth and parents reported about symptoms of social anxiety in youth (Figures 16 and 17). Youth and parents reported similarly with respect to youth social anxiety symptoms. About 25% of youth and parents reported that youth feel socially anxious 'all' or 'most of the time', about another 25% feel socially anxious 'sometimes', and approximately 50% are 'hardly ever' or 'not at all' socially anxious.

Figure 16: Youth Report Youth Social Anxiety

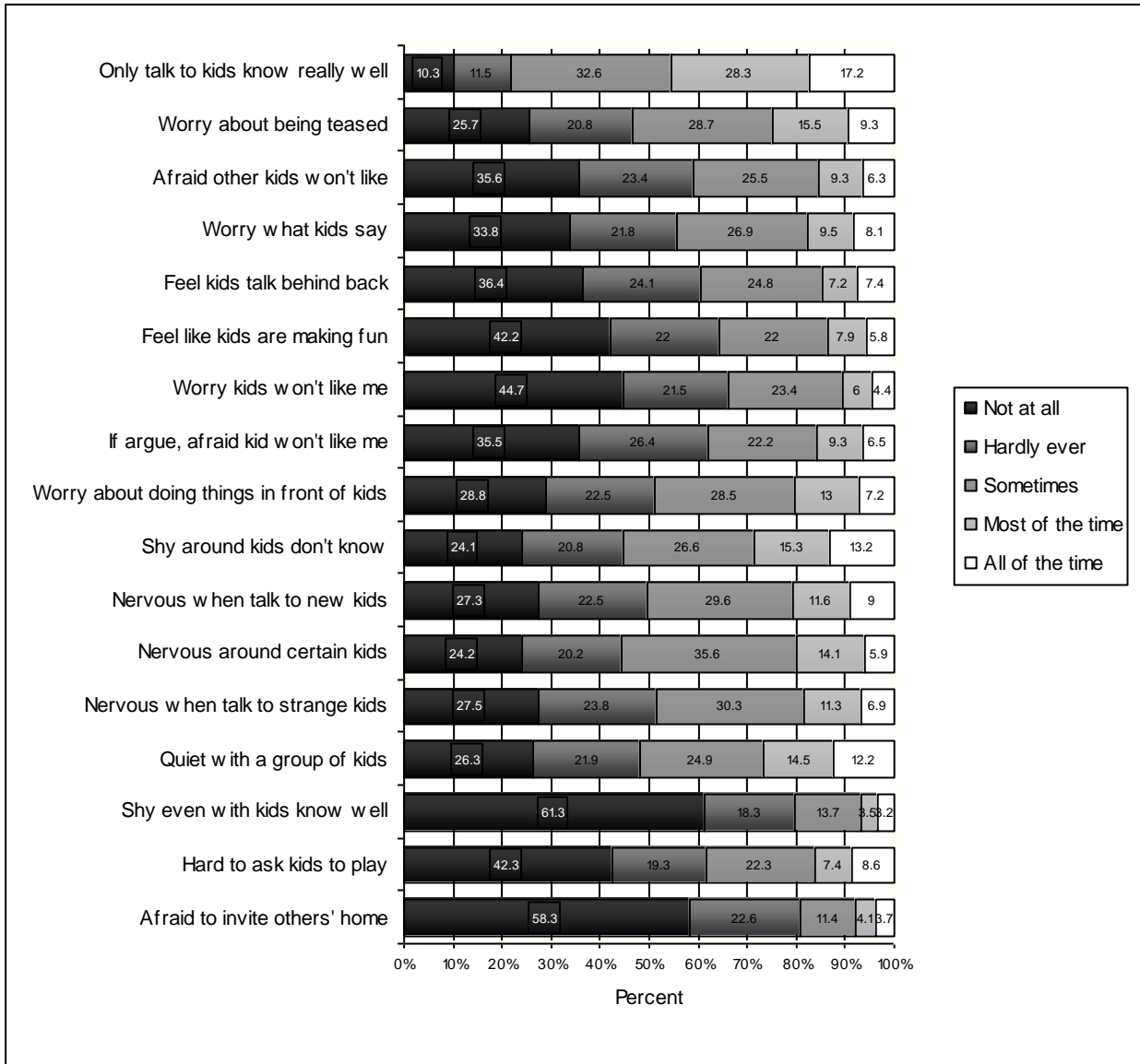
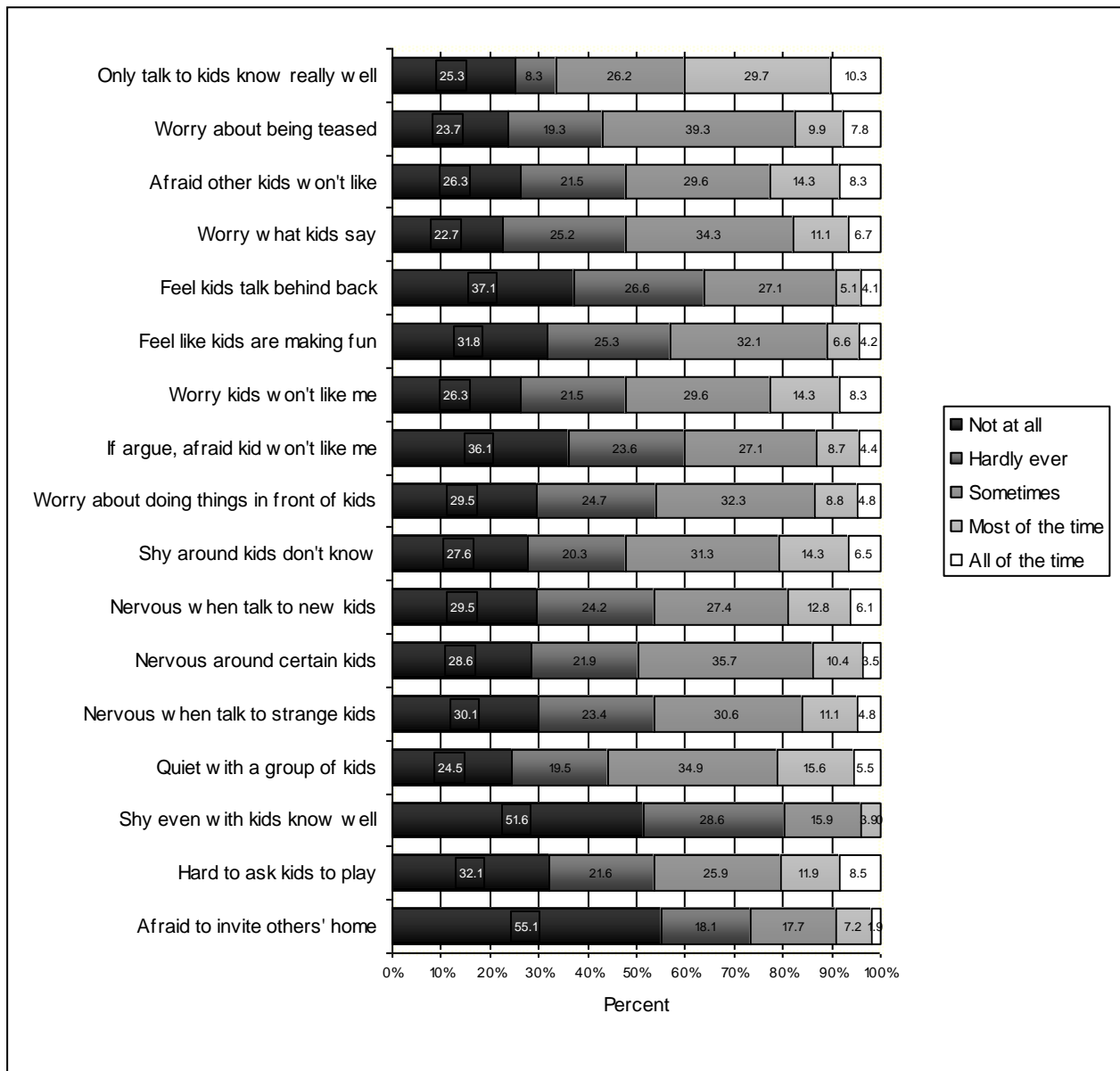


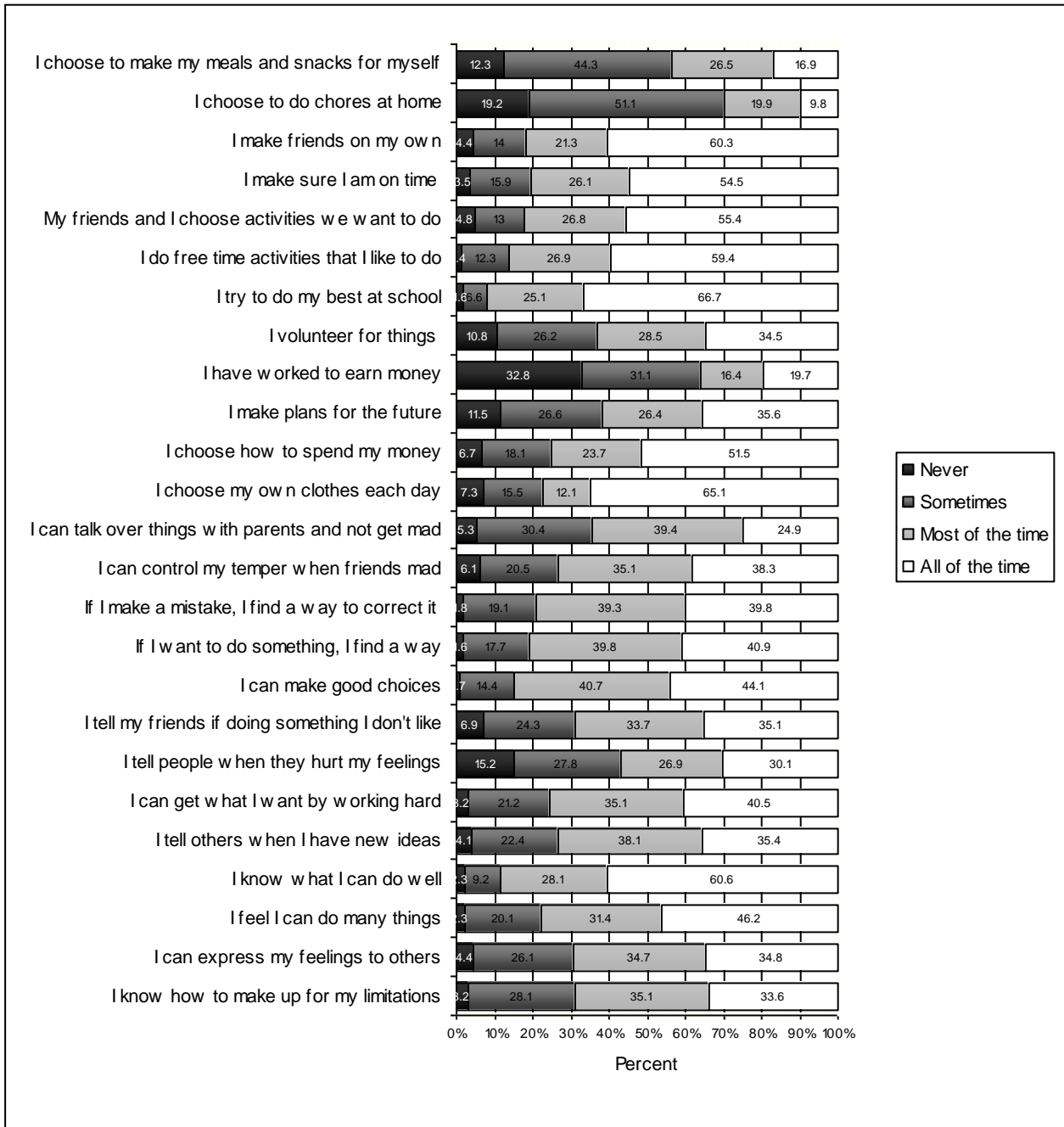
Figure 17: Parent Report Youth Social Anxiety



Self-determination

Self-determination can be described as having the power and will to make choices in life. Youth were asked to report on questions about their self-determined behaviour. For most questions, the greatest percentage of youth (at least 60%) reported being self-determined 'all' or 'most of the time'. Exceptions were having worked to earn money, choosing to make own meals and snacks, and choosing to do chores at home.

Figure 18: Youth Report Youth Self-determination



4. YOUTH SOCIAL WELL-BEING

Participation in Basic Daily Activities/Mobility

Both youth and parents were asked questions about the youths' participation in basic daily activities and mobility in social environments (Figures 19 and 20). The majority of youth and parents reported youths' participation in basic daily activities and mobility to be the 'same' as or 'a bit less than peers'. However, for all questions, a greater percentage of parents than youth reported youth participation to be 'much less than peers' or that youth were 'not able' to participate.

Figure 19: Youth Report Basic Daily Activities/Mobility

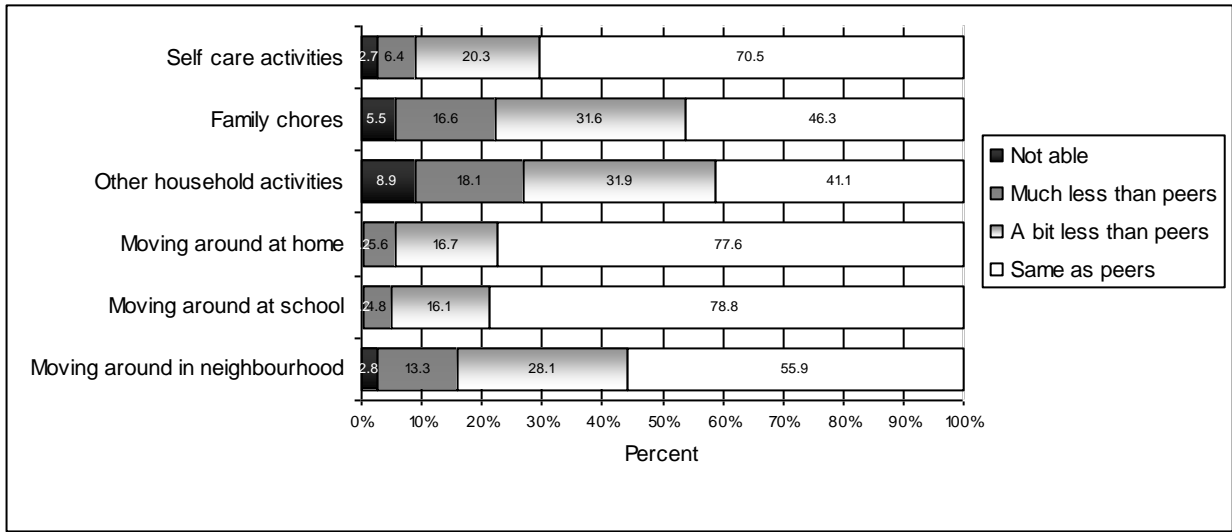
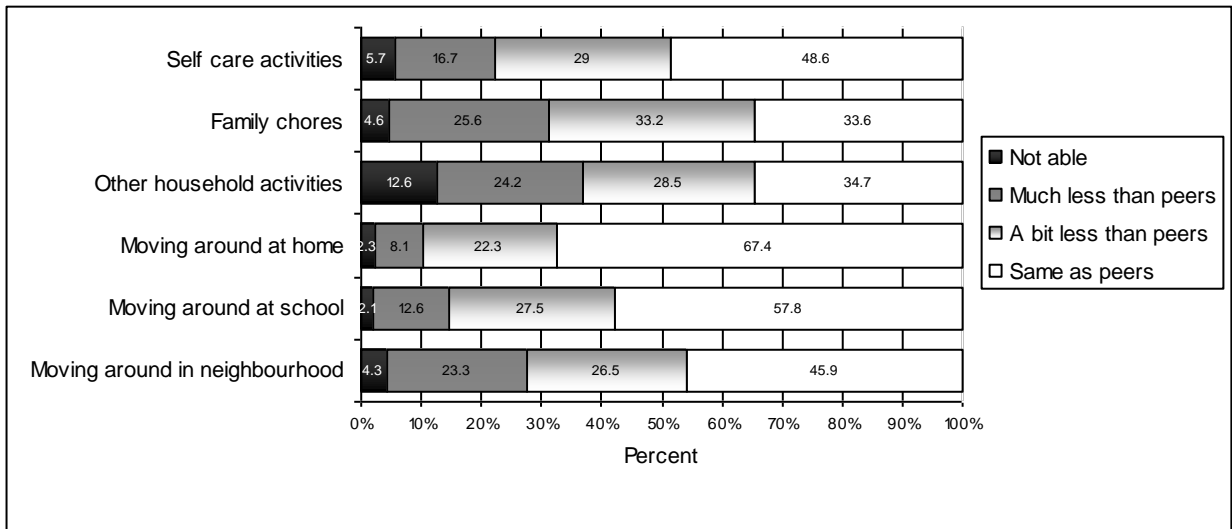


Figure 20: Parent Report Basic Daily Activities/Mobility



Participation in Advanced Daily Activities

Both youth and parents were asked questions about the youths' participation in advanced daily activities (Figures 21 and 22). As with basic activities/mobility, the majority of youth and parents reported youths' participation to be the 'same' as or 'a bit less than peers'. Again, as with basic activities/mobility, a greater percentage of parents than youth reported youth participation for all questions to be either 'much less than peers' or that youth were 'not able' to participate.

Figure 21: Youth Report Advanced Daily Activities

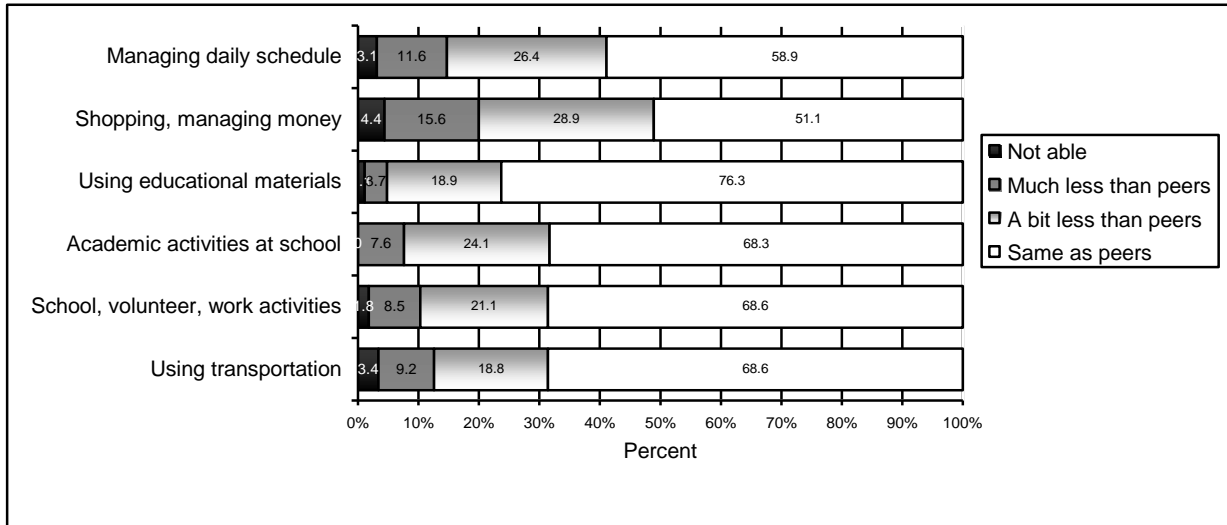
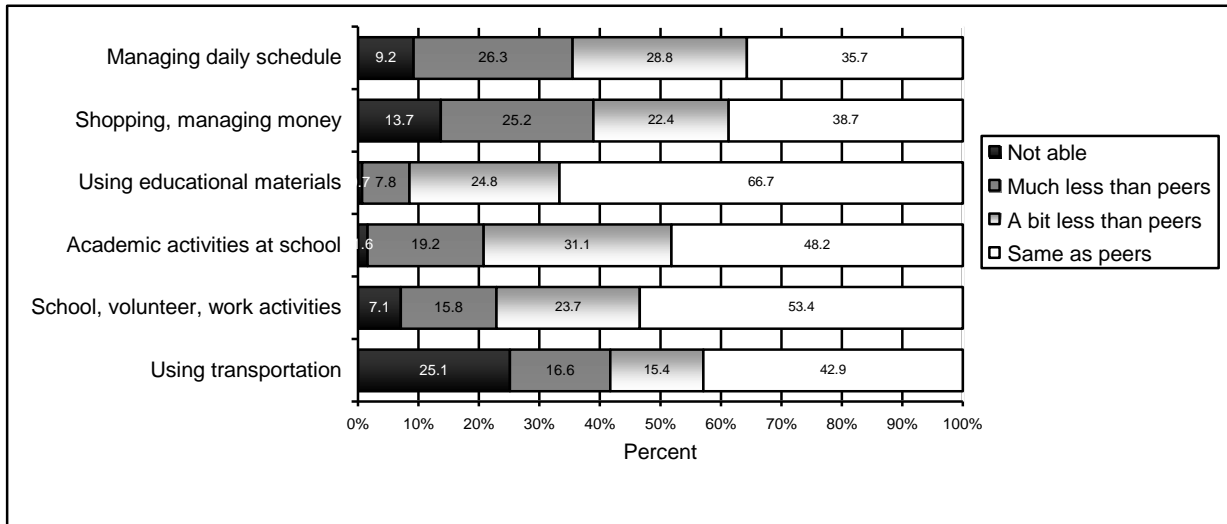


Figure 22: Parent Report Advanced Daily Activities



Leisure and Social Participation/Communication

Both youth and parents were asked questions about the youths' participation in leisure and social participation and communication with others (Figures 23 and 24). Once again, the majority of youth and parents reported it to be the 'same as' or 'a bit less than peers'. And again, a greater percentage of parents than youth reported youth participation for most questions to be either 'much less than peers' or that youth were 'not able' to participate.

Figure 23: Youth Report Leisure and Social Participation/Communication

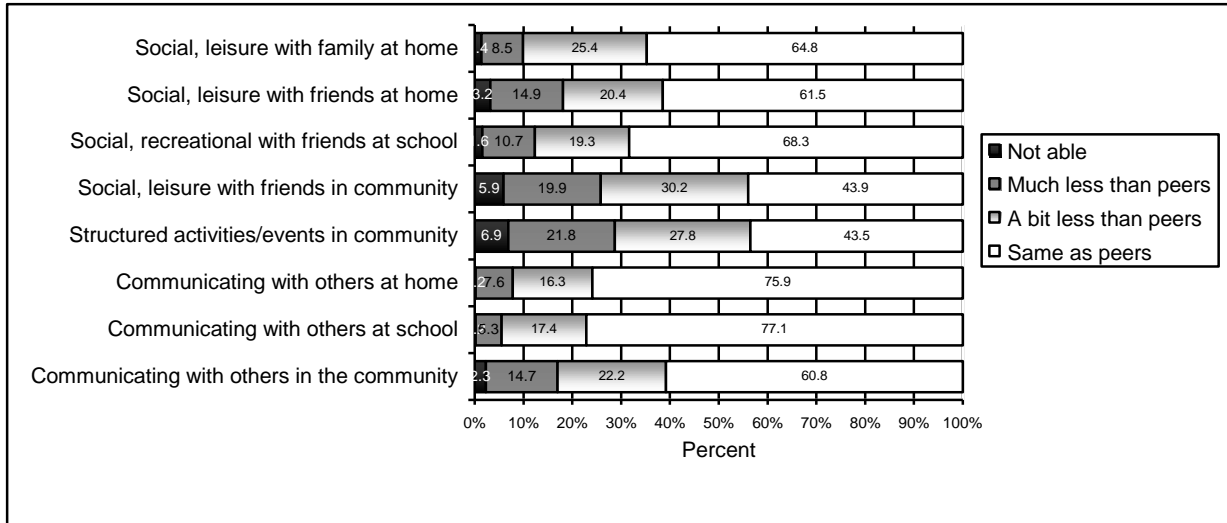
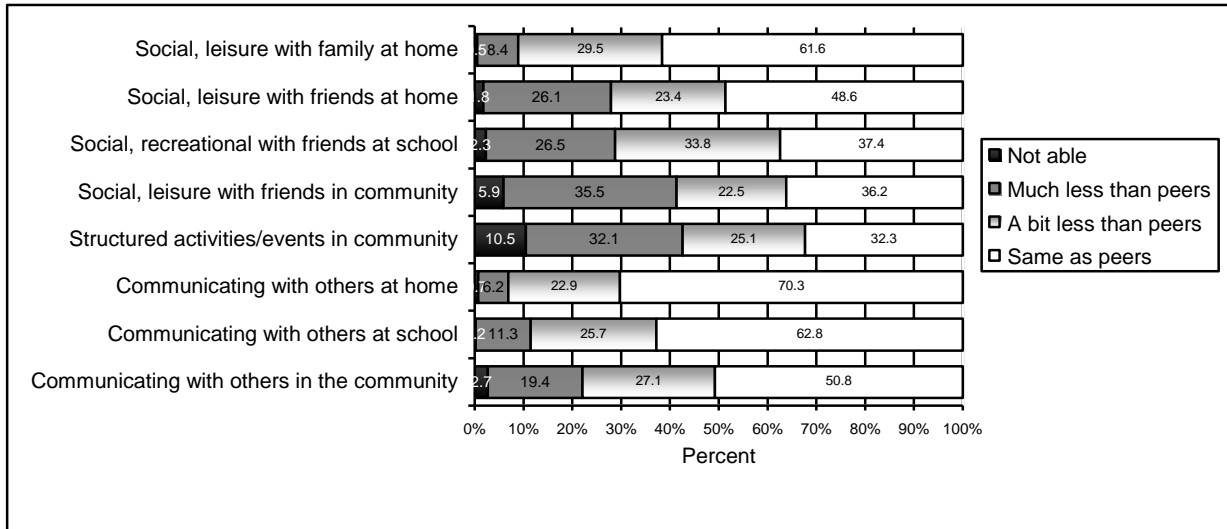


Figure 24: Parent Report Leisure and Social Participation/Communication



Social Support

Youth were asked a series of questions about the social support they received from family, close friends, teachers, and classmates (Figures 25 to 28). Examples of questions youth were asked include: “Can you count on your family/teachers for help or advice when you have problems?” Do you think your family/friends/teachers/classmates care about you?” Youth who reported their social support as ‘always’ or ‘most of the time’ were considered to have ‘high’ support. Those who reported their social support as ‘sometimes’ were considered to have ‘medium’ support. Finally, those who reported their social support as ‘hardly ever’ or ‘never’ were considered to have ‘low’ support.

Support was viewed as highest from family and lowest from classmates by youth, with 82% of youth reporting high support from family, and 59% reporting high support from classmates. Only 4% of youth reported low support from family, friends, and teachers, whereas 13% reported low support from classmates.

Figure 25: Social Support Family

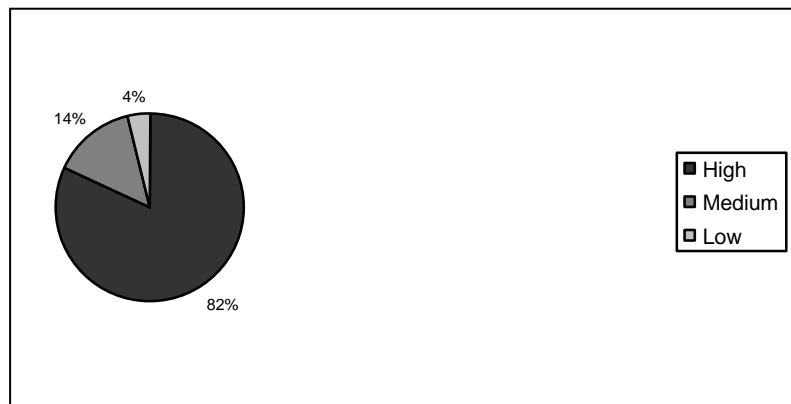


Figure 26: Social Support Close Friends

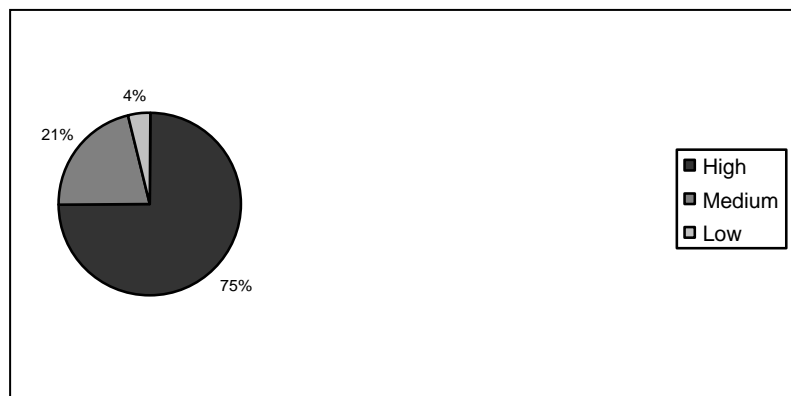


Figure 27: Social Support Teachers

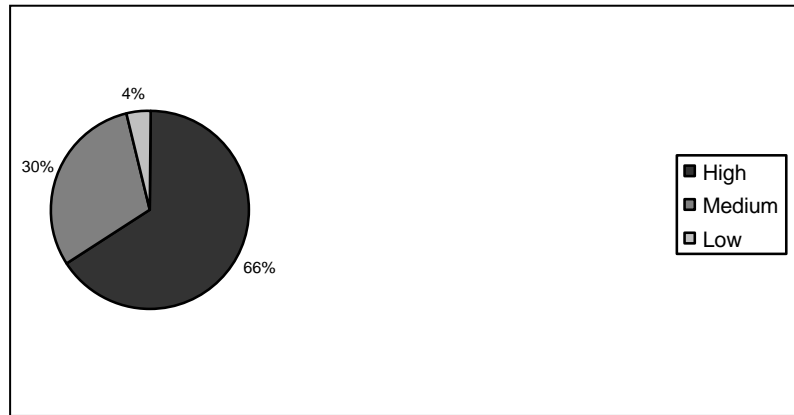
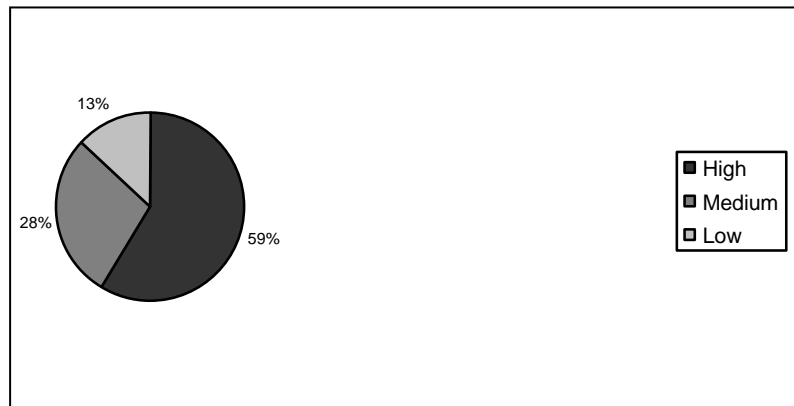


Figure 28: Social Support Classmates

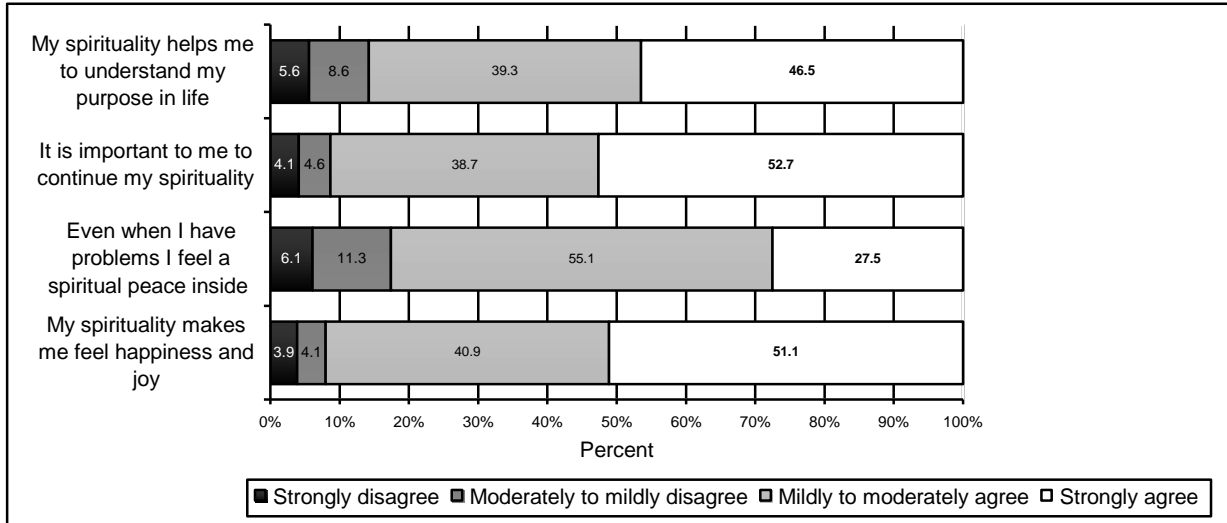


5. YOUTH SPIRITUAL WELL-BEING

Spirituality

Youth were asked questions about the importance of spirituality to their lives. Spirituality was defined as ‘anything you may have deep feelings or beliefs about.’ The vast majority of youth agreed that spirituality was important to them, with a large percentage in strong agreement.

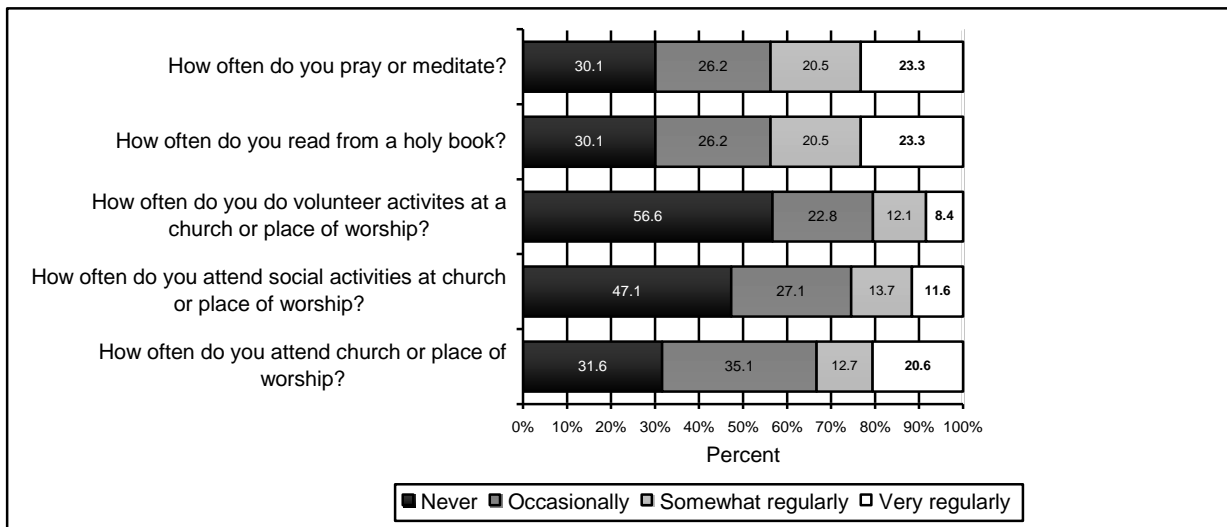
Figure 29: Youth Report Spirituality



Religious Behaviour

Youth were asked about their religious behaviour. Approximately 30% ‘never’ prayed, meditated, read from a holy book, or attended church or a place of worship, about 50% did so ‘occasionally’ or ‘somewhat regularly’, and about 20% did so ‘very regularly’. About 50% attended social activities or volunteered at a church or place of worship either ‘occasionally’, ‘somewhat regularly’ or ‘very regularly’.

Figure 30: Youth Report Religious Behaviour

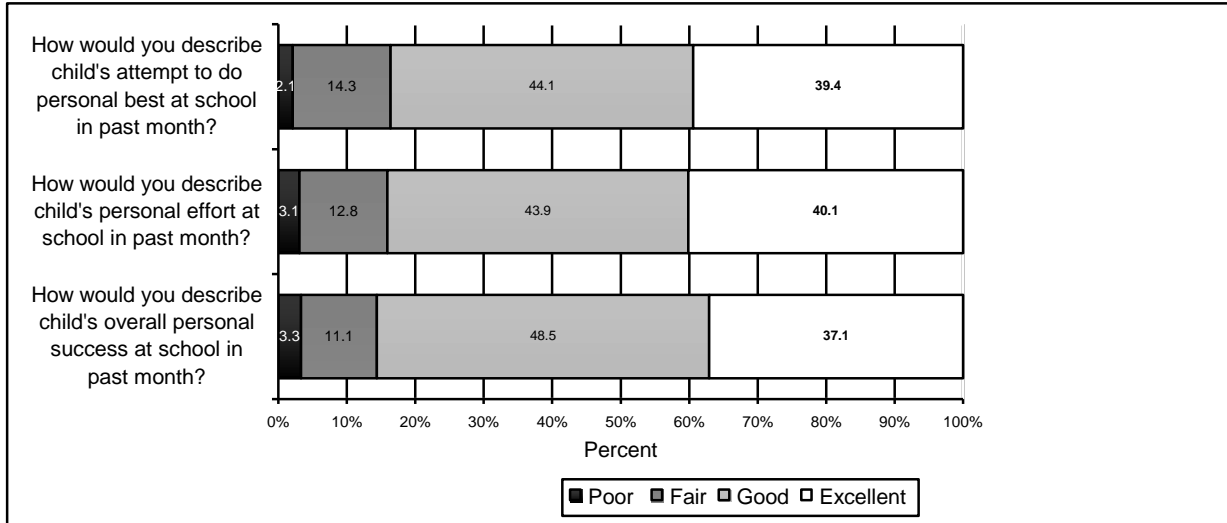


6. YOUTH EDUCATIONAL WELL-BEING

School Productivity/Engagement

Parents were asked to report about youths' school productivity/engagement (Figure 31). Over 80% reported youth school productivity/engagement to be 'good' to 'excellent'.

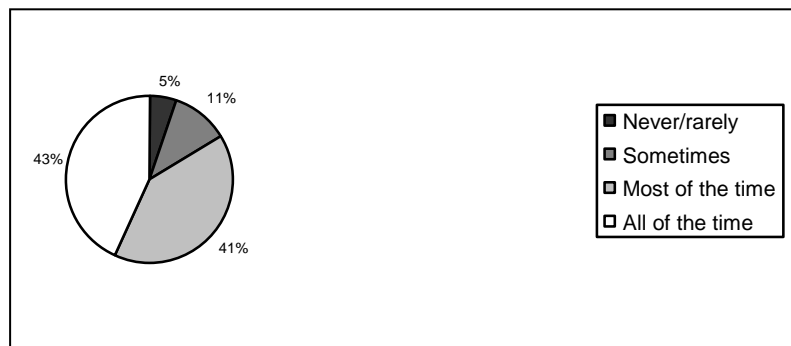
Figure 31: Parent Report School Productivity/Engagement



Homework Completion

Parents were asked to report about youths' homework completion (Figure 32). Over 80% reported that youth completed their homework 'most' or 'all of the time'.

Figure 32: Parent Report Homework Completion

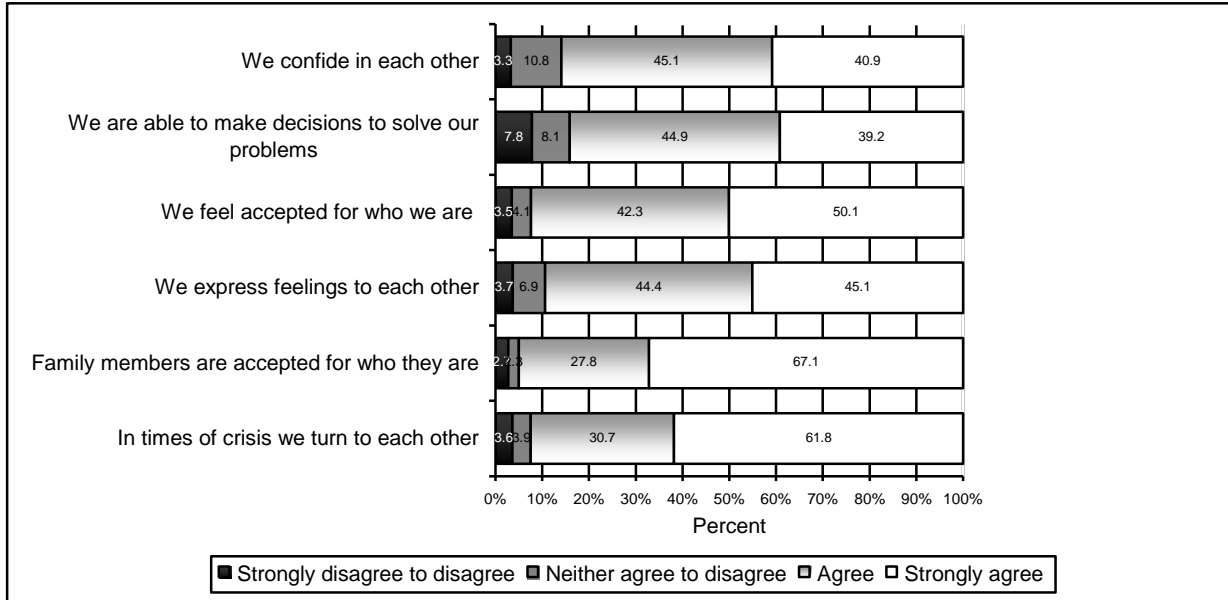


7. SUPPORTIVE ENVIRONMENTS FOR YOUTH

Family Functioning

Parents responded to a series of statements about how well their family works and gets along together (Figure 33). The greatest percentage of parents 'agreed' to 'strongly agreed' with all statements.

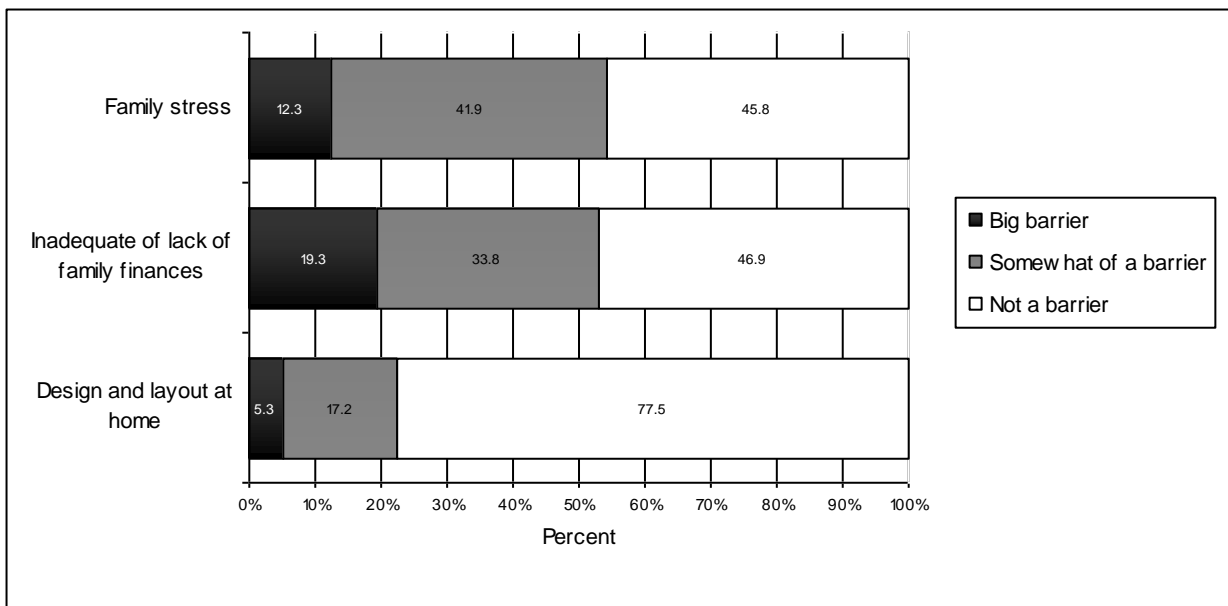
Figure 33: Parent Report Family Functioning



Barriers at Home

Parents were asked questions about any barriers youth might be experiencing with aspects of the home environment (Figure 34). The majority of parents (77%) said the design and layout of the home was 'not a barrier'. More than half of the parents said inadequate or lack of family finances (53%) and family stress (54%) were 'somewhat of a barrier' to a 'big barrier'.

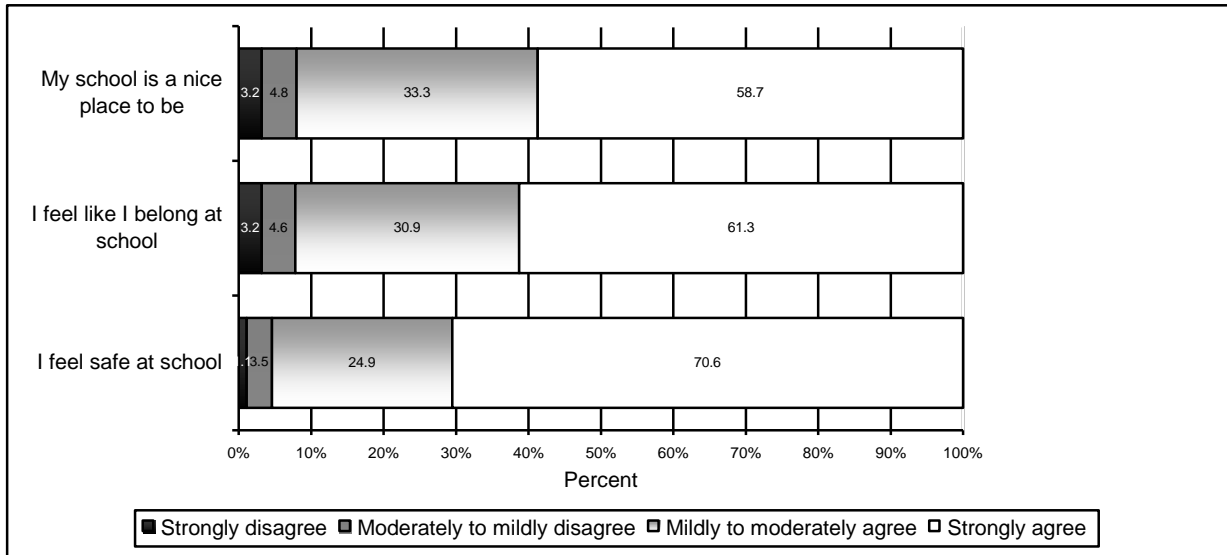
Figure 34: Parent Report Barriers at Home



School Belongingness/Safety

Youth reported about their sense of school belongingness and their sense of safety at school (Figure 35). The greatest percentage of youth 'strongly agreed' that they felt safe at school, that they belonged there, and that school was a nice place to be. About another 30% of youth 'mildly' to 'moderately agreed' with these statements.

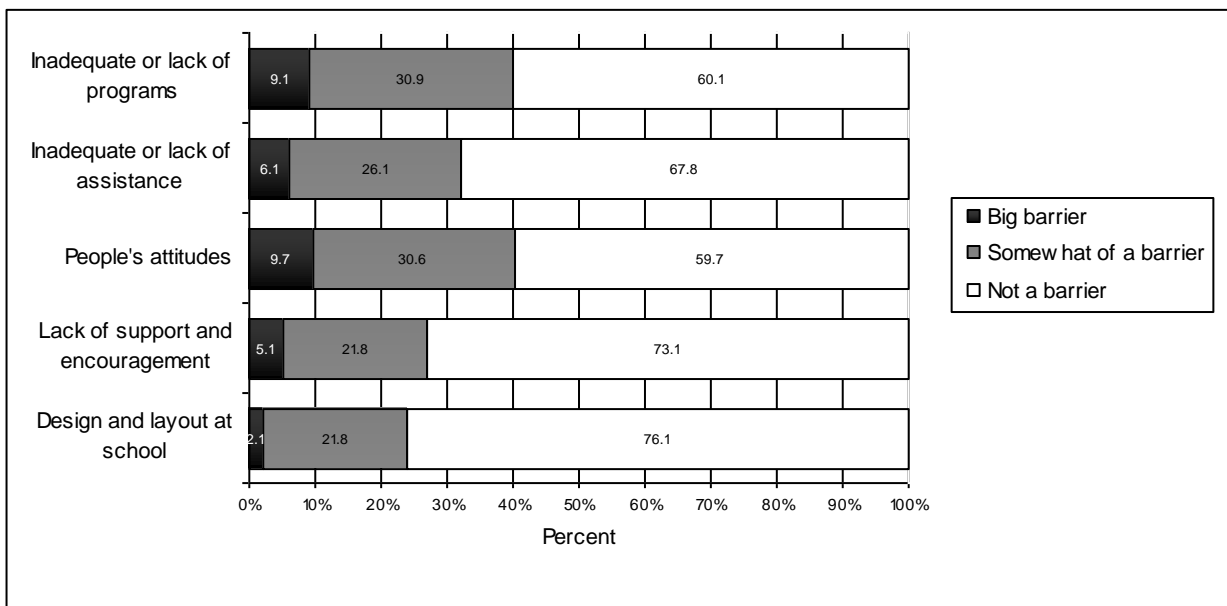
Figure 35: Youth Report School Belongingness/Safety



Barriers at School

Parents were asked questions about any barriers youth might be experiencing with aspects of the school environment (Figure 36). The majority of parents said all aspects of the school environment were not barriers. However, 40% of parents said inadequate or lack of programs and people's attitudes were 'somewhat of a barrier' to 'a big barrier'.

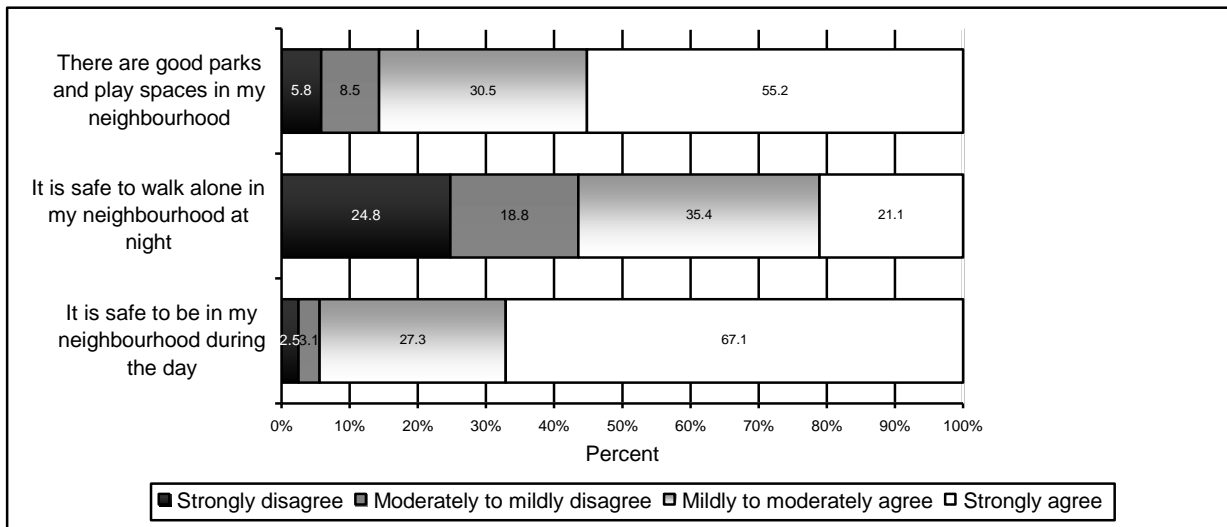
Figure 36: Parent Report Barriers at School



Neighbourhood Cohesion/Safety

Youth were asked questions about the cohesiveness and safety of their neighbourhood (Figure 37). The majority of youth 'strongly agreed' that their neighbourhood was safe during the day and that there were good parks and play spaces. Close to 45% of youth 'disagreed' that their neighbourhoods were safe to walk alone in at night.

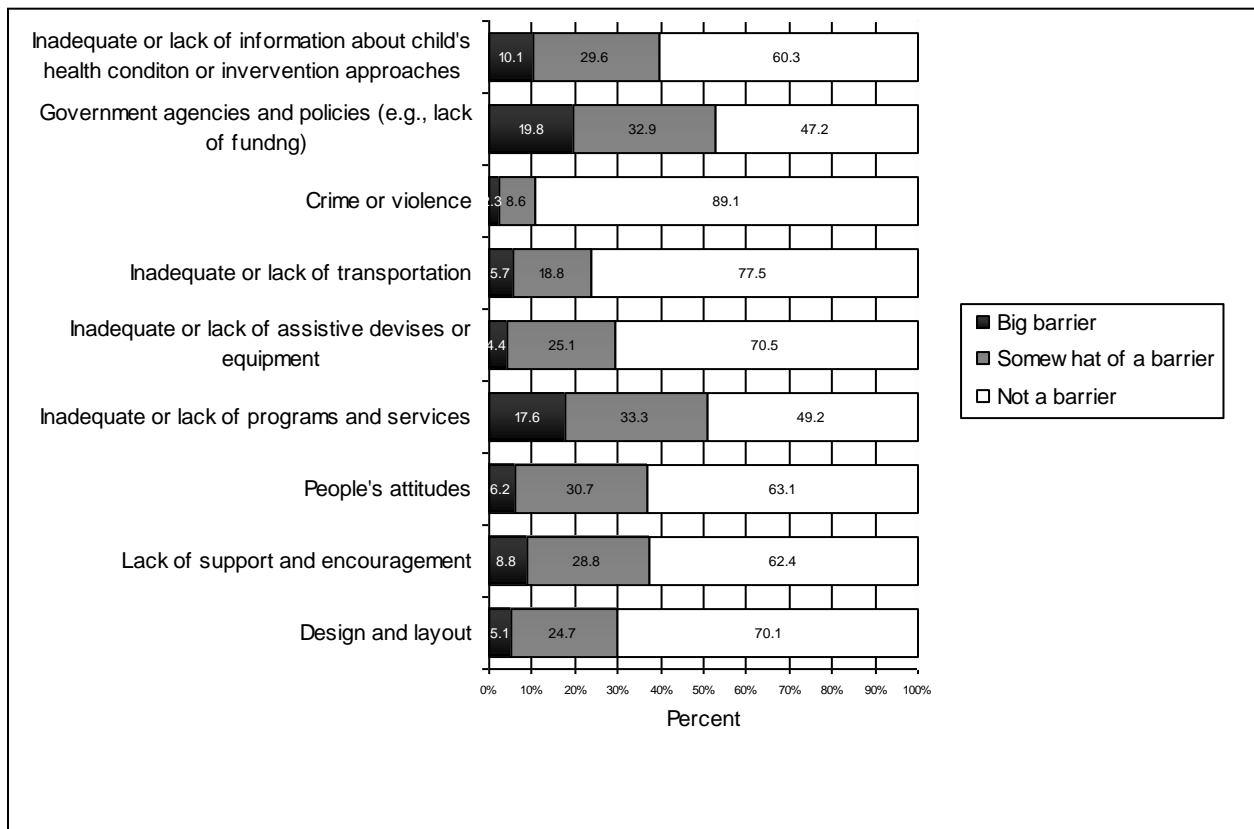
Figure 37: Youth Report Neighbourhood Cohesion/Safety



Barriers in Neighbourhood/Community

Parents reported about barriers for youth in the neighbourhood and community (Figure 38). The majority of parents said most aspects were not barriers. However, over 50% said government agencies/policies and lack of programs and services were barriers.

Figure 38: Youth Report Barriers in Neighbourhood/Community



8. PERCEIVED QUALITY OF LIFE

Youth Satisfaction with Life Domains

Youth and parents were asked to report on youth satisfaction with various life domains of importance to youth (Figures 39 and 40). For all domains, the greatest percentage of both youth and parents said that youth were 'mostly satisfied' to 'delighted'. For all domains, more youth than parents said that youth were 'delighted'. Close to 50% of youth were 'delighted' with most domains of life. The exception was school experience, where just over 25% of youth were 'delighted' and close to 20% were 'mixed' to 'mostly dissatisfied'.

Figure 39: Youth Report Youth Satisfaction with Life Domains

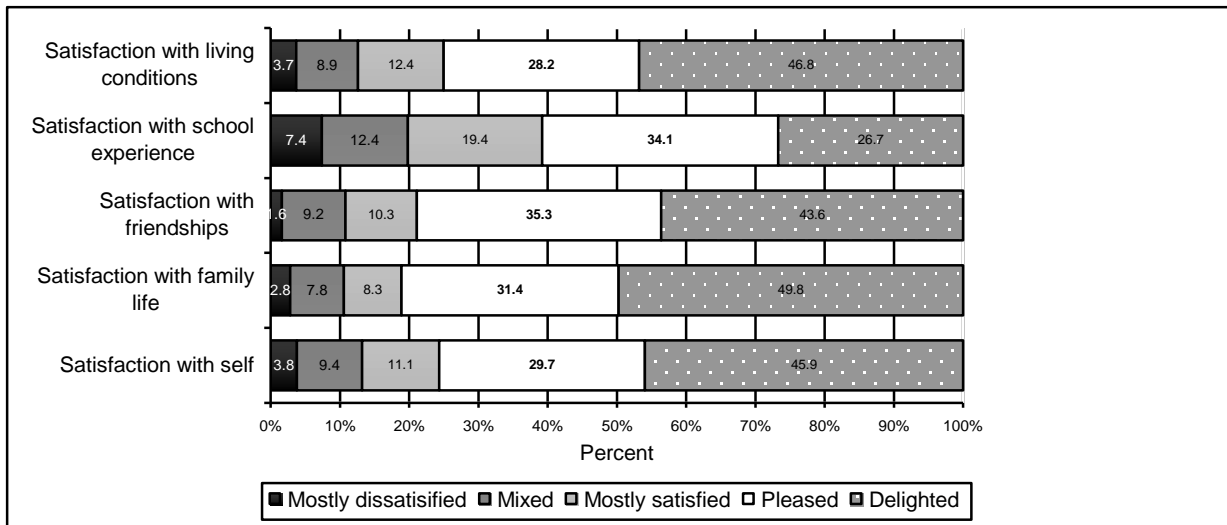
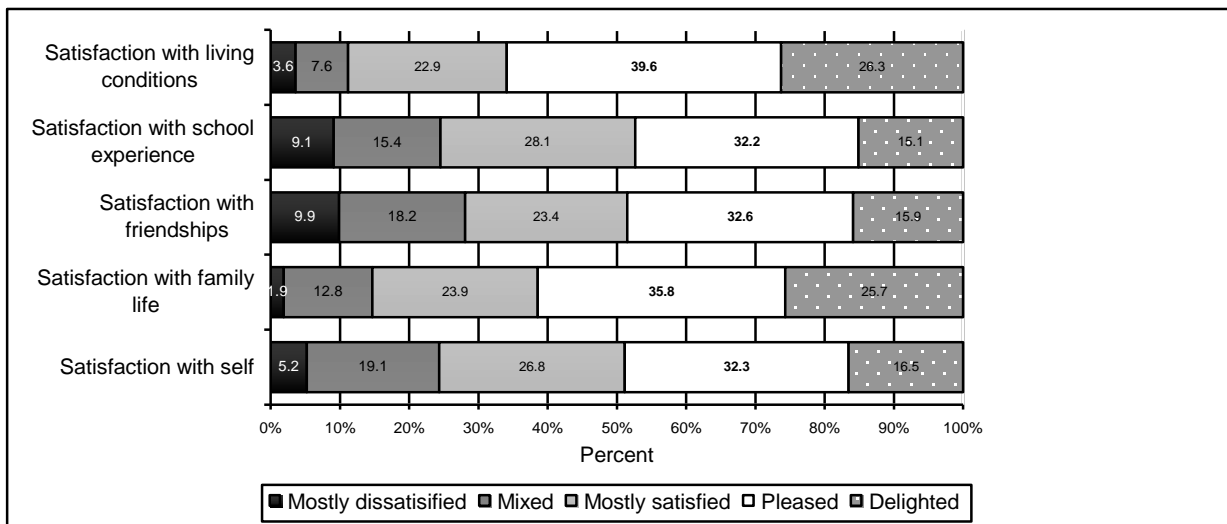


Figure 40: Parent Report Youth Satisfaction with Life Domains



Youth Overall Perceived Quality of Life

Both youth and parents were asked to respond to a series of statements about youths' overall perceived quality of life (Figures 41 and 42). Most youth and parents 'moderately' to 'strongly agreed' that youth quality of life was high. Across all statements, more youth than parents 'strongly agreed' that their quality of life was high.

Figure 41: Youth Report Youth Overall Perceived Quality of Life

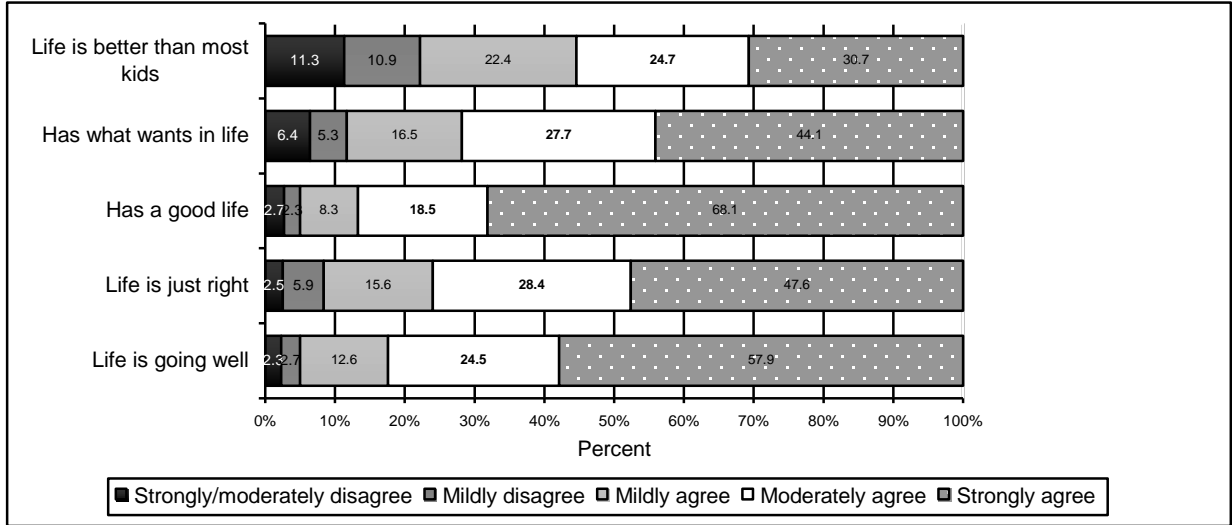
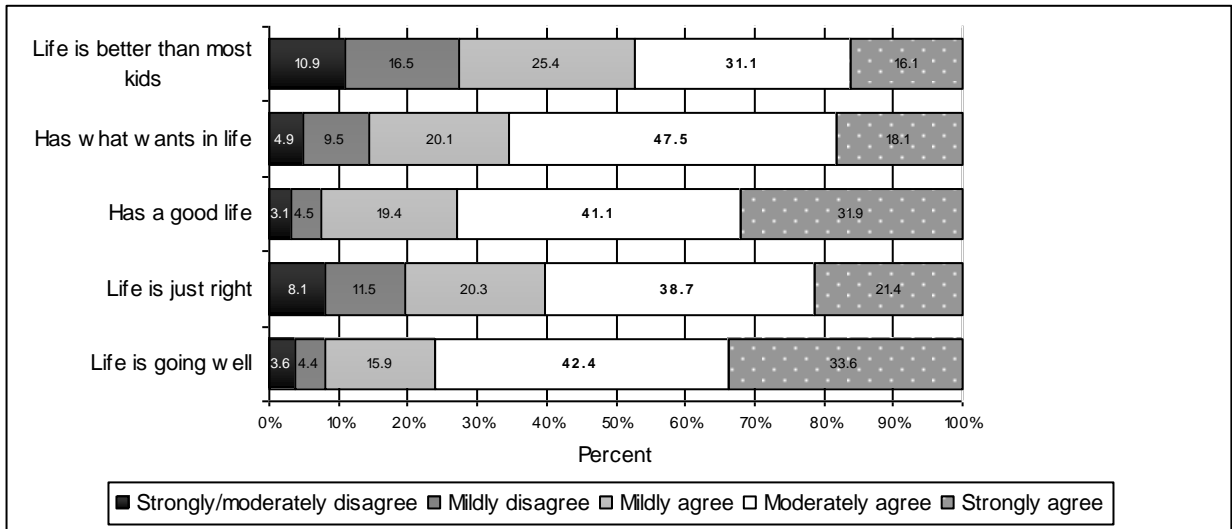


Figure 42: Parent Report Youth Overall Perceived Quality of Life



Youth Desire for Life Change

Both youth and parents were asked to respond to two statements about youths' desire for life change (Figures 43 and 44). Close to 80% of parents and about 55% of youth 'mildly' to 'strongly agreed' that youth would like to change things in their life. About 55% of parents and 35% of youth 'mildly' to 'strongly agreed' that they wished they had a different kind of life.

Figure 43: Youth Report Youth Desire for Life Change

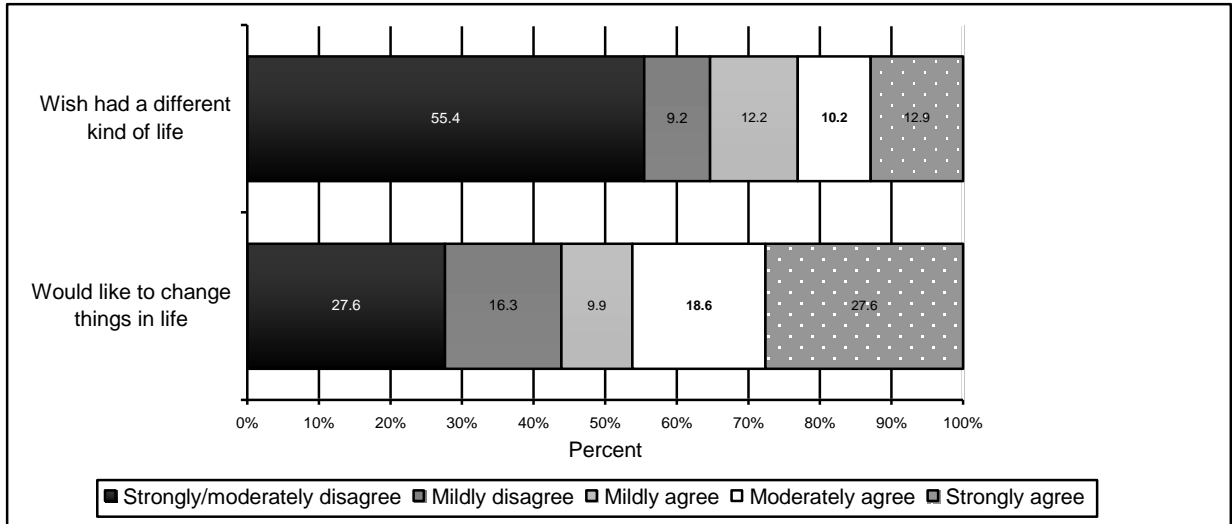
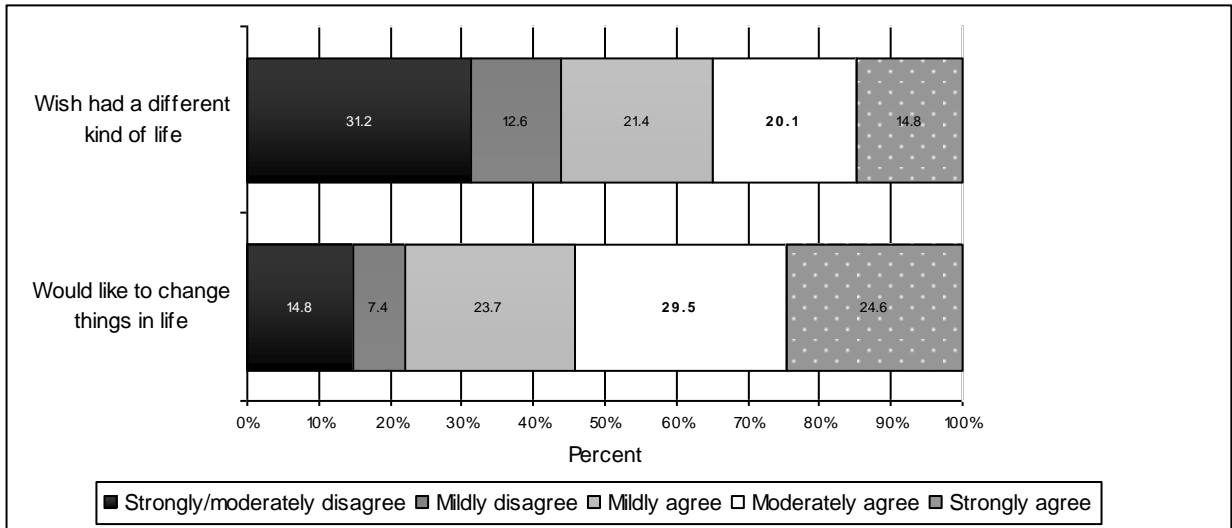


Figure 44: Parent Report Youth Desire for Life Change



9. FACTORS RELATED TO YOUTH PERCEIVED QUALITY OF LIFE

Initial Relationships

This report provides a snapshot in time of youth and their parents' perceptions of: a) youth physical, emotional, behavioural, social, spiritual, and educational well-being; b) the supportiveness of the home, school, and community environments for youth; and c) youth satisfaction with specific aspects of their lives and quality of life overall, from the perspectives of both youth and their parents. The initial baseline findings of the study suggest that the majority of youth and their parents moderately to strongly agree that youth quality of life is high. However, a small but noteworthy number of youth and parents mildly to strongly disagree that youth life quality is high. Moreover, the majority of youth and their parents report that youth would like to see changes in their lives that could improve their overall quality of life.

We conducted an initial regression analysis of our baseline findings to examine which factors had the greatest impact on youth quality of life, from the perspectives of both youth and their parents. In this analysis, the effects of socio-demographic characteristics of youth and families (age, gender, chronic condition, family income, etc.) were controlled for so that we could focus on the types of personal, interpersonal, and environmental factors that are more amenable to change.

This research was the **first to explore personal, interpersonal, and environmental factors associated with global perceived quality of life for youth with chronic conditions** from the perspective of youth and parents. Both perspectives were obtained because it was thought that youth and parents might place different values on what is important to youth perceived quality of life. Surprisingly, for both youth and parents, the same or related factors were associated with facilitating or hindering perceived quality of life for youth. That the same or related aspects of life were linked with youth perceived quality of life from both perspectives provides added support for these as *key factors*. Personal, interpersonal, and environmental factors were all significantly related to youth perceived quality of life, indicating the benefits of a holistic approach to both assessment and enhancement of life quality for youth. Below is a brief description of our findings and some initial recommendations for service delivery. Please keep in mind these findings are preliminary and cross-sectional.

Key factors:

- Both youth and parent analyses indicated that **pain/other physical symptoms** and **emotional symptoms** were negatively associated with youth perceived quality of life. Pain and mental health can often be overlooked and go unaddressed in children and youth with chronic conditions. These findings suggest that pain/other physical symptoms and mental health should be high priorities of assessment and intervention for youth.
- **Spirituality**, described as 'any deep feelings or beliefs youth may have', was positively associated with perceived quality of life in both the youth and parent analyses. Although rarely a part of standard care, the value of listening to youth and understanding the importance of personal meaning in their lives, and attending to associated needs as well as building on strengths within the context of pediatric rehabilitation services, is supported by this research. Adopting a holistic approach to rehabilitation services is recommended that encompasses mind, body and spirit.
- The **social support youth received from their family** was positively related with their perceived quality of life, while overall **functioning of the family** was positively associated with parent perspectives of youth perceived quality of life. **Barriers at home** such as family stress were also negatively associated with parent perspectives of youth perceived quality of life. This research supports the position that the provision of family-centred service, with an emphasis on addressing parent and family wellbeing as part of pediatric rehabilitation services, is fundamental to the wellbeing of youth with chronic conditions.
- **School productivity/engagement** was also positively associated with perceived quality of life in both the youth and parent analyses. It is also noteworthy that **self-determination** in terms of goal-orientation was moderately and positively associated with perceived quality of life in the youth analysis. These findings suggest that having a chronic condition is not a detriment to youths' desire for personal development and achievement.
- Indeed, school life appeared to be a very important environmental context to the life quality of youth. Specifically, **a sense of school belongingness/safety** was positively related to perceived quality of life in the youth analysis. **School barriers**, such as poor attitudes and lack of programs and **social anxiety**, in terms of fear of peer rejection were also related to poorer perceived quality of life in the parent analysis. **Community barriers** such as lack of support and encouragement were also negatively associated with parent perspectives of youth perceived quality of life. Health and education professionals and policy makers need to be aware of the importance of youth school productivity/engagement, and of the school and community environments to perceived quality of life and support youths' desire to be successful and included.

10. CONCLUSION

Future Work and Summary

Caution should be used when generalizing findings to youth with chronic conditions who do not receive services from children's treatment centres and who do not fit the socio-demographic and health-related profile of study participants. The research presented in this report used baseline, cross-sectional data derived from our longitudinal study. The longitudinal data will allow an examination of the factors that influence changes over time in perceived quality of life for youth with chronic conditions. It will help us to unravel the complex ongoing interrelationships among personal, interpersonal, and environmental factors and perceived quality of life.

A number of factors included in this report were hypothesized to impact perceived quality of life for youth. Certain *key* factors emerged as significantly related to youth perceived quality of life from the study baseline data. That the other hypothesized factors were not significantly related to perceived quality of life in these analyses does not suggest that they may not be important to the lives of youth. Indeed, the most important factors to life quality will vary for individual youth and **each youth's situation should be considered and treated as unique**. For example, movement problems, hyperactivity/inattention, classmate support, or social participation may be specific issues for certain youth. What this study does is identify key factors that impact perceived quality of life at one point in time **across a substantial group of youth** with chronic conditions, **giving families and service providers a main starting-point** for considering and assessing youths' strengths and needs and the supportiveness of the environment. In addition, identification of **primary issues** related to quality of life that exist across chronic conditions can **provide policy makers with a foundation for the development of policies and interventions** applicable to a large number of youth.

The factors explored in this baseline work as having an impact on youth perceived quality of life go well beyond consideration of the physical impairments and functional limitations of individuals with chronic conditions. In addition to working toward alleviating physical impairments and functional limitations, these baseline findings suggest services could be beneficial that are designed to **enhance other life dimensions**, like youth emotional wellbeing and family wellbeing, as well as providing additional supports such as spiritual care for youth and their families, and advocating for supportive school and community environments where youth can thrive and develop to their full potential.

An article has been published in the scientific journal, *Disability and Rehabilitation* that explains this baseline research in greater detail. Please visit the "Quality of Life" webpage at <http://www.tvcc.on.ca/qol/> to obtain a copy of the article. Baseline study findings are being shared widely so that they can be considered when services for youth with chronic conditions and their families are being provided and planned for. We will inform you of the findings from our longitudinal data once it has been collected and analysed.

11. THANK YOU

We would like to thank all youth and their families for giving their precious time and energy to the “Quality of Life” study. Your perspectives are invaluable.

We would also like to thank the study co-investigator, project coordinators, research assistants, study interviewers, and centre collaborators for their participation. All team members that have taken part thus far are named below.

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Quality of life means to me...

“that you live life to the fullest and you never give up.”

“doing the best you can with your circumstances and abilities.”

“how you enjoy life and get the best out of life.”

“waking up and feeling happy.”

- Youth Study Participants

