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# THE EFFECT OF FREE PLAY ON QUALITY OF LIFE, MOTOR DEVELOPMENT AND SOCIAL ADAPTIVE SKILLS OF PRESCHOOL CHILDREN WITH DEVELOPMENTAL DISABILITIES

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A Thesis Submitted in Partial Fulfilment of the Requirements for the Degree of Master of Philosophy

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### ABSTRACT

This study aimed to investigate the effect of free play on quality of life, social adaptive behavior and gross motor performance of preschool children with developmental disabilities. In order to measure these three aspects objectively, The Peabody Developmental Motor Scales-2 (PDMS-2) was used to measure gross motor function. The Hong Kong Based Vineland Adaptive Behavior Scale (HKBABS) was used to measure adaptive behavior for the children. Since there is no existing Chinese scale for measuring quality of life suitable for this study, The Pediatric Quality of Life Inventory (PedsQL) was translated and validated prior to the main study.

One hundred and eighty seven children and parents were involved in varied stages of the validation of the Chinese PedsQL. Internal consistency (Crobach>0.862), test-retest reliability (ICC=0.617 to 0.993), known group differentiation and correlation between parent proxy-report and child self-report (r=0.315 to 0.782) were examined and were found to be satisfactory with some exceptions. The validated Chinese version of PedsQL was then used as an outcome measure of quality of life of the children participated in this study.

Test-retest reliability of all tests and inter-rater test for PDMS-2 (as it need subjective observation in scoring the items) were also done prior to the main study. The results showed good inter-rater reliability of PDMS-2 (ICC>0.955). Test-retest reliability was also moderate to good (ICC from 0.617 to 0.991) for all total scores and subtest scores of the three measures.

For the main study, 35 children with disabilities were recruited from two special child care centres of The Heep Hong Society in Hong Kong. Eighteen of them were in intervention group in which they received intervention of free play program in addition to the usual programs. The other 17 children served as control and received no additional free play intervention. Two half-hour weekly sessions were provided for 14 weeks for children in the intervention group. Significant differences were obtained in social, motor function and activities of daily living subtests of the HKBABS (p<.001 to .048) but not in the other measures.

Findings of this study suggested that free play probably has a positive effect on the development of children. The insignificant result could be due to small sample size. However, this study seems to show that there is positive value of play for adaptive behavior. Benefits of free play should be examined in future studies to determine if it should form part of the daily training for children with developmental disabilities.

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# CHAPTER 1

All children like to play. Play seems to be an intrinsic need of children, whether they are with or without disabilities. Play is part of children's daily life. Children learn and develop though play. It is an intrinsic need of them (Moyles, 1989). After reviewing the research conducted by different disciplines on the significance of children's play, McArdle (2001) concludes that play may be "central" to typical personality development. It is obvious that play is important to normal development of children. Children learn to survive and to develop physically, psychosocially and intellectually through play.

However, children have little opportunity to play in Hong Kong. They are expected to sit and listen in class for a long time everyday. It was found that primary school children in Hong Kong spent less than an hour to play each day (Yip, 1999). Their play activities are usually skill oriented rather than social or creativity oriented. According to the Yip's study, 16.6 % of the 614 primary school children it surveyed did not play at all during the weekend. It involved the use of a questionnaire to survey on the actual play or leisure activities of the children on the Sunday preceding the survey. The content of the questionnaire covers favourite play activities, toys, and play mates. The three activities that the children like most was revealed as television watching (86.5%), electronic games (76.9%), ball games (68.2%) and computer games (65.9%). The most popular toys were electronic games (39.9%). For the children who engaged in play, most of them were in practice play (17.5%) (e.g. cycling, skipping), electronic games (17.4%) (e.g. Game Boy) and ball games (15.6%) (e.g. football, badminton). These three most popular plays were largely skill oriented but less social interaction. Social pretend play, functional play and constructive play that associate with creativity were found to be the least popular play activities. The result of this study indicated that children in Hong Kong lack of play engagement and the play activities were comparatively passive and non-social.

The situation of limited play engagement is similar of children with disabilities in special school. Ostrosky et al (1994) observed and counted the amount of time that the children spent in programmed activities of preschool special education classes. It was found that the time actually spent in play was only 14.21%. The result also showed that the time spent in play was significantly shorter than the time scheduled for play.

Children with disabilities need play opportunities much more than those without disabilities (Fine, 1996). However, children with disabilities spend large amount of their time sit in class to learn. The motor behaviors of young children with physical disabilities were observed in both integrated and segregated preschool classroom in the United State (Ott & Effgen, 2000). Stability behavior especially

in sitting occurred at very high rate than mobility and transfer behavior. About one-third of transfer and mobility behavior did not involve active movement by the child. The result was similar in both settings of preschool. A similar study was conducted by Effgen (2001) in a Conductive Education program in Hong Kong. The finding was similar to that of the United States. Children with cerebral palsy spent most of their time in sitting during the lessons. It is obvious then that the children with disabilities might spend too much time daily in table task or sit and listen in class. They seldom play liberally. However, play is an important part of early childhood. It is the most effective way children learn to live in this world. (Zeece & Graul, 1990). This study aims to investigate if play can facilitate the potential of development in children with disabilities.

Although play is thought to be an important of part of children, few studies have been conducted to investigate the effect of play on neuromotor and psychosocial ability in handicapped children. Roswal et al. (1984) was one of the researchers conducted a study to examine the effect of a developmental play program on psychosocial and motor performance of children with mild disabilities. The study was conducted to 32 children aged 5 to 13 who attended special education program. Sixteen children were in experimental group and other 16 were in control group. The program was provided with a wide variety of guided play for each child individually in 9 weeks with 2 hours per week. The result showed significant positive effect of developmental play on self concept and motor proficiency.

Health care professionals usually focus their treatment outcome in terms of biomedical data or functional status rather than the quality of life (QoL) of the individuals. However, the objective condition is not a direct indicator of subjective quality of life (Verri et al., 1999). Interest in quality of life has increased in the research field of medical care (Eiser & Morse, 2001; Felce, 1997). According to World Health Organization (1947), health is the "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." Cummins (1996) defines quality of life as both objective and subjective dimensions each composed of seven domains: material well-being. Objective domains comprise culturally relevant measures of objective well-being. Subjective domains comprise domain satisfaction weighted by their importance to the individual.

There is few researches examining the QoL of children with disabilities. The relationship between play and QoL has seldom been studied also. This project explored if free play intervention can improve the quality of life of children with developmental disabilities. There are few measures of quality of life applicable to children in young age. Eiser and Morse (2001) have reviewed a number of measures of quality of life for children with chronic illness. Of the generic measures, Pediatric Quality of Life Questionnaire (Varni, 1999) is age appropriate for the present study. It provides self-report and proxy-report and is

reliable and validate. Besides, it is brief and was recommended for assessment of psychosocial intervention. However, as suggested by Eiser and Morse (2001), other measures needed to be included for specific aims of the intervention. So gross motor performance and adaptive behavior were also investigated with quality of life in order to make the outcome measurement more comprehensive and including different dimensions of children development.

### Statement of Aim and Objectives

### Aim:

To investigate the effectiveness of free play intervention on quality of life, adaptive behavior, and gross motor development of preschool children with developmental disabilities.

### Objectives:

- 1. To prepare and validate outcome measures in quality of life, adaptive behavior and gross motor performance for children.
- To measure quality of life, adaptive behavior and gross motor performance of the children participated in this study.
- 3. To investigate the effect of Free Play Program on quality of life, adaptive behavior and gross motor development of preschool children with disabilities.

### Organization of the Chapters

Chapter two reviews the literature about play including its definition, the theory and development of play, and the importance of play proclaimed by studies from different research fields and professions. Chapter three presents the translation and validation study on of one of the outcome measures – The Pediatric Quality of Life Inventory (PedsQL). Chapter four reports the main study of this project. Preparation of reliability of another two outcome measures of adaptive behavior and motor performance -- Hong Kong Based Adaptive Behavior Scale (HKBABS) and Peabody Developmental Motor Scales-2 edition (PDMS-2) will be addressed first. Methods and results in investigation of effectiveness of free play intervention for children with disabilities is the body of this chapter. The whole study will be discussed in chapter five and conclusion will be presented in chapter six.

# CHAPTER TWO

### **Definition of Play**

There are different ways of defining play. "It is the spontaneous activity of children, a recreational activity, the absence of serious or harmful intent, to take part into a game, and to toy or fiddle around with something" (Merriam-Webster's Collegiate Dictionary). "Play is spend time doing enjoyable things, such as using toys and taking part in games" (English Dictionary for Advanced Learners-Collins Cobuild). "Play is doing things for amusement, do things for pleasure" (Oxford Advanced Learner's Dictionary-Oxford). Researchers of different disciplines including animal ethologists, educationalists, psychoanalysts and psychologists have also defined play differently (Bracegirdle, 1992). Piaget (1962) thought that play is primarily mere functional or reproductive assimilation (cited in Bracegirdle, 1992).

Cohen (1987) doubted whether we could get a perfect definition of play because it is such a wide behavior. Garvey (1977) (cited in Bracegirdle, 1992) has tried to list factors that are critical to define play. To him, play is pleasurable, enjoyable and positively valued by the player. It has no extrinsic goals and motivation to play is intrinsic. It is a spontaneous activity involves active engagement and is

not obligatory.

Rubin and colleagues (1983) (as cited in Zeece & Graul, 1990) identified six criteria from the research literature that characterize children's play behavior:

- 1. Play is intrinsically motivated. The motivation for engaging in play behavior comes from the child, rather than the adult.
- 2. Play involves attention to the means rather than the end. The focus of play is on the activity rather than the end product.
- 3. Play is dominated by child. Children gain a sense of mastery and self-worth in play because they are in control. In addition, objects may perform magic.
- 4. Play is related to instrumental behavior. Pretense helps to widen children's perspectives and lessen their egocentrism.
- 5. Play is not bound by formal rules. Unlike games, the flexibility of real play allows young children to change rules as they interact.
- 6. Play requires active participation. Unlike daydreaming, play requires children to move and create. Thus, behaviors are considered play only when children engage in them actively.

Johnson et al (1999) stated five features of play:

- 1. Play is characterized by a play frame that has no fix pattern. It separates from daily experience that the internal reality goes beyond the external reality.
- 2. Play is an intrinsic motivation.
- 3. Process of play is more important than product.

- 4. Play is a free choice especially for young children
- 5. Play has positive affect. It always provides pleasure and enjoyment.

### **Types of Play**

### **Social Play**

According to Parten (1932) (cited in Johnson et al, 1999), the developmental of social play was in 4 stages. Solitary play refers to play alone and independently, no interaction with others. In stage of parallel play, child plays independently but near or among others, with similar toys or activities. Associative play is the stage in which a child plays with other; conversation is about common activity, but does not subordinate own interests to groups. Cooperative play refers to activity which is organized and with differentiation of roles and complementing actions.

### **Object Play**

It is a type of play using objects during play e.g. pretended cooking activity, constructions from blocks and other materials. It needs considerable development of cognitive, social, affective, physical, and linguistic. Stimulus properties motivate the child to interact with objects. In the first year after birth, play actions develop as a result of experience. Object play progresses from repetitious and undifferentiated activity to more organized and sequenced action patterns.

From a Piagetian point of view, objects direct the infant's action at first and then come under control of the infant. There are two categories of assimilation: (1) reproductive or functional (repeating actions on an object) and (2) generalizing (extending these actions to additional objects).

#### Symbolic Play

According to Gowen (1995), developmental stages of symbolic play are as follows:

- Prepretense child engages in approximate pretense but gives no confirming evidence of pretense. E.g. child briefly touches telephone to ear; briefly puts bottle to doll's mouth.
- Pretend self child engages in pretense behavior, directed toward self, in which pretense is apparent. E.g. child raises cup to lip, tips cup, makes drinking sounds.
- Pretend other child engages in pretense behavior directed away from child toward other; pretends the behaviors of other people. E.g. child feeds doll with toy baby bottle or cup.
- 4. Substitution child uses an apparently meaningless object in a creative or imaginative manner, or uses an object in a pretense act in a way that differs from its usual use. E.g. child feeds doll with block as "bottle"; puts piece of play dough on plate and calls it a hamburger.
- 5. Imaginary objects or being child pretends that an object, substance, person, or animal is present. E.g. child tips empty teapot over cup and

says "coffee"

- 6. Active agent child animates a toy (e.g., doll, toy animal) that represents a being so that toy becomes an active agent in the pretend activity. E.g. child hops toy animal across rug as though it were running, puts doll's hand to its mouth as though it were feeding itself.
- Sequence, no story child repeats a single pretense act/scheme with multiple receivers. E.g. child gives mother a drink from the cup, then gives doll a drink from the cup.
- Sequence story child uses more than one related scheme in pretense activity. E.g. child stirs in cup, drinks from cup, and says "Mmmm, taste good"
- Planning child engages in pretend play preceded by evidence of planning. E.g. child says that she will feed the baby before putting toy baby bottle to doll's mouth.

### Motor Play

Motor play occurs in play with objects, people, and symbols. It often occurs with the other forms of play. It overlaps with object play to a great extent and some motor play overlaps with social play.

### **Theories of Play**

According to Johnson et al (1999), classical theories of play originated in 19<sup>th</sup> and

early 20<sup>th</sup> centuries. They are Surplus-Energy Theory ---- animals get rid of the energy more than is needed for survival by play, which is assume as a purposeless behavior. Recreation Theory --- opposite to surplus-energy theory --- is a theory stated that the purpose of play is to restore the energy expended in work, by engaging in an activity differ greatly from the work that consume the energy. Recapitulation Theory --- play repeat the behavior in the developmental stages of human evolution in same order. The purpose of play is to eliminate the primitive instincts that are no longer need in modern adult life. Practice Theory --- play is a way to practice and strengthen the instinct survival skill required for adult life. All of these classical theories have its limit and weakness, but does made some influence in modern theories of play (Johnson et al, 1999).

The modern theories developed after 1920 (Johnson et al, 1999). Johnson et al reviewed the history and summarized as follows: Psychodynamic theory (Freud, 1961) (cited in Johnson, 1999) considered that play can have a cathartic effect which make children get rid of negative feelings from unpleasant events. Cognitive Theories includes Piaget's theory (1962) (cited in Johnson, 1999) stated that play reflects the level of children's cognitive development and contribute to it. Children do not learn new skills in play. But they practice and consolidate the newly acquired skills when they play. Vygotsky's theory (1976) (cited in Johnson, 1999) claimed that play is important to social, emotional and cognitive development. All three domains of development interrelate. E.g. Symbolic play is crucial to the development of abstract thinking. Bruner's theory

(1972) (cited in Johnson, 1999) proposed that process in play is more important than the product of it. Children learn behavior in play to solve the problems in real-life. Sutton-Smith's theory (1967) (cited in Johnson, 1999) stated that makebelieve play promotes the 'symbolic transformations' ability in cognition thus enhances the flexibility of children's mental. More recently, Sutton-Smith (1998) (cited in Johnson, 1999) proposed 'adaptive variability' of play. Play assures broad adaptive potential in human development. "Play's function at early stages might ... be to assist the actualization of brain potentiality... to save in both brain and behavior more of the variability that is potentially there than would otherwise be saved if there was no play." Singer's theory (1973, 1990) (cited in Johnson, 1999) claimed that play and especially imaginative play is a positive force in development. Play is seen as influencing the general symbolic capacity of the developing child.

### Importance of Play

As play has interesting features to the children, it has long been used by multidisciplines for different purposes. Play can be used as diagnosis or assessment tools (Gitlin-Weiner, Sandgrund & Schaefer, 2000). For the educators, play has been used to promote learning and development of children. For the clinical psychologists, psychiatrists, social workers, counselors and family therapists, they treat children with psychological, behavioral or emotional problems though play. Play therapy is a mean using play as a medium of communication between

child and therapist to help children cope with distress in their life. Occupational therapists incorporate play into treatment programs especially for children. Physical therapists use playful measures to facilitate desired motor performance for children with motor disabilities. In addition to play is utilized as intervention or treatment.

Roswal et al (1984) investigated the effect of a Children's Developmental Play behavioral and neuromotor functioning of children with Program on developmental disabilities. The result showed that the program served as a valuable resource to children, teacher and community. It based on the concept that pleasurable movement experiences are meaningful to children. It used physical play medium to increase body awareness and facilitate fundamental movement skills, and thus provide a basis for social skills. Sixteen children with mild mental retardation ages 5 to 13 years participated in this developmental play program for nine weeks in total of 18 hours. The other sixteen children with similar condition in control group received no intervention. The result indicated that the experimental group exhibited a significant change in self-concept and motor proficiency over the control group. It also supported that self-concept and motor proficiency were correlated. Much earlier similar researches found developmental play program improves self-concept of children with special needs (Roswal et al, 1984). Enhancement of motoric functioning by various play programs had been reported by some researches done in early years (Roswal et al, 1984).

With a play context intervention, social communication behavior was improved in six preschool children at risk for language delays and behavior problems. Increases in linguistic complexity and diversity and play complexity were also noted after this adult guided play intervention focus on teaching children vocabulary and social language (Craig-Unkefer & Kaiser, 2002).

Therapeutic play presented by an interactive puppet show has been demonstrated as a valid way to reduce the stressful responses to hospitalization and surgery for children in Lebanon (Zahr, 1998). Children who received the therapeutic play intervention showed significant less anxiety, more cooperation, lower mean blood pressures and pulse rates than control group during preoperative injection. After surgery, the experimental children need less time to void their bladder. And they obtained significant lower scores in Post Hospital Behavior Questionnaire which rates the adverse behavioral changes on six behavioral categories.

### **Structured Play vs Free Play**

Most researches about play were interested in structured play program in which play program was designed with specific method and follows the instruction or lead by adult (Kok et al, 2002; Miller & Reid, 2003; Van Berckelaer-onnes, 2003). They used structured play as an intervention and test the effect of it on different

aspects of interest as psychosocial, physical or behavioral change of the target children. The forms of structured play has no definite model; they designed by the researchers according to their study objectives and interest. Vukelich (1994) studied effects of play intervention enriched with environmental print on young children's reading ability. Tyson (1998) used structured play activities of physical movement as intervention protocol to examine its effect on motor skill development in kindergarten students. Sparling et al (1984) examined the effect of educational play in drama and art on gross motor, fine motor, language, cognitive, social-emotional and activity of daily living (ADL) performance. Most studies involved 'free play' took it as a media to observe the behavior or specific area of development of the children. Free-play behaviors were compared between preschool and kindergarten children by Rubin et al (1978) and between middle- and lower-class preschoolers (Rubin et al, 1976). Play interactions of young children with and without disabilities were observed during free play (Hestenes & Carroll, 2000). Social behaviors with peers were videotaped in free play context in the classroom (Sanchez-Martin et al, 2000). Social skills and free play behaviors of maltreated and no maltreated children of 3 to 5 years were compared by Darwish et al (2001). Rarely 'free play' was used as an intervention for positive change of development. However, as reviewed previously, play was defined by the pioneers in this field that play is not a structured activity. It is selfdirected by the child, no limit boundary, no end goal and free to be chosen by the child. And as children play liberally, they development and learn to survive in this world. Only a few studies examined the effect of free play quantitatively. However,

their findings were positive. Wide variety of outdoor and gymnasium play activities provided to children to participate freely (Roswal et al, 1984). The experimental group of this study showed significant change in self concept and motor proficiency over the control group. Free play in outdoor natural environment in preschool children was showed to have significant effect on their balance and coordination abilities (Fjortoft, 2001).

There is no definition on free play and structured play. However, after reviewing the studies about these two kinds of play, simple inference could be summarize that free play is directed by child and structured play is directed by adult. Some researchers might think that intervention should be structured and under controlled in order to facilitate more effect on the target objectives. This might be the reason that free play was seldom used as a method of intervention.

Children through play explore the environment around them and develop mastery of skills. These skills can be divided into physical, social and psychological aspects. Among them, the most important are the gross motor performance and adaptive behavior aspects. It was believed that, with a good mastery of these components, children are able to lead a life with quality.

The preschool children with developmental disabilities such as with a global delay, cerebral palsy, Down's syndrome are common to present with problems with motor functions. The Peabody Developmental Motor Scales (PDMS) (Folio

& Fewell, 2000) is the measure usually used for assessing and diagnosing children with development disabilities at the preschool level. Motor delays very often are associated with failure in developing age-relevant adaptive behavior. As a matter of fact, delays in motor and adaptive behavior co-exist among the children with developmental disabilities.

In recent years, quality of life has become a common outcome used for studying effects of health related interventions for children. Enhancement of quality of life is the ultimate goal of health services. A review of the literature suggested that there is no study on exploring the relationships between play and quality of life. In this study, we intend to explore to what extent the quality of life of children with disabilities could be improved by providing them with more play opportunity.

### Adaptive Behavior

Doll (1935) proposed the concept 'social competence' which was referred to social responsibility and personal independence of human. It became a term 'adaptive behavior' nowadays (Kwok et al, 1989). It is an ability of an individual to satisfy the demands and expectation in social community (Grossman, 1983) (cited in Kwok et al, 1989). The classification manual of The American Association of Mental Deficiency (AAMD) defined it as "the effectiveness or degree with which individuals meet the standards of personal independence and social responsibility expected for age and cultural group" (Grossman, 1983, p.1) According to Horn & Fuchs (1987), it "emphasizes the capacity to respond to demands of immediate environment and community". It changes as an individual progress his life cycle in time and place. So it is relative and dynamic. For the young child, it is an ability to walk and to talk; for the adult, it is a capacity to be responsible in his job and hold a family.

In the early years, diagnosis of mental retardation depended on assessment of intellectual ability (Horn & Fuchs, 1987; Kowk et al, 1989). The concept of adaptive behavior was emerged as a result of the emphasis of training and educational program for people with mental retardation (Patton, 1986). However, Dunn (1968) (cited in Horn & Fuchs, 1987) found that intelligence tests were over emphasized in the identification of mental retard. In the early 1970s, it was found that many people with intelligence quotient (IQ) score below 70 did not have adaptive problem (Leland, 1972) (cited in Horn & Fuchs, 1987). By late 1970s, American Association on Mental Deficiency (AAMD) definition of mental retardation included the deficit of adaptive behavior associated with subnormal intelligence (Grossman, 1983).

The inclusion of concept of adaptive behavior in the assessment of mental retardation led to development of numerous adaptive behavior scales (Horn & Fuchs, 1987). Heath (1986) (cited in Harrison, 1987) reported 129 studies about adaptive behavior have been published during the last 10 years. However, most

of them addressed measurement and scales of adaptive behavior, few studies were about its theory. Major scales as Vineland Social Maturity Scale (Doll, 1965); AAMD Adaptive Behavior Scale (Nihira, Foster, Shellhaas, & Leland, 1975) are still frequently used now. Harrison (1987) conducted a review of researches using totally 25 scales of adaptive behavior and he drawn out several conceptual conclusions. Some of them were as follows: There is moderate to moderately high relationship between different measures of adaptive behavior; there is moderate relationship between adaptive behavior and intelligence; adaptive behavior scales differentiate among different groups of individuals as normal, mental retarded, learning disabled, emotional disturbed.

Reschly (1982) (cited in Kamphaus, 1987) identified typical domains assessed by several widely used adaptive behavior scales are: motor / physical, self-help / independence, interpersonal I/ social, responsibility / vocational, cognitive / communication. Some popular adaptive behavior scales were mentioned when Craig & Tasse (1999) discussed cultural features of adaptive behavior. These are: Adaptive Behavior Inventory for Children, ABIC (Mercer & Lewis, 1978); Adaptive Behavior Scale, ABS (Nihira, Leland, & Lambert, 1993); Children's Adaptive Behavior Scale, CABS (Richmond & Kicklighter, 1980); Scales of Independent Behavior-Revised, SIB-R (Bruininks, Woodcock, Weatherman, & Hill, 1996); System of Multicultural Pluralistic Assessment, SOMPA (Mercer & Lewis, 1978); Vineland Adaptive Behavior Scales, VABS (Sparrow, Balla, & Cicchetti, 1984). Among these, VABS is the most frequently used to measure adaptive behavior

(Craig & Tasse, 1999). It composed of four major domains of adaptive skills as communication, daily living skills, socialization, and motor skills. It has norm from birth to age 19. This scale was adapted for Hong Kong Chinese by Kwok et al (1989) to Hong Kong Based Adaptive Behavior Scale (HKBABS).

### Motor development

As defined by Gallahue & Ozmun (1999, p. 20), motor development is the "progressive change in motor behavior throughout the life cycle brought about by interaction among the requirements of the task, the biology of the individual, and the conditions of the environment". Payne & Isaacs (2002) stated that it is the study of the progressively changes of human motor performance over the lifespan, and the factors that affect them.

Peabody Developmental Motor Scales (PDMS) (Folio & Fewell, 2000) are designed for assessment of gross and fine motor skills at developmental level from 1 to 72 months. It consists of 6 scale scores for gross motor as: reflexes, balance, nonlocomotor, locomotor, receipt and propulsion of objects and total; and 5 scale scores for fine motor as: grasping, hand use, eye-hand coordination, manual dexterity and total. Its advantage is that it permit quantification of motor development.

The author selected PDMS-2 as a measuring tool for gross motor in this study. It

was because this scale is age appropriate, focus on motor performance, applicable to different type of disabilities and it was commonly used world wide (Kolobe et al, 1998) and in Hong Kong clinically.

# **CHAPTER THREE**

# TRANSLATION AND PRELIMINARY VALIDATION OF PEDIATRIC QUALITY OF LIFE INVENTORY (PedsQL)

## Introduction

The role of medical care professionals is not just saving but to improve life quality in those with illness. Nowadays, many chronic illnesses are still not curable. Children with disabilities have to suffer from complications like physical or mental handicapped. These affect the quality of life of both the child and his/her family. However, measures such as early intervention, physical or occupational therapy can be taken to relieve the sufferings from these chronic illnesses. Medical care services have put much effort in doing this during the decades (Hughes, 1995). As there is changes in the epidemiology of disease from acute to chronic and the treatment change from focus on curing to palliative, the concept of quality enhancement and quality assurance impact on health services, measurement related to total life well being has to be presented in order to measure the effect of the effort (Eiser & Morse, 2001; Schalock, 1994; Campo et al, 1997). Measurement of life quality can comprehensively reflect the conditions of the well-being of the clients. As a result, the design and use of the scales measuring quality of life has escalated.

Quality of life is a complex and abstract concept that most researchers agree that it is multi-dimensional. Cummins (1996) defined quality of life as a construct with both objective and subjective axis, each of them includes seven domains namely material well-being, health, productivity, intimacy, safety, community and emotional well-being. Felce (1997) proposed a model of quality of life and defined it as ' an overall general well-being that comprises objective descriptors and subjective evaluations of physical, material, social, productive, emotional and civic well-being all weighted by a personal set of values.' As this is a complex constructs, how to measure it reasonably then become an important issue.

There were few measures available for assessing quality of life in children and adolescents until the late 1990s (Landgraf, 2002). Eiser and Morse (2001) reviewed quality of life articles of children published from 1980 to 1999. Forty-three new developed QoL measures for children were identified. Nineteen of them were generic scales. Among these measures, only 2 fulfill all criteria which are important in a QoL measure mentioned by the authors. The three criteria are: having satisfactory psychometric properties, availability of both child-self report and parent-proxy report, and brief (<30 items). Pediatric Quality of Life Inventory (PedsQL) (Varni, 1999) is one of them. Moreover, it covers broad age range for ages 2 to 18 with 4 parallel forms which developmentally appropriate to 4 age range: 2 to 4, 5 to 7, 8 to 12, 13 to 18. By this advantage, scores can be compared across different ages that other measures do not have.

Pediatric Quality of Life Inventory (PedsQL) is a modular measure health- related quality of life (HRQOL) in youngsters 2 to 18 years of age, with or without acute or chronic diseases. It integrates both generic core scales and disease-specific modules into one measurement system. It provides specific modules for asthma, rheumatology, diabetes, cancer, and cardiac conditions supplement the Generic Core Scale. Specific modules provide more measurement sensitivity and generic core scales provide comparison across groups of different condition with or without diseases. As there is discrepancy between self-report and proxy-report in HRQOL assessment (Guyatt et al, 1997), it is necessary to have a measuring instrument report by the child his/herself. PedsQL aims to fulfill this need (Varni, 2001). It has been developing for more than 15 years to have PedsQL 4.0 version established. The questionnaire composes of 4 domains: physical, emotional, social and school functioning dimensions that are delineated by WHO about health concept. Each domain consists of 5 to 8 items with a 3-point rating (child-self report for 5 to 7 year-olds) or 5-point Likert scale (for parent-proxy and other children reports). It takes only 5 to 10 minutes to complete by selfadminister or asked by tester through interview or telephone. The scores are 0, 1, 2, 3, 4 for response choice of 'never', 'almost never', 'sometimes', 'often' and 'almost always' in all parent reports and child self-report of ages 8-18. For selfreport of age 5 to 7, the scores are 0, 2, 4 for 'not at all', 'sometimes', 'a lot'. Raw scores will be transformed to scale scores of 100, 75, 50, 25, 0 and 100, 50, 0 respectively in both kinds of reports for data analysis.
The psychometric properties of PedsQL 4.0 were satisfactory (Varni, 2001). Feasibility of administration is high that the questionnaire is easy to perform. Missing item response is 1.54% and 1.95% for self-report and proxy-report. Item response distributed to full range of score though slanted toward higher HRQOL. There were no floor effects but ceiling effects ranged from minimal to moderate (1.9% in total score of ill children self-report and 58.1% in social functioning subscale of healthy children proxy-report). Healthy children reports demonstrated more ceiling effects than those of children with illness-which is in expected direction. Item internal consistency demonstrated that most items (19/23) in child self-report and all items in parent proxy-report met or exceeded the 0.40 standard corrected item-subscale correlation. Internal consistency for subscale is good in all except one subscales in both reports with Cronbach's alpha >0.70. Construct validity in terms of known group comparison showed difference between groups of healthy, chronic ill and acute ill children with healthy children showed higher scores than ill children (p<0.05 by one-way ANOVA). Correlations between PedsQL and indicators of morbidity and illness burden including care needed, days missed from school for children and missed from work for parents, impact on routine work and concentration in work were acceptable (r range from -0.11 to -0.50, p<0.01). Factor structure of the PedsQL subscales was examined by Multitrait-Multimethod. It showed that the correlation between subscales in same report is medium (0.42 to 0.49). Correlation between same subscales among both reports is medium to large (0.36 to 0.50). And correlation between different subscales and different report is small (0.17 to 0.26). The result is

concordance to expectation.

Most measures in QoL for children published were in English; few were in Chinese or had been validated for Chinese especially in pediatrics. There is a need to have Chinese language pediatric quality of life measures which is suitable for research and clinical use. When adopting a quality of life measure with cultural differences, some psychometric properties are important to be investigated. Reliability in term of internal consistency and reproducibility (test-retest and inter-rater agreement); validity in terms of content-related, construct-related and criterion-related are the common properties need to be determined before using into target population. The Scientific Advisory Committee of the Medical Outcomes Trust had developed a set of health related quality of life instrument review criteria in 1996 & 2002 (Lohr, 1996; SAC, 2002). They defined eight essential attributes includes conceptual and measurement model, reliability, validity, responsiveness, interpretability, respondent and administrative burden, alternative forms, and cultural and language adaptations (translations).

Reliability is the extent of consistent and free from error of a measurement. It is the reproducibility or dependability of the scales (Portney & Watkins, 2000). Generally there are four approaches to test the reliability: internal consistency, test-retest reliability, rater reliability and alternate forms reliability. Which approaches should be estimated are depend on the features of the measuring instruments.

Internal consistency or homogeneity of an instrument reflects the relationship among items and the correlation of item scores to the total score. It is usually assessed in instruments of questionnaire form. Cronbach's coefficient alpha is usually used for its estimation.

Test-retest reliability is the extent of ability of the instrument to obtain same results with repeated measures by same rater for same subject. It is the capability of the instrument to measure a variable consistently with the testing conditions keep as constant as possible. It is commonly estimated by intraclass correlation coefficient (ICC) model 3.

Rater reliability refers to the stability of data obtained by one rater over two or more trials (intrarater reliability) or by two or more raters measuring same group of subjects (interrater reliability) with the assumptions that the instrument and response variable are stable. It can be established using ICC model 2 or 3. Though it is possible to obtain this for the present instrument, as there are no subjectivity involves, so no need to be done.

Validity is the feature of a testing instrument that how accurate it can measure the intended context in specific population. Its question is how much a test can infer the magnitude of interest construct based on the values obtained from the test. Are the testing values related proportionally to the actual intensity of what it

measure? There are several types of validity: Face validity, content validity, construct validity, and criterion-related validity which can be tested as concurrent and predictive validity or prescriptive validity. As face validity is weak in power and most subjective (Portney & Watkins), this study will not examine.

Though content validity is also subjective, it is commonly used in validation. It can be done by experts review or representatives from the target population who give comments on the test items by grading the appropriateness item by item to determine if the items actually measure the target construct. For questionnaire or inventories designed for parents, it is most appropriate to recruit parents to evaluate the content validity.

Construct validity is determined by measuring observable concepts to reflect the feature and magnitude of the abstract target idea need to be test. It is objective and matches to the general meaning of validity (Lo, 2001). The constructs or concepts we want to measure are mostly abstractive and multidimensional. In some cases, what we measure in the instrument is what we define of the concept especially in questionnaire. Construct validity can be determined by procedures such as Known Groups Comparison (Contrast-group comparison), Convergent and Divergent Validity and Factor Analysis.

In this study, reliability in term of internal consistency, test-retest reliability was established as they are objective and quantitative. As no rater subjective

judgment need to be involved, inter-rater or intra-rater reliability are not assessed. Neither did the original English version. Validity in term of content validity (done in step 2), construct validity demonstrated as known group comparison (factor analysis will not perform as it need more resource out of this study), and correlation between parent proxy-report and child self-report were also demonstrated.

Criterion-Related Validity is one of the most practical and objective approaches to validity testing (Portney & Watkin, 2000). It is established by comparing the result of the target test with those of a gold standard or criterion measure for the same concept to be measured. Concurrent validity is determined when both measures are administered at the same time. It is useful when a new instrument is potentially more efficient than the old gold standard measure. If the result of the instrument can be used to predict the outcome of the subjects, then predictive validity can be determined. As there is no existing standard HRQOL generic measures comparable to PedsQL, this kind of validity was not done.

The aim of this study is to translate PedsQL 4.0 generic core scale of age range 2 to 4 and 5 to 7 years into Chinese and investigate the essential psychometric properties use in the main study. That is the study about effectiveness of Play to development of children with disabilities. The translated Chinese PedsQL and the other two instruments will be used as the measuring outcomes. The original English version was translated and validated according to Translation

Methodology proposed by the original author. The process includes forward and backward translation of the measure, validation of the content of the Chinese version PedsQL using a specific content validity technique call cognitive interviewing. Then the instrument was administered to the field population to assess its reliability and other validities.

# Methods and Results

At to the request of the original author of PedsQL, the instrument was translated and validated following the PedsQL Translation Methodology. The goal is to develop a Chinese version that is a 'conceptual and technical equivalence' of the original English version. The process includes forward-translate the original English version into Chinese, and translate it backward into English, then administer the Chinese version to small sample of target subject as a pilot test of content validity using cognitive interviewing and respondent debriefing technique. The translated version was then tested for its internal consistency, test-retest reliability, age trend, gender bias and known group difference.

# Step 1. Forward and Backward Translation

# **Participants**

Eight independent experts of different professions were recruited in this process. They included three occupational therapists and a physical therapist (the author),

a medical doctor, two translators and a dentist. Each of them was involved in one of the three parts of the translation process. Five of them have 3 to more than 10 years of experience in treating children with diseases or special needs. All of them were Chinese. They had their professional training based on English languages and being proficient in English.

### Instrument

Pediatric Quality of Life Inventory (PedsQL) is a questionnaire constructed by James W. Varni (1998) in U.S.A (Appendix 1). There are different questionnaires (or called report) for different age groups as 2 to 4, 5 to 7, 8 to12 and 13 to18 years. With the exception of the youngest age group, the PedsQL consists of a child self-report and a parent proxy-report. For the youngest group, only the parent-proxy form is used. Each report consists of the instruction and is a list of short questions separate into four parts: physical, emotional, social and school functioning. Each part contains 3 to 8 items. Each report includes 21 to 23 items. For the report for ages 2 to 4, number of items in each subtests are 8, 5, 5, and 3 respectively. Totally there are 21 items in this report. For age 5 to7 reports, number of items are 8, 5, 5, 5 for each subtest with total 23 items for both proxy-report and self-report. It was tested to be reliable and valid for distinguish between healthy and diseased children and also responsive to clinical change over time.

#### Procedure

The English PedsQL was forward translated into written Chinese by two independent persons. One of them is an experienced translator. The second person is a medical doctor with experience in research study. The two forward versions were then discussed and revised item by item by a three-person committee made up of one physical therapist and two occupational therapists. The two versions were then combined into the First Chinese PedsQL (appendix 4).

The first Chinese version was then translated back into English by three independent persons. One of them is a professional translator. The second person is a senior occupational therapist who had lived in U.S. for more than 10 years and can speak and write English fluently. The third person is a dentist with more than 10 years of clinical experience. The backward-translated versions were then sent to the PedsQL Project Team in San Diego for comments and approval.

#### Results

The two forward translated Chinese versions (Forward-1 and Forward-2) were combined or modified to produce the First Chinese PedsQL version. Each term and phrase in the two forward versions were compared and discussed in the translation committee. Table 3.1 shows the terms that were translated differently and how they were compromised or modified. The Chinese terms or wordings were accepted if they were identical to the meaning of the original English. For example, the term 'a problem', we chose '困難' (difficulty) rather than '問題'

(problem) because '問題' (problem) also has a meaning of 'question' in Chinese. If those used in both versions were not appropriate for the meaning of the English version, the committee had figured out other terms which were most suitable (the items with a \*). For example, we used '調査清單' for 'inventory' because it has the meaning of "a list of question for survey". Another example is 'might be a problem', we modified it to '可能是個困難' which is most appropriate in meaning and wording. The complete formats of Forward-1, Forward-2 and First Chinese PedsQL are in Appendix 2, 3 and 4 respectively.

Original English	Forward-1	Forward-2	First Chinese
PedsQL			PedsQL
Inventory *	問卷調查	記錄	調查清單
	(questionnaire)	(record)	(survey
			checklist)
Parent report for	問卷對象:學步兒	學步兒童之父母報	學步兒童之父母
toddlers	父母 (interviewee:	告 (parent report	報告 (parent
	toddlers' parent)	of toddlers)	report of
			toddlers)
might be a	可能是個難題或困	可能是一個難	可能是個困難
problem *	擾 (might be a	題 (might be a	(might be a
	problem or	trouble)	difficulty)
	trouble)	,	
how much of a	每個項目的困擾程	每一項的難題有多	每個事項的困難
problem each	度 (level of	困難 (how	程度 (the
one has been *	trouble of each	difficult in each	difficulty of
	item)	problem)	each item)
a problem	問題 (question)	困難 (difficulty)	困難 (difficulty)
never	一點也不是	從不	從不
	(not a bit)	(never)	(never)
almost never	幾乎從來不是	幾乎從不	幾乎從不
	(almost never)	(almost never)	(almost never)
sometimes	有時候是	有時	有時
	(sometime is)	(sometimes)	(sometimes)

often	經常 (often)	時常 (always)	經常 (often)		
almost always *	幾乎一直是	幾乎是	幾乎總是		
	(almost	(almost is)	(almost		
	everytime)		everytime)		
active play	激烈的遊戲	主動遊戲	激烈的遊戲		
	(active play)	(active play)	(active play)		
Having hurts or	經常受傷或疼痛	曾有受傷或痛楚	曾有受傷或疼痛		
aches	(often hurt or	(have hurt or	(have hurt or		
	pain)	pain)	pain)		
Doing the same	從事其他小朋友也	做同年齡同樣做的	從事其他朋輩也		
school activities	能進行的學校活動	學校活動	進行的		
as peers	(Doing the same	(Doing the same	學校活動		
	school activities	school activities	(Doing the same		
	as the other	as the same age	school activities		
	children)	children)	as peers)		
Missing school/	田色自體不適而知	田色不滴钟運武不	田色咸到不適而		
davcare	四向才虚个週间队	<b>口时的</b> 的小型以下了	四局您到个週间 知罪/审		
because of not	i杯 (Absonce of the	上口间照触中心 (absonce of the	(absonce of the		
feeling well *	class due to	day care centre			
Ŭ	illness)	due to unwell)	felling unwell)		
Parent report for	問卷對象:幼童父	幼童之父母報告	幼童之父母報告		
young children	日日本 55里八	(report from	(report from		
	(subject: parents)	parents)	parents)		
Walking more	步行招過兩個路口	步行多於一棟樓的	步行招過一個路		
than one block *	的距離	距離	口的距離		
	(Walking more	(Walking more	(Walking more		
	than two	than one block)	than one		
	intersection)	,	intersection of		
			the road)		
Taking a bath or	自己洗澡	他/她自己洗澡或	他/她自己洗澡或		
shower by him	(Taking a bath or	沐浴	沐浴		
or herself	shower by him or	(Taking a bath or	(Taking a bath or		
	herself)	shower by him or	shower by him or		
	+	herself)	herself)		
Doing chores,	幫忙做家事,	做家務,例如收拾	做家務,例如收		
	例如:收拾自己的	他/她的玩具	拾他/她的玩具		
nis or ner toys	玩具	(Doing chores,	(Doing chores,		
	(helping to do	like picking up his	like picking up		
	chores, like	or ner toys)	nis or her toys)		
	picking up his or				
Morning of suit	ner toys) 協ご版合改正 <del>と</del> 加	挽百收合七廿南古	施之收合改业十		
what will happen	<u></u>	扂愛府曾月嵒熤争	<u></u> 擅心形曾贺生仕		

to him or her	/她身上的事情	發生在他/她身上	他/她身上的事情
	(Worrying about	(Worrying about	(Worrying about
	what will happen	what kind of	what will happen
	to him or her)	things will happen	to him or her)
		to him or her)	
Getting along	與別的孩子融洽相	與其他孩子相處	與別的孩子融洽
with other	處	(Getting along	相處
children	(Getting along	with other	(Getting along
	with other children	children)	with other
	harmoniously)		children
			harmoniously)
Young child	問卷對象:幼童	幼童報告	幼童報告
report	(subject: child)	(young child	(young child
		report)	report)
might be a	可能很難	可能是一個困難	可能是一個困難
problem	(may difficult)	(might be a	(might be a
		problem)	problem)
how much of a	這些事情可能有	這些困難可能有	這些事情…可能
problem any of	多難	多少	有多難
these things	(how much of a	(how much of a	(how much of a
	problem any of	problem any of	problem any of
	these things)	these things)	these things)
a problem	1月月百		困難
	回起 (a problem)		
not at all	(a problem) 空  入  不	(a uniculty) 	(a unincuity) 之心右
	(not at all)	(completely no)	(completely no)
a lot	總是如此		(completely no) 有很多
	(always like that)	a lot)	a lot)
Is it hard for you	福指發出聲音,對	你是否很難彈手指	谓指發出聲音,
to snap your	你本沿县不困難	(Is it hard for you	對你本鉛是不困
fingers	(To snap with	to snap your	部
	your fingers is	fingers?)	<sup>,</sup> <sup>≠⊭</sup>
	hard for you, isn't	<u> </u>	
	it?)		fingers?)
	,		
Think about how	想一想過去幾個星	想一想你過去幾個	想一想過去幾個
you have been	期的你	星期所做渦的事情	星期你渦得如何
doing for the last	(think about how	(think about what	(think about how
few weeks *	you were in the	have you done in	you have being
	past few weeks)	the past few	in the past few
	. ,	weeks)	weeks)
how much of a	對你來說有多困擾	困難對於你有多少	這些事情對你來
problem this is	(how difficult is	(how much of a	說有多困難

for you *	this for you)	problem this is for you)	(how difficult of those problems this is for you)
Do you ever feel too tired to play *	有沒有過累得不想 玩的感覺 (Do you have the feeling of too tired to play)	有沒有覺得倦到不 想玩 (Do you feel too tired to play)	你有沒有曾覺得 累到不想玩 (Do you ever feel too tired to play)
Do you worry about what will happen to you *	擔心可能會發生在 自己身上的事 (worrying about what will happen to you)	你會不會擔憂你將 會發生的事 (Do you worry about what will happen to you)	你有沒有擔心將 會發生在你身上 的事 (Do you feel concern about what will happen to you)
Is it hard to keep up with school work *	跟不上學校的功課 (Hard to keep up with school work)	是否在家課的跟進 上有困難 (Is it hard to keep up with homework)	你是否很難跟得 上學校的功課 (Is it hard for you to keep up with school work)

Key: new phase was used for the items with a \*

The First Chinese PedsQL was backward translated to English in order to examine if the wording used in this Chinese version can produce other English versions which are same in meaning to the original one. If yes, then the Chinese version is acceptable.

After backward translation, the key phrases or sentences of three backward translated versions were compared with the original English PedsQL (Table 3.2) It was found that the phrases used in Backward-B are most similar to the original version. The translator of it is an occupational therapist worked for Pediatric when lived in U.S.A. for ten years. It might be the reason that her translation was most equivalent to the original. However, the wordings in all three backward

translated versions are comparable to the original and there is no significant difference in concept and meaning between them. (Please refer to appendix 5, 6, and 7 for details).

Table 3.2 Comparison of phrases or sentences among the original PedsQL and the three backward translated versions.

Original English	Backward-A	Backward-B	Backward-C	
Pediatric quality	Quality of	Pediatrics quality	Quality of life in	
of life	children's life	of life	children	
inventory	assessment	questionnaire	list of survey	
	checklist			
Parent report for	For parents of	Toddler's report	The parental	
toddlers	toddlers	from parents	report of toddler	
a problem	is difficult	a problem	considered as a	
			difficulty	
never	never	never	never	
almost never	almost never	rarely	seldom	
sometimes	sometimes	sometimes	sometimes	
often	always	frequently	always	
almost always	almost every time	almost always	often	
how much of a	how difficult it is	degree of difficulty	degree of	
problem			difficulty	
Physical	Physical problems	Physical function	Physical (difficult	
functioning		(Difficult in)	to)	
(problems with)				
Emotional	Emotional	Emotional	Emotion	
Social	Social interaction	social	social	
Participating in	Participating in	Participates in	Attending	
active play or	games or sport	rigorous play or	physical activity	
exercise	activities	exercises	or sports	
Feeling afraid or	Feeling frightened	Feels afraid or	Feel frighten or	
scared	or scared	startles	scare	
Other kids not	Other kids were	Other children not	Other children	
wanting to play	not willing to play	willing to be	refuse to play	
with him or her	with him/her	his/her friends	with him/her	
Missing school/	Absence from	Absent from	Absence from	
daycare because	school because	classes due to	class due to sick	
of not feeling well	he/she was sick	sickness		

Therefore, the First Chinese PedsQL was adopted for conducting content validity.

# Step 2. Content Validity

Content validity may be examined by soliciting the views of an expert panel and revising it in order to make sure the content of the instrument is valid for measure the target construct (Portney & Watkins, 2000). This can also improve the grammatical and wording usage so that the questionnaire can be understood effectively. An alternate and yet better method for a questionnaire is that administrating the instrument to small sample of the target population (Varni, 1998). This step involved conducting the Chinese version to small groups of parents with children by cognitive interview and then by respondent debriefing techniques.

Cognitive interviewing technique is a method to improve the quality of data collected by questionnaire. By understanding the thinking process employed by the respondents in answering survey questions, better questionnaire can be constructed and formulated. It can be done using a number of techniques during the questionnaire interviews. These are concurrent thinkaloud, probing questions, paraphrasing and confidence ratings (Schwarz & Sudman, 1996). Concurrent thinkaloud interviewing refers to one to one interviews in which respondents are instructed to describe what they think when they answer the questionnaire. Interviewer will guide them to do so by reminding them to "tell me what you are thinking" or "say more about that". By this process, difficulties of comprehension or misunderstanding of questions can be identified. Probing questions can be

asked when information provided by respondents during thinkaloud is incomplete in order to know how the terms or questions are interpreted. Respondents can be asked to repeat the question items by their own words that are paraphrasing so that misinterpretation of the wording or better wording would be identified. After the interview, the respondent can be asked to rate their level of confidence in answering the questions. All these techniques can be incorporated in a protocol supplement to the target instrument when it is administered in this stage.

Respondent debriefing technique is similar to the above technique (Schwarz & Sudman, 1996; Campanelli, et al, 1991). It is conducted during field test by asking follow up question after the questionnaire interview is finished. The purpose of the follow up questions is to determine whether the sentences in questionnaire are fully understood. We can also identify the reasons of misunderstanding. Redundant or irrelevant sentences or necessity of additional questions will be discovered. Open-ended or closed-end debriefing questions can be asked.

# Step 2a Cognitive Interviewing Technique

#### Participants

Ten pairs of parent-child (five in age 2 to 4 and five in age 5 to 7) were interviewed in out-patient clinic in a children hospital in Shenzhen using cognitive interviewing technique.

# Instruments

- a) The First Chinese PedsQL (Appendix 4)
- b) Cognitive interviewing technique protocol
  - 1. In the beginning of each interview, the respondent was asked to "tell me what you think when you answer the questions" (thinkaloud technique)
  - 2. After reading the instruction, the respondent was asked "Do you understand the above instruction?"
  - Probing questions as Table 3.3 were asked incorporate to questions in instrument.

Table 3.3 Probing questions for some question items

Question item	Probe
提舉較重之物	如哪些東西
曾有受傷或疼痛	在哪裡
擔憂	如什麼事
不能做別的同年齡孩子所能做的事情	有哪些
從事其他朋輩也進行的學校活動	你知朋輩的意思嗎
步行超過一個路口的距離	有多遠
精力不足	如何不足
擔心將會發生在他/她身上的事情	如有什麼事
忘記東西	如什麼事情
體能活動或運動對你來說是否困難	如有哪些運動
提起一些大物件對你來說是否困難	如什麼東西
你有沒有曾覺得累到不想玩	什麼時候
你有沒有擔心將會發生在你身上的事	擔心什麼事
別的孩子是不是能做一些你辦不到的事	如什麼事

4. After the interviews, the respondents were asked to rate their confidence

level of each subscales in percentage.

### Procedure

The instrument was administered with the cognitive interviewing protocol as described above. Each questionnaire was conducted by one-to-one interview. The questions were read out by the interviewer to the parents or children and let the parents saw the questionnaire. Probing questions were asked depending on the answers of the parents or children in order to know what they think about the items in the questionnaire and how they choose their response. After each interview, the respondents were asked by the interviewer to rate their confidence level in answering the questions.

## **Results and Discussion**

Eight out of ten parents reported more than 90% confidence. (Table 3.4) The average confidence level is 93.0 %. The confidence rating of children were not showed as they did not understand the concept of percentage. However, one child of 6.4 years old reported high confidence level in physical functioning and moderate level in social function. For the emotional and school functioning, she only gave a smile instead of answer. Other children did not report the confidence rating.

The respondents answered the probing questions quite appropriately indicated that they really understand and interpreted the questions as they should be. For example, when probing question "what are you worrying about?" asked for the child, one child said "examination in school" another child said "mother and father

divorce". They both chose the 'sometimes' response for that item 'Do you worry about what will happen to you?' Another example, one parent did not answer the school functioning subscale because her kid did not go to school that month, indicated that she recalled the time period (in past one month) of the instruction. However, no one respondent had reported what he/she thought during the interviews (thinkaloud). Instead, one parent paraphrased the terms sad, blue, and angry in Chinese with appropriate words. However, as some children did not know how to "snap the finger" (彈指發出聲音 in Chinese), it might be a cultural difference, "jump on one leg for two times" (單腳跳兩次 in Chinese) was used for substitution in Instruction part of child self-report in ages 5 to 7.

Subject	no.	(age	Physical	Emotional	Social	Schooling	average
range)							
1 (5-7)			90	70	90	90	85
2 (2-4)			90	90	90	NA	90
3 (2-4)			90	90	90	90	90
4 (2-4)			80	90	100	NA	90
5 (2-4)			99	99	99	99	99
6 (2-4)			80	90	90	NA	86.7
7 (5-7)			90	100	99	99	97
8 (5-7)			100	100	100	100	100
9 (5-7)			100	100	100	100	100
10 (5-7)			100	90	90	90	92.5
Average							93.0

Table 3.4. Confidence rating (%) in cognitive interview of parents

NA=Not Applicable as the child did not go to school or daycare center

No one reported difficulty in understanding the questions when they were asked. Instead, the interviewer found that during the interviews some wordings in the questionnaire could be changed as more verbally and comprehensible to produce Second Chinese PedsQL (Appendix 8). The revision shows in Table 3.5.

First Chinese PedsQL	Second Chinese PedsQL
	可能會有些困難
在每個事項的 <b>困難程度</b>	每件事情有 <b>多少困難</b>
從不	從來沒有
幾乎從不	幾乎沒有
有時	偶爾有
經常是	經常有
幾乎總是	一直有
困難於	困難在於
激烈的	活躍的
提舉較重之物	提起較重的東西
感覺憤怒	感到生氣
被別的孩子戲弄	被其他孩子作弄
不能做別的同年齡孩子所能做的事情	其他同年齡孩子能做的事情,他不能做
因爲感到不適而缺課/席	因爲身體不舒服而缺課/席
忘記東西	忘記事情
可能有多難	有多少困難
彈指發出聲音	單腳跳兩次
步行對你來說是否困難	步行對你有困難嗎
憂傷	傷心
憤怒	生氣
你有沒有擔心將會發生在你身上的事	你有沒有擔心會有事發生在你身上
別的孩子有沒有說不願意與你一同玩耍	其他孩子有沒有說不想跟你一起玩

Table 3.5 Items modified from First to Second version

Step 2b Respondent Debriefing Technique

# **Participants**

Twenty pairs of parent-child (ten in each age group 2 to 4 & 5 to 7) from the same hospital were involved in the respondent debriefing interview.

#### Instruments

- a) The Second Chinese PedsQL revised from Test 1. (Appendix 8)
- b) Debriefing interviewing protocol.

After each interview, the respondents were asked "What is your comment about the content of this questionnaire? Is there any wording can be improved?" (你對這份問卷有什麼意見?有什麼字詞可以改善?)

# Procedure

This process involved Respondent Debriefing techniques in administration of the instrument. After an introduction of the purpose of the research and instruction of the questionnaire, the parents were asked to complete the questionnaire by themselves or have the questions read to them. For the children aged 5 to 7 years, the instrument was administered by reading the instructions and each item to the young child word by word. After each respondent has completed the report, the interviewer had asked the respondent if there is any problem in understanding and answering each question. And they were asked the debriefing question as above.

### Result and Discussion

These are some of their responses. One parent (no.13) of a 2 to 4 year child hesitated in answering 'helping to pick up his or her toys' because she was not sure if the problem means "problem of function of the child's hands" or "the child does not want to pick up". Besides, she forgot the one-month time interval in answering the no. 3 question in school functioning. She changed her answer after reminding by the interviewer.

During the interview, the interviewer should emphasize the time interval (during the past ONE month) before each session. Each response choice should add " $\mathbb{M}$   $\mathbb{H}$ " (problem) to emphasize the words "never, almost never, sometimes, often, almost always" refer to the frequency or quantity of **problem or difficulty** in performing the task, rather than the frequency or ability of completing the task itself. Because some sentences in the questions possess a positive ability itself (like "Playing with other children") but some questions have negative meaning (like "Getting teased by other children"). This may lead to misinterpretation if the respondents neglect the words "problem with …" in the beginning of each session. And this is not a matter of translation of culture.

The instrument was revised again to produce the Third Chinese PedsQL (Appendix 9) and was sent to PedsQL Project Team in San Diego for final review and approval for other step of validation.

Second Chinese PedsQL	Third Chinese PedsQL
從來不是	完全不是
較重的	一些重的
從來沒有	完全沒有困難
幾乎沒有	幾乎沒有困難
偶爾有	偶爾有困難
經常有	經常有困難
一直有	一直有困難
悲哀	傷心
憂傷	沮喪
微笑圖樣	笑臉
圖樣	臉
表情	圖
對你是否困難	對你是不是很難
完全沒有	完全沒有困難
有時有	有時有困難
有很多	有很多困難
表情	回應圖
對你有困難嗎	對你難不難

Table 3.6 Items modified from Second to Third Chinese version

# Step 3. Examination of reliability and other validity

This field test phase is to establish the reliability and validity of the translated instrument, i.e. to examine if the translated instrument can get data which is consistent, reproducible, and accurate. This was done by administration of the Third Chinese PedsQL to the target population and then analysis the obtained data by specific statistical methods.

# **Participants**

A. For internal consistency and other validities

Children were recruited in three kindergartens and one special school in Taiwan.

There are 42 children in ages 2 to 4. Their reports were answered by their parents. In ages 5 to 7, there are 45 children and 37 parents with 26 of them are paired parent-child that both parents and children had answered the questionnaires. There were 6 children with disabilities in each age range. Totally there are 45 child-reports and 79 parent-reports. (Table 3.7)

### Table 3.7 Number of reports obtained in each age range

Child-report	Parent-report	
	42	6 were special children
45	37	6 were special children,
		26 were available in both reports
45	79	124
	Child-report 45 45	Child-reportParent-report42374579

# B. For test-retest reliability

Eighteen children with disabilities of aged 2 to 6 were recruited from Special

Child Care Centres of Heep Hong Society in Hong Kong.

# Instrument

The Third Chinese PedsQL.

## Procedure

All parent proxy-reports were self-administered by the parents in 2 to 4 and 5 to 7 age range. All child-reports in 5 to 7 age range were completed by reading out the questions in the scale to the children by their teachers in one to one interviews. The children then chose their answers by pointing out the chosen template attached in the questionnaire. Test-retest reliability was administered for another 18 children between 1 to 2 weeks.

#### Data analysis

All item raw scores '0, 1, 2, 3, 4' were transformed to scale scores '100, 75, 50, 25, 0'. Higher scores indicate better HRQOL. The four subscale (physical, emotional, social, school functioning) scores were obtained by summing the scores of relevant items and divided by the number of items in that subscale. The psychosocial health summary score was computed by summing the scores over the items in the emotional, social and school functional subscales. The physical health summary score was the physical functioning subscale score. The total score was the average score of all the items; hence all the scores ranged from 0 to 100.

Data were analyzed using Statistical Package for the Social Sciences (SPSS) V11.5 for Window. The data were run in three sets: 42 proxy-reports of age 2 to 4, 37 proxy-reports of age 5 to 7 and 45 children's self-reports of age 5 to 7. The data were analyzed in item level, subscale level and total score level as indicated in PedsQL Translation Methodology (Varni, 1998).

Internal consistency of the scales was estimated by Cronbach's alpha. Alpha values ranging from 0.7 to 0.9 were considered showing strong internal consistency of the scale and moderate correlation among the items (Portney & Watkins, 2000). In this study, alpha >0.70 was adopted for establishing the

internal consistency reliability as compared to reliability study of the original version (Varni et al, 2001). On the other hand, corrected item-total correlation greater than 0.40 was suggested as the items were appropriately correlated to the subscale or the whole instrument.

Test-retest reliability was assessed using Intra-Class Correlation Coefficient (ICC) for subscale and total scores. Many studies considered ICC>0.7 as high correlation (Lo, 2001), and this rule was adopted in the present study.

As the questionnaires were self-administered by the participants with no rater involved, the assessment of inter-rater reliability was not necessary.

Construct validity was established by known-groups comparison method. Differences in scores were compared between groups of healthy children and children with disabilities for each gender using Mann-Whitney Test. Difference of scores in ages groups were test by Kruskal Wallis Test. Although the overall level of significance was set to 0.05, individual alpha levels were adjusted for using the Sharpened Bonferroni method when multiple testings were performed (Benjamini and Hochberg, 1995).

Correlation between parent proxy-report and child self-report of age 5 to 7 was examined by Spearman test for item-level score and by Pearson test for subscale and total scores Correlation coefficient (r) ranging from 0.00 to 0.25

indicate little or no relationship; fair for 0.25 to 0.50; moderate to good for 0.50 to 0.75; and good to excellent for values above 0.75 (Portney & Watkin, 2000).

#### Result

Strong internal consistency was observed in all the three reports (Table 3.8), with alpha values ranging from 0.709-0.896 in subscales and 0.928 in total score of age 2 to 4 parent-proxy reports; and 0.752 - 0.919 in subscales and 0.945 in total score of parent-proxy reports in ages 5 to 7. For child-self reports of ages 5 to 7, alpha coefficients were 0.862 for total score, 0.713 to 0.824 for physical, psychosocial and social functioning subscales, whereas alpha for emotional and school functioning were 0.617 and 0.551, respectively.

The corrected item-subscale correlations were good in proxy-reports of age 2 to 4 and 5 to 7 (Table 3.8), with only one item in each report (trouble sleeping and missing school because of not feeling well, respectively) lower than 0.4. However, eight out of twenty-three items in self-reports of age 5 to 7 were poor (corrected item-subscale correlation < 0.4) (Table 3.8).

The test-retest reliability was generally high. ICC was 0.788 for the total score; 0.805 and 0.769 respectively for the physical and emotional subscales; and 0.683 and 0.617 respectively for the social and school functioning (Table 3.9). The healthy group and the disable group were significantly different in total scores and all subscale scores except physical functioning in the age 2 to 4

(p=0.332) and age 5 to 7 child-report (p=0.26) (see Table 3.10). All p values for comparison of gender groups (Table 3.11) and age groups (Table 3.12) were non-significant, indicating no differences in scores between boys and girls and among different age groups.

Good correlations between parent proxy-report and child self-report, as well as between the total score and physical functioning were observed (all r>0.75, p=0.000). Subscales of psychosocial health, social functioning and school functioning had moderate to good correlation (r=0.660 to 0.673, p=0.000). Correlation was fair in emotional functioning (r=0.315, p=0.79) (Table 3.13).

Scales/items	Nun	nber of it	ems		Alpha		Correct	ted item-s correlatior	ubscale า	Cor	rected iter correlatio	n-total n
Age range	2-4pa	5-7pa	5-7ch	2-4pa	5-7pa	5-7ch	2-4pa	5-7pa	5-7ch	2-4pa	5-7pa	5-7ch
Total Score	21	23	23	.928	.945	.862						
Physical Functioning	8	8	8	.896	.896	.753						
Walking							.808	.733	.475	.802	.679	.506
Running							.829	.707	.571	.793	.648	.542
Sport activity or exercise							.804	.766	.484	.752	.638	.312
Lift heavy							.712	.737	.507	.654	.724	.346
Bath							.515	.503	.446	.473	.535	.539
Doing chores							.570	.712	.491	.527	.713	.498
Hurt or ache							.561	.756	.282	.550	.725	.425
Low energy level							.659	.618	.395	.631	.641	.310
Psychosocial Health Summary	13	15	15	.888	.919	.824						
Emotional Functioning	5	5	5	.709	.790	.617						
Feel afraid or scared							.484	.588	.509	.454	.641	.549
Feel sad or blue							.514	.699	.450	.334	.522	.421
Feel angry							.654	.640	.573	.523	.453	.551
Trouble sleeping							.265	.431	031	.311	.478	.015
Worrying							.434	.504	.439	.460	.631	.410
Social Functioning	5	5	5	.883	.887	.713						
Get along with other kids							.749	.689	.355	.735	.713	.653
Other kids not be friends							.633	.795	.536	.639	.710	.424
Get teased by others kids							.726	.702	.609	.724	.682	.494
Do things other peers do							.809	.726	.475	.799	.830	.455
Keep up with others							.705	.734	.393	.756	.786	.583
School Functioning	3	5	5	.710	.752	.551						
Pay attention in class							а	.550	.448	а	.556	.399
Forgetting things							а	.663	.445	а	.681	.546
Keep up with schoolwork							.407	.653	.361	.762	.846	.553
Miss school-not well							.727	.271	.133	.505	.302	.111
Miss school-see doctor							.482	.458	.183	.319	.503	.298

# Table 3.8 Internal Consistency Reliability of the Three Reports

a= Items are not included in report for ages 2 to 4, ch= child self-report, pa= parent proxy-report

Scales	n	Test 1	Test 2	ICC	95%	o C.I.
		Mean (SD)	Mean (SD)		Lower	Upper
Total Score	17	64.99 (9.31)	65.83 (9.18)	.79	.513	.917
Physical Functioning	17	64.24 (16.92)	64.34 (18.59)	.81	.543	.924
Psychosocial Health	17	65.54 (10.54)	66.81 (10.57)	.67	.300	.869
Emotional Functioning	17	73.61 (16.07)	72.06 (14.15)	.77	.472	.909
Social Functioning	17	55.83 (17.93)	59.41 (16.00)	.68	.331	.870
School Functioning	17	67.59 (15.57)	70.20 (16.05)	.62	.202	.842

Table 3.9. Mean, SD and ICC Results of Test-Retest Reliability of Chinese PedsQL

Table 3.10 Mean, SD and Differences Between Healthy and Disabled Children of the Three Reports

Reports		2-4 parent proxy-report 5-7 parent proxy-report					5-7 child self-report					
	Mea	an (SD)			Mea	n (SD)			Mea	an (SD)		
Scales/Items	Healthy (n=36)	Disabled (n=6)	_ 0	р	Healthy(n=31)	Disabled(n=6)	U	р	Healthy (n=39)	Disabled (n=6)	- 0	р
Total Score	78.80 (9.70)	52.38 (25.63)	35.50	.007 **	75.84 (11.84)	49.46 (17.88)	14.00	.000 **	75.19 (13.75)	47.83 (18.34)	25.50	.001 **
Physical Functioning	81.25 (11.60)	54.69 (42.05)	80.50	.332	81.05 (12.96)	53.65 (27.34)	26.00	.004 **	75.96 (17.82)	50.00 (30.10)	51.00	.026
Walking	97.22 (7.97)	50.00 (54.77)	60.00	.088	95.16 (13.57)	70.83 (40.05)	56.50	.135	98.72 (08.01)	58.33 (49.16)	60.50	.058
Running	95.83 (9.45)	50.00 (54.77)	63.00	.111	96.77 (10.69)	62.50 (41.08)	38.00	.022 **	89.74 (26.11)	58.33 (49.16)	73.50	.150
Active exercise	87.50 (16.37)	41.67 (49.16)	52.50	.044	93.55 (12.86)	62.50 (41.08)	46.00	.054	78.21 (35.90)	41.67 (37.64)	56.00	.041
Lift something heavy	77.08 (22.66)	50.00 (47.43)	74.50	.235	78.23 (22.12)	54.17 (33.23)	52.50	.096	50.00 (42.92)	41.67 (37.64)	104.5	.684
Bathing	68.06 (29.04)	62.50 (37.91)	100.50	.793	60.48 (31.47)	29.17 (18.82)	38.50	.022 **	67.95 (42.13)	41.67 (37.64)	74.00	.160
Help to pick up toys	70.14 (25.23)	66.67 (40.83)	107.00	.986	73.39 (22.30)	41.67 (30.28)	38.50	.022 **	87.18 (31.87)	41.67 (37.64)	41.50	.009 **
Hurts or aches	73.61 (21.50)	58.33 (34.16)	82.00	.369	68.55 (21.38)	41.67 (25.82)	40.50	.028 **	73.08 (30.01)	58.33 (37.64)	90.50	.386
Low energy level	80.56 (19.00)	58.33 (40.83)	74.50	.235	82.26 (19.57)	66.67 (25.82)	59.50	.172	62.82 (37.55)	58.33 (20.41)	103.0	.660
Psychosocial Health Summary	77.30 (10.90)	50.67 (17.94)	21.00	.001 **	73.06 (13.12)	47.22 (13.44)	12.00	.000 **	74.79 (15.56)	46.67 (13.98)	23.00	.001 **
Emotional Functioning	72.36 (14.66)	54.17 (15.94)	41.00	.014 **	68.39 (16.30)	51.67 (12.91)	40.00	.028 **	71.28 (20.67)	46.67 (17.51)	43.00	.011 **
Feel afraid or scared	66.67 (23.91)	54.17 (29.23)	78.00	.297	66.13 (24.62)	41.67 (12.91)	41.00	.031	71.79 (35.90)	50.00 (00.00)	66.00	.092
Feel sad or blue	68.06 (23.61)	66.67 (20.41)	101.00	.820	64.52 (23.07)	58.33 (12.91)	79.00	.587	69.23 (33.67)	50.00 (00.00)	72.00	.140
Feel angry	59.72 (23.36)	37.50 (26.22)	59.00	.081	59.68 (22.98)	45.83 (18.82)	63.00	.231	65.38 (36.55)	25.00 (27.39)	49.50	.021
Trouble sleeping	83.33 (18.90)	58.33 (37.64)	63.00	.111	78.23 (22.12)	54.17 (18.82)	38.00	.022 **	76.92 (34.12)	50.00 (31.62)	64.50	.079
Worrying	84.03 (15.98)	54.17 (33.23)	46.00	.024	73.39 (21.35)	58.33 (20.41)	61.50	.200	73.08 (34.12)	58.33 (37.64)	89.50	.368
Social Functioning	82.64 (13.44)	46.67 (24.83)	21.00	.001 **	78.71 (14.43)	49.17 (22.45)	21.50	.002 **	76.15 (19.28)	45.00 (26.65)	36.00	.005 **
Play with others	79.86 (19.66)	45.83 (33.23)	40.00	.012 **	76.61 (21.35)	58.33 (30.28)	59.00	.172	87.18 (29.73)	33.33 (25.82)	23.00	.001 **
Other kids not want to play	77.78 (19.62)	62.50 (34.46)	80.50	.332	72.58 (18.66)	54.17 (29.23)	54.50	.114	71.79 (32.03)	58.33 (37.64)	92.50	.423
Getting teased	80.56 (17.02)	54.17 (18.82)	35.50	.007 **	75.81 (18.80)	50.00 (22.36)	38.00	.022 **	70.51 (31.87)	50.00 (31.62)	77.00	.192
Do things like others	84.72 (19.16)	37.50 (34.46)	24.00	.001 **	83.87 (18.87)	41.67 (25.82)	17.50	.001 **	66.67 (31.06)	41.67 (37.64)	73.00	.150
Keep up with others	90.28 (13.73)	33.33 (25.82)	2.00	.000 **	84.68 (15.38)	41.67 (25.82)	12.50	.000 **	84.62 (30.68)	41.67 (37.64)	45.00	.014 **
School Functioning	76.62 (14.34)	48.33 (17.08)	19.00	.002 **	72.10 (13.95)	40.83 (9.17)	1.50	.000 **	76.92 (17.34)	48.33 (14.72)	25.00	.001 **
Pay attention in class	а	а	а	а	65.32 (22.06)	25.00 (22.36)	20.00	.001 **	73.08 (32.13)	25.00 (27.39)	36.00	.005 **
Forgetting things	а	а	а	а	67.74 (20.61)	12.50 (13.69)	1.50	.000 **	67.95 (33.42)	33.33 (40.83)	61.00	.063
Keep up activities	86.11 (17.37)	45.00 (27.39)	16.00	.001 **	82.26 (17.31)	37.50 (34.46)	24.00	.003 **	85.90 (27.98)	50.00 (44.72)	61.00	.063
Miss school-not well	70.83 (20.27)	50.00 (17.68)	43.50	.063	72.58 (20.77)	66.67 (20.41)	76.50	.506	76.92 (30.01)	83.33 (25.82)	106.0	.732
Miss school-see doctor	72.92 (20.16)	50.00 (17.68)	39.00	.042	72.58 (20.77)	62.50 (26.22)	71.50	.385	80.77 (24.64)	50.00 (44.72)	69.00	.114

U=Mann Whitney U value a=items not available in report of ages 2 to 4 \*\* p values significant after adjustment

Reports	2-	4 parent proxy-rep	ort		5-	7 parent proxy-rep	oort		5-7 child self-report			
Scales/Items	Mea	n (SD)			Mea	n (SD)			Mea	n (SD)		
	Male (n=24)	Female (n=18)	U	р	Male (n=20)	Female (n=17)	0	р	Male (n=23)	Female (n=22)	U	р
Total Score	72.02 (17.18)	79.03 (12.99)	155.00	.121	71.73 (12.93)	71.35(19.56)	163.50	.845	75.33 (14.29)	67.59 (19.01)	180.50	.099
Physical Functioning	74.61 (23.13)	81.25 (16.11)	171.00	.251	78.75 (14.64)	74.08 (22.74)	150.50	.557	79.89 (14.83)	64.77 (24.59)	152.00	.021
Walking	88.54 (28.53)	93.06 (23.95)	195.50	.422	95.00 (15.39)	86.76(26.68)	139.00	.357	95.65 (20.85)	90.91 (25.05)	230.50	.301
Running	87.50 (28.55)	91.67 (24.25)	198.00	.523	92.50 (20.03)	89.71(25.09)	157.00	.707	93.48 (22.89)	77.27 (36.93)	195.00	.059
Active play or exercise	77.08 (30.32)	86.11 (24.58)	179.00	.297	93.75(17.90)	82.35 (26.16)	116.50	.104	82.61 (32.36)	63.64 (41.35)	188.50	.090
Lift something heavy	70.83 (29.18)	76.39 (27.74)	189.00	.470	75.00 (22.94)	73.53 (28.60)	168.00	.964	56.52 (40.74)	40.91 (42.64)	201.00	.210
Bathing	61.46 (33.76)	75.00 (22.68)	169.50	.220	55.00 (32.03)	55.88 (32.51)	166.00	.916	80.43 (32.82)	47.73 (44.93)	151.50	.011
Help to pick up toys	68.75 (27.82)	70.83 (27.45)	209.50	.862	72.50 (22.79)	63.24 (29.47)	139.50	.357	89.13 (25.92)	72.73 (42.89)	210.00	.194
Hurts or aches	64.58 (24.35)	80.56 (20.21)	136.00	.031	67.50 (20.03)	60.29 (28.03)	146.00	.478	69.57 (29.15)	72.73 (33.55)	233.00	.611
Low energy level	78.12 (25.86)	76.39 (21.81)	196.00	.588	78.75 (18.62)	80.88 (24.25)	151.50	.577	71.74 (29.49)	52.27 (39.27)	184.00	.088
Psychosocial Health Summary	70.36 (16.03)	77.67 (13.16)	168.00	.222	68.00 (13.80)	69.90 (18.98)	147.50	.497	72.90 (17.04)	69.09 (19.19)	224.00	.508
Emotional Functioning	68.13 (14.87)	71.94 (17.58)	196.00	.608	62.00 (16.25)	70.00 (16.95)	115.00	.097	72.17 (18.82)	63.64 (24.21)	202.50	.247
Feel afraid or scared	65.63 (24.24)	63.89 (26.04)	207.50	.822	60.00 (23.50)	64.71 (26.60)	155.50	.662	76.09 (29.66)	61.36 (37.58)	200.00	.183
Feel sad or blue	67.71 (20.16)	68.06 (26.85)	208.50	.841	56.25 (21.26)	72.06 (19.53)	101.00	.036	67.39 (32.36)	65.91 (32.32)	246.50	.870
Feel angry	53.13 (24.79)	61.11 (24.58)	180.50	.344	52.50 (22.79)	63.24 (21.86)	117.00	.110	67.39 (35.70)	52.27 (39.27)	199.00	.187
Trouble sleeping	77.08 (25.44)	83.33 (21.00)	187.00	.427	70.00 (25.13)	79.41 (20.22)	136.50	.311	71.74 (39.39)	75.00 (29.88)	252.50	.990
Worrying	77.08 (25.44)	83.33 (14.85)	197.50	.604	71.25 (20.31)	70.59 (23.77)	169.00	.988	78.26 (33.12)	63.64 (35.13)	192.50	.125
Social Functioning	72.50 (21.41)	84.17 (15.55)	139.50	.050	75.25 (16.01)	72.35 (22.64)	160.00	.775	73.48 (18.73)	70.45 (26.63)	252.50	.991
Play with other children	68.75 (27.82)	83.33 (17.15)	152.00	.085	71.25 (21.87)	76.47 (25.72)	143.00	.424	89.13 (25.92)	70.45 (39.82)	190.00	.072
Other kids not play with	67.71 (23.86)	86.11 (15.39)	120.50	.010	70.00 (19.19)	69.12 (24.25)	168.00	.964	67.39 (32.36)	72.73 (33.55)	228.00	.528
Getting teased	73.96 (20.16)	80.56 (18.30)	178.50	.303	73.75 (18.97)	69.12 (24.25)	155.50	.662	65.22 (27.94)	70.45 (36.71)	220.50	.412
Doing things other peers do	73.96 (30.82)	83.33 (21.00)	184.00	.381	77.50 (24.19)	76.47 (27.20)	170.00	1.00	56.52 (34.72)	70.45 (29.52)	199.00	.174
Keep up with others	78.12 (25.86)	87.50 (24.63)	162.00	.128	83.75 (14.67)	70.59 (29.62)	130.50	.232	89.13 (25.92)	68.18 (39.48)	179.00	.039
School Functioning	70.65 (17.38)	76.39 (16.97)	163.00	.242	66.75 (14.26)	67.35 (21.36)	167.00	.940	73.04 (20.77)	73.18 (18.62)	243.00	.817
Pay attention in class	а	а	а	а	52.50 (22.79)	66.18 (29.23)	121.50	.141	58.70 (38.88)	75.00 (29.88)	196.00	.156
Forgetting things	а	а	а	а	57.50 (23.08)	60.29 (34.30)	157.50	.707	60.87 (36.79)	65.91 (35.81)	234.00	.639
Keep up with activities	79.35 (24.60)	83.33 (21.00)	190.00	.628	77.50 (21.30)	72.06 (31.72)	163.50	.845	89.13 (25.92)	72.73 (36.93)	192.00	.081
Miss school-not well	68.48 (21.60)	68.06 (20.66)	202.00	.888	73.75 (20.63)	69.12 (20.78)	144.00	.442	76.09 (29.66)	79.55 (29.52)	236.00	.653
Miss school-see doctor	64.13 (18.19)	77.78 (22.50)	128.50	.029	72.50 (19.70)	69.12 (24.25)	153.50	.619	80.43 (24.95)	72.73 (33.55)	228.00	.513

Table 3.11. Mean, SD and Mann-Whitney Test of Gender Difference of the Three Reports.

a= items not available in report for age 2 to 4 All p values are not significant.

		2-4 parent proxy-report 5-7 parent proxy-report								5-7 child self-	report	
Scales/items	Mean (SD)		р		Mean (SD)		р	Mean (SD)			р	
	2 (n=7)	3 (n=22)	4 (n=11)		4 (n=9)	5 (n=21)	6 (n=7)		4 (n=9)	5 (n=28)	6 (n=8)	_
Total Score	73.30 (19.83)	74.02 (17.09)	79.00 (10.45)	.924	69.08 (13.95)	74.33 (13.11)	66.46 (25.54)	.563	76.81 (12.49)	71.27 (17.08)	66.58 (21.33)	.640
Physical Functioning	68.30 (24.56)	77.31 (22.65)	81.53 (9.92)	.333	76.39 (15.71)	77.53 (13.57)	74.11 (33.74)	.716	75.00 (17.12)	71.21 (20.86)	74.22 (29.02)	.711
Walk one block	82.14 (37.40)	90.22 (28.93)	95.45 (10.11)	.649	91.67 (17.67)	94.05 (15.62)	82.14 (37.40)	.670	100.00 (0.00)	92.86 (22.42)	87.50 (35.36)	.572
Running	78.57 (36.59)	89.13 (29.02)	95.45 (10.11)	.354	94.44 (16.66)	92.86 (17.92)	82.14 (37.40)	.667	88.89 (33.33)	83.93 (30.59)	87.50 (35.36)	.671
Sport activity	71.43 (36.59)	79.35 (29.82)	88.64 (17.18)	.553	94.44 (11.02)	86.90 (20.33)	85.71 (37.79)	.505	66.67 (43.30)	75.00 (37.27)	75.00 (37.80)	.862
Lift heavy	64.29 (34.93)	70.65 (28.85)	81.82 (22.61)	.419	75.00 (21.65)	76.19 (23.01)	67.86 (37.40)	.943	44.44 (46.40)	44.64 (41.59)	68.75 (37.20)	.334
Bathing	53.57 (30.37)	73.91 (31.51)	59.09 (23.11)	.082	44.44 (34.86)	55.95 (26.10)	67.86 (42.60)	.348	83.33 (25.00)	57.14 (44.54)	68.75 (45.81)	.304
Doing chores	60.71 (28.34)	69.57 (27.13)	72.73 (28.40)	.584	66.67 (17.67)	67.86 (23.90)	71.43 (41.90)	.575	88.89 (33.33)	82.14 (33.92)	68.75 (45.81)	.468
Hurts or aches	64.29 (19.67)	71.74 (25.34)	72.73 (23.59)	.620	63.89 (22.04)	64.29 (21.75)	64.29 (34.93)	.948	66.67 (35.36)	73.21 (28.81)	68.75 (37.20)	.896
Low energy level	71.43 (26.72)	73.91 (25.53)	86.36 (17.18)	.308	80.56 (20.83)	82.14 (17.92)	71.43 (30.37)	.737	61.11 (41.67)	60.71 (36.91)	68.75 (25.88)	.912
Psychosocial Health	76.37 (18.23)	71.92 (15.09)	77.45 (11.70)	.543	65.19 (14.35)	72.62 (14.55)	62.38 (21.71)	.241	77.78 (13.84)	71.31 (18.53)	62.50 (18.84)	.270
Emotional Functioning	74.29 (15.66)	68.70 (16.25)	71.82 (14.53)	.594	61.67 (18.71)	69.52 (15.81)	59.29 (16.69)	.312	75.56 (24.04)	67.86 (22.34)	60.00 (16.04)	.273
Feel afraid or scared	71.43 (22.49)	58.70 (26.76)	70.45 (18.76)	.314	55.56 (24.29)	66.67 (24.15)	57.14 (27.81)	.479	72.22 (36.32)	69.64 (36.87)	62.50 (23.15)	.646
Feel sad or blue	71.43 (22.49)	66.30 (23.36)	65.91 (23.11)	.902	55.56 (24.29)	69.05 (20.77)	57.14 (18.89)	.260	77.78 (36.32)	64.29 (32.93)	62.50 (23.15)	.386
Feel angry	67.86 (27.81)	55.43 (23.78)	56.82 (19.65)	.513	55.56 (20.83)	60.71 (21.75)	50.00 (28.86)	.445	66.67 (35.36)	64.29 (35.64)	37.50 (44.32)	.224
Trouble sleeping	82.14 (12.19)	81.52 (21.60)	81.82 (22.61)	.954	69.44 (24.29)	79.76 (18.74)	64.29 (31.81)	.370	88.89 (22.05)	67.86 (36.55)	75.00 (37.80)	.289
Worrying	78.57 (22.49)	81.52 (17.21)	84.09 (16.85)	.858	72.22 (23.19)	71.43 (19.82)	67.86 (27.81)	.958	72.22 (36.32)	73.21 (34.65)	62.50 (35.36)	.678
Social Functioning	77.86 (24.47)	76.52 (20.80)	81.82 (14.01)	.902	70.56 (13.10)	77.38 (18.14)	67.86 (27.67)	.368	81.11 (13.64)	72.14 (22.83)	61.25 (28.00)	.284
Get along with other	71.43 (30.37)	71.74 (26.44)	86.36 (13.05)	.295	69.44 (20.83)	76.19 (23.01)	71.43 (30.37)	.710	83.33 (35.36)	82.14 (33.92)	68.75 (37.20)	.433
Others not be friends	75.00 (28.86)	75.00 (22.61)	79.55 (18.76)	.909	69.44 (16.66)	72.62 (23.59)	60.71 (19.67)	.512	88.89 (22.05)	69.64 (31.45)	50.00 (37.80)	.056
Get teased by others	75.00 (20.41)	76.09 (19.18)	81.82 (19.65)	.657	66.67 (17.67)	75.00 (22.36)	67.86 (23.78)	.497	72.22 (26.35)	69.64 (34.26)	56.25 (32.04)	.503
Do things like others	78.57 (36.59)	78.26 (26.44)	79.55 (24.54)	.893	72.22 (19.54)	83.33 (19.89)	64.29 (40.45)	.300	61.11 (41.67)	67.86 (31.07)	50.00 (26.73)	.355
Keep up with others	89.29 (19.67)	81.52 (29.40)	81.82 (19.65)	.642	75.00 (17.67)	79.76 (21.82)	75.00 (35.35)	.692	100.00 (0.00)	71.43 (37.09)	81.25 (37.20)	.062
School Functioning	77.38 (19.07)	69.70 (17.35)	79.55 (14.12)	.276	63.33 (16.58)	70.95 (15.46)	60.00 (23.80)	.348	76.67 (12.25)	73.93 (21.32)	66.25 (19.96)	.512
Pay attention	а	а	а	а	63.89 (18.16)	61.90 (28.08)	42.86 (27.81)	.261	72.22 (26.35)	64.29 (38.15)	68.75 (37.20)	.912
Forgetting things	а	а	а	а	55.56 (30.04)	65.48 (25.58)	42.86 (31.33)	.280	72.22 (26.35)	67.86 (36.55)	37.50 (35.36)	.089
Keep up activities	85.71 (19.67)	79.55 (26.31)	84.09 (16.85)	.898	75.00 (12.50)	77.38 (26.10)	67.86 (40.08)	.746	88.89 (33.33)	82.14 (31.07)	68.75 (37.20)	.280
Miss school-not well	78.57 (26.72)	62.50 (18.50)	75.00 (19.36)	.141	61.11 (22.04)	73.81 (20.11)	78.57 (17.25)	.215	72.22 (36.32)	76.79 (28.81)	87.50 (23.15)	.589
Miss school-doctor	67.86 (23.78)	67.05 (20.96)	79.55 (18.76)	.248	61.11 (22.04)	76.19 (18.50)	67.86 (27.81)	.223	77.78 (26.35)	78.57 (28.64)	68.75 (37.20)	.788

Table 3.12. Mean, SD and Kruskal Wallis Test of Age Difference in Three Reports

a= items not available in report of age 2 to 4. p= p value obtained by Kruskal Wallis test. All are not significant.

Scales/Items	Correlation	a
	Coefficient (r)	1-
Total Score	.78	.000
Physical Functioning	.77	.000
Walking	.58	.001
Running	.47	.007
Active play or exercise	.35	.053
Lift something heavy	.51	.003
Bathing	.48	.005
Help to pick up toys	.46	.008
Hurts or aches	.17	.352
Low energy level	.28	.128
Psychosocial Health Summary	.66	.000
Emotional Functioning	.32	.079
Feel afraid or scared	.41	.019
Feel sad or blue	.19	.297
Feel angry	.32	.079
Trouble sleeping	.38	.031
Worrying	.19	.308
Social Functioning	.67	.000
Play with other children	.33	.064
Other kids not wanting to play with	.46	.009
Getting teased	.07	.691
Doing things other peers do	.38	.031
Keep up when play with others	.56	.001
School Functioning	.66	.000
Pay attention in class	.56	.001
Forgetting things	.47	.006
Keeping up with school activities	.45	.010
Miss school-not well	.28	.117
Miss school-see doctor	.44	.013

Table 3.13. Correlation of Parent and Child Reports of Ages 5 to 7 (n=32).

Correlation coefficient and p values were obtained by Spearman test for items scores and by Pearson test for total, summary and subscale scores.

### DISCUSSION

Through the iterative procedures of translation process, the Chinese PedsQL acquired conceptual and structural equivalence to the original English version. Words and phrases were used carefully in repeat revision in order to make the questionnaire most interpretable and most exactly identical to the original meaning.

The internal consistency reliability is generally good indicating that the items in the instrument are homogenous and correlated to the intended measure construct. Test reliability is generally high. Lowest ICC in school functioning might due to actual change as the children with disabilities easily get sick that make them miss school.

The significant result in group comparison between healthy children and children with disabilities represented that this Chinese PedsQL do discriminate HRQOL in groups. As we assumed that children with disabilities would have low HRQOL. However, the insignificant p value in Physical functioning subscale may be due to the large difference of motor performance among the small sample of subjects. This can be observed by the high SD of disabled children (42.1 and 30.1). But the mean between two groups in this subscale still have difference.

The scores between boys and girls and among each ages showed no difference might concluded that the translated instrument do not has gender and age bias. It is its advantage that it can measure difference types of children in different ages and compare their HRQOL simultaneously.

The correlation between parent proxy-report and child self-report quite different among subscales. Physical functioning as can be observed most objectively, the correlation is the highest. Moderate are the subscales showing social function as they are less observable. The least correlated is the emotional subscale that is the most subjective. However, the overall high correlation coefficient in total score indicates that both reports are good correlated and representative mutually.

The psychometric properties established in this study were good and comparable to those of the original.

### SUMMARY

Three scales of the Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales (Varni, 1999) were translated into Chinese and their validities were examined in this study. This included the Parent Report for the 2 to 4 and 5 to 7 year groups and the Child Report for the 2 to 4 year group. A total 124 children and parents were involved in various stages of this process. Content validity and construct validity (age, gender and known group differentiation); internal consistency, test-retest reliability; and correlation between parents and children reports were examined. The results showed that the internal consistency is good (Cronbach's alpha of total score of the three scales are 0.862 to 0.945, alphas of subscales are >0.7 except emotional and school functioning of children reports in age 5 to7). Test-retest reliability ranged from moderate to good (ICC=0.617 to 0.805). Differences in QoL between the disabled and non-disabled group were significant in all the subscales and total scores in the three scales with the exception of the physical functioning subscales in 2 to 4 age group and children report of age 5 to 7. The correlation between parent and children reports of age 5 to 7 is moderate to high in all subscales and total scores (r=0.660 to 0.782) except emotional function subscale (r=0.315). There is no significant difference in age groups and gender groups. We conclude that The Chinese PedsQL in generic core modules of ages 2 to 4 and 5 to 7 are reliable and valid to be used as a measure of health-related quality of life in Chinese population as research and clinical applications.
# CHAPTER FOUR MAIN STUDY AN INVESTIGATION OF THE EFFECT OF FREE PLAY

## Introduction

The aim of this main part of the study was to investigate the effectiveness of free play on several developmental dimensions of children with disabilities. A play room was set up for children to play freely as intervention in regular time schedule, which was integrated into the daily program of the Special Child Care Centres (SCCC) that the children attended every day.

In general, in order to assess the efficacy of a treatment or an intervention on human subjects, the experiment should be conducted as randomized controlled trial (RCT) (Matthews, 1999). In RCT, recruited subjects are divided into two groups. The experimental group receives the treatment or intervention to be test of its effectiveness, the control group receives no treatment or the treatment or intervention which has been usually used. Besides, subjects are allocated randomly into these two groups in order to make the two groups comparable with one another. The structure of randomized controlled trial contains five key features: a population of eligible subject satisfies the entry criteria, a sample of subjects recruited from this population, at least two treatment

groups (one is control group), randomized allocation of subjects to treatment groups, comparison of outcomes of two groups after the intervention. Moreover, in order to eliminate the assessment bias in a trial if the patient and investigator know which treatment or intervention the subject is receiving, single- or double-blind trial should be conducted. In a single-blind study, the subject does not know which treatment is received. In a double-blind trial, neither assessor nor subject knows what treatment is being given.

In conducting clinical studies, much endeavor should be put on using randomized clinical trial method. However, the demands of very stringent control and random assignment are usually impractical or unethical in a naturalistic clinical setting. Quasi-experimental design therefore could be an alternative method to be used for clinical studies (Portney & Watkins, 2000). It is characterized by not adhering to a random assignment process and possibly without a comparison group. For example, patients cannot be blind in trials comparing surgical and non-surgical treatment. This situation is especially common in studies of behavior science. Sparling et al (1984) conducted a research without control group to study the effect of educational play as intervention on children's performance. In a study of effect of a developmental play program on self concept, risk-taking behaviors, and motoric proficiency of mildly handicapped children (Roswal et al, 1984), subjects were not randomly allocated and assessment was not blind. In another study to examine the effects of a three-component intervention on the social-communicative interactions of at risk preschool children (Craig-Unkefer & Kaiser,

2002), no control group was included.

In present study, subjects were recruited from two Special Child Care Centres (SCCC) of Heep Hong Society in Hong Kong. One center on Hong Kong Island, and one center in Kowloon. Hong Kong Island and Kowloon are two main districts in Hong Kong. The criteria for sampling were that the children at least could mobile (walk or crawl) with minimal support and without behavior problems. Children in SCCC were classed according to their type and level of special needs. As the program must be conducted for whole classes, random sampling was deemed not possible. As a result, two classes of children with similar features were recruited from each center. One class was designated as the intervention group, whilst the other one was the control group. Baseline variables and outcome measurement were collected and compared for two groups. To eliminate assessment bias, test-retest and inter-rater reliabilities were investigated.

In order to measure the 'effectiveness of the program' effectively, it is important to choose the measuring instruments carefully. One of them was PedsQL, which has already been described in Chapter 3. We will describe two other selected measuring scales— the Hong Kong Based Adaptive Behavior Scale (HKBABS) (Kwok et al, 1988) and Peabody Developmental Motor Scale-second edition (PDMS-2) (Folio & Fewell, 2000) --- in this chapter. The test-retest reliability of these instruments for using in the population under study was examined for both tools. As the PDMS-2 requires subjective

judgment, inter-rater consistency was also examined.

HKBABS was derived from Vineland Adaptive Behavior Scale (VABS) (Sparrow, et al 1984) that its previous version – the Vineland Social Maturity Scale (VSMS) (Doll, 1965) has been used by Hong Kong rehabilitation professionals for many years. (Kwok et al, 1988). VABS and its original scale VSMS is popular in international for special education service to provide information about student's adaptive behavior especially for mental retardation (Oakland & Houchins, 1985).

Adaptive behavior is a construct that describe the degree of which an individual meets the social standard of personal independence and social responsibility. (Grossman, 1983; cited in Horn & Fuchs,1987). It is a common concept assessment and treatment of individuals with mental retardation (Horn & Fuchs,1987) and can be also used for individuals with physical impairment (Pollingue, 1987).

Most children with developmental delay might have some sort of physical impairment`. In order to obtain a global assessment of the effect of play on developmental change to these children, gross motor performance was decided as a measuring trait too. Considering that the children in SCCC are all ages 2 to 6 and combined with a wide range of diagnosis, Peabody Developmental Motor Scales-second edition (PDMS-2) was adopted. It is age appropriate for the target population compared with other tests of gross motor development. It provides comprehensive evaluation of gross motor and fine

motor function and Motor Activities Program also available; it is commonly used in special child care setting by diverse professional in rehabilitation and special education.

## Methods

## **Participants**

Thirty-five children in ages 2 to 6 with a range of disabilities were recruited from two Special Child Care Centers (SCCC) of Heep Hong Society in Hong Kong. There were 18 children in experimental group and 17 children in control group. The Heep Hong Society provides early education and training service to children with special needs and support parents of special children with multiple services. Daily care, training and education are provided for children two to six years of age with physical or mental handicaps or behavioral problems in 11 SCCC. Due to administration problems, it was difficult to randomize children from different classes and allocated into two groups. Hence, entire classes (each class had about six children) had to be recruited. Classes that met the criteria were selected. The criteria were 1) the child could be able to mobile independently or with minimal support, 2) no severe behavior problem. As a result, two classes (12 children) in Center A were allocated in the intervention group, and two other classes (10 children) were allocated to the control group. Center B had one class (6 children) in intervention group and one other class (7 children) in control group. The classes selected were mild to moderate global delay in development. The classes only contain children with Autism were excluded as we hope that there would be a diversity

of diagnosis of the children. The characteristics of the studied subjects are shown in Table 4.1.

## Instruments

In order to measure the changes in different dimensions of the children development, three outcome measures were adopted.

	Intervention	Control	All
	group	group	participants
	(n=18)	(n=17)	(n=35)
Male	9	8	17
Female	9	9	18
Mean age (years)	4.42	4.08	4.26
Age range	2.33-5.83	2.75-6.08	2.33-6.08
Diagnosis:			
Developmental delay	Λ	Б	0
(unknown etiology)	4	5	9
Down's syndrome	3	4	7
Cerebral Palsy	2	1	3
Delay with Autistic features	2		2
Hypotonia with Lateral gaze deficit	1		1
Global delay with eyesight problem	1		1
Complex Cyanotic heart disease	1		1
Rubinstein-Taybi Syndrome	1		1
Spelslion Syndrome	1		1
Periventricular Leukomalacia	1	1	2
Cytomegalovirus infection	1		1
Tuberous Sclerosis		1	1
Intracerebral Haemorrhage		1	1
Meningitis		1	1
Epilepsy		1	1
Microcephalies		1	1
Delay with Spondylo-chondromatosis		1	1

Table 4.1 Characteristics of the Studied Subjects

## Pediatric Quality of Life Inventory (PedsQL 4.0) Generic Core Scale (Varni, 1998)

PedsQL is a measure of health-related quality of life outcome of children. It was developed in English in 1998 and was translated and validated into Chinese in this study (see the Chapter 3). This scale includes four modules for different age ranges: 2 to 4, 5 to 7, 8 to 12 and 13 to 18. Parent proxy-reports were developed parallel with child self-reports (for age 2 to 4, only parent report is available). It provides Generic Core Scale and Disease-specific Scale. In this study, only parent reports of ages 2 to 4 and 5 to 7 in Generic Core Scale were adopted as outcome measures of quality of life though child-report was also translated. It was because most children recruited in this main study could not understand the questionnaire effectively. Reliability in term of internal consistency and test-retest reliability is excellent and high respectively. Content validity has been conducted through cognitive interviewing and respondent debriefing techniques to refine the translation. Qualitative and quantitative result were obtained and showed satisfactory. Construct validity was established by known group comparison that showed different significantly. The psychometric properties of this translated instrument are acceptable for clinical use and research.

#### Hong Kong Based Adaptive Behavior Scale (HKBABS) (Kwok et al, 1988)

It was utilized to assess the social competence or adaptive behavior of the children. Its

scale items were adapted from the Vineland Adaptive Behavior Scale (Sparrow, 1984). It is usually used for assessment of behaviors about personal independence and social adaptive function at home, in school or vocational settings and in the community for those aged 3 to11. It can be used for individuals without disability but has often been administered to those with disability.

The scale consists of four domains and eleven sub-domains. The Communication Skills domain includes Receptive, Expressive and Written sub-domains with 78 items. Socialization Skills domain composes of three sub-domains as Interpersonal Relationship, Play and Leisure, Coping Skills with 68 items. Daily Living Skills domain includes sub-domains of Personal, Domestic and Community in 103 items. Motor Skills domain consists of Fine and Gross sub-domains in 41 items. The Scale has total 290 items.

Each item is scored as 2, 1, 0, N, DK. A score of 2 denotes the behavior of that item is performed habitually and satisfactorily, not only just 'can' do it. A score of 1 means the individual can do that activity sometimes or partially but not routinely. A score of 0 refers to the person being assessed never or very seldom performs the activity; it might due to immature or beyond the ability of the individual. A 'N' means No Opportunity of the activity to be performed due to limiting circumstances. For example, there is no telephone in the individual's home. This score can only be mark for some items. A 'DK' denotes the respondent 'Don't know' about the individual's performance of that item. For

example, the activity can only occur in other settings that are out of the respondent's observation.

The HKBABS was validated in reliability, factorial structure and norm. For reliability, test-retest and split-half or internal consistency were reported. Test-retest reliability has good coefficient values. The reliability coefficients of its subdomains, domains and Adaptive Behavior Composite (total score) were 84% more than 0.7. Under the Communication Skills, Socialization Skills and Motor Skills domains; 90%, 87% and 87% of the respective items have coefficients over 0.8. For items under Daily Living Skills domain, 65% achieved 0.8 or more. For internal consistency, split-half coefficients of subdomains reported 83% above 0.7; for domains level reported in age group, all coefficients are above 0.73 except two values as 0.64 and 0.62. The coefficients for Adaptive Behavior Composite were high (0.83 to 0.95).

Validity was established as content validity and construct validity. A multi-disciplinary Advisory Committee determined content validity. Construct validity was assessed by the developmental progression of scores and by factor analysis. Developmental progressions of the scores showed that the scores of HKBABS increase with age. Further analysis by t-tests gave significant difference between board age groups in Communication and Daily Living Skills domains. This supported the definition of adaptive behavior as age-related. The result of factor analysis of domains and subdomains strongly support the organization of subdomains into their respective

domains.

In this study, before the pretest started, test-retest reliability of HKBABS has been established to ensure the consistency when using it for children with disability and under condition in this study. Parents of 18 children in intervention group were interviewed with this instrument twice in around two weeks before the Free Play Program started. All ICC coefficients of its subdomain and total score are above 0.77 (0.77 to 0.88). The full results can be found in appendix 10.

#### Peabody Developmental Motor Scales-Second Edition (PDMS-2) (Folio & Fewell, 2000)

It was adopted to examine the motor performance of the children in gross motor. It can be used for children with or without motor impairment. It is widely used by pediatric physical therapist in Hong Kong. Although no Hong Kong norm this study interested in raw score. This version is the modified from the original edition (Folio & Fewell, 1983). It was composed based on the knowledge in motor development of children by identifying the sequential maturational stages. PDMS-2 incorporated qualitative (how well of the skill performed) and quantitative (how much of the skill performed) assessment for motor development from 0 to 72 months (Folio & Fewell, 2000).

The scales make up of six subtests: Reflexes, Stationary, Locomotion, Object Manipulation, Grasping and Visual-Motor Integration. Subtest Reflexes consists of 8

items used for age under one year. Three of the first 4 subtests could be composed to form Gross Motor Quotient (GMQ) that measures the use of large muscle systems. Scores of subtests Grasping and Visual-Motor Integration forms the Fine Motor Quotient (FMQ) that measures the small muscle systems. The Total Motor Quotient (TMQ) is formed by combining the above results and is able to assess the overall motor abilities. In this study, the gross motor scale was adopted. And because the children participated in this study were all older than one year old, Reflexes subtest was not performed. So only Stationary, Locomotion and Object Manipulation subtests were administered. Items are scored as 2, 1, and 0 with specific criteria for each item. The general criteria for scoring are: 2 if the child performs the items mastery; 1 if the child performs the skill similar to but not fully meet the specific criteria; 0 if the child does not attempt the item or the skill does not emerge.

As this assessment tool need observational judgments for scoring, inter-rater reliability has been done to ensure reliability. A second rater was invited to rate the score independently while the chief rater administered the scale to the 18 children (of the intervention group). About two weeks later, the chief rater conducted the scale again to same sample of children under same condition to determine the test-retest reliability for this tool. The ICC coefficients of test-retest reliability range from 0.88 to 0.99 for subtest and total score (Appendix 10). The result of inter-rater reliability showed excellent with ICC range from 0.95 to 0.99 of subtest and total score (see Appendix 11).

#### Procedures

Approval granted from the Heep Hong Society and consents from parents of the participants were obtained before the study started.

#### 1. Pretest

Before the Free Play Program started, pretest was administered with the above instruments for the children and their parents in intervention group. The children were assessed individually with PDMS following the administration instruction of the manual. At the same time, their parents took part in one-to-one interviews to answer the questionnaires of PedsQL and HKBABS. Child self-report of PedsQL was not used, as most children sampled did not understand the questions. Afterwards, the three instruments were administered to the 17 children in control group as conditions same as intervention group.

### 2. Free Play Program

As the programs scheduled in SCCCs were so compact and tight, it was difficult to add other program for them. The Free Play Program was conducted for the intervention classes in the two SCCCs of Heep Hong Society by substituting two gross motor lessons that were routinely scheduled three times per week for each class. The control group classes attended the lessons as usually scheduled with three gross motor lessons per week. The gross motor lesson that the centers routinely scheduled was a session that the children might leave their classroom and go the activity room to play ball, sliding or riding on tricycle or pedal car. The Free Play Program was conducted for 14 weeks. Every week two sessions of Free Play Programs of 25 to 30 minutes were provided in each center.

During the Free Play Program, the activity rooms in the centers were set up with play corners. Each of the corners had equipped with different types of play activities (p.74). As Center A had a total of 12 children participated in the program, it used a larger sized room which had at least nine play corners. Center B had six children participated, and a smaller sized room with six play corners was used. Different types of play included those involving fine motor play, gross motor play and pretend play. They covered social play, object play, symbolic play and motor play.

Fine motor play emphasized manipulating toys with hands. The arrangement was that one piece of toy was placed on a small table. There were six corners of this type in Center A and four in Center B. Examples of this type of play are pegs and board, beads and strings, simple puzzles, Lego, stamping and play dough.

Gross motor play is put a focus on physical play that encouraged the children to have fun with physical activity. Some examples are slide and ladder; plastic soft tunnel for crawling; large plastic or paper blocks for building and constructing; basket ball and obstacle jump rod. In each session, two to three gross motor play corners were set up in Center A and one to two in Center B.



Figure 1. The format of a play room.

Pretend play provided opportunity for children to act out different life roles. Toy kitchen hardware and utensils, dolls, toy bottle and toy bed were used. There was one corner equipped with this type of play in both Centers A and B.

The children in the intervention group were given the opportunity to choose their preferred play during each session. Three to four adults in Center A and two adults in Center B supervised the sessions. The ground rules of order like 'Don't run!' 'Don't push!' 'Don't argue!' 'Line up for sliding' were the same for both groups. Children were briefed on the ground rules each time they attended the session. In contrast, children in the control group were only participated in gross motor lesson which was partly regular curriculum of the center.

#### 3. Posttest

Immediately after the Free Play Program, the three measuring tools were administered to all children and their parent in both groups again in condition same as pretest.

## **Data Analysis**

The data were analyzed using SPSS 11.5. After collecting pretest and post-test measurements, data were tabulated according to the features of each tool. For PedsQL, the raw scores (0, 1, 2, 3, 4) of each item were transformed to scale scores (i.e. 100, 75, 50, 25, 0 respectively) as indication of scoring instruction of the instrument. The mean of

each subscale was then computed by adding the scale scores of relevant items and divided by the number of items in that subscale. The total or overall score was then calculated as the mean of the four subscales. As a result, one total score and four subscale scores of QOL were obtained: QOL-total, QOL-physical, QOL-emotion, QOL-social and QOL-schooling. The maximum for each score was 100.

For HKBABS, items scores were added up to form subdomain scores; and sum of subdomain scores formed the total score. Hence, there were one total score and four subdomain scores for adaptive behavior (AB-total, AB-communication, AB-ADL (activity of daily living), AB-social, AB-motor). The tabulating method of PDMS-2 was the same as HKBABS. Items were sum up to form subtest scores, and subtest scores were sum up to form total score of gross motor. One total score and three subtest gross motor (GM) scores were obtained eventually using PDMS-2: GM-total, GM-stationary, GM-locomotion and GM-manipulation.

Mean and standard deviation for each total and subscale score were computed for each group (intervention and control) at each stage (pretest and posttest).

To assess the effectiveness of the play program, analysis of covariance (ANCOVA) was used to compare the difference of changes between two groups with pre-test scores as covariates. According to Dawson & Trapp (2004), ANCOVA can be used to control for the influence of confounding factors which usually occur when subjects were not randomly assigned. It is a statistical method to equate the initial difference between

groups in pretest scores and adjust the posttest scores accordingly (Portney & Watkins, 2000). This method was considered appropriate as it was found that the pretest mean scores in adaptive behavior and motor performance of the children in control group was lower than those in intervention group (Table 4.2). While the overall significance level was set at 0.05, the Sharpened Bonferroni method (Hochberg, 1988) was used to adjust for individual alpha level when multiple testing were performed.

## Results

Table 4.2 shows the ANCOVA results of effectiveness of the Free Play Program. The mean and standard deviation for each subtest and total score are shown in mean and standard deviation (SD) for both experimental and control group at both pre-test and post-test. Three Bonferroni corrected p values (AB-ADL: corrected p<0.001; AB-social: p=0.039; AB-motor: p=0.048) were significant. The difference in post-test scores between the intervention and control group, after adjusting for baseline scores, for these three subtests were 11.6 (95% CI: 6.0 to 17.2), 6.7 (95% CI: 2.3 to 11.1) and 5.8 (95% CI: 2.1 to 9.4), respectively. A negative value implies that the average post-test score for the experimental group was lower than that for the control group. This was observed in QOL scores but the differences were small (-1.8 in QOL-total, -0.8 in QOL-physical, -1.0 in QOL-social and -2.0 in QOL-school) and non-significant. Positive differences were observed for all AB and GM scores, although only three AB scores were significant.

		Mea	n (SD)	Adjusted diff in		
Scores in subscale		Intervention	Control	nost-test score	t (32)	n *
or total		group	group	(95% CI)	(02)	٢
		(n=18)	(n=17)			
	Pre-test	65.0 (9.3)	65.0 (13.0)	-1.8(-8.2  to  1.7)	- 56	583
	Post-test	67.0 (12.1)	68.8 (9.2)	-1.0(-0.2(0+.7))	50	.505
	Pre-test	64.2 (16.9)	65.8 (20.4)	-8(-0.1  to  7.5)	- 20	8/7
QOL-physical	Post-test	67.7 (17.6)	69.3 (12.1)	0 (-9.1 10 7.3)	20	.047
	Pre-test	73.6 (16.1)	73.5 (12.3)	9(-96 to 11/1)	17	863
	Post-test	74.2 (17.0)	73.2 (14.8)	.9 (-9.0 to 11.4)		.000
	Pre-test	55.8 (17.9)	60.6 (14.8)	-1 0 (-9 2 to 7 1)	- 26	797
	Post-test	58.1 (19.1)	62.4 (12.3)	-1.0 (-3.2 to 7.1)	20	.131
OOL-schooling	Pre-test	67.6 (15.6)	56.3 (14.8)	-2 0 (-14 8 to 10 9)	- 31	759
QUE Schooling	Post-test	69.3 (18.7)	72.0 (15.4)	2.0 ( 14.0 to 10.0)	.01	.700
AB-total	Pre-test	252.7 (37.9)	175.5 (26.3)	15 7 (-2 1 to 33 5)	1 80	082
	Post-test	296.8 (48.1)	192.0 (32.3)	10.7 ( 2.1 to 00.0)	1.00	.002
AB-communication	Pre-test	75.8 (21.8)	38.6 (8.2)	69 (-35 to 172)	1 35	185
	Post-test	92.2 (25.7)	43.0 (15.1)	0.0 ( 0.0 to 17.2)	1.00	.100
AB-ADI	Pre-test	68.5 (15.7)	48.8 (11.1)	11 6 (6 0 to 17 2)	4 22	< 001
	Post-test	83.3 (14.9)	55.4 (10.8)	11.0 (0.0 to 11.2)	7.22	2.001
AB-social	Pre-test	55.3 (7.2)	43.4 (6.1)	6 7 (2 3 to 11 1)	3 1 1	048
	Post-test	62.2 (6.7)	47.3 (6.3)	0.7 (2.0 to 11.1)	0.11	.040
AB-motor	Pre-test	53.1 (12.4)	44.8 (7.5)	5.8(2.1  to  9.4)	3 10	030
	Post-test	59.1 (11.6)	46.4 (8.0)	0.0 (2.1 (0 0.4)	0.10	.000
GM-total	Pre-test	180.1 (43.6)	154.6 (21.1)	4.2(-1.0  to  9.3)	1 65	110
	Post-test	196.5 (46.5)	166.1 (20.3)	4.2 ( 1.0 to 0.0)	1.00	.110
GM-stationary	Pre-test	42.2 (4.4)	39.1 (2.5)	8(-6  to  23)	1 15	257
OW-Stationary	Post-test	45.3 (5.5)	41.1 (2.7)	.0 (=.0 10 2.0)	1.15	.201
GM-locomotion	Pre-test	112.2 (30.8)	96.9 (14.7)	32(-5  to  69)	1 75	090
	Post-test	122.4 (31.3)	104.3 (13.4)	0.2 ( .0 10 0.0)	1.70	.000
GM-manipulate	Pre-test	25.7 (9.4)	18.6 (5.9)	8(-1/1  to  3.0)	7/	465
	Post-test	28.8 (10.6)	20.8 (5.9)	.0 ( <sup>-</sup> 1. <del>1</del> 10 0.0)	.14	05

Table 4.2 Results of ANCOVA after adjusting for baseline values

\* p values shown were corrected using the Sharpened Bonferroni procedure.

Key: QOL --- Quality of life; AB --- Adaptive Behavior; GM--- Gross Motor ADL---Activity of Daily Living

## Discussion

From the results, all statistical significant differences were found in the Adaptive Behavior (AB) scores. It seems that this Free Play Program could promote adaptive behavior especially in ADL, social and motor area. It is not surprising as many studies about the effect of free play showed positive result in a variety of areas such as physical. social or psychological development. Though no quantitative study was found in the literature about the effect of play on adaptive behavior, there is some theories substantiating the importance of play for children to practice and strengthen the skill required for survive. For example as reviewed in chapter 2, early in 1962, Piaget stated that children practice and consolidate newly acquired skills when play. Vygotsky (1976) assured the important of play to social, emotional and cognitive development. But may be this is a common sense that play is important and is need by children, sometimes adult might neglect it, especially when we think that training and structured intervention are more important than play. This issue worth more consideration when we plan program for our children with special needs as their disabilities might prevent them from engaging in play actively.

The significant result might also attribute to the fact that VAB scores were obtained using a semi-structure questionnaire in one-to-one interviews, so that more information could be obtained from the fine designed questions, and the probing questions during the interview could provide more information in giving correct rating. Hence, selection of outcome measure would be important in examining the effectiveness of intervention.

The two groups showed little difference in change of QOL; in fact, the changes of scores were higher for the control group in some domains, although none of the differences were statistically significant. This might be due to only parent proxy-report was administered in this study. The subjective perception in life quality before and after the intervention could not be collected. However, positive responses were heard during the intervention as some children hoped that more play session could be given. The children showed very happy when they were in the play program. Thought no statistical change, the perceptive life quality should be positive during the program. Other factor attribute to this result might be the fact that the programs provided in the Special Child Care Center were intensive, integration of this Free Play Program might not make significant change in guality of life. Power analysis showed that the statistical power for testing the differences in quality of life scores was generally low, ranging from 0.053 to 0.084. While the low power could be attributable to the small sample sizes, a further examination revealed that the differences were truly small, as the effect size ranged only from 0.07 to 0.20 (mean effect size = 0.12) for this domain. Hence, it is evident that the change in quality of life between the two groups was similar.

Some positive differences (4.2, 0.8, 3.2, 0.8 for GM-total, GM-stationary, GMlocomotion, and GM-manipulate, respectively) were obtained for gross motor scores measured using PDMS-2, though they did not reach statistical significance. One reason that might contribute to this result is that the children with disability participated in this

study had only mild physical dysfunction. Most of them could walk without any support, except for two children who needed minimal support by adult. Physical developmental changes might be little in such a short period in this plateau stage. Another possibility is that comparing to the intensive programs provided by SCCC, the effect of Free Play Program on motor development might be small. Besides, compare to intervention group that received one session of gross motor lesson and two sessions of Free Play Program per week, the control group had received three sessions of gross motor lesson per week. It is reasonable that the change on motor performance of two groups was similar. However, the change of motor in intervention group was greater than that of control group.

The statistical power for testing the differences in GM between the two groups was again low, ranging from 0.11 to 0.40. Using the guidelines given in Cohen (1977), i.e., an effect size of 0.1 being low, 0.25 as medium, and 0.4 as high, the effect of the intervention on GM can be considered medium because the average effect size was 0.22 (ranged from 0.13 to 0.31). The implication of this is that if the sample size can be increased to approximately 80 per group, then the differences would be statistically significant. This supports the findings by Palisano et al (1995) in evaluating the validity of PDMS-GM as a measure to infants receiving physical therapy. The finding was that a sample size of 68 per group would be needed when using PDMS-GM as an outcome measure in research.

Different scale has different sensitivity in measuring the changes of target constructs. It is important to choose appropriate instrument to detect the effects. Moreover, the total amount of time spent in the Free Play Program might be too short (a total of less than 14 hours in about 2.5 months) to provide huge effect in the developmental changes.

## **CHAPTER FIVE**

## DISCUSSION

Translation and preliminary validation of PedsQL

The first part of this study involved translation and preliminary validation of an instrument of quality of life for children (PedsQL). As there is no existing Chinese instrument of quality of life applicable to our target population, it is essential to contribute to the establishment of a good measure for future using. PedsQL has many advantages over other similar tools in that it is applicable to wide age range from very young age (2 to 18 years); provides child self report parallel to parent proxy-report; consists of generic scales compliment with disease-specific scales. It was standardized and easy to use in short time (5 to 10 minutes).

In this study the results of reliability and validity for age groups 2 to 4 and 5 to 7 are good and comparable to the original study (Varni, 2001). Reliability in internal consistency generally exceeded the standard of 0.70. Test-retest reliability is good. Content validity was done by cognitive interview and respondent debriefing that might be better than experts panel as the feed back was from the target population directly (Campanelli et al, 1991; McColl et al, 2003). Construct validity though done in a small group established by known group comparison showed significant difference between groups of healthy and children with disabilities in most subtest and all total scores in three reports. This showed that the translated instrument can differentiate the specific

groups examined. The non-significant findings compare between gender groups and ages groups indicating that the quality of life level is not affect by gender and age. The scores could be compared across wide range of age and between genders. Correlation between parent and child reports was not presented by Varni. The findings in this study were good in total scores and physical function but fair in emotional functioning. This supports the development of child self-report instead of rating the quality of life by proxy-report alone, though the child self-report was not used in this study as communication with the children in this study was not effective. As some parts of quality of life is subjective perception e.g. emotion (Cummin, 1996). In summary, this validated Chinese PedsQL for ages range 2 to 4 and 5 to 7 is worth to be used for further studies about health-related quality of life and for clinical assessment.

## The Effect of Free Play

The premise of this study was based on the belief that to allow children play liberally will facilitate normal development of the children. The result findings were significant to adaptive behavior in subdomains of activity daily living (ADL), social function and motor function but non-significant in total scores and social subdomain. It seems that this free play can elicit positive change in adaptive behavior. The change is most significant in ADL (p<.001). Free play might promote ADL functioning. It might because some activities of play (e.g. pretend play) are quite similar to daily activities. It can be argued that this change might attribute to excellent program from the special child care centers and maturational effects. However, the subjects from control group were from same centers of intervention group. The baseline values of ANCOVA results were also

adjusted. There is no effect observed in communication subdomain of this instrument. It might be the reason that the children seldom talk to each other during the Free Play Program. From this findings, free play could be incorporated in program in purpose of facilitate adaptive behavior.

Results about quality of life and gross motor performance showed minimal change. Power analysis for effect on quality of life was low. It could be due to small sample sizes. Further examination showed that the change in quality of life between the two groups was similar. It might be inferred that the effect of this program on quality of life could not detect by this instrument.

Some positive change was gained in gross motor scores though they were not significant. The non-significant result could be attributed to their physical impairment were mild to moderate as they might reach the plateau stage of motor development. Most children recruited can walk without support except two children need supervision or minimal support during walking. For these two children, however some change did observe by their teachers and the investigator in later stage of Program. They could walk with lesser support and even walk without support for about 10 feet. This might attribute to the opportunity for walking during Free Play as they need to walk or transfer from one play corner to other play corner to play. The motivation to walk would be higher than routine transfer which mostly supported by staff in fear of falling. This kind of change might not show in group analysis. Power analysis revealed that the non-significant seems due to small sample size. The diverse range of diagnosis might also be a factor to non-significant change as the progress rate of motor development might

be different.

## The Free Play Intervention Program

In this study, non-structure free play was chosen as the main theme of the Play Program. According to the play criteria proclaimed by Rubin and colleagues (1983), play is intrinsically motivated, dominated by the child, and not bounded by formal rules. Similarly, Johnson et al (1987) also proposed that play has no fix pattern and stem from intrinsic motivation. It should be freely chosen by the child in term of how to play in the process without the purpose of end product. So in this Free Play Program, there had no formal rules except for some basic ground rules for safety seek. No adult was involved to guide or provide methods to teach the children how to play or help the child choose what to play except for safety supervision. Of course sometimes children might need help to climb up the slide but the child should has initiated the participation. The purpose for this measures was to provide a relax atmosphere that the children can play without pressure. Under this free and pleasurable conditions, the children then can learn and develop in their pace effectively.

Compared to other play intervention researches in the literature, few were in this format. Most of the interventions were structured and guided by adults (Roswal et al, 1984; Craig-Unkefer & Kaiser, 2002; Zahr, 1998). They have different formats and different goals, but the similarity is that all interventions were in playful context. Unlike the others, the Free Play Program focused on spontaneous play strives of the children just as the non-special children always do. Roswal's Developmental Play Program (1984) was

provided by one to one guided gymnasium and outdoor activities in games for total 18 hours in 10 weeks. The significant effects were showed in self concept and motoric functioning. The present study was non-structure and in group format with 14 hours in 14 weeks. The effort given in this study was lesser than study of Roswal, but significant effect was obtained too. This favors the value of free play in group setting. If we can incorporate free play into daily routine in special child care service or in parenting, the value would be substantial.

The programs in the Special Child Care Centers (SCCC) were intensive and fully planned by rehabilitation professionals and special educators. There was limited time and space to conduct program like this. The effect seems not easy to be detected. However, the feedback from parents and children was positive that some children were 'wait for next session'. This might indicated that free play like this program was seldom provided.

The three traits this study intended to measure are quality of life, adaptive behavior and gross motor performance. The effect of play on quality of life was seldom discussed in the literature. It is worth to examine it though no change observed. Adaptive behavior is an index of psychosocial development of human. It was chosen because play can improve this part of development. And the researcher would like to examine how play has effects on it. In this study, it was proved that play has effects only on adaptive behavior. Gross motor development is a dimension that physical therapists concern when treating their pediatric clients. As the researcher is a physical therapist, she would like to exam if play has effect on motor development. Moreover, choosing of these three

traits to be measure is intended to cover diverse spectrum of human development.

## Implications

There were relatively few studies explore the effect of free play on the development of children in particularly enhancing quality of life. The results of this study reveal positive effects of play on improving children's performance but not their quality of life. Further studies are recommended to explore the effects of play on other developmental dimensions such as cognitive function, fine motor development, and learning ability. The intervention program in free play can be conducted in a more naturalistic environment, i.e. outdoor (Fjortoft, 2001). To further understand the mechanism of changes in children's function, further studies should focus on how different components of play would modify adaptive behavior of children. Last but not the least, further studies could adopt different instruments for measuring the dependent variables such as those with higher sensitivity and specificity. Selection of outcome measures for study of intervention is critical.

## Limitation of this study

Using quasi-experimental design (Cook and Campbell, 1979) for clinical research and in social field is not uncommon. However, some threats to internal validity should be noticed if random sampling and group assignment was not used. In the present study, children participants were not randomly assigned to the intervention and control groups. The threat of selection effect, inequivalent group at baseline, may exist. Unfortunately,

this was the case in our study that was reflected from the differences in the adaptive behavior and motor function scores across the two groups. With this in mind, analysis of covariance procedure was used with an aim to adjust for the differences at the baseline. The threat of history may also exist as the two groups were recruited from different classes. The participants could have received different kinds of lessons of their curriculum. This would have confounded the changes in the posttest scores. This error could have been controlled by designing the lessons and activities as similar as possible for both groups.

## CHAPTER SIX

## CONCLUSION

A new instrument for health-related quality of life---Pediatric Quality of Life Inventory (PedsQL)--- was translated and validated in Chinese. Psychometric properties in term of internal consistency reliability, test-retest reliability, content validity, construct validity, and correlation between parent proxy-report and child self-report were examined. The results were satisfactory and comparable to original study. This Chinese PedsQL is appropriate for research studies or in clinical setting to investigate the quality of life of children. Further validation is suggested to conduct to larger sample size for factor analysis.

The effect of free play on development of children with disabilities was investigated. Three outcome measures were adopted to examine the changes. The newly translated PedsQL examine the quality of life. HKBABS was used to test the adaptive behavior. Gross motor performance was examined by PDMS-2. Free Play Intervention Program was conducted in two Special Child Care Centres of Heep Hong Society in Hong Kong for 18 children with 17 children in control group. The Program was conducted in a frequency of two sessions (30 minutes each) per week for 14 weeks. Each session provided six to nine play corners with different types of play materials set up in an activity room.

The results showed significant effect was obtained in adaptive behavior only. The

subdomains that had changed are activity of daily living (ADL), social and motor. Minimal changes were found in quality of life and gross motor. As free play contributes some effect to adaptive behavior, regular program for free play was suggested to special child care service. The factors contributed to these results were discussed.

For further study about play intervention, sample size could be increased. Selection of instrument is important as different tools might have different sensitivity. Further study in play interact with quality of life could be done by other instrument. Free play effects on children with moderate physical disabilities (i.e. crawlers) could be examined.

Appendix 1 Original English PedsQL

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# Pediatric Quality of Life Inventory

Version 4.0

## PARENT REPORT for TODDLERS (ages 2-4)

DIRECTIONS : On the following page is a list of things that might be a problem for your child. Please tell us how much of a problem each one has been for your child during the part ONE month by circling: . : • 0 if it is never a problem 1 if it is almost never a problem 2 if it is sometimes a problem . 3 if it is often a problem 4 if it is almost always a problem There are no right or wrong answers. If you do not understand a question, please ask for help. . . 

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

PHYSICAL FUNCTIONING (problems with)	Never	Almost Never	Some- times	Often	Almost Always
1. Walking	0	3	2	3	4
2. Running	0	1	2	3	4
3. Participating in active play or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	Э	4
5. Bathing	Q	1 1	2	3	4
6. Helping to pick up his or her toys	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	: 4

EMOTIONAL FUNCTIONING (problems with)	Never	Almost Never	Some- times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	. 1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying	. 0	1	2	3	4

SOCIAL FUNCTIONING (problems with)	Never	Almost Never	Some- times	Often	Almost Always
1. Playing with other children	D	1	2	3	4
2. Other kids not wanting to play with him or her	0	1	2	3	. 4
3. Getting teased by other children	D	1	2	3	4
<ol> <li>Not able to do things that other children his or her age can do</li> </ol>	0	1	2	3	4
5. Keeping up when playing with other children	0	. 1	2	3	4

### \*Please complete this section if your child attends school or daycare

SCHOOL FUNCTIONING (problems with)	Never	Almost Never	Some- times	Often	Almost Always
1. Doing the same school activities as peers	0	1	2	3	4
2. Missing school/daycare because of not feeling well	0	1	2	3	4
<ol> <li>Missing school/daycare to go to the doctor or hospital</li> </ol>	D	1	2	3	4

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# Pediatric Quality of Life Inventory

Version 4.0

## PARENT REPORT for YOUNG CHILDREN (ages 5-7)

On the following pag Please tell us how in during the past ONI	e is a list of things that might be a problem for your child nuch of a problem each one has been for your child E month by circling:
	0 if it is never a problem
	1 if it is almost never a problem
	2 if it is sometimes a problem
· · · · · · · · · · · · · · · · · · ·	3 if it is often a problem
	4 if it is almost always a problem

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In the past <b>ONE mon</b> t	<b>h,</b> how much of a	problem has	your child had with
------------------------------	-------------------------	-------------	---------------------

PHYSICAL FUNCTIONING (problems with)	Never	Almost Never	Some- times	Often	Almost Always
1. Walking more than one block	Q	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores, tike picking up his or her toys	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
6. Low energy level	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with)	Never	Almost Never	Some-	Often	Atmost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	Q	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

SOCIAL FUNCTIONING (problems with)	Never	Almost Never	Some-	Often	Almost Always
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	Э	4
3. Getting teased by other children	0	1	2	3	4
<ol> <li>Not able to do things that other children his or her age can do</li> </ol>	σ	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

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

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## PedsQL Pediatric Quality of Life Inventory

Version 4.0

#### YOUNG CHILD REPORT (ages 5-7)

Instructions for interviewer:

I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these things might be for you.

Show the child the template and point to the responses as you read.

If it is not at all a problem for you, point to the smiling face

If it is sometimes a problem for you, point to the middle face

If it is a problem for you a lot, point to the frowning face

I will read each question. Point to the pictures to show me how much of a problem it is for you. Let's try a practice one first.

	 Not at all	Sometimes	A lot
is it hard for you to snap your fingers	0	<b>(</b> )	$\otimes$

Ask the child to demonstrate snapping his or her fingers to determine whether or not the question was answered correctly. Repeat the question if the child demonstrates a response that is different from his or her action.

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## Think about how you have been doing for the last few weeks. Please listen carefully to each sentence and tell me how much of a problem this is for you.

After reading the item, gesture to the template. If the child hesitates or does not seem to understand how to answer, read the response options while pointing at the faces.

PHYSICAL FUNCTIONING (problems with)	Not et all	Some- times	A Jot
<ol> <li>Is it hard for you to walk</li> </ol>	0	. 2	4
2. Is it hard for you to run	0	2	4
<ol><li>Is it hard for you to play sports or exercise</li></ol>	0	2	4
<ol><li>Is it hard for you to pick up big things</li></ol>	0	2	4
<ol><li>Is it hard for you to take a bath or shower</li></ol>	0	2	4
6. Is it hard for you to do chores (like pick up your toys)	0	2	4
7. Do you have hurts or aches (Where? )	0	2	4
<ol><li>Do you ever feel too tired to play</li></ol>	0	2	4

Remember, tell me how much of a problem this has been for you for the last few weeks.

EMOTIONAL FUNCTIONING (problems with)	et ali	times	AIO
1. Do you feel scared	0	2	4
2. Do you feel sad	0	2	4
3. Do you feel mad	0	2	4
4. Do you have trouble sleeping	0	2	4
5. Do you worry about what will happen to you	0	2	4

Social Functioning (problems with)	Not at all	Some- times	A lot
1. Is it hard for you to get along with other kids	0	2	4
2. Do other kids say they do not want to play with you	0	2	4
3. Do other kids tease you	0	2	4
4. Can other kids do things that you cannot do	0	2	4
<ol> <li>Is it hard for you to keep up when you play with other kids</li> </ol>	0	2	4

SCHOOL FUNCTIONING (problems with)	Not at all	Some- times	A lot
<ol> <li>Is it hard for you to pay attention in school</li> </ol>	0	2	4
2. Do you forget things	0	2	4
<ol><li>Is it hard to keep up with schoolwork</li></ol>	0	2	4
<ol><li>Do you miss school because of not feeling good</li></ol>	0	2	4
<ol><li>Do you miss school because you have to go to the doctor's or hospital</li></ol>	0	2	4

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Not at all



Sometimes :

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Appendix 2 Forward-1

## PedsQL<sup>TM</sup> 兒童生活品質 問卷調査 <sup>第四版</sup>

問卷對象:學步兒(2-4歲)父母

指引 下頁所列出的項目,有些對您的孩子而言,可 的方式告訴我們,過去一個月來您的孩子在這	[他是個難題或因優。證以圖選 國項目的困 <b>擾程度。</b>
如果該項目對您的孩子一 一點也不是個問題 幾乎從來不是個問題 有時候是個問題 經常是個問題 幾乎一直是個問題	請圈 0 諸圈 1 行圈 2 請卷 3 請徵 4
這裡的答案沒有所謂對錯。 如果有不明白的地方,請要求區動。	

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身體功能 (下列各項對您的孩子是否是個難題 或困擾?)	一點 也不是	<del>幾乎</del> 從來不是	有時候是	經常是	<del>幾</del> 乎 →直是
1. 步行	Ô	1	2	3	4
2. 跑步	0	1	2	3	1
3. 參與激烈的遊戲或運動	U	1	2	<sub>1</sub> 3	4
1.提擧較重之物	0	1	2	3 -	4
5. 洗澡	0	1	2	- 3	4
6. 奮忙救搶自己的玩具	Û	1	2	3	-1
7.經常受傷或疼痛	0	]	2	3	4
8. 精力不足	0	1	2	3	4

#### 在過去一個月中,您的孩子面對下列各項問題的困擾程度....

情緒功能 (下列各項對您的孩子是否是個難題 或困擾?)	一點也不是	<b>幾乎</b> 從來不是	有時候是	經常是	幾乎 一直是
1.感覺害怕或驚嚇	0	1	2	3	4
2.感覺悲哀或憂傷	0	1	2	.3	4
3. 感覺憤怒	0	1	2	3	-1
4. ) ) ) ) (1) (1	0	1	2	3	4
5	Ð	1	2	- 3	4

社交功能 (下列各項對您的孩子是否是個難選 或困擾?)	一-點 也不是	幾乎 從來不是	有時候是	經常是	幾乎 一直是
1. 鄭温的孩子一同玩耍	0	1	2	3	-1
2. 別的孩子不願與他/她玩耍	Ð	1	2	3	4
3. 被別的孩子戲弄	U	1	2	3	4
4. 無法做別的同年齡孩子所能做的事情	0	1	2	- 3	4
5. 與別的孩子死耍時能與得上	0	1	2	3	4
*如果您的孩子有上璧或是没任兒所,請你	民道部份				

就學功能 (下列各項對您的孩子是否是個難觀 或困擾?)	點 也不是	<del>幾乎</del> 從來不是	有時候是	經常是	<del>親</del> 乎 一直是
1. 從事其他小朋友也能進行的	U U	1	2	3	4
學校活動			•		
2. 因爲身體不適而缺課	0	]	2	3	4
3. 因爲要看醫生或到醫院而缺課	0	1	2	3	1

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## PedsQL<sup>TM</sup> 兒童生活品質 問卷調査

第四版

問卷對象:幼童(5-7歲)父母

指引	
在下頁所列出的項目中,有些對您的孩子而言 審選的方式告訴我們,過去一個月來您的孩子	·可能是個難題或困擾,總以 在每個項目的困擾程度。
如果該項目對您的孩子一	
一點也不是個問題	請選 0
幾乎從來不是個問題	.請選1
有時候是個問題	請題2
經常是個問題	ing版 3
幾乎一直是冒問題	讀國 4
這裡的答案沒有所謂對諧。 如果有不明白的地方, 請要求協助。	

PedsQL 4.0 - Parent (5-7)01/00

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身體功能 (下列各項對您的孩子是否是 個難題或困擾?)	一點 也不是	<del>幾</del> 乎 從來不是	有時候是	經常是	<b>幾乎</b> 一直是
生步行超過兩個路口的運難	0	1	2	3	4
.2. 跑步	U U	1 1	2	3	-1
3. 參與體能活動或運動	1 0	1	2	3	1
4. 提舉較重之物	j ()	1	2	3	4
5. 自己洗澡	0	1	2	3	4
6.割怕做家事,例如:政治自己的玩具。	0	1	2	3	4
7.經常受傷或疼痛	0	1	2	3	4
8. 精力不足	0	1	2	3	4
情緒功能 (下列各項對您的孩子是否 	一點 也不是	<del>農</del> 乎 從來不是	有時候是	經常是	幾乎 一直是
<u>1.感覺害怕或驚嚇</u>	0	· I	2	3	-1
2.感覺悲哀或憂傷	Û	1	2	3	1
3. 感覺憤怒	. 0	1	2	3	4
4. 睡眠困難	ί U	1	2	3	4
5. 擔心將會燈生在他/威身上的事情	0	1	2	3	4
社交功能 (下列各項對您的孩子是否 是個困擾?)	一點 也不是	<del>幾乎</del> 從來不是	有時候是	網常是	幾乎 一直是
1. 與別的孩子融洽相處	0	1	2	3	4
2. 別的孩子不願和他/她作朋友	Ü	1	2	.3	4
3. 被别的孩子戴弄	0	1	2	3	4
4. 沒法做別的同年齡孩子所能做的事情	0	l	2	3	4
5. 與別的孩子玩耍時能跟得上	U	1	2	3	4
就學功能 (下列各項對您的孩子是否 是個難題或困擾?)	點 也不是	幾乎 從來不是	有時候是	經常是	<b>幾乎</b> ──直是
1. 上課時集中精神	0	l	2	3	4
2. 忘東忘西	0	1	2	3	1
3. 殿得上學校的活動	U	1	2	3	4
4. 因態身體不適前缺課	0	1	2	3	4
5. 因為要看醫生或到醫院而缺課	0	.	2	3	4

在過去一個月中,您的孩子面對下列各項問題的困難程度......

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## PedsQL<sup>TM</sup> 兒童生活品質 問卷調査 <sup>第四版</sup>

### 問卷對象:幼童(5-7歲)

訪問者:

我現在要問你一些問題,問題裡提到的事情對有些小朋友回能很難。我想知道這些事情對你可能有多難。

顯示表情間給小孩看,並且在遺下列說明的同時,一邊指著每個所提到的表情。

如果對你來說<u>一點都不是</u>問題,請指向徵笑圖樣

如果對你來說有時候是個問題,請指向中間的圖樣

如果對你來說是一個<u>很嚴重的</u>問題,讀指向數眉的圖樣

我會讀出每一道題目。請指出一個哀情,來晉訴我所提到約事對你來說有多困難,現在。 我們先來練習一下。

	完全不	有時	總是如此
彈指發出聲音,對你來說是否困難	$\odot$		8

要求小孩做彈手指的動作,以確定他/她是否正確作答。如果小孩指出的表情和他/她的動 作不符,重覆近來的問題。

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## 想一想過去幾個星期的你。請仔細聽清楚每個句子,然後告訴我,我問你的事情對你來說有多困擾。

在讀過每項問題之後,把孩子引向表情圖。如果小孩遲疑或看來似乎不明白該如何回答, 請在閱讀回應選項同時指向該項表情。

身體功能(這件事對你來說難不難、 或者有沒有這方面的困擾)	完全不	有時	總是如此
1. 参行	0	2	4
2. 飯夕	n	2	
3. 體能活動或運動	0	- 2	4
4.拿起一些大物件	0	2	4
5. 洗澡	0	2	-1
6. 帮忙做家事(如收拾自己的玩具)	V	2	4
7.身上常有受傷或疼痛	· 0 · · ·	2	4
( <b>在哪裡?</b> )	1		
8. 有沒有調素得不想研的感覺	Û	2	4
		A CONTRACTOR OF A CONTRACTOR O	

記住,先想想過去幾個星期的你,然後告訴我,我開你的事情對你來說是多大的困擾。

情緒功能(你有沒有這些問題…)	完全不	有時	制是如此
1. 感覺書伯或驚慕	0	2	4
2.感覺臺傷	0	2	4
3. 感覺牛氣	0	2	-1
4.	0	2	:4
5. 遶心可能會發生在自己身上的前	Ü	2	4

社交功能(你有沒有這些困擾…)	完全不	有時	總是如此
1 和別的孩子相處,是不是很難	0	2	4
2. 別的孩子有沒有說不願意與你一同玩要	Û	2	4
3. 別的孩子有沒有戲弄你	Û	2	4
4. 別的孩子是不是會做一些你辦不到的事	Ų	2	4
5. 在與別的孩子玩耍時,你會不會覺得跟	ü	'n	4
不上位們	,,		-

就學功能(你有沒有這些問題)	完全不	有時	總是如此
1. 主學時很難集中注意力	Ö	2	4
2. 忘東窓西	0	; 2	4
3. 跟不上學校的功課	0	2	-1
4. 因為身體不舒服而缺課	0	2	·ł
5. 医烏要看醫生或到醫院而缺課	Ü.	2	4

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Appendix 3 Forward-2

# PedsQL<sup>TM</sup> 兒童生活品質記錄

第四版

父母替學行兒童作答(年齡2-4歲)



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### 在遗去的一個月,你孩子的難題有多困難......

惯格功能(困難爲)	從不	幾乎不是	有時	時常	幾乎是
1. 步行	0	1	2	.3	! 4
2. 跑步	Ú	1	2	3	- 1
3. 參與遊戲活動或練習	0	]	2	3	4
4.提起一些重物	0	1	2	3	4
5. 洗澡	υ .	1	2	3	4
6.協助拿起他/她的玩具	0		2	3	4
7.經歷受傷或痛熱	0	1	2	3	4
8. 低龍量水44	0	1	2	3	4
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[情緒功能(困難為)	廃生	幾乎不足	_ 有:時		幾乎是
1.感覺害怕或驚嚇	0	l	2	3	4
2. 感覺悲哀或憂傷	- ft	1	2	3	4
3. 感覺憤怒	0	1	2	3	4
4. 盱眠困難	Û	1	2	3	1
5. 擔憂	0	1	2	3	4

赶交功能(困難爲)	從不	幾乎不是	有時		幾乎是
1. 與其他孩子玩要	0	1	2	3	4
2. 其他孩子不赢购他/她玩耍	0	1	2	3	۰ŀ
3. 被其他孩子戲弄	0	1	2	3	4
4. 沒法做與他/她同年齡孩子所能做的	0	1	2	3	4
1. 河南					
5. 與其他孩子玩耍時能跟得上	0	1	2	3	4

#### \*如果你的孩子是就學或在目間惡顧中心,請完成這部份。

學習坊能(困難爲)	従不	幾乎不是	有時	时嘗	幾乎是
1.做同年齡同樣做的學校活動	Û.	I	2	3	4
2. 缺课或不正日調照顧中心因爲不適	0	1	2	3	4
3. 缺課或不已日間照顧中心因爲要睇醫	ų.	1	2	3	4
化或到醫院					

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# PedsQL<sup>TM</sup> 兒童生活品質記錄

第四版

父母替兒童作答(年齡 5-7 歲)



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在過去的一個月,你孩子的難愿有多困難......

髑格功能(困難爲)	従不	幾乎不是	右時	「時常」	幾乎是
1.步行上多於一梯級	0	: 1	2	3	4
[2. 跑步	0	1	2	3	4
3. 參與遊戲活動或練習	0	1	2	3	- 4
4. 穩起一些衝物	Ü	1	2	3	4
5. 他/她自己洗澡或沐浴	0	1	2	3	4
6. 做家務、例如政捨他/她的玩具	- 0	I	- 2	3	4
7. 經歷受傷或痛楚	Ű	1	2	3	-1
8. 低能量水平	Ü	1	2	3	+
					<b>—</b> ———
情緒功能(困難爲)	2 従不	幾乎不是	有時	時常	幾乎是
1.减癥害怕能驚臟	0	1	2	3	- 4

L 感覺習怕或驚嚇	0	1	2	3	4
2 感覺悲哀或憂傷	0	1	2	3	4
3. 感覺慣怒	Û	1	2	3	4
4. 睡眠困難	0	1	2	3	4
5. 擔憂他/始將會發生的事	Ú	1	2	3	1

社交功能(困難爲)	從不	幾乎不是	有時	時常	幾乎是
1. 與其他孩子相處	0	1	2	3	4
2. 其他孩子不願與他/她成爲朋友	0	1	2	3	4
3. 被其他孩子就弄	, υ	1	2	3	1
主沒法做與他/她同年齡孩子所能做的。	[ U	1	2	3	4
- <b>売</b> 売					
5. 與其他孩子玩耍時能跟得	0	1	2	3	4

\*如果你的孩子是就學或在目實際額中心,講完成這部份。\_\_\_\_

學習功能(困難爲)	從不	幾乎不是	有時	時常	幾乎是
1. 上课時能集中精神	U U	1	2	3	-1
2. 忘記事情	0	1	2	3	4
3. 我上學校的活動	0	1	2	3	4
4. 缺誤或不会日間照顧中心因為不適。	0	1	2	3	4
5. 缺誤或不同目间照顧中心因爲要睇醫	0	1	2	3	4
生或到醫院					

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# PedsQL<sup>TM</sup> 兒童生活品質記錄

第四版

### 幼兒作答(年齡5-7歲)

訪問者手曰:

我現在開始問你一些具他兒童可能有問題的難題。我希望知道這些難題對你來說可能造成 的問題。

顯示圖樣板給小孩看,亞且指示顯笑的圖樣。

如果對你來說這並不全是一個問題,請指向微笑圖樣

如果對你來說有時是一個問題,請指向中間的圖樣

如果對你來說是一個大問題,指向皺眉圖樣

我會讀每一述進出。括向圖樣板以告訴我難題對你來說有多大的問題。首先,讓我們來一 個練習。

	並不全是	有時	大部份
突然使手指發出聲音	$\odot$		8

要求小孩示能使他/婉的手指發出聲音、以便決定問題本身是正確與否。重新問問題如果 小孩要求示能的與他/她所做的動作不一樣。

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想一想你過去的幾個星期所撤過的事情。請小心聽清楚每一句子和告訴我困難對於你有多少。

在讀過項目之後,指示圖樣,如果小孩有遲疑或看來有些不明白如何回答,當閱讀反應選 擇時指示圖樣。

體格功能(困難爲)	並不至是	有時	幾多是
1.步行對你來說是否困難	Ü	2	
2. 跑步蜀豹來說是否困難	0	2	4
3. 運動或練習對你來說是否困難	0	2	-1
4. 提起一些大物件對你來說是否困難	Ü	2	4
5. 洗澡或沐浴對你來說是否困難	0	2	4
6. 做家務(如收拾你的玩具)對你來說	D)	2	4
是否困難			
7. 有沒有受傷或痛楚(在那裡)	0	2	-1
8. 有沒有覺得倦到不忍玩	U	2	4

記得,告訴我在過去幾週你有多少困難

情緒功能(困難爲)	並不全是	有時	幾多是
1. 你會不會感覺告怕或驚嚇	0	5	4
2.你會不會感覺憂傷	0	2	4
3. 感覺憤怒	0	2	4
生你有沒有睡眠困難	Ū	2	4
5. 你會不會擔憂你將會幾生的事	0	2	4

社交功能(因難爲)	並不全是	有時	幾多是
1. 你是不是與其他孩子相處困難	Ú	2	+
2. 其他孩子有否說他們不願與你玩耍	0	2	4
3. 其他孩子有沒有戲弄你	0	2	4
4.你是否沒法做其他孩子所能做的事情。	U	2	4
5.在與其他孩子況要時你是否有困難跟	0	2	4
; 得上			

學習功能(困難爲)	並不全是	有時	幾多是
1.你在上學時是否難集中注意力	0	2	4
2. 你會不會忘記事物	0	2	+
3.是否在家课的跟渡上有困難	0	2	·I
4.你有沒有缺课因為不適	Ú	2	4
5.你有沒有缺課因爲要看醫生或到醫	0	2	4
院			

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Appendix 4 First Chinese PedsQL

# **PedsQL**<sup>TM</sup>

## 兒童生活品質 調査清單 <sup>第四版</sup>

學步兒童之父母報告(年齡2-4歲)



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在過去一個月中,您的孩子面對下列各項問题的困難程度......

身體功能(困難於)	從不	幾乎從不	有時	經常是	幾乎轉是
1. 步行	0	1	2	- 3	4
2.跑步	0	1	2	3	4
3. 參與激烈的遊戲或運動	0	1	2	3	4
1. 提舉較重之物	U	1	2	3	4
5. 洗澡	0	1	2	3	4
6.割忙设拾他/她的玩具	0	1	2	3	4
7. 曾有受傷或疼痛	0	!	2	3	4
8.精力不足	0	1	2	3	4

情緒功能(困難於)	從不	<b>幾乎從</b> 不	有時	經常是	幾乎總是
1. 感覺告怕或驚嚇	0	1	2	3	4
2. 感覺悲哀或變傷	0	1	2	3	4
3. 感覺憤怒	0	1	2	3	4
4. 延眠 困難	0	1	2	3	4
5. 擔憂	0	1	2	3	4

社交功能(困難於)	從不	幾乎從不	有時	絕常是	幾乎總是
1. 與別的孩子玩耍	0	1	2	3	4
2. 別的孩子不顾师他/她玩耍	0	1	2	3	4
3. 被别的孩子戴乔	0	1	2	3	·
4. 不能做別的同年齡孩子所能做的事情	Ü	1	2	3	4
5. 與別的孩子玩要時能跟得上	0	l	2	3	4

#### \*如!果您的孩子有上學或是没托兒所,請完成這部份。

就學功能(困難於)	從不	幾乎從不	有時	經常是	幾乎總是
1. 從事其他周輩也進行的學校活動	Ü	1	2	3	4
2. 因爲感到不適而缺課/席	0	: ]	2	3	4
3. 因爲要看醫生或到醫院而缺課/席	; 0	1	2	3	4

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# **PedsQL**<sup>TM</sup>

## 兒童生活品質 調査清單 <sup>第四版</sup>

幼童之父母報告(年齡 5-7 歲)



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在過去一個月中,您的孩子面對下列各項問題的困難程度......

身體功能(困難於)	從不	幾乎從不	有時	經常是	幾乎總是
1.步行超過 [[[路口的距離]]	U	1	2	.3	4
.2. 跑步	υ	1	2	3	4
3. 參與體朝活動或運動	0	1	2	3	4
4.提升較重之物	Ú	1	2	3	4
5. 他/她自己洗澡或沐浴	0	1	2	! ૧	4
6. 做家務, 例如收拾他/她的玩具	0	1	2	3	
7. 曾有受傷或疼痛	0	1	2	3	4
8. 精力不足	U	1	2	3	4
······································					

情緒功能(困難於)	従不	幾乎從不	有時	經常是	幾乎轉是
1.感覺害怕或驚嚇	0	]	2	3	4
2. 感覺悲哀或憂傷	0	1	2	3	4
3. 感覺憤怒	0	1	2	3	4
4. [[[]]]]]]]]]]]]]]]]]]]]]]]]]]]]]]]]]]	Ü	1 1	2	3	. 1
5. 擔心將會發生在他/她身上的事情	1 0	: 1	2	3	·ł

社交功能(困難於)	從不	幾乎從不	有時	絕常是	幾乎總是
1. 與別的孩子融洽相處	U	1	2	3	4
2. 別的孩子不願和他/她作朋友	0	l	2	3	4
3. 被別的孩子戲弄	0	. 1	2	3	4
玉不能敬则的同年齡孩子所能做的事情	0	1	2	3	4
5. 與別的孩子玩吸時能跟得止	0	1	2	3	4

就學功能(困難於)	● 樅不二	幾乎從不	有時	羅常是	幾乎總是
1. 上課時集中精神	D.	1	2	3	4
2. 忘記東西	U	1	2	3	4
3.跟得上學校的活動	0	l	2	3	
4 因爲感到不適而缺課	0	1	2	3	-1
5. 因爲要看醫生或到醫院而缺課	Û	1	2	3	4

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# **PedsQL**<sup>TM</sup>

## 兒童生活品質 調査清單

#### 第四版

### 幼童報告(年齡 5-7 歲)

訪問者指引:

我現在要問你一些問題,問題裡提到的事情對有些小朋友可能是一個困難。我想知道這 些事情對你可能有多難。

顯示表情劑給小孩看,並且閱讀下列說明,同時指著每個所提到的表情。

如果這對你來說完全沒有困難,請指向微笑圖樣

如果這對你來說有時候有困難,請指向中間的圖樣

刘杲道對你來說有很多困難,請指向數層的圖樣

我會讀出每一道題目。請指出一個表信,來告訴我這件事對你來說有多困難。讀我們先 來練習一下。

	完全沒有	有時	有很多
彈指發出聲音,對你來說是否困難	$\odot$		3

要求小孩示範僅他或她的手指,以確定問題是否記確回答。如果小孩指出的表情和他/她 的動作不符,重覆原来的問題。

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### 想一想過去幾個星期你過得如何。請仔細聽清楚每個句子,然後告訴我,這些事情對你 來說有多困難。

在讀過每項問題之後,把孩子引向表情圖,如果小孩遲疑或似乎不明白該如何回答,便謝 讀回燒雞項同時指向該表情。

身體功能(困難於)	完全沒有	有時	有很多
1. 步行對你來說是否困難	0	2	4
2. 跑步對你來說是否困難	0	2	4
3. 體能活動或運動對你來說是否困難	0	2	. 1
4.提起一些大物件對你來說是否困難	Ü	Ë	4
5. 洗澡或沐浴到你來說是否困難	0	2	4
6 敏家務(如政拾你的玩具)對你來說是否困難。	0	2	4
7.你有沒有受傷或疼疼(在那裡?)	0	2	-1
8. 你有沒有曾覺得累到不想玩	i 0	2	4

記住,告訴我在過去幾個星期內,這些事情對你來說有多困難。

情緒功能(困難於)	完全沒有	有時	有很多
1.你有沒有感覺害怕或驚嚇	i D	2	4
2. 你有沒有感覺憂傷	U	2	-1
3. 你有沒有感覺慣怒	0	2	+
4. 你睡覺有沒有困難	0	2	4
5.你有沒有擔心將會發生在你身上的事	U	2	-1

社交功能(困難於…)	完全沒有	有時	有很多
1. 與別的孩子相處,對你來說是否困難	0	2	4
2. 别的孩子有沒有說不顧意與你一同玩耍	0	2	4
3. 別的孩子有沒有戲弄你	0	2	4
4. 别的孩子是不是能做一些你辦不到的事	<u> </u>	2	4
5. 在與其他孩子玩耍時你是否很難跟…他們	0	2	4

就學功能(你有沒有這些問題)	完全沒有	有時	有很多
1. 你在上學時是否很難集中注意力	0	2	4
2.你有沒有宗記東西	Ű	2	i 4
3. 你是否很難張得上學校的功課	0	2	-4
4.你有沒有因爲感到不適而缺課	0	j 2	4
5. 你有沒有因為要看醫生或到醫院而缺課	0	2	4

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Appendix 5 Backward A

# **PedsQL**<sup>TM</sup>

## Quality of Children's Life Assessment checklist

Forth Edition

For parents of toddlers (Age 2 - 4)

#### Instructions

Your child may have problems in the things mentioned in the following page. Please evaluate how difficult it is to your child in doing the following things or did he/she have the following mentioned problems last month, and circle the appropriate answers.

0 If he/she never finds it is difficult

If he/she finds it is almost never difficult.

2 If he/she sometimes finds it is difficult

3 If he/she always finds it is difficult

If he/she finds it is difficult almost every time

There is no absolute answer to the questions. If you have problems in understanding any of the questions, please ask for assistance.

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Did your child have difficulty in doing the following things? Or did he/she have problems of the followings in last month?

Physical problems	Never	Almost Never	Sometimes	Aiways	Almost every time
1. Walking	0	1	2	3	4
2. Running	<u>0</u>	1	2		4
3. Participaung in games or sport activities	0	1	2	3	4
4. Lifting up heavy objects	0	1	2	3	4
5. Taking a bath	0	1	2	j _3	4
6. Helping to tidy up his/her own toys	Ű	1	2	3	4
7. Being injured or feeling painful	0	l	2	3	4
8. Always feeling fired	0	1	2	3	4
Emotional problems	Never	Almost Never	Sometimes	Always	Almost every time
1. I ceiing frightened or scared	Ú	1	2	3	4
2. Feeling sad or sorrow	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Having problem in sleeping	0	1	2	3	+
5. Ecching anxious	0	1	2	3	4
Problems in social interaction	Never	Almost Never	Sometimes	Always	Almost every time
1. Playing with peers	[ U _	1	2	ĥ	4
<ol><li>Other kids were not willing to play with him/her</li></ol>	0	1	2	3	
3 Being hulhed by other kids	. ()	1	2	3	-1
4. Unable to do the same things as kids of j similar sec	0	1	2	3	
5. Following other kids when playing	<u> </u>	1	2	3	<u>ز_ب_</u>

#### \*If your child is going to school or nursery, please finish the following parts.

Problems in school	Never	Almost Never	Sometimes	Always	Almost every
<ol> <li>Participating in school activities as his/her schoolmates</li> </ol>	Ū	1	2	3	4
2. Absence from school because he/she was	Û	1	2	3	+
3. Absence from school because he/she went to doctor or hospital	0	1	2	3	

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# **PedsQL**<sup>TM</sup>

## Quality of Children's Life

## Assessment checklist

Forth Edition

For parents of children (Age 5 - 7)

- 0. If he/she never finds it is difficult
- 1 If he/she finds it is almost never difficult
- 2 If he/she sometimes finds it is difficult
- 3. If he/she alwaya finds it is difficult
  - If he/she finds it is difficult almost every time

There is no absolute answer to the questions. If you have problems in understanding any of the questions, please ask for assistance.

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Did your child have difficulty in doing the following things? Or did he/she have the problems of followings last month?

Physical problems	Never	Almost	Sometimes	Always	Aimost
1. Walking for more than one block distance	···	1 1 1 1		+ · · _	every time
2. Running	$+ \frac{\circ}{\circ}$	<u>+</u> _1	<u> </u>	1 3	4
3. Participating in physical exercises of sport	$-\frac{0}{0}$		<u>-</u>	· · <u>· · · · · · · · · · · · · · · · · </u>	44
activities	1 0		2	3	4
4. Lifting up heavy objects	- <u>-</u>				<u> </u>
5. Taking a bath or shower by himself/herself	+ <u> </u>	+	$\frac{2}{2}$	· · · · · ·	4
6. Doing housework, such as tidying up his/her		i — .	+	Ļ_`	4 _
own toys	0	1	2	3	4
7. Being injured or feeling painful	+ 0 - 0	+ <u> </u>			
8. Always feeling too tired	0	1	+		
Emotional problems	Never	Almost	Sometimes	A herioarce	4
· · · · · · · · · · · · · · · · · · ·		Never	CONTENTINE &	niways	Almost
1. Feeling frightened or scared	0	1	<u>+</u>	3	cvery une
2. Feeling sad or sorrow	† <u>0</u>	+ <u>-</u>			<sup>+</sup>
3. Feeling angry	0 -	1	2		<del>- 4</del> - 1
4. Having problem in sleeping	0	1	<u></u>		<del>-</del>
5. Feeling anxious on what may happen to	0	+ <u>-</u> 1	<u>+ -</u>		
him/her					
Broblems in market		Almost	<u> </u>	·· <del>···</del> · ·	Almost
a mole line in social interaction	Never	Never	Sometimes	Always	every
1 Cetting alana with act on bill	<u> </u>	<u> </u>	<b></b>		time
2 Orber Iride unity and a the state	$\frac{1}{1}$ $\frac{0}{1}$	<u>  1</u>	2	3	4
him that	0	l 1	2	3	4
Baing bulling by set as 1 1		<u>!</u>			
4 Uzahla to du chines 10	i . <u>0</u>	1	2	3	4
age	0	1	2	а Т	
5 Following when hids the state	, <u> </u>	· -		.1	·+
3. I blowing onict kids when playing together		!	2	3	4
Problems in school			_		Almost
	Never	Ahmost	Sometimes /	Always	Every
1. Concentrating in classes		Never			time
2. Forgetting things	<u> </u>	1	2	3	4
3. Participating in school activities	— ° —		2	3	4
4. Absence from school begance hadden and it	<u> </u>		2	3	4
5. Absence from school because he /she was sick	- <u>-</u> 11	1	<sup>2</sup>	3	4
doctor or hospital	0	1	2	3	4
	· · ·		I	1	1

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## PedsQL<sup>TM</sup> Quality of Children's Life Assessment checklist Forth Edition

## For Children (Age 5 - 7)

Instructions to interviewers 3

I am going to ask you some questions. Some children will find that the things mentioned in the following sentences are difficult. Please let me know how difficult these things are for you.

Show the child the picture of the three facial gestores to him/her. Read the following instructions and point to the relevant pictures at the same time.

If the thing in the sentence is not difficult to you at all, please point to the smiling face,

If the thing in the sentence is sometimes difficult to you, please point to the face in the middle.

If the thing in the sentence is very difficult to you, please point to the unhappy face.

Pll read the questions and please point to the pictutes that you think how difficult it is to you. Let have a practice first.

Is it difficult to you to make a sound with	Not difficult	Sometimes difficult	Very difficult
your fingers?			8

Ask the child to make a sound and make sure that he/she is pointing to the correct answer. If the child points to a different picture with bis/her answer, repeat the question to him/her again.

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## Try to think how's your life in the past few weeks. Please listen to every sentence carefully and tell me if you have problems as followings in the past few weeks.

After reading each sentence, show the child the pictures of the facial gestures. If the child hesitates or seems not understand what to do, read the instructions regarding the choices again and points to the relevant pictures.

Physical problems	Not difficult	Sometimes difficult	Very difficult
1. Is walking difficult to you?	0	2	<u> </u>
2. Is running difficult to you?	0		<u> </u>
3. Is playing sport games or physical exercises	; <u> </u>	2	
difficult to you?		-	т
4. Is lifting up a big object difficult to you?		2	
5. Is taking a shower or a bath difficult to you?		2	+
6. Is doing housework, for example tudying up your		— <u>-</u>	t── ∡───┥
own toys, difficult to you?	_	2	
7. Have you been injured or felt hurt in the past few		— , <u> </u>	
weeks? (Where did you hurt?)		-	
8. Have you ever felt too tired to play?	0		└──_₄ ──┤

Remember, tell me that did you have the following problems in the past few weeks?

Emotional problems	Not difficult	Sometimes difficult	Very difficult
1. Have you felt frightened or scared?	0	2	+
2. Have you felt sad?	0	2	4
3. Have you felt angry?	0	2	4
4. Did you have problems in sleeping?	0	2	<u> </u>
5. Did you worried about what may happen to you?	0	2	÷ <u> </u>
Problems in social interaction	Not difficult	Sometimes	Very difficult
1. Is getting along with other kids difficult to you?	0	2	1 <u> </u>
<ol> <li>Did any of your peers telling you that he/she didn't want to play with you?</li> </ol>	0	2	4
3. Have you ever been builled by other kids?	0		4
4. Did other kids do something that you cannot do?		2	
5. Is it difficult to follow other kids when playing together?	0	2	
Problems in school	Not difficult	Sometimes difficult	Very difficult
1. Is it difficult to concentrate in classes?	0	2	! 
2. Have you forgotten something?	0	2	1
3. Is it difficult to follow the homework from school?	· · · · · ·	2	4
4. Have you been absent from school because you were sick?	0 +	2	4
5. Have you been absent from school because you went to doctor or hospital?	0	2	4

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## Appendix 6 Backward B

## Pediatrics Quality of Life Questionnaire (Version 4) Toddler's Report from Parents (Age 2-4)

#### Instructions:

Your child may find some of the tasks listed in the following page difficult to perform. Please indicate the degree of difficulty that you think your child has encountered for the past month by circling the appropriate choice.

- 0 If the task has never been a problem
- 1 If the task rarely is a problem
- 2 If the task sometimes is a problem
- 3 If the task frequently is a problem
- 4 If the task almost always is a problem

There are no right or wrong answers to the questions. If there are queries to any of the questions, please ask for help.

During the past month, the degree of difficulty that you think your child has encountered for each of the following questions:

```
Never / Almost never / Sometimes / Frequently / Almost always /
```

Physical function (Difficult in)

- 1. Walks
- 2. Runs
- 3. Participates in rigorous play or exercises
- 4. Lifts objects of different weights
- 5. Baths
- 6. Helps in putting own toys away
- 7. Had been injured or hurt
- 8. Lack of energy

Emotional function (Difficult in ... )

- 1. Feels afraid or startles
- 2. Feels sad or worried
- 3. Feels angry
- Difficulty in sleeping
- 5. Worries

Social Function (Difficult in ...)

- 1. Plays with other children
- 2. Other children not willing to be his/her friends
- 3. Teased by other children
- 4. Cannot perform tasks that same age peers can do
- 5. Can catch up with other children in play

Learning Function (Difficult in ...)

- 1. Engages in school activities that same age peers do
- 2. Absent from classes due to sickness
- 3. Absent from classes due to doctors' or hospital's visits

## Pediatrics Quality of Life Questionnaire (Version 4) Child's Report from Parents (Age 5-7)

#### Instructions:

Your child may find some of the tasks listed in the following page difficult to perform. Please indicate the degree of difficulty that you think your child has encountered for the past month by circling the appropriate choice.

- 0 If the task has never been a problem
- 1 If the task rarely is a problem
- 2 If the task sometimes is a problem
- 3 If the task frequently is a problem
- 4 If the task almost always is a problem

There are no right or wrong answers to the questions. If there are queries to any of the questions, please ask for help.

During the past month, the degree of difficulty that you think your child has encountered for each of the following questions:

Never / Almost never / Sometimes / Frequently / Almost always

Physical function (Difficult in)

- 1. Walks more than one block's distance
- 2. Runs
- 3. Participates in physical activities or exercises
- 4. Lifts objects of different weights
- 5. He /she bathes on his/her own
- 6. Performs housekeeping tasks, for example, putting own toys away
- 7. Had been injured or hurt
- 8. Lack of energy

Emotional function (Difficult in ... )

- 1. Feels afraid or startles
- 2. Feels sad or worried
- 3. Feels angry
- 4. Difficulty in sleeping
- 5. Worries about things that can happen to him/ her

Social Function (Difficult in ...)

- 1. Gets along well with other children
- 2. Other children not willing to be his/her freinds
- 3. Teased by other children
- 4. Cannot perform tasks that same age peers can do
- 5. Can catch up with other children in play

Learning Function (Difficult in ...)

- 1. Concentrates during class
- 2. Forgetful
- 3. Able to follow school activities
- 4. Absent from classes due to sickness
- 5. Absent from classes due to doctors' or hospital's visits

### CHILD'S REPORT (AGED 5 -7)

Instruction for Administration of questionnaire:

Now I am going to ask you a few questions. In these questions, I may mention some tasks that some children may find difficult to do. I would like you to tell me how difficult you think these tasks are for you.

(Show the child the expression pictures, and read to the child the following instructions and point to each expression picture as you mention it.)

If the task is not difficult to you at all, please point to the picture with the smilie face. If the task you sometimes find difficulty in doing, please point to the expression picture in the middle.

If the task is very difficult for you to do, please point to the picture with a frownie face. I will read out each question, please point to one expression picture to tell me how difficult you think the task is for you. Let us first have a trial practice.

#### Do you think it is difficult for you to snap your fingers to make a noise?

(Not at all / sometimes / always)

Ask the child to demonstrate with his/her fingers to determine if the question has been answered correctly or not. If the expression picture to which the child has pointed differs from his/ her action, repeat the original question.

## Think about how you have done in the past few weeks. Listen to every sentence carefully. Then tell me how difficult the task is for you.

After reading each question, direct the child to the expression pictures. If the child hesitates or seems not knowing what to do or how to answer, read the response choices to the child again and at the same time point to the expression pictures.

/ Not at all / Sometimes / Always

Physical Function (Difficult in ...)

- 1. Do you think it is difficult for you to walk?
- 2. Do you think it is difficult for you to run?
- 3. Do you think it is difficult for you to do physical activities or exercises?
- 4. Do you think it is difficult for you to lift up a big object?
- 5. Do you think it is difficult for you to take a bath?
- 6. Do you think it is difficult for you to help in household chores such as putting toys away?
- 7. Have you been injured or hurt? (where ?)
- 8. Have you felt too tired to play?

Remember, tell me for the past few weeks, what you think how difficult the task has been for you?

Emotional Function (Difficult in ...)

- 1. Have you felt frightened or startled?
- 2. Have you felt worried?
- 3. Have you felt angry?
- 4. Do you have difficult in sleeping?
- 5. Have you worried about things that could happen to you?

Social Function (Difficult in ...)

- 1. Do you think it is difficult for you to get along with other children?
- 2. Are other children willing to play with you?
- 3. Have other children teased you?
- 4. Are there things that other children can do but you cannot?
- 5. Is it difficult to catch up with other children in play?

Learning Function (Difficult in ...)

- 1. Is it difficult for you to concentrate in class?
- 2. Have you forgotten about things?
- 3. Do you have difficulties in catching up school work?
- 4. Have you been absent from school because you do not feel well?
- 5. Have you been absent from school because you need to go to a doctor's or hospital's visit?

To what extent is the task of difficulty to you?

/Completely None / Sometimes / Most Frequently

Appendix 7 Backward C

## PedsQL The list of the survey on the quality of life in children 4th edition

The parental report of toddler (age 2 to 4)

Instructions

For your child, some of the situations listed in the following page, may possibly experience certain level of difficulty. Please circle the answers and tell us the degree of difficulty of your child experienced on each event in the last month.

- 0 if it has never been considered as a difficulty
- 1 if it has seldom been considered as a difficulty
- 2 if it has sometimes been considered as a difficulty
- 3 if it has always been considered as a difficulty
- 4 if it has often been considered as a difficulty

There is no absolutely correct answer. If you do not understand the question, please ask for assistance. In last month, what is the degree of difficulty of your child in the following situations...

Physical function (difficult to)	Never	Seldom	Sometimes	Always	Often
1. Walking	0	1	2	3	4
2. Jogging	0	1	2	3	4
3. Attending physical activity or	0	1	2	3	4
sports					
4. Lifting heavy object	0	1	2	3	4
5. Taking bath	0	1	2	3	4
6. Tidy up his/her toys	0	1	2	3	4
7. Get injury or have pain	0	1	2	3	4
8. Not energetic	0	1	2	3	4
Emotional function (difficult to)	Never	Seldom	Sometimes	Always	Often
1. Feel frighten or scare	0	1	2	3	4
2. Feel grief or upset	0	1	2	3	4
3. Feel angry	0	1	2	3	4
4. Difficult to get sleep	0	1	2	3	4
5. Anxiety	0	1	2	3	4
Social function (difficult to)	Never	Seldom	Sometimes	Always	Often
1. Experience difficulty in relating	0	1	2	3	4
with other children					
2. Other children refuse to play with	0	1	2	3	4
him/her					
3. Other children play a joke on	0	1	2	3	4
him/her					
4. Something that he/she do not	0	1	2	3	4
have the ability to accomplish,					
when compare to other children					
with similar age?					
5. Catch up with other children while	0	1	2	3	4
playing					
	1	T		1	1
Schooling function (difficult to)	Never	Seldom	Sometimes	Always	Often
1. Participate in the school activity as	0	1	2	3	4
the peer					

1. I articipate in the sensor activity as	0	1	4	5	т
the peer					
2. Absence from the class due to sick	0	1	2	3	4
3. Absence from the class due to	0	1	2	3	4
attending to physician or hospital					

# The list of the survey on the quality of life in children 4th edition

## The parental report of young children (age 5 to 7)

#### Instructions

For your child, some of the situations listed in the following page, may possibly experience certain level of difficulty. Please circle the answers and tell us the degree of difficulty of your child experienced on each event in the last month.

- 0 if it has never been considered as a difficulty
- 1 if it has seldom been considered as a difficulty
- 2 if it has sometimes been considered as a difficulty
- 3 if it has always been considered as a difficulty
- 4 if it has often been considered as a difficulty

There is no absolutely correct answer. If you do not understand the question, please ask for assistance. In last month, what is the degree of difficulty of your child in the following situations...

Physical function (difficult to)	Never	Seldom	Sometimes	Always	Often
1. Walking up to a distance of a block	0	1	2	3	4
2. Jogging	0	1	2	3	4
3. Attending physical activity or sports	0	1	2	3	4
4. Lifting heavy object	0	1	2	3	4
5. Taking bath or shower by	0	1	2	3	4
himself/herself					
6. Doing domestic work such as tidy	0	1	2	3	4
up his/her toys					
7. Get injury or have pain	0	1	2	3	4
8. Not energetic	0	1	2	3	4
¥					
Emotional function (difficult to)	Never	Seldom	Sometimes	Always	Often
1. Feel frighten or scare	0	1	2	3	4
2. Feel grief or upset	0	1	2	3	4
3. Feel angry	0	1	2	3	4
4. Difficult to get sleep	0	1	2	3	4
5. Worry something will happen on	0	1	2	3	4
him/her					
Social function (difficult to)	Never	Seldom	Sometimes	Always	Often
1. Experience difficulty in relating with	0	1	2	3	4
other children					
2. Other children refuse to play with	0	1	2	3	4
him/her					
3. Other children play a joke on	0	1	2	3	4
him/her					
4. Something that he/she do not have	0	1	2	3	4
the ability to accomplish, when					
compare to other children with					
similar age?					
5. Catch up with other children while	0	1	2	3	4
playing					
	I	I	1		
Schooling function (difficult to)	Never	Seldom	Sometimes	Always	Often
1. Get concentration in the class	0	1	2	3	4
2. Forget things	0	1	2	3	4
3. Catch up with the school activity	0	1	2	3	4
4. Absence from the class due to sick	0	1	2	3	4
5. Absence from the class due to	0	1	2	3	4
attending to physician or hospital					
## The list of the survey on the quality of life in children 4th edition

The report of young children (age 5 to 7)

Instructions to the interviewers:

Now, I will ask you some questions concerning the situations that some children may consider them to be the difficult circumstances. And I like to know the degree of difficulty you will be expected in those situations.

Present the pictures with different 'faces' to the children, read the following instructions and point to the corresponding faces.

If you consider it produces absolutely no difficulty to you, please point to the 'smiling' face.

If you consider that sometimes it appears to have difficulty to you, please point to the middle picture.

If you consider it contains much difficulty to you, please point to the 'sad' face.

I will read out each question. Please point to one of the 'face' and tell us how difficult you experience on this event. Let us practise once.

	No	Sometimes	Always
Is it difficult for you to produce a sound by			
flicking your fingers?			

Ask the child to show how to flick his/her fingers to ensure giving the correct answer. If the child points to the picture that is inconsistency to the action, please repeat the question again.

## Try to remember the feelings in the past few weeks and listen carefully to each sentence, then tell me how difficult you experienced on the following events.

After you read out the question, show the pictures of different 'faces' to the children. If the children doubt or seem to be not understood to the questions, please read the choices of answer and point to different 'faces'.

Physical function (difficult to)	No	Sometimes	Always
1. Did walking produce any difficulty to you?	0	2	4
2. Did running produce any difficulty to you?	0	2	4
3. Did physical activity or exercise produce any difficult to you?	0	2	4
4. Did lifting large object produce any difficulty to you?	0	2	4
5. Did taking a bath or shower produce any difficulty to you?	0	2	4
6. Did domestic work (such as tidy up your toys) produce any	0	2	4
difficulty to you?			
7. Did you get injury or pain? Where?	0	2	4
8. Did you ever feel tried and didn't want to play?	0	2	4

Remember, please tell me, in the past few weeks, about the degree of difficulty you experienced on these events.

Emotional function (difficult to)	No	Sometimes	Always
1. Did you feel frighten or scare?	0	2	4
2. Did you feel grief?	0	2	4
3. Did you feel angry?	0	2	4
4. Did you have difficulty to get sleep?	0	2	4
5. Did you worry something will happen on you?	0	2	4

Social function (difficult to)	No	Sometimes	Always
1. Did you have any difficulty in relating with other children?	0	2	4
2. Did any child refuse to play with you?	0	2	4
3. Did any child play a joke on you?	0	2	4
4. Did you have anything that you do not have the ability to	0	2	4
accomplish, when compare to other children?			
5. Did you hard to catch up with other children while playing?	0	2	4

Schooling function (Do you have these problem?)	No	Sometimes	Always
1. Did you hard to get concentration in school?	0	2	4
2. Did you ever forget things?	0	2	4
3. Did you hard to catch up with the school works?	0	2	4
4. Did you absence from the class due to sick?	0	2	4
5. Did you absence from the class due to attend the physician or	0	2	4
hospital?			

How difficulty you will expect?

No / Sometimes / Always
Appendix 8 Second Chinese PedsQL

# **PedsQL**<sup>TM</sup>

## 兒童生活品質 調査問卷

學步兒童之父母報告(年齡2-4歲)



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在過去一個月中,您的孩子面對下列各項事情有多少困難......

身體功能(困難在於)	從來沒有	幾乎沒有	偶爾有	經常有	一直有
1. 步行	Ŭ	Ι	2	3	4
2. 购步	0	1	2	3	4
3. 参加活躍的遊戲或運動	0	1	2	3	+
4.提起較重的東西	0	l	2	3	+
5. 浣澡	Ú	1	2	3	4
6. 幫忙收拾他/她的玩具	0	1	3	3	-1
7. 曾經受傷或有疼痛	0	1	2	.3	4
8. 稍力不足	Ú	1	2	3	4

情緒功能(困難在於)	從來沒有	幾乎沒有	偶爾有	經常有	一直有
1 感到害怕或驚嚇	0	1	2	3	-4
2. 感到悲哀或漫傷	0	1	2	3	4
3. 感到供氣	0	1	2	3	-+
4. 峄岐有困難	Ů	1	2	3	4
5. 擠憂	0	1	2	3	4

社交功能(困難在於)	從來沒有	幾乎沒有	偶爾有	經常有	一直有
1. 與其他孩子玩要	Ü	1	2	- 3	4
2. 其他孩子不要跟他/她玩要	0	1	2	3	4
3. 被其他孩子作弄	0	1	2	3	4
4.其他同年齡孩子能做的虾情,他不能	0	1	2	3	1
5.玩耍诗跟上其他孩子	0	f	2	3	4

#### \*如果您的孩子有上學或是送托兒所,請完成這部份。

就學功能(困難在於)	從來沒有	幾乎沒有	偶爾有	泛常有	一直有
1. 做其他朋辈也進行的學校活動	0	1	2	3	4
2.因爲身體不舒服而試課/席	U U	1	2	3	-1
3. 因爲要看醫生或到醫院而缺課/為	T 0 —	1	2	3	4

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# **PedsQL**<sup>TM</sup>

## 兒童生活品質 調査問卷 <sup>第四版</sup>

### 幼童之父母報告(年齡 5-7 歲)



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在過去一個月中。您的孩子面對下列各項事情**有多少困難......** 

身體功能(困難在於)	從來沒有	幾乎沒有	個爾有	經常有	一直有
1.步行起過一個路口的距離	0	1	2	3	4
2. 炮步	0	1	2	3	4
3. 參加體解活動或運動	0	1	2	3	4
4. 提起重的東西	0	1	2	3	4
5. 他/她自己洗澡或沐浴	Ú	1	2	3	-1
6. 徽家務、像:收拾他/她的玩具	0	1	2	3	4
7. 曾經受傷或有疼痛	0	1	2	3	4
8. 精力不足	0	1	2	3	4

情緒功能(困難在於)	從來沒有	幾乎沒有	偶爾有	經常有	一直有
1.感到害怕或驚嚇	Ú	1	. 2	3	4
2. 感到悲哀或憂傷	0	I	2	3	4
3. 感到生氣	0	1	2	3	+
4. 睡眠有困難	Ü	1	2	3	-1
5. 擔心會有事發生在他/她身上	0	1	2	3	4

社交功能(困難在於)	從來沒有	幾乎沒有	個葡萄	經常有	直有
1.與其他孩子和睦相處	Ċ	1	2	3	4
2. 其他孩子不要跟他/她作朋友	0	1	2	3	4
3. 被其他孩子戲弄	A	1	2	3	4
4. 其他同年齡核子能做的事情,他不能 效	A	1	2	3	4
5. 玩耍時服上其他孩子	V	1	. 2	3	+

就學功能(困難在於)	從來沒有	幾乎沒有	偶爾有	經常有	
1. 上課時集中精神	0	1	2	3	Ţ
2. 忘記對情	0	'	2	3	4
3. 跟上學校的活動	U	1	2	3	4
4. 医爲身體不舒服而缺課	0	1	2	3	· <b>1</b>
5.因爲要看醫生或到醫院而缺課	ถ	1	2	3	4

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# PedsQL<sup>TM</sup> 兒童生活品質 調査問卷

### 幼童報告(年齡5-7歲)

訪問者指引:

我現在要問你一些問題,問題裡提到的事情對有些小朋友可能是一個困難。我想知道這 些事情對你會有多少困難。

顯示表情圖給小孩看,並且閱讀下列說朝,同時指著每個所提到的表情。

如果它對你完全沒有困難,請指向微笑圖樣

如果它對你有時候有困難,請指向中間的圖樣

如果它對你有很多困難,請指向數層的圖樣

*我會讀出每一道題目。請指出一個表情,來告訴我那件專對你有多少困難。讓我們先讓* 習一次。

	完全沒有	有時有	有很多
軍腳跳兩次,對你是否困難	0		$\odot$

請小孩做出單腳跳,以確定問題是否正確回答。如果小孩指出的表情和他/她的表現不 符,重覆此問題。

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#### 想一想過去幾個星期你怎麼樣。請小心聽清楚好一句,然後告訴我,這些事情對你有多 少困難。

右讀用每項問題之後,把孩子引向表清圖,如果小孩遲疑或似乎不到自該如何回答,便讀 用回應選項並同時指向該表情,

身體功能(困難在於,,)	完全沒有	有時有	有很多
1.步行對你有困難嗎	. 0	2	-1
2.跑步對你有困難嗎	0	2	4
3 參加體育活動或運動對你有困難嗎	۵	2	: 4
4. 拿起人的東西對你有困難嗎	0	2	4
5.洗澡或沐浴對你有困難嗎	. 0	2	-1
6 做家務(像收拾你的元具)對你有困難嗎	Û	2	4
7.你有沒有受傷或疼痛(在那裡? )	0	2	4
8. 你有沒有曾經覺得累到不想玩	U	2	4

記住。告訴我在過去幾個星期內,這些事情對你病多少困難。

情緒功能(困難在於)	完全沒有	郁	夺有	有很多
1.你有沒有感到害怕	0		2	4
2. 你有沒有感到傷心	D		2	4
3. 你有沒有感到生氣	0		2	+
4. 你有沒有睡覺困難	0		2	1
5. 你有沒有協心會有事發生在你身上	0		2	4

社交功能(困難在於…)	完全沒有	有時有	有很多
1.與其他孩子相處,對你有困難嗎	0	2	4
2. 其他孩子有沒有說不想跟你一起玩	Û	2	4
3. 其他孩子有沒有作弄取笑你。	Ü	2	4
王其他孩子是不是能做一些你做不到的儿	0	2	4
5. 跟其他孩子玩耍時你跟上他們有困難嗎	0	2	4

就學功能(困難在於)	完全沒有	有時有	有很多
1. 在学校你很難集中注意力嗎	0	2	4
2. 你有忘記事情嗎	0	2	4
3.跟上學校的功課困難嗎	U U	2	4
4 你有沒有因爲感到不能服而缺謬	0	2	-1
5. 你有沒有因意要有醫生或去醫院面試影	¥ <u>ö</u>	2	4

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Appendix 9 Third Chinese PedsQL

## PedsQL<sup>TM</sup> 兒童生活品質 調査問卷 <sup>第四版</sup>

學步兒童之父母報告(年齡2-4歲)



PerisQL40 Parent (2-4)01/00 未經許可不得翻印。 版權低 JW Vana, Ph.D 所有。 "在過去一個月中,您的孩子在下列各項事情有多少困難.......

身體功能(困難在於)	完全沒有 困難	幾乎沒有 困難	偶爾有 困難	経常有 困難	一直有困難
1. 步行		I	2	3	4
2. 跑步	Û	1	2	3	j 1
3. 參加活躍的遊戲或運動	0	1	2	3	4
4.提起一些重的東西	0	- 1	2	3	4
5.洗澡	0	1	2	3	4
6.幫忙救措他/她的玩具	0	1	2	3	-1
7.曾經受傷或有疼痛	0	1	2	3	4
8. 精力不足	0	1	2	3	1

情緒功能(困難在於)	完全沒有	<b>券</b> 乎沒有	倒爾有困	經常有	一直有
	() <u>Kroświe</u>	· <u><u></u></u>	2	3	- di Azaitata
- 2833月1日2月26月36月36日 2月28日月1日(1月26月36日) 2月28日日(1月26月36日)		1	- 	- 3	4
▲33.41笏℃%34 <u>4</u>	i 0	, , 1			, 1
	0	1		3	1
	<u></u> μ. δ	: ······ 1	2	3	.1
2. ////////////////////////////////////	v		ت ا	·	

社交功能(困難在於)	完全沒有	幾乎沒有	偶爾有	繼常有	一直有
	困難	困難	困難	医離	離困
1. 與其他孩子玩耍	Ŭ	1	2	3	4
2. 其他孩子不要跟他/她玩耍	0	1	2	3	4
3. 被其他孩子戲弄	0	1	2	3	-1
王 其他司年齡孩子能做的申请,他不能做	0	1	2	3	4
5. 玩耍時報上其他孩子	0	1	2	3	4

#### \*如果您的孩子有上學或是送托兒所,請完成道部份。

就學以能(困難在於)	完全沒有	幾乎沒有	偶爾有	經常有	一直有
	玉難	困難	機	困難	困難
1. 做其他閒輩也進行的學校活動	0	1	2	3	4
2.因爲身體不舒服而缺課/席	0	1	2	3	4
3. 因為要看醫生或到醫院而缺課/常	0	j 1	2	3	4

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## **PedsQL**<sup>TM</sup> 兒童生活品質 調査問卷 第四版

幼童之父母報告(年齡 5-7 歲)



PedsQL40 Parent (5-7)01/00 一 未經許可不得翻印 版權感JW Varnt, Ph.D. 所行

花過去**一個月中**。您的孩子在下列各項事情**有多少困難......** 

身體功能(困難在於)	完全沒有	幾乎沒有	偶爾有	繩常有	一直有
	困難	困難	困難	困難	困難
1 步行認識一個路口的距離	0	1	2	3	4
2. 现步	0	1	2	3	-1
3. 參加禮能活動或運動	Ü	1	2	3	4
4. 提起一些重的未两	0	1	2	3	4
5.他/她自己洗澡或沐浴	0	I	2	3	4
6.做家務·像:收拾他/她的玩具	0	1	2	3	4
7. 曾經受傷或有疼病	Ú.	1	2	3	4
8.精力不足	0		2	3	4

情緒功能(困難在於)	完全沒有	幾乎沒有	偶爾有	經常有	一直有
	困難	困難	困難	困難	困難
1.感到害怕或驚恐	Ű	1	2	3	4
2. 感到傷心或沮喪	Ð	1	2	3	j +
3. 感到生氣	0	1	2	3	4
4. 睡眠有困難	υ	1	2	3	-1
5. 擔心會有事發生在他/她身上	Ü	1	2	3	- 4

社交功能(困難在於)	完全沒有	幾乎沒有	偶爾有	經常有	一直有
	困難	困難	困難	困難	困難
1. 與其他孩子和睦相處	0	1	2	3	4
2.其他孩子不要跟他/她作朋友	υ		2	3	4
3. 被其他孩子激弄		1	2	.3	4
4. 其他同年齡孩子態做的事情,他不能做	Ü	1	2	3	-1
	. 0	1	2	3	+

就學功能(困難在於)	完全沒有 困難	<u> </u> 券子沒有 困難	偶爾有 困難	経常有 困難	一直有 困難
1. 上課時集中注意力	0	1	2	3	4
2. 忘記事情	0	1	2	3	4
3. 限上學校的活動	Ü	l	2	3	4
4.因爲身體不舒服而缺躁	Û	1	2	3	4
5. 因爲要霍醫生或到醫院而缺誤	0	1	2	3	4

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## PedsQL<sup>TM</sup> 兒童生活品質 調査問卷 <sup>第四版</sup>

#### 幼童報告(年齡 5-7 歲)

訪問者指引:

我現在要問你一些問題,問題裡提到的事情對有些小朋友可能是一個困難,我想知道這些 些事情對你有多少困難,

顯示表情圖給小孩看,閱讀下列說明,亞同時指著每個所提到的表情。

如果它對你完全沒有困難,請指向笑臉

如果它對你<u>有時</u>候有困難,請指向中間的臉

如果它對你有很多困難,請指向數眉的臉

我會讀出每一這題目。請指出一個圖·來告訴我那件事對你有多少困難。讓我們洗練習 一次。

	完全沒有困難	有時有困難	有很多困難
<b>單腳跳兩次,對你是不是很難</b>	©	•	6

請小孩做出單腳碰,以確定問題是否正確回答,如果小孩捂出的回應圖和他/她的動作表 現不符,重覆此問題。

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#### 想一想過去幾個星期你怎麼樣。請小心聽清楚每一句,然後告訴我,這些事情對你有多 少困難。

在讀出每項問題之後,把孩子到向表情圖。如果小孩遲疑或似乎不明白該如何回答,便讀 出回應選項並同時指向該表情臉。

身體功能(困難在於)	完全沒有	有時有	有很多
1. 走游對你難不難	0	2	4
2. 跑步對你難不難	0	2	+
3.參加體育活動或運動劉你難不難	Ú	2	4
4. 拿起大的東西對你難不難	Ų	2	4
5. 洗澡或沐浴對你有困難嗎	0	2	4
6. 做家務(像收拾你的玩具)對你難不難	0	2	 +
7.你有沒有受傷或疼痛(在那裡? )	0	2	4
8. 你有沒有曾經覺得累到不想玩	Ű	2	4

記住,告訴我在過去幾個星期內,這種事情對你有多少困難。

情緒功能(困難在於)	完全沒有	有時有	有很多
1.你有沒有感到害怕	i 0	2	
2.你有沒有感到傷心	0	2	1
3.你有沒有感到生氣	0	2	-1
4.你有沒有睡覺的問題	U	2	4
5.你有沒有條心會有事發生在你身上	0	2	4

社交功能(困難在於…)	完全沒有	有時有	有很多
1.與其他孩子相處,對你辦不難	0	2	-1
2.其他孩子有沒有說不想跟你玩	0	2	4
3.其他孩子有沒有作弄取笑你	0	2	4
工具他孩子是不是能做一些你做不到的事	0	2	4
5. 跟其他孩子玩耍時你跟上他們難不難	0	2	-1

就學功能(困難在於)	完全沒有	有時有	有很多
1. 在學校你是不是很難集中注意力	0	2	્ય
2.你有沒有忘記事情	0	2	-1
3. 眼上學校的功課與不難	U U	2	4
年你有沒有因為感到不舒服而缺課	Ú	2	4
5. 你有沒有因為要看醫生或去醫院而缺課	j O	2	. 1

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Test or subtests	Ν	Test 1	Test 2	ICC	95%	C.I.
		Mean	Mean		Leuren	Uppor
		(sd)	(sd)		LOwer	Opper
QOL-total	10	64.9	65.8	707	512	017
	10	(9.3)	(9.1)	.101	.515	.917
	18	64.2	64.3	805	543	024
QOL-phylcal	10	(16.9)	(18.5)	.005	.545	.924
	18	73.6	72.0	768	170	C.I. Upper .917 .924 .909 .870 .842 .948 .938 .910 .931 .931 .959 .997 .997 .997 .957 .998
QOL-emotional	10	(16.0)	(14.1)	.700	.472	.909
	18	55.8	59.4	683	331	870
QUE-SOCIAI	10	(17.9)	(15.9)	.005	.551	.070
OOL schooling	18	67.5	70.1	616	202	842
QUL-schooling	10	(15.5)	(16.0)	.010	.202	.042
AB-total	18	252.7	268.6	.844	153	0/8
		(37.8)	(41.1)		.400	.940
AB communicate	10	75.8	84.8	826	500	038
AB-communicate	10	(21.7)	(21.6)	.020	.505	.000
	18	68.5	70.2	770	483	910
	10	(15.6)	(13.20	.112	.405	.910
AB-social	18	55.3	57.7	811	484	031
AD-30Clai	10	(7.2)	(6.5)	.011	.+0+	.301
AB-motor	18	53.0	55.8	887	602	950
	10	(12.4)	(13.2)	.007	.052	.000
GM-total	18	180.1	184.9	000	808	007
	10	(43.5)	(43.8)	.330	.000	.551
GM-stationary	18	42.2	43.5	870	618	957
Civi-Stationary	10	(4.4)	(4.7)	.019	.010	.301
CM less stirs	18	112.2	115.1	002	876	008
	10	(30.7)	(31.2)	.332	.070	.550
GM manipulato	18	25.6	26.2	054	885	082
GM-manipulate	18	(9.4)	(9.2)	.954	.000	.302

#### Appendix 10 Mean, SD and ICC Results of Test-Retest Reliability

Notes: QOL=Pediatric Quality of Life Inventory PedsQL; AB=Hong Kong Based Adaptive Behavior Scale (HKBABS); GM=Peabody Developmental Motor Scales-Second Edition (PDMS-2)

Test or	N	Rater 1	Rater 2	ICC	95%	CI		
Subtest								
		Mean	Mean		Lower	Uppor		
		(SD)	(SD)		Lower	Opper		
CM total	10	180.1	183.2	.993	069	009		
GIM-total 18	10	(43.6)	(44.9)		.900	.990		
	10	42.2	42.1	055	.885	.983		
GIVI-Stat	10	(4.4)	(4.5)	.900				
	10	112.2	113.7	004	000	000		
GIM-IOCO 18	10	(30.8)	(31.7)	.994	.903	.990		
GM-manip	10	25.7	27.4	066	705	000		
	18	(9.4)	(9.9)	.966	./85 .9	.990		

#### Appendix 11 Mean, SD and ICC Results of Inter-rater Reliability of PDMS-2

Note: GM=Peabody Developmental Motor Scale (PDMS-2)

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