DEVELOPMENT, IMPLEMENTATION AND EVALUATION OF NUTRITION MODULE FOR TRAINERS OF PERSONS WITH DISABILITIES IN COMMUNITY-BASED REHABILITATION CENTRES, KELANTAN

by

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Thesis submitted in fulfilment of the requirements
for the degree of
Doctor of Philosophy

February 2014

ACKNOWLEDGEMENT

First of all, I would like to express my deepest appreciation and gratitude to my principal supervisor, Dr. Sakinah Harith, for her invaluable guidance, understanding and encouragement throughout the whole research process and this thesis writing. I also wish to express my sincere appreciation and thanks to my three co-supervisors, Professor Hans Van Rostenberghe, Dr. Azriani Ab Rahman and Dr. Soo Kah Leng, for their relentless effort, expert advice and support in my doctoral journey.

I acknowledge Universiti Sains Malaysia for providing me the financial support under USM Fellowship Scheme. Also, for funding my research project through the Research University Grant (1001/PPSP/812049), Postgraduate Research Grant Scheme (1001/PPSK/8144001) and grants from Division of Industry and Community Network (BJIM).

I offer special thanks to all persons with disabilities, their families as well as the CBR teachers from Kelantan, Terengganu, Perlis, Pulau Pinang and Perak who had involved directly or indirectly in this study. Many thanks for their cooperation and support throughout the study. I am deeply grateful to the Sustainable Optimal Services for The Disabled (S.O.S OKU) research team members, staffs of Dietetics and Nutrition Programmes, and the statisticians for their assistance and guidance.

I would express my heartfelt appreciation to all my good friends, in particular Miss Loy See Ling, Ms. Nur Nadia Mohamed and Miss Tan Sze Lin for their moral support and countless help offered to me in a myriad of ways.

My utmost gratitude always goes to the most special person in my life, Ms. Seow Choy Ha, my beloved mother and best friend, for her endless love, encouragement and trust in me. Special thanks to my father (Mr. Chen Ker Yam) and sister (Ms. Chen Seong Voon) for their compassionate support. Last but not least to my dearest husband, Mr. Chung Weng Hong, who always provides me the strongest inspiration and motivation. Thank you for your understanding, support and love in this journey. I dedicate this thesis to all my loved ones.

TABLE OF CONTENTS

APPENDICES

LISTS OF PUBLICATIONS

LIST OF TABLES

LIST OF FIGURES

LIST OF SYMBOLS AND ABBREVIATIONS

ADA	American Dietetic Association
ADHD	Attention deficit hypersensitivity disorder
AIFO	Italian Association Amici di Raoul Follereau
α	Cronbach's alpha
ANCOVA	Analysis of covariance
ASD	Autism spectrum disorders
BAKTI	*Badan Amal dan Kebajikan Tenaga Isteri-Isteri*
BMI	Body mass index
BMR	Basal metabolic rate
CBR	Community-based rehabilitation
CDC	Centres for Disease Control
CI	Confidence interval
CITC	Corrected items-to-total score correlation
CP	Cerebral palsy
D	Discrimination index
dB	Decibel
EI	Energy intake
F	Female
FAO	Food and Agriculture Organization
Fr	Factor
GDP	Gross domestic product
GERD	Gastro-esophageal reflux disease
HSG	High scorer group
ICC	Intraclass correlation coefficient
ID	Intellectual disability
IDF	International Diabetes Federation

IPH	Institute for Public Health
JIFSAN	Joint Institute of Food Safety and Applied Nutrition
JKM	Jabatan Kebajikan Masyarakat
KAP	Knowledge, attitude and practice
KAP-nOKU	Nutrition Knowledge, Attitude and Practice Questionnaire about Persons with Disabilities
KMO	Kaiser-Meyer-Olkin
KR	Kuder-Richardson
LSG	Low scorer group
M	Male
MOH	Ministry of Health
MUAC	Mid-upper arm circumference
n	Frequency
N/A	Non-applicable
NCCFN	National Coordinating Committee on Food and Nutrition
NCHS	National Centre for Health Statistics
NHLBI	National Heart, Lung and Blood Institute
OKU	*Orang kurang upaya*
PDK	*Pusat pemulihan dalam komuniti*
PWD	Persons with disabilities
RNI	Recommended Nutrient Intake
ROI	Return-on-investment
SD	Standard deviation
SPFII	Secretariat of the Permanent Forum on Indigenous Issues
T	Teacher
T0	Baseline
T1	At 1-month interval after intervention
T2	At 6-month interval after intervention

UN	United Nations
WHO	World Health Organization
WHO/DAR	WHO Disability and Rehabilitation Team

PEMBINAAN, PELAKSANAAN DAN PENILAIAN MODUL PEMAKANAN UNTUK JURULATIH ORANG KURANG UPAYA DI PUSAT PEMULIHAN DALAM KOMUNITI, KELANTAN

ABSTRAK

Orang kurang upaya (OKU) mudah terdedah kepada malpemakanan. Akan tetapi, maklumat tentang status pemakanan dan strategi pemakanan dalam kalangan OKU tempatan agak terhad. Kajian ini dijalankan dari Jun 2010 hingga Julai 2012. Ia bertujuan untuk menilai taraf pemakanan OKU serta membina dan menilai keberkesanan Modul Pemakanan untuk Jurulatih Orang Kurang Upaya di pusat pemulihan dalam komuniti (PDK) Kelantan. Kajian ini meliputi tiga fasa. Penilaian taraf pemakanan OKU di PDK Kelantan telah dilakukan dalam fasa pertama. Seramai 467 orang OKU (281 orang kanak-kanak dan remaja; 186 orang dewasa) telah diambil dan maklumat pemakanan serta antropometri telah dikumpulkan. Modul pemakanan dan Soal Selidik Pengetahuan, Sikap dan Amalan Petugas PDK terhadap Makanan dan Pemakanan OKU (KAP-nOKU) dibina dan disahkan dalam fasa kedua. Satu kajian intervensi telah dijalankan dalam fasa ketiga. Seramai 45 orang guru PDK dari Kelantan telah diambil sebagai kumpulan intervensi dan 42 orang guru PDK dari Terengganu sebagai kumpulan perbandingan. Kumpulan intervensi menerima latihan modul pemakanan manakala kumpulan perbandingan dididik tentang isu penjagaan kesihatan umum OKU. Penilaian awal (T0) dan penilaian susulan KAP-nOKU pada sebulan (T1) dan enam bulan (T2) selepas intervensi telah dilaksanakan dalam kedua-dua kumpulan. Temu bual separa berstruktur kualitatif telah dilakukan dalam kalangan 13 orang guru dari kumpulan

intervensi untuk mengkaji faktor-faktor yang mendorong dan menghalang guru dalam pengurusan pemakanan OKU di PDK. Hasil kajian menunjukkan bahawa prevalens kekurangan berat badan dan berlebihan berat badan dalam kalangan OKU adalah sebanyak 20.3% (17.8% kanak-kanak dan remaja; 24.2% dewasa) dan 22.8% (15.2% kanak-kanak dan remaja; 33.9% dewasa). Dalam fasa kedua, KAP-nOKU yang telah disahkan mengandungi 57 item dan domain-domain pengetahuan (KR20=0.63), sikap (α=0.67) dan amalan (α=0.82) didapati mempunyai konsistensi dalaman yang baik. Analisis ANCOVA berulangan langkah dalam fasa ketiga menunjukkan bahawa kumpulan intervensi telah mencapai skor pengetahuan (p<0.001) dan amalan (p=0.001) pemakanan yang lebih tinggi daripada kumpulan perbandingan pada T1 (perbezaan min pengetahuan= 6.95; perbezaan min amalan= 2.93) dan T2 (perbezaan min pengetahuan= 10.30; perbezaan min amalan= 4.78). Skor sikap (p=0.004) pemakanan yang lebih tinggi bagi kumpulan intervensi diperhatikan pada T2 (perbezaan min= 3.08). Hasil kualitatif menunjukkan bahawa sifat peribadi guru yang positif merupakan faktor penting yang mendorong amalan pengurusan pemakanan OKU di PDK. Manakala, sikap rintangan OKU terhadap strategi pemakanan yang positif serta kekurangan sokongan sosial daripada ibu bapa merupakan halangan yang utama. Kesimpulannya, modul pemakanan ini adalah berkesan dalam meningkatkan pengetahuan, sikap dan amalan guru dalam pengurusan pemakanan OKU di PDK Kelantan.

DEVELOPMENT, IMPLEMENTATION AND EVALUATION OF NUTRITION MODULE FOR TRAINERS OF PERSONS WITH DISABILITIES IN COMMUNITY-BASED REHABILITATION CENTRES, KELANTAN

ABSTRACT

Persons with disabilities (PWD) are susceptible to malnutrition. However, little is known about the nutritional status and nutrition strategies among the local disability population. This study was conducted from June 2010 to July 2012. It aimed to assess the nutritional status of PWD, develop and evaluate the effectiveness of Nutrition Module for Trainers of Persons with Disabilities in community-based rehabilitation (CBR) centres, Kelantan. This study included three phases. At Phase 1, nutrition assessment of PWD in CBR centres, Kelantan was conducted. A total of 467 PWD (281 children and adolescents; 186 adults) were recruited and their feeding and anthropometric data were collected using a structured questionnaire. The nutrition module and Nutrition Knowledge, Attitude and Practice Questionnaire about Persons with Disabilities (KAP-nOKU) were developed and validated in Phase 2. At Phase 3, an intervention study was conducted. Forty-five CBR teachers from Kelantan were recruited as the intervention group and 42 CBR teachers from Terengganu as the comparison group. The intervention group received the nutrition module training while the comparison group was trained on general health care issues about PWD. Baseline (T0) and follow up KAP-nOKU assessments at 1-month (T1) and 6-month (T2) intervals after intervention were administered for both groups. Qualitative semi-structured interviews were conducted among 13 teachers

from intervention group to explore the perceived motivations and barriers to their nutrition management for PWD at CBR centres. Results showed that there was a prevalence of 20.3% of PWD (17.8% children and adolescents; 24.2% adults) who were underweight while 22.8% (15.2% children and adolescents; 33.9% adults) were overweight or obese. At Phase 2, the validated KAP-nOKU contained 57 items with good-to-excellent internal consistencies for knowledge (KR20=0.63), attitude (α=0.67) and practice (α=0.82) domains. At Phase 3, repeated measures ANCOVA demonstrated that intervention group attained significantly higher nutrition knowledge (p<0.001) and practice (p=0.001) scores than comparison group at T1 (mean difference for knowledge= 6.95; mean difference for practice= 2.93) and T2 (mean difference for knowledge= 10.30; mean difference for practice= 4.78). Significant higher nutrition attitude (p=0.004) score for intervention group was observed at T2 (mean difference= 3.08). Teachers' positive personal attributes were identified as the primary motivation while PWD's resistance to teachers' positive nutrition management and lack of parental social support were the major barriers. In conclusion, this nutrition module is effective on improving the nutrition knowledge, attitude and practice of CBR teachers in Kelantan.

CHAPTER 1

INTRODUCTION

1.1 Background of the study

Persons with disabilities (PWD), commonly known as *orang kurang upaya* (OKU) in Malaysian context is a complex term referring those who experience long term physical, mental, intellectual and (or) sensory impairments which result in barriers that prevent them from full and effective participation in the society (Law of Malaysia, 2008). PWD, being the most vulnerable group, are susceptible to malnutrition especially those living in rural, low-income and less-resourced areas.

International studies have been reported that PWD, especially the children and adolescents with neurological disorders, are predisposed to undernutrition and growth failure as compared to their healthy peers (Yousafzai *et al.*, 2003; Tomoum *et al.*, 2010). Studies by Marchand *et al.* (2006) in the United States and Sánchez-Lastres *et al.* (2003) in Spain had described almost 50% of children with cerebral palsy were underweight while Bertoli *et al.* (2006) reported 40% of the children with refractory epilepsy in his study at Italy were undernourished and further 24% were wasted.

On the other hand, overweight and obesity among PWD remains another issue of concern as this problem also records a remarkable higher prevalence than the general population (Marshall *et al.*, 2003; Hove, 2004). Overweight problems are

common in both children and adult population with disabilities. Alarming prevalence of around 40% of overweight or obese children and adolescents with disabilities were reported in the United States (33.5%) (Rimmer *et al.*, 2011) and Taiwan (37.7%) (Lin *et al.*, 2010). Among the adult population, data from the United Kingdom suggested that overweight problem affects almost half of the adults with intellectual disabilities (48.7%) being studied (Bhaumik *et al.*, 2008). Similar condition (42.1%) was noted in an Asian study among the institutionalised adults with intellectual disabilities (Hsu *et al.*, 2012).

Malnutrition, either undernutrition or overnutrition, can potentially exacerbate the risk of co-morbidities and further impair the residual functional ability. All these collectively impose greater suffering and burden to the disabled as well as the family, both emotionally and financially (Neyestani *et al.*, 2010).

PWD greatly rely on caregivers for nutrition intake and activities of daily living especially for those who are severely disabled. Several studies have demonstrated that increased caregiver's nutrition knowledge resulted in positive impacts on the nutritional status of children (Smith and Haddard, 2000). Besides, there is opinion suggests that school, child-care or other learning setting provides a link on promoting good nutrition practices between home and school (Hammerschmidt *et al.*, 2011) as the children routinely eat at least one meal in school every day (Freedman and Alvarez, 2010). Teachers, child-care providers or trainers in such settings, therefore, play a crucial role in defining the students' eating environment which will eventually influence the students' nutrition intake, food preferences and also food choices (Hendy and Raudenbush, 2000; Nicklas *et al.*,

2001). Hence, improving nutrition knowledge among primary care providers may show positive effect on reducing the prevalence of malnutrition in PWD.

1.2 Statement of the problem

Malnutrition has become an epidemic in recent years. Numerous cross-sectional and intervention studies globally as well as at national level have been targeted to combat the problem of malnutrition among the general population. However, little is known about the nutritional status and nutrition strategies among those with disabilities, the most vulnerable group of the population. Baseline data on the nutritional status of population with disabilities is imperative to increase the society awareness and concern. Highlighting the nutritional status of PWD can further aid in eliminating the health disparities among this subgroup.

Population with disabilities require a wide range of rehabilitation effort that currently remains challenging to furnish effectively in developing countries (Yousafzai *et al.*, 2003). PWD living in low-income, low-literacy and less-resourced rural areas are even having less opportunity to access to those facilities. Kelantan is recorded as the poorest state and has the lowest urbanization rate in Malaysia (Department of Statistics, 2011). The disadvantaged socioeconomic condition in Kelantan further predisposes the PWD to higher risk of malnutrition. To date, data on the prevalence of malnutrition among PWD in Malaysia is still limited.

In Malaysia, in order to minimize the marginalisation of this population, PWD who are too severely disabled and not accepted by the special education

mainstream will be placed at the community-based rehabilitation (CBR) centres which are under the authority of the Department of Social Welfare. Trainers, or normally known as "teachers', are the persons who teach, train and prepare meals for the PWD in the centres. To be recruited as a CBR teacher, no certification on special education endorsement, early intervention for children with disabilities, elementary or secondary education is required. According to the information obtained from the department and CBR teachers, though periodical training workshops are offered to them, there is still lack of proper and consistent nutrition training courses available to them. Due to insufficient exposure to nutrition information, CBR teachers experienced difficulties in preparing healthy and well balanced diet for the PWD. Additionally, they also faced challenges in managing the PWD with specific feeding difficulties and nutrition problems. Sharing nutrition knowledge with parents as the mutual effort to reinforce the healthful eating behaviour among the PWD is not possible. Subsequently, teaching nutrition message towards PWD in order to influence their food preferences and choices is viewed as a hard chore due to the lack of knowledge and skill.

Besides, there is no current research-tested training material, a nutrition module or guidelines specifically addressing the nutrition needs of PWD, to be used in educating the CBR teachers in Malaysia. The nutrition condition and food practice among PWD in Malaysia may differ from other countries. Moreover, there are also substantial differences in the educational, socioeconomic and cultural background of the local CBR teachers as compared to the trainers in other countries. Hence, adoption of related nutrition module from foreign countries to educate the CBR

teachers in Malaysia is not feasible and ethical. All these emphasize the rationale of having a socio-cultural sensitive and appropriate nutrition module.

1.3 Significance of the study

This study can add considerably to the body of literature pertinent to the prevalence of malnutrition and the common feeding and nutrition problems among PWD in Malaysia. This fundamental data may indicate the future research directions as it can stimulate multiple research ideas especially in the aspects of epidemiology and interventional studies towards this group. Besides, these findings can also raise the stakeholders' attention and provide important insights into the need of policy making in order to provide equal health benefits for those with disabilities.

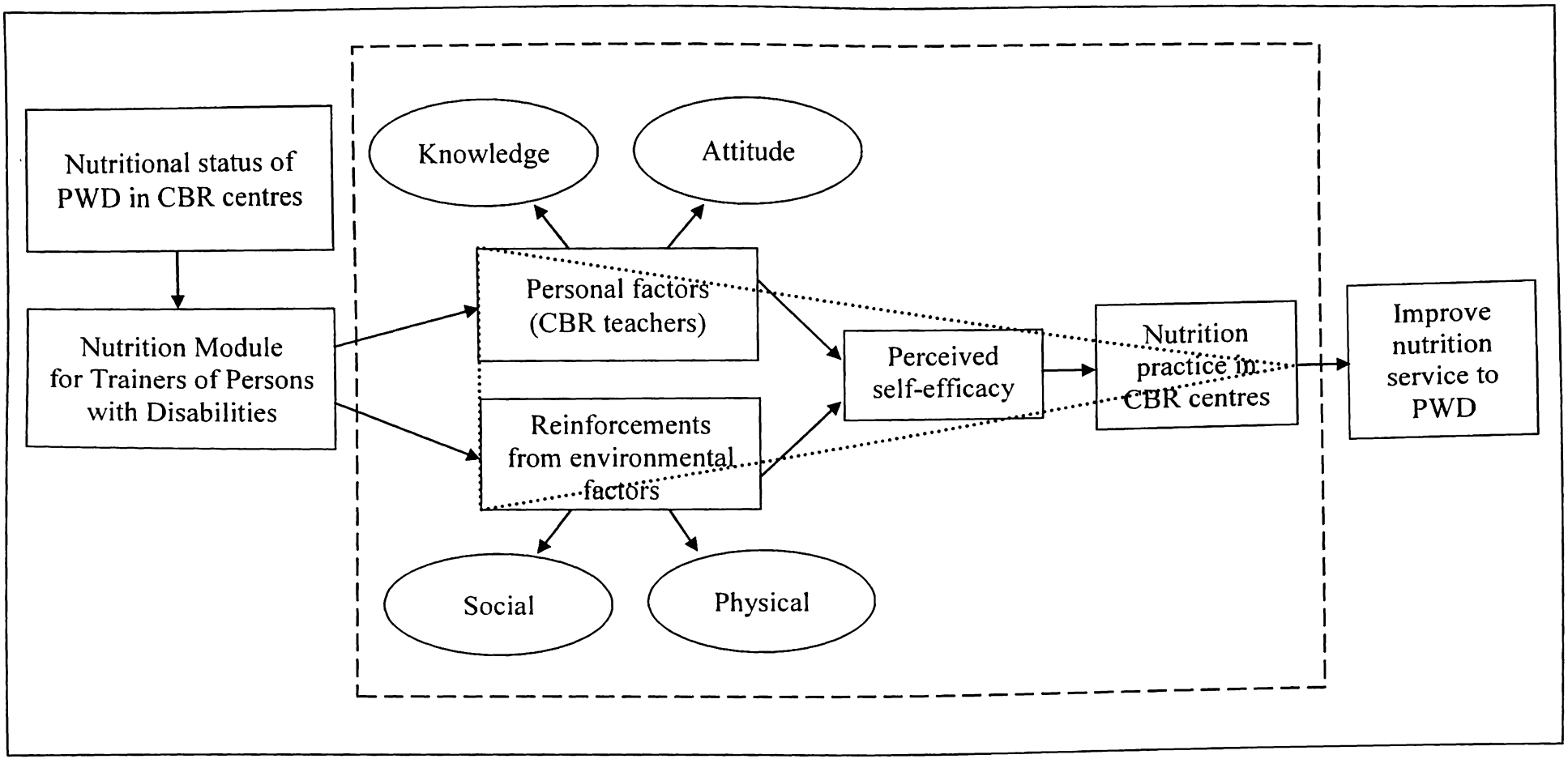
The development of an evidence-based and research-tested nutrition module can facilitate the professionals or other health care practitioners to conduct consistent and effective nutrition education to all teachers in CBR centres in Malaysia. This module, on the other hand, can serve as the reference material in every CBR centre in Malaysia to guide the care providers in positive nutrition practices. The module might also be valued and adopted by other developing countries for the same purpose based on their condition and pertinence. This study holds relevance for the public, authorities, researchers, health care practitioners, care service providers as well as family members in garnering shared effort for the well-being of the PWD.

1.4 Conceptual framework

Figure 1.1 illustrates the conceptual framework for the present study. This framework is grounded on Bandura's Social Cognitive Theory (Bandura, 1989) for understanding the health behavioural change. The Social Cognitive Theory sets the foundation for designing, developing, implementing and evaluating a program. It incorporates three main factors: personal, environmental and behavioural for evaluating the behavioural change (round dotted triangle in Figure 1.1). In current study, this theory is appropriately relevant to the evaluation of a training using Nutrition Module for Trainers of Persons with Disabilities on improving the knowledge, attitude and practice of teachers in nutrition management for the PWD in CBR centres. This conceptual framework hypothesized that, following the nutrition module training, the teacher's personal factors such as increased nutrition knowledge and positive attitude along with the positive reinforcements from environmental factors, for instance the social support from the colleagues and the availability of facility, will motivate the teachers as well as increase their belief and self-confidence to successfully perform good nutrition practices for the PWD in the CBR centres.

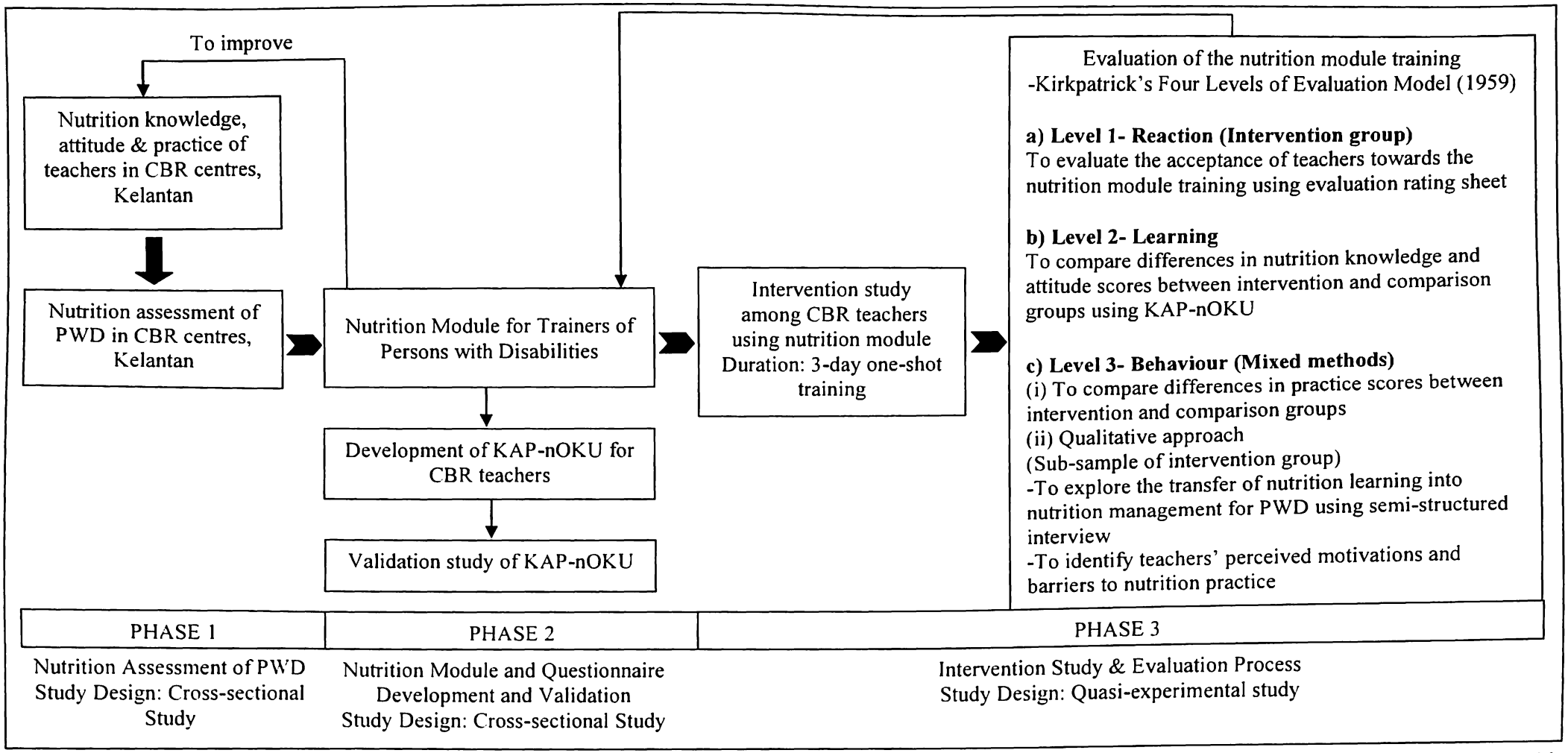
1.5 Methodological framework

The methodological framework for the study is summarized in Figure 1.2. This study was conducted in three phases. Phase 1 was a descriptive cross-sectional study to assess the nutritional status of PWD in CBR centres, Kelantan. Phase 2 comprised of two components. First component was the development of Nutrition Module for Trainers of Persons with Disabilities based on the information obtained from Phase 1



Note: PWD-persons with disabilities; CBR-community-based rehabilitation

Figure 1.1 Conceptual framework of the study



Note: PWD-persons with disabilities; CBR-community-based rehabilitation; KAP-nOKU-Nutrition Knowledge, Attitude and Practice Questionnaire about Persons with Disabilities

Figure 1.2 Methodological framework of the study

The second component was the development and validation study of the Nutrition Knowledge, Attitude and Practice Questionnaire about Persons with Disabilities (KAP-nOKU). The final phase, Phase 3, was an intervention study using the nutrition module among teachers from CBR centres, Kelantan with a comparison group of teachers from CBR centres, Terengganu.

1.6 Research questions

This study addresses several research questions as follows.

1. What is the nutritional status of PWD in CBR centres, Kelantan?
2. Is Nutrition Module for Trainers of Persons with Disabilities a valid training material in nutrition intervention for CBR teachers?
3. Is Nutrition Knowledge, Attitude and Practice Questionnaire about Persons with Disabilities (KAP-nOKU) valid and reliable to assess the nutrition knowledge, attitude and practice of CBR teachers towards nutrition management for PWD?
4. Are the CBR teachers in Kelantan satisfied with the nutrition module training (intervention)?
5. Is the nutrition module intervention effective on improving the knowledge, attitude and practice of teachers in nutrition management for PWD in CBR centres, Kelantan?
6. What are the teachers' perceived motivations and barriers in implementing nutrition management for PWD in CBR centres, Kelantan?

1.7 Objectives of the study

1.7.1 General objective

The general objective of this study is to assess the nutritional status of PWD, develop and evaluate the effectiveness of Nutrition Module for Trainers of Persons with Disabilities in CBR centres, Kelantan.

1.7.2 Specific objectives

The specific objective for Phase 1 is:

1. To assess the nutritional status of PWD in CBR centres, Kelantan.

The specific objectives for Phase 2 are:.

1. To develop and validate the Nutrition Module for Trainers of Persons with Disabilities.
2. To develop and validate the Nutrition Knowledge, Attitude and Practice Questionnaire about Persons with Disabilities (KAP-nOKU).

The specific objectives for Phase 3 are:

1. To evaluate the acceptance of CBR teachers in Kelantan towards the nutrition module training.
2. To evaluate the effectiveness of the nutrition module on improving the knowledge, attitude and practice of teachers in nutrition management for PWD in CBR centres, Kelantan.

3. To identify the teachers' perceived motivations and barriers in implementing nutrition management in CBR centres, Kelantan.

1.8 Hypotheses

There are four research hypotheses that are relevant to Phase 2 and 3.

The alternative hypotheses for Phase 2 are:

H1.The Nutrition Module for Trainers of Persons with Disabilities is a valid training material in nutrition intervention for CBR teachers.

H2.The Nutrition Knowledge, Attitude and Practice Questionnaire about Persons with Disabilities (KAP-nOKU) is valid and reliable to assess the nutrition knowledge, attitude and practice of CBR teachers towards nutrition management for PWD.

The alternative hypotheses for Phase 3 are:

H3.CBR teachers in Kelantan are satisfied with the Nutrition Module for Trainers of Persons with Disabilities training.

H4.The Nutrition Module for Trainers of Persons with Disabilities is effective on improving the knowledge, attitude and practice of teachers in nutrition management for PWD in CBR centres, Kelantan.

1.9 Definition of terms

Persons with disabilities (PWD): Persons who have long term limitation in physical, mental, intellectual and (or) sensory ability that can inhibit them from full and effective interaction with the society (Law of Malaysia, 2008).

Community-based rehabilitation (CBR) centre: Training centre which is managed by the local community that provides skills training and therapy services using local resources for PWD who are severely disabled.

Community-based rehabilitation (CBR) teacher: Trainer who is in charge of teaching, training, caring and preparing meals for PWD in CBR centres.

Malnutrition: A pathological state resulting from relatively or completely deficient or excess in one or more essential nutrients (Park, 2000). In this study, malnutrition refers to undernutrition and overnutrition, which are indicated by underweight and overweight or obesity, respectively.

Nutrition Knowledge, Attitude and Practice Questionnaire about Persons with Disabilities (KAP-nOKU): A nutrition questionnaire which acts as an instrument to assess the CBR teacher's nutrition knowledge, attitude and practice towards nutrition management for PWD.

Special education: Formal education modified for physically or mentally handicapped students whose needs cannot be met by the standard school curriculum.

CHAPTER 2

LITERATURE REVIEW

2.1 Disability- size of the problem

Population with disabilities accounts for a considerable portion of the world population. The latest World Report on Disability (WHO, 2011) documented that more than one billion people in the world, which represented 15% of the global population, were living with some forms of disability; and approximately 200 million of them (one in five) encountered substantial difficulties in functioning. The prevalence of disability is on the rise. The figure has been increased as much as around 60% in 10 years time (650 million were reported in 2003). PWD are known to be the world's largest minority, of whom 80% of them are living in developing countries (UN, 2012).

In Malaysia, an estimated rate of 2.8 million people lived with various forms of disability; yet, until August 2010, there were only 313,685 PWD who have registered with the Department of Social Welfare (Zulkiple, 2011). This national registry fails to present the actual picture of PWD in the country as there might be even a larger number go undetected. Among the children population, it was suggested that more than 850 thousand children below 15 years (which constituted 10% of the children population in Malaysia) had a disability with at least one third of them were severe (Amar-Singh, 2008). This data is consistent with Juanita (2011)

who stated that a total of 900 thousand children in Malaysia were diagnosed with various disabilities in 2011.

In spite of the robust healthcare strategies and disability rights movement, PWD are still prevalent to poor health. Issues on availability, accessibility, and sustainability of culturally-sensitive rehabilitation services remain questionable (WHO, 2011).

2.2 Community-based rehabilitation

Community-based rehabilitation (CBR), established by the WHO in the 1980s, is a multi-sectoral strategy that empowers the PWD in developing countries and urban poor areas to gain access to all aspects of rehabilitation services (WHO/DAR & AIFO, 2002). The idea of CBR is that services needed by the PWD should be available to them at affordable cost as well as offered in such a way that suit their regular ways of living, whether in a village or a city (Miles, 2001). Hence, CBR has been defined as a strategy within the general community development for rehabilitation, equalisation of opportunities, reduction of poverty and social inclusion of all children and adults with disabilities (WHO, 2004). It is implemented through the joined efforts of PWD themselves, their families, local communities, relevant governmental and non-governmental health, social, education, vocational and other services (WHO, 2004).

In Malaysia, CBR program is jointly managed by the Department of Social Welfare and Ministry of Health (MOH) since 1984 and is primarily focused at rural

regions. It targets five main objectives, i) to enhance sense of concern and responsibility among local community in rehabilitation effort towards PWD; ii) to gather local resources for the development of rehabilitation services; iii) to encourage the use of appropriate, reasonable and effective methods or techniques which are sensitive to the need of local condition; iv) to utilise the available local infrastructures for developing the rehabilitation services; and v) to expand and decentralize comprehensive service delivery based on the needs of PWD (JKM, 2011).

The CBR centres in Malaysia, or known as *pusat pemulihan dalam komuniti* (PDK), provide rehabilitation training for PWD who are too young, too severely disabled and not accepted by the special education mainstream. No age limitation or specific requirement for PWD enrolment is indicated. A total of 428 CBR centres were established in Malaysia by 2010 (JKM, 2011). Table 2.1 lists the number of CBR centres, trainers and PWD registered in each state of Malaysia. Based on the registration criteria of the Department of Social Welfare, PWD are categorized into one of the seven disability categories upon registration (JKM, 2012). The disability categories are hearing, visual, speech, physical, learning, mental and multiple disabilities. Table 2.2 details the explanation for each category.

The CBR centres function as registration, referral, rehabilitation, training and resource centres (Isa *et al.*, 2013). Training services offered including gross motor and fine motor skills, social and language development, activities of daily living, writing, reading and counting, vocational, sports and recreation (JKM, 2011).

Table 2.1 Number of CBR centres, trainers and PWD registered in Malaysia

State	Number			
	CBR centres	Supervisors	Trainers	PWD
Perlis	5	5	17	242
Kedah	27	27	126	1471
Pulau Pinang	20	20	69	647
Perak	36	36	114	1286
Selangor	39	39	162	2257
WP Kuala Lumpur	9	9	45	380
Negeri Sembilan	40	40	231	1639
Melaka	17	17	77	715
Johor	63	63	271	2853
Pahang	45	45	131	1424
Kelantan	33	33	103	1218
Terengganu	40	40	123	1354
Sarawak	25	25	150	1932
Sabah	27	27	88	1465
WP Labuan	2	2	7	60
Total	**428**	**428**	**1714**	**18943**

Source: JKM (2011)

In Kelantan, there are 33 CBR centres and each centre is operated by three to four trainers. The PWD (*Pelatih OKU*) attend classes from 8am to 1pm, from Sunday to Wednesday. On Thursdays, the CBR trainers pay home visits to those home-based PWD, mostly the severely disabled children. Each PWD receives a monthly allowance of RM150 from the Department of Social Welfare. PWD take one lunch meal which is prepared by the trainers in the centres each day. Food budget is obtained from the deduction on PWD's allowance and the amount deducted is based on the consensus of the authority and parents of PWD in each centre. In general, an amount of RM20 to RM30 is collected from each PWD for food expenses.

The CBR trainers (*Petugas PDK*), or commonly known as CBR teachers (*Cikgu PDK*), are recruited on voluntary basis to provide service at the centres with a monthly salary of RM800. They are usually belonged to the local community where the centre locates. Recruitment is neither based on their educational level nor age.

Table 2.2 Disability categories

No.	Category	Explanation
1	Hearing	Inability to hear clearly in both ears with or without the use of hearing aids. Hearing disability can be divided into four levels: • Minimum- 15-<30dB (children) and 20-<30dB (adult) • Intermediate- 30-<60dB • Severe- 60-< 90dB • Profound- ≥ 90dB
2	Visual	Poor vision in both eyes; blindness in one or both eyes. Poor vision is defined as visual acuity of less than 6/18 but equal to or better than 3/60 or corresponding visual field loss to less than 20°. Blindness is referred to visual acuity of less than 3/60 or corresponding visual field loss to less than 10°.
3	Speech	Inability to produce sound correctly or fluently; and the speech cannot be understood by others during communication. Diagnosis for children to be assessed only after five years old.
4	Physical	Permanent physical disability, either caused by loss of limbs or any impairment which limits the physical function of one or more limbs. For instance, • Limb defects (congenital or acquired) • Spinal cord injury • Stroke • Traumatic brain injury • Achondroplasia • Cerebral palsy
5	Learning	Disorder in learning, cognition and intelligence that is inconsistent with the biological age. For example, • Global developmental delayed (less than 5 years old) • Down's syndrome • Intellectual disability (more than 5 years old) • Autism spectrum disorders • Attention deficit hyperactive disorder • Specific (dyslexia, dyscalculia and dysgraphia)
6	Mental	Severe mental illness or disorder that impairs one's ability to function effectively in own living or interaction with the society. For instance, • Organic mental disorder • Schizophrenic, paranoid and other psychotic disorder • Mood disorder (depression and bipolar)
7	Multiple	Having a combination of two or more disabilities and generally inappropriate to be classified into category 1 to 6.

Source: JKM (2012)

In addition, no qualification on special education or early childhood program is required (Chen *et al.*, 2012) and most of the teachers only attain their highest educational level at lower (Form 3) or upper secondary school (Form 5). The teachers are exposed to the training courses on skills in handling PWD only after their recruitment. These training courses are usually organized by the Ministry of Health, higher education institutions and non-governmental organizations. Most of the trainings offered are focusing on physiotherapy or occupational therapy, sexual education and vocational training for the PWD. In the centres, the teachers play a crucial role in training, teaching and preparing meals for the PWD as well as supporting the caregivers in taking care of their children (Chen *et al.*, 2012; Isa *et al.*, 2013). The PWD and their families highly depend on the CBR teachers for rehabilitation services and information to promote good health, especially those in rural and low-literacy areas. According to the information given, food preparation or menu standardization for all CBR centres in Kelantan was not indicated as there was no specific guideline provided by the authorities. Food prepared was usually based on the PWD's preferences, teachers' convenience and availability of food sources.

Various health strategies have been provided by the Malaysia Ministry of Health to ensure a comprehensive health care for PWD to achieve optimal health and maximum independence. Since 1986, Early Intervention Programme for Children with Special Needs was initiated and mainly focused on early detection of disability population at health clinics and referral to hospitals for rehabilitation. Beginning 1996, rehabilitation services are started at selected health clinics and managed by trained public health nurses. The nurses undergo various in-service trainings which mostly emphasize on basic techniques for handling PWD with gross motor and fine

motor delay; visual impairment; activities of daily living, communication, personal social and behavioural, sexual and reproductive health problems. The Health Care for PWD Plan of Action 2011-2010 was also developed in line with the Convention on the Rights of PWD and the PWD Act 2008 to outline the health service plans for PWD. In 2011, together with *Badan Amal dan Kebajikan Tenaga Isteri-Isteri* (BAKTI), MOH developed and launched a manual on healthy lifestyle, "*PDK KU SIHAT: Garis Panduan & Manual Aktiviti*", which focuses on healthy eating and regular exercise for PWD. This manual was only distributed among CBR centres in Kelantan at August 2012. In this program, health personnel such as public health nurses, nutritionists and occupational therapists are in charge of providing outreach services such as advice on healthy menu, healthy meal preparation and safe physical activity to CBR centres within operational area of the health clinics. However, issues of accessibility and sustainability of the above strategies remain uncertain.

2.3 Disabilities and nutritional concerns

A disability can occur at prenatal, perinatal, neonatal or at any stage of an individual's life. These disabilities may be brought about by diseases harming mother during pregnancy; genetic abnormalities; oxygen deprivation and acquired brain injury during birth; accidents, infections or diseases acquired after birth. Disabilities involving brain and central nervous system are permanent, irreversible and affecting a wide range of developmental, motor and muscular, sensory, learning and cognitive abilities (Almond *et al.*, 2007).

PWD frequently have nutritional concerns (Van Riper, 2010) resulted from their disablement that may lead them to poor health. Besides, they are also prone to develop co-morbid conditions such as obesity, diabetes mellitus or cardiovascular diseases that will further worsen their functional abilities (Traci *et al.*, 2002). The following section discusses the types of disability most prevalent in the CBR centres in Malaysia and their related nutritional concerns.

2.3.1 Down's syndrome

Down's syndrome is a genetic disorder caused by the presence of an extra chromosome 21 or known as Trisomy 21. Down's syndrome occurs in approximately 1 per 660 live births in Malaysia (Zulkiple, 2012). Children with Down's syndrome are affected with cognitive deficit and growth impairment (Nehring, 2010). They are also at risk for multiple congenital anomalies, such as congenital heart defects, respiratory infections, gastrointestinal problems (e.g. constipation and celiac disease) and endocrine abnormalities (Roizen and Patterson, 2003; Almond *et al.*, 2007; Van Riper, 2010).

Feeding difficulties are common among children with Down's syndrome (Lewis and Kritzinger, 2004; Almond *et al.*, 2007). These feeding problems are associated with decreased muscle tones- hypotonia, which affects the strength and mobility of oral muscles (Kumin *et al.*, 1991) and results in weak lip closure, poor sucking, chewing and swallowing (Almond *et al.*, 2007). Additionally, the genetic anomaly causes multiple cranial skeletal abnormalities (Lewis and Kritzinger, 2004) which in turn contribute to their feeding difficulties. Small oral cavity, large tongue,

short and narrow palate, enlarged tonsils along with decreased nasal passages may interfere the oral feeding in children with Down's syndrome (Lewis and Kritzinger, 2004). Congenital heart defects occur in 40 to 50% of children, are important risk factors for the feeding problems (Pueschel, 1990; Lewis and Kritzinger, 2004; Freeman *et al.*, 2008). Children with heart defects may experience breathing difficulty, vomiting and easily fatigue during eating (Lewis and Kritzinger, 2004). All these combined conditions can lead to inadequate food intake and poor weight gain in children with Down's syndrome.

On the other hand, there is also a high tendency for persons with Down's syndrome to become overweight or obese (Cronk *et al.*, 1988; Rubin *et al.*, 1998; Murray and Ryan-Krause, 2010). Some studies suggest that a rate of 30 to 50% of these children are obese (Harris *et al.*, 2003). Endocrine dysfunctions such as hypothyroidism which leads to decreased basal metabolic rate (Luke *et al.*, 1994; Bauer *et al.*, 2003) and abnormal leptin level that impairs regulation of satiety (Cento *et al.*, 1999; Magni *et al.*, 2004), serve as the main culprits. Furthermore, delayed gross motor abilities (Holcomb *et al.*, 2009) and negative behavioural tendency, for instance the inattention, non-compliance and oppositional behaviours (Jahromi *et al.*, 2008) among persons with Down's syndrome cause them to live in a sedentary lifestyle and have less engagement in physical activity. These collectively increase the prevalence of overweight and obesity.

2.3.2 Cerebral palsy

According to Blair *et al.* (2007), cerebral palsy (CP) refers to a group of permanent disorders involving movement and posture which are resulted from non-progressive interference or lesion in the developing brain. CP is estimated to occur in 2 to 3 per 1000 live born infants (Yeargin-Allsopp *et al.*, 2008; Benfer *et al.*, 2012). A host of disabilities co-occur with CP. These include intellectual impairment, seizure, sensory (visual, hearing, touch) and communication disorders (Odding *et al.*, 2006; Rosenbaum *et al.*, 2007; Van Riper, 2010).

The neurologic lesion greatly impairs the oral motor functions and manifests a range of complex feeding problems (Andrew *et al.*, 2011; Benfer *et al.*, 2012). Reilly and Skuse (1992) explained that feeding dysfunction in persons with CP is always due to three interacting conditions: i) the impaired oral motor functions (hypotonia, persistent tongue thrust, weak lip closure); ii) diminished neurologic maturation (hyperactive gag reflexes and reduced swallowing coordination); and iii) poor truncal support and head control result in inappropriate seating posture that make mealtime an unpleasant experience. They frequently suffer from dysphagia or swallowing difficulties, coughing, choking, vomiting or sensory impairment to clearly communicate pain, hunger or satiety (Tomoum *et al.*, 2010; Van Riper, 2010; Andrew *et al.*, 2011). In addition, their reduced feeding skills can be further aggravated by specific medical conditions such as gastro-esophageal reflux disease (GERD), aspiration, constipation and seizure (Almond *et al.*, 2007; Tomoum *et al.*, 2010; Andrew *et al.*, 2011). Furthermore, drooling which is defined as the unintentional loss of saliva (Reddihough *et al.*, 2010), is another common problem in

children with CP. Dehydration, impaired mastication function, oral mouth infections (Van der Burg *et al.*, 2006) and aspiration pneumonia (Walshe *et al.*, 2010) are the nutritional concerns inherent to the drooling problem.

The aforementioned oral-motor involvement causes lengthy mealtimes, increases fatigue and mealtime resistance and further contributes to insufficient energy intake and eventually growth failure (Tomoum *et al.*, 2010; Van Riper, 2010; Andrew *et al.*, 2011). In a multicentre study involving 230 children and adolescents with CP, Fung *et al.* (2002) had demonstrated that the extent of feeding difficulties is directly associated with the degree of undernutrition. Gisel *et al.* (2000) and Fung *et al.* (2002) further added even children who experienced mild feeding dysfunction had inadequate food intake and poor growth.

2.3.3 Autism spectrum disorders

Autism spectrum disorders (ASD) is defined as a set of lifelong neurodevelopment disabilities characterized by social and communication deficits and presence of stereotyped and repetitive behaviours (Matson, 2007; Soden *et al.*, 2012; Zimmer *et al.*, 2012). In Malaysia, ASD has a prevalence of 1 in 625 children (Dolah *et al.*, 2011). Common co-morbidities identified among persons with ASD are learning disabilities (but surprisingly, some may have average or above Intelligence Quotient level), attention deficit hypersensitivity disorder (ADHD), altered gastrointestinal functions, fear or anxiety, and epilepsy (Connor, 2007; Twachtman-Reilly *et al.*, 2008; Parellada *et al.*, 2011).

Based on an early report by DeMyer (1979), more than 90% of children with ASD have some feeding and mealtime problems. These problems have been documented by several investigators over the years and are classified into three main categories: i) food selectivity or "picky eating"; ii) food refusal; and iii) disruptive mealtime behaviours (Ahearn *et al.*, 2001; Schreck and Williams, 2006; Bandini *et al.*, 2010). Some children with ASD are overly selective and only eat a restricted range of food (Bandini *et al.*, 2010). They can have strong aversions to specific colours, smells, textures or temperature. This rigidity can extend to food brands or packaging, food presentation and mealtime environments (Williams *et al.*, 2000; Schreck *et al.*, 2004; Schreck and Williams, 2006; Connor, 2007; Bandini *et al.*, 2010). Hence, introduction of new food may be challenging and distressing. Field *et al.* (2003) further added that some may even refuse to eat the entire food group, for instance the milk and dairy products (Zimmer *et al.*, 2012). These negative food behaviours are detrimental to their nutritional status. Nevertheless, numerous studies demonstrated conflicting findings about the nutrition deficiencies of this population (Zimmer *et al.*, 2012). Macronutrients intake of children with ASD is not different from their healthy peers, as reported by Emond *et al.* (2010) and Johnson *et al.* (2008). However, micronutrient deficiencies are evident especially for calcium, iron, Vitamin A, Vitamin C and Vitamin D (Lindsay *et al.*, 2006; Herndon *et al.*, 2009; Bandini *et al.*, 2010; Zimmer *et al.*, 2012).

Problematic mealtime behaviours are another matter of concern. Persons with ASD have minimal verbal skills and have difficulties to communicate experience, feelings or symptoms (Buie *et al.*, 2010). Additionally, the sensory processing deficits restrict their ability to identify the source of body discomfort or pain