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# A Proposed Framework on Working with Parents of Children with Special Needs in Singapore

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Abstract: Parents of children with special needs are often forgotten or not included in any form of participation in the special education scene. The authors felt that it is very important to involve parents of these children by helping them to understand their children's learning and behavioural challenges so that they can appreciate what the teachers in special education (SPED) schools and/or allied educators in mainstream schools are doing their best to provide for their children's needs. The main focus of this paper is on establishing a proper working framework for SEPs so that they are better informed how they can work best to help parents of children with special needs. The authors have proposed their 2PH model that comprises of three key phases, beginning with phileogogy via parakaleogogy to heutagogy. Each of the three main phases is further divided into sub-phases to show how the entire framework on working with parents of children with special needs can become operational when put into application.

Keywords: Grief, Parental Participation, Special Education, Special Needs

#### I. Introduction

Singapore has come a long way from 1988 with the publication of the Report of the Advisory Council on The Disabled [1]. Four years later, in 1992, the Ministry of Education introduced the Learning Support Programme (LSP) to provide assistance to children who require additional support in the acquisition of literacy skills. "Pupils are identified for LSP through a systematic screening process carried out at the beginning of Primary 1" (para.2) [2]. In 2006, the Ministry of Education also introduced the "Learning Support for Mathematics (LSM) to provide additional support to pupils who do not have foundational numeracy skills and knowledge to access the Primary 1 maths curriculum" (para.4) [2]. Like LSP, pupils have to go through a screening procedure to be identified before they are emplaced in LSM.

With the beginning of the new millennium, the Compulsory Education Act was passed by the Singapore Parliament in 2003 "to legislate that all children born after 1 January 1996 must attend a national primary school" (p.3-10) [3]. However, the Act has excluded some groups of children, including children with special needs. As a result, there were sentiments amongst parents and advocates that children with special needs are not given equal and fair treatment as their non-disabled peers. In the same year, the Early Intervention Programme for Infants and Children (EIPIC) was introduced under the many-helping-hands approach involving a tripartite relationship amongst the voluntary welfare organisations (VWOs), National Council of Social Service and two government ministries, i.e., the Ministry of Education and the then-Ministry of Community Development, Youth and Sports (now known as the Ministry of Social and Family Development), to provide developmental and therapy services for children with moderate to severe disabilities from birth to age of six years. Currently, there are 17 EIPIC centres managed by (VWOs), such as the Asian Women's Welfare Association, Rainbow Centre, the Society of Moral Charities, the Autism Association of Singapore, the Autism Resource Centre, the Spastic Children's Association of Singapore (now known as the Cerebral Palsy Alliance Singapore) and Fei Yue Community Services, and the programme is heavily subsidised by the Government.

In 2004, Prime Minister Lee Hsien Loong called for Singapore to be an inclusive society during his speech at the opening of the Spastic Children's Association of Singapore's Cerebral Palsy Centre [4]. This is what the Prime Minister said in his speech: "Every society has some members with disabilities. How the society treats the disabled, takes care of them, and helps them integrate into the mainstream, reflects the kind of society it is. We want ours to be a society that cares for all its members; one that does not ignore the needs of those who are born or afflicted with disabilities" [4]. With his initiating call for more efforts to integrate disabled individuals into mainstream society, the landscape of special needs services including special education (SPED) schools has evolved rapidly since then.

With the introduction of *Teach Less, Learn More* by the Ministry of Education in 2005, there has been a shift away from a one-size-fits-all educational approach to help mainstream schools to better support teachers working with an increasingly heterogeneous group of students in both primary and secondary schools [5] [6]. In 2005, Special Needs Officers (now known as Allied Educators for Learning and Behaviour Support) and

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teachers trained in special needs were introduced to provide better support for mildly disabled children who are attending mainstream schools. During the early years of the training of Special Needs Officers, they were trained to handle children with either dyslexia or autism spectrum disorder (ASD).

In 2007, the Response, Early intervention and Assessment in Community mental Health (REACH) – a community-based programme involving a multidisciplinary team comprising psychologists, social workers, therapists and nurses – led by the Institute of Mental Health in collaboration with the Ministry of Education, the National Council of Social Service, VWOs and family doctors, was introduced to help emotionally, behaviourally and developmentally challenged students. More recently, the Government introduced the Development Support Programme in 2012 to provide support for children with mild developmental needs at mainstream pre-schools [1].

#### **II.** Challenges Facing Special Education Professionals

In Singapore, special education professionals (SEPs for short) are made up of four groups of educators working in different sectors: teachers working in special schools; resource teachers in international as well as private schools; learning support teachers and allied educators for learning and behaviour support working in mainstream schools, which include both public schools and government-aided schools; and educational therapists working outside special and mainstream schools such as those working in the learning centres run by the Dyslexia Association of Singapore and other VWOs (e.g., Care Corner Community Services). Their formal and/or informal professional training and working experience in special education vary widely, ranging from a special school teacher with a Certificate in Special Education to an educational therapist with a master's or doctorate degree in special education. As a result, there is currently a heterogeneous set of challenges (e.g., professional knowledge, competence and experience) that confront the SEPs in Singapore today.

The most common challenges encountered by SEPs are the lack of a thorough professional training programme for this allied education professionals, a poor career prospect (e.g., low salary, slow promotion and long working hours), demanding clients (especially difficult parents of children with severe to profound disabilities), a lack of resources, and the list can go on and on. On a more serious note, the turnover rate of SEPs is rather high and hence, the break in the continuity of passing essential knowledge and skills from the more experienced SEPs to the next generation of new or younger SEPs.

However, the Singapore Government has begun to look into the issue of providing quality special education in SPED schools run by various VWOs (excluding those private SPED schools, e.g., Genesis School and St Clare School, and international schools, e.g., Dover Court Preparatory School and Melbourne Specialist International School) as well as learning and behaviour support, which include school-based counselling, provided by allied educators in mainstream schools. As mentioned earlier in the Introduction, more mainstream teachers are currently being trained by the National Institute of Education – the sole tertiary institution, which is part of Nanyang Technological University, Singapore, to provide teacher training – to teach students with special needs.

VWOs such as the Dyslexia Association of Singapore and the Autism Resource Centre are also training both parents and educators how to work with their children with special needs, especially those who have been diagnosed with dyslexia and autism spectrum disorder (ASD). In addition, there is also the College of Allied Educators, a private training service provider, which offers courses to those interested to work in the fields of special education and counselling. Most, if not all, of its courses are validated and approved by the College of Teachers, London, UK, which awards certificates and diplomas. There are also other private training consultancies such as Learning Bridge and Bridging Talents that cater not only training workshops but also providing intervention programmes for children with special needs.

## III. A Proposed Systematic Framework On Working With Parents Of Children With Special Needs

This paper is not about parents or how to work with parents of children with special needs per se. Its focus is on the authors' proposal for a proper systematic framework for SEPs who are working with parents of such children.

Currently, there are already some frameworks or models on case management (CM) and support coordination for disabled populations as reported in literature [7]. There are different CM models such as the assertive community treatment or intensive model, the clinical or rehabilitation model, the generalist (also known as brokerage) model, and the strengths-based model [8]. Most, if not all, models offer the same core functions: assessment, planning, linking, monitoring, and advocacy [7]. They are distinguished from one another basing on their features, the degree of service provision, the client participation and the involvement of the case manager [9].

In Singapore, teachers in both special schools and mainstream schools are familiar with the APIE case management system, where APIE is the acronym for Assessment-Planning-Implementation-Evaluation, and it is

used as "a planning tool applied within the managerial context of a mainstream school to support students with special needs" (p.14) [7]. The second model is known as the Triple-D model first introduced by Chia and Kee in 2012 [10] for training of allied healthcare professionals under the administration of the Singapore chapter of the International Association of Counsellors and Therapists based in the United States. According to Wong et al. [7], the special education professionals (SEPs) "need to 'carefully explore how student learning, thinking and behaviour change as a result of a lesson taught' (para.4) [11]" (p.16). However, there is no one systematic framework designed to examine and focus solely on working with parents of children with special needs in Singapore.

In 2012, the Ministry of Education has published a booklet – A Parent's Guide for Children with Special Educational Needs [12] – which is available online to help parents who may be concerned about the school choices for their children with special needs in terms of "(1) what special educational needs are, (2) how they can help their child, (3) what schools can do to help their child, and (4) how to apply to a special education (SPED) school" (p.3). In the guide, parents will learn about the common disabilities among children in Singapore, assessment to be done, choice of school, i.e., between a SPED school and a mainstream school, and the procedure of application to a SPED school. However, what is lacking is the human touch that parents of children with special needs need most. In many instances, parents are lost and confused, and they need assurance and reassurance from the professionals in the field of special education to advise them so that they can make their decision about their preferred choice of follow-up action.

It is for this reason that the authors of this paper decided to propose their framework, which they have termed as 2PH model, that comprising of three main components -phileogogy, parakaleogogy and heutagogy — to show a proper system how parents of children with special needs can be involved in helping their children in a more pro-active and effective way (see Figure 1). The flow of the working model goes in the following dual directional way: phileogogy  $\leftrightarrow$  parakaleogogy  $\leftrightarrow$  heutagogy  $\leftrightarrow$  phileogogy. Each of these three components will be briefly described below.

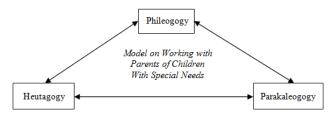


Figure 1. 2PH Model on working with Parents of Children with Special Needs

#### 1.1 First Phase – Phileogogy: To lead with love

It is important for SEPs and interested parties especially VWOs that provide services to disabled individuals should practise *phileogogy*, where the Greek words *phileo*- means "to love" and *-gogy* means "to lead", and it means to lead with love [1]. This is the first phase of the three in the 2PH model on working with parents of children with special needs.

In the past decades, the movement for early identification and early intervention has been most successful in identifying children with special needs at the earlier phase of their development such as at preschool and lower primary levels [13]. However, some of these children's needs may not become apparent until much later, especially, after they begin formal primary school education as in the Singapore situation when such children with special needs are picked up during the Primary 1 LSP and/or LSM screening. For disabilities that are the result of some unfortunate external events such as an accident (e.g., physical injury resulting in the loss of limbs and traumatic brain injury) or an illness (e.g., loss of cognitive capacity caused by a severe febrile fever) may happen at any point during a child's early lifespan development as well as during his/her school years. In other words, labelling a child as disabled (e.g., be it dyslexic or autistic) can occur at any level of schooling. "Parents often develop wishes, expectations, and dreams for their children, even long before the child is born. At a minimum, parents wish for a healthy baby ("We don't care whether it's a boy or a girl, just as long as it's healthy" is the cliché that is repeated over and over), and they assume that it will be so" (p.53) [13]. However, when parents are told that their child has been diagnosed with a disability, it dashes their dreams and hopes they have been holding about their wished-for child. Time and private space are needed for parents to grieve the loss of these hopes and dreams before they can move on to "dream new dreams" [13].

Sadness related to the child's disability may trigger what is known as the cycle of grieving, which involves five stages [see 14 for more detail]: denial, anger, bargaining, depression and acceptance (some say there are seven stages: shock or disbelief, denial, anger, bargaining, guilt, depression, and acceptance

and hope). This not a fixed sequence of events nor does grieving occur in a linear progression, but the process takes chaotic twists and turns.

According to Seligman [15], the cycle of grieving is a form of defence mechanism "that projects blame to an external source" (p.41), also known as projection, "where an action or behaviour is attributed to another person, group, or institution" (p.41). Through projection, an unconscious guilt is gradually built up and "may be converted into blaming the teacher for a child's slow progress" (p.42) [15]. Denial comes next and it is during this phase when parents attempt "to establish the myth that there is nothing wrong with the child and since this pretence serves to protect them from anxiety ... to maintain the myth against great odds" (p.63) [16]. This is followed by rationalization which "means justification, or making a thing appear reasonable, when otherwise its irrationality would be evident. It is said that a person 'covers up,' justifies, rationalizes an act or an idea that is unreasonable and illogical" (p.645) [17]. Intellectualization comes next and it is "a systematic over-doing of thinking, deprived of its affect, in order to defend against anxiety attributable to an unacceptable impulse" (p.68) [18]. Seligman [15] explained that anxiety is warded off by verbal excesses, especially in situations where strong emotions are aroused.

Finally, repression, suppression, displacement and withdrawal are other forms of defense mechanism that may also occur, but do not necessarily happen in that order. Repression is defined by Ross [16] as "the mechanism through which unacceptable and threatening psychological content is kept from conscious awareness. Repressed activities, impulses, and conflicts which are thus excluded from consciousness are not eliminated and they continue to cause stress" (p.53). This can result in what is often known as the caregiver stress syndrome whose "signs and symptoms include frequent fatigue, sleep problems, anxiety, depression, headaches, memory loss, hypertension, decreased immunity and a feeling of frustration" [19]. Suppression is often used interchangeably with repression but they are significantly different. "Suppression is the act of consciously inhibiting an impulse, idea, or emotion – a deliberate attempt to forget something" (p.45) [15]. For example, it is difficult to talk to a parent who wishes to suppress an uncomfortable thought by saying "It is upsetting that I don't wish to talk about my child." As for displacement, it refers to "the shifting of an impulse from one source to another in order to 'solve' a conflict and avoid anxiety" (p.45) [15]. For instance, the husband quarrels with his wife and accuses her of having bad genes that are passed to their child born with disability. Finally, withdrawal is a reaction to a threatening situation and becomes a characteristic way of responding suggesting that excessive anxiety may still be present [15].

Since July 2012, the Ministry of Education in Singapore conducted a pilot project involving 14 primary schools to provide parents with post-diagnosis services from two VWOs, i.e., Students Care Service and Touch Family Services [20]. Counsellors from these two VWOs provide emotional support and assistance to parents of children with special needs in order that they make informed decisions about whether their children should be transferred from mainstream schools to SPED schools. Because of the stigma that is often associated with SPED schools, "[P]arents find it hard to accept the fact that their child is special and need specialised support" (p.1) [20].

Chia [21] has listed two reasons how to make special education a success by changing the mindset of parents about SPED schools. Firstly, emotional support provided by counsellors from voluntary welfare organisations to parents of children with special needs "is especially essential when parents need to make an informed choice and decide whether to take their children with special needs out of mainstream schools and put them into special education (SPED) schools" (p.12) [21]. This is because majority of parents felt guilty if they chose to withdraw their special needs children from mainstream schools too early. These parents thought that they were being cruel in doing so as it would deprive their children of a proper regular education. In fact, many parents would prefer to let their children with special needs stay longer in the mainstream school hoping that eventually, they would be able to catch up with their neuro-typical peers. Such a misperception or false belief should be addressed as soon as possible and could be best achieved through close collaboration involving staff members from both mainstream and SPED schools. Secondly, there is also the need to focus on the well-being of children with special needs. For such a child to be transferred from a mainstream school to a SPED school, it can be quite challenging for him or her. "Besides learning to adapt to a SPED environment, the child must learn how to socialise with other exceptional children, whose diverse learning and behavioural challenges could range from moderate to profound level of severity. More time may be needed to prepare the child for a proper transition and smooth integration into the new environment" (p.12) [21].

Chia [21] argues that to ensure the success of these new SPED initiatives, there is a need to apply to special education the same fundamentals that underlie a student-centric, values-driven education mentioned by Mr Heng Swee Keat, "the Education Minister at the Ministry of Education Work Plan Seminar in September this year: That for every SPED school to become a good school, it should involve every SPED teacher as a caring educator; every parent, a supportive partner; and every child with special needs, an engaged learner" (p.12).

#### 1.2 Second Phase - Parakaleogogy: To lead with a helping hand

Whatever initiative or programme introduced by the Government to help individuals with special needs, its success depends on the end-users, i.e., SEPs providing the services and parents together with their children with special needs receiving them. Chia [1] has suggested three important inter-playing factors that SEPs should be aware when they are helping, advising and guiding parents of children with special needs: the *appropriateness* and its *applicability* (see Figure 2).

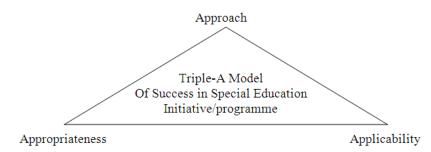


Figure 2. The Triple-A Model of Success in Special Education Initiative/Programme

According to Chia [1], the success of the approach carried out by SEPs (service providers) to help disabled individuals (as well as their families) will depend on following three key elements (p.21):

- Involvement of a trans-disciplinary collaboration among the SEPs;
- Use of multi-sensory strategies; and
- Incorporation of the universal design for learning and living as well as transition between both

Next, the approach must be appropriate in terms of the content knowledge and essential skills to be taught by SEPs [1].

Lastly, the applicability of the approach should consider the following two elements (Chia, 2015, p.21):

- Intensity which involves consistency, frequency and duration; and
- Delivery, which should be systematic and structured so that disabled students can benefit from the programme.

Chia [22] has argued that very often SEPs tend to forget that parents are also fellow humans with feelings. They need to work collaboratively with parents and their children with special needs, to beseech, encourage, guide and comfort them. This is *parakaleogogy*, derived from Greek, which means "to lead and guide along the way". It constitutes the second phase of the 2PH model on working with parents of children with special needs. According to Chia [22], "[W]hat parents need is the will to meaning in life to help their own children with disabilities" (p.18) and to rise above life challenges they face daily in what Viktor Frankl (b.1905-d.1997), an Austrian neurologist and psychiatrist as well as a Holocaust survivor, has termed it "tragic optimism."

Chia and Kee [23] have argued the need for parents to find meaningfulness in life through what is known as the sense of coherence, which Antonovsky [24] has defined as "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that the stimuli deriving from one's internal and external environments in the course of living are structured, predictable and explicable; the resources are available to one to meet the demands posed by these stimuli; and these demands are challenges, worthy of investment and engagement" (p.19). The approach to a healthy sense of coherence is known as *salutogenesis* – coined by Antonovsky [25] – referring to how people manage stress and stay well. In this case, the focus is on parents of children with special needs and how they are managing their children, coping with the stress that comes with it and staying mentally healthy [see 23 for more detail].

### ${\bf 1.3\ \ Third\ Phase-Heutagogy:\ To\ lead\ with\ a\ self-determined\ choice\ of\ action}$

Heutagogy – first coined by Hase and Kenyon [26] – constitutes the third and last phase of the 2PH model on working with parents of children with special needs. According to Hase and Kenyon [26], heutagogy "is the study of self-determined learning ... an attempt to challenge some ideas about teaching and learning that still prevail in teacher-centred learning and the need for knowledge sharing rather than knowledge hoarding" (para.1). In this last phase, parents, after having undergone the two earlier phases, may have come to terms with their current situation and accept the fact that their child has a disability or special needs. Being better informed than before, through their interactions with SEPs and other allied professionals as well as their accumulated experience raising a child with special needs, these parents (with whatever resources that are available to them) are now in a better position to decide what is best to be done for the benefits of their child.

However, there are also parents who may choose to continue in the state of denial and/or seek other complementary and alternative treatments (CAT) for their children with special needs. In the last three decades, there is an astronomical increase in the use of complementary and alternative medicine or treatment (CAM/T) in the West [27]. This has also become a worldwide phenomenon and the World Health Organization [28] estimates 80% of the populations worldwide depend on CAT. Its use is more widespread in the East than the West, e.g., Yamashita et al. [29] reported 76% of Japanese use CAT. In Singapore, Lim et al. [30] reported a prevalence of between 76% and 81% of Singaporeans using CAT. According to a survey study done by Chia and Kee [31], their findings suggest that many parents in Singapore continue to seek CAT despite inconclusive or conflicting results of research studies on the efficacy of the treatment [see 32 for detail).

According to Chia and Kee [31], the choice made by parents of children with special needs to go for CAT was "based on the qualities of the provider, desire for individualized treatments, and their perception of overall effectiveness rather than efficacy ... and include a positive valuation of CAT, the ineffectiveness of conventional or orthodox treatment for their complaint and dissatisfaction with care and communication with professionals providing the treatment" (p.38).

Finally, it must be noted that whatever decision parents have made are very much self-determined basing on three key factors: information and education they can get, collaborative consultation with SEPs, and professional advice and referral offered to them [33]. How successful the 2PH model will be depends heavily on SEPs' working relationship with parents through collaborative consultation based on mutual agreement and trust between them.

#### **IV. Conclusion**

This paper is not about the different types of parents or problem parents [see 15, pp.155-184, for detail], whom SEPs will work or be working with, nor is it about the effects of different phases of parenthood development that influence parental perspectives and attitudes towards raising their children with special needs. Its main focus is on establishing a proper working framework for SEPs so that they are better informed how they can work best to help parents of children with special needs.

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