



FROM TEACHERS AND FAMILY TO COMMUNITY: WHAT SUPPORT IS AVAILABLE FOR OUR CHILDREN WITH SPECIAL NEEDS

Boon Hock Lim¹ⁱ,

Kok Hwee Chia²

¹PhD, Special Education Consultant, Malacca, Malaysia

²EdD, Special Needs Consultant, Singapore

Abstract:

One of the most pressing issues that most countries, including Malaysia and Singapore, are facing today is meeting the needs of their children with special needs. Teachers in mainstream schools (as well as special schools) have seen more and more children with special needs in their regular classroom settings and these children are unable to cope with the regular curriculum. Families with children with special needs are also desperate for help from the schools their children are attending as they are unable to cope with them at home. As the community begins to see more and more children with special needs in their midst, there is now a conscious awareness of the need to provide adequate services and appropriate resources to support these children. In this paper, the authors have attempted to raise this issue by exploring and questioning what kind of support teachers, family and community can provide in terms of services and resources for children with special needs, if there is, indeed, such a support available.

Keywords: community, family, parents, support services, teachers

1. Introduction

The traditional African proverb says, *"It takes a village to raise a child"* and this has been widely quoted, especially when we examine *"the partnerships required during the maturation of our youth"* (Connected Principals, 2014, para.1). Our "village" (we prefer to use the word "community") has never been more necessary than it is today.

ⁱ Correspondence: email azagape@yahoo.com

In this millennium, we are living in a fast-paced, instant information via Internet, and pressure-packed world where post-truth reporting of events has also entrenched in our lives today. Not only we, but our children are facing a myriad of both challenges and opportunities not only in school or at home but also beyond school and home – the community at large where they live with others. What if this child happens to be one with special needs? A unique child with special needs unlike the typical one that every parent knows and nurtures ...? Is not this child going to encounter even a bigger mountain of lifelong challenges ahead beyond his/her available resources and capability to cope? Our concern will be what kind of support is currently available to such a child when he/she needs help.

There are many levels of support that we can provide for children with special needs. Not only for these children, but also for their primary caregivers: the child's parents, the child's siblings, the child's other family members. Very often, the family members have to suffer in silence for fear of being ostracized by the community. Perhaps it is because of the social stigma that in most instances, families are reluctant to bring their children with special needs out for a walk in the open, only to attract staring eyes and uncalled remarks from strangers who do not understand. Do we provide sufficient support for families who have members with special needs? Have we educated the public well enough about individuals with special needs so that they will not develop any misconception?

In this paper, we want to explore the three kinds of possible support for such children with special needs with the aim to raise the current awareness of the public: (1) Teacher support; (2) Family support; and (3) Community support (see Figure 1).

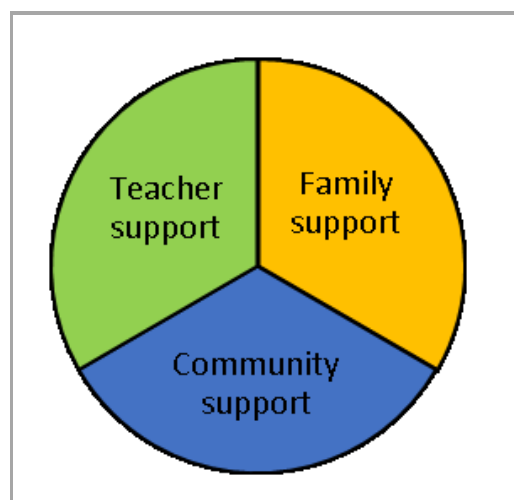


Figure 1: Three Kinds of Support for Children with Special Needs

2. Teacher Support for Children with Special Needs

Generally, what we have identified basing on our respective personal observations in Malaysia and Singapore, are two forms of teacher support (see Figure 2):

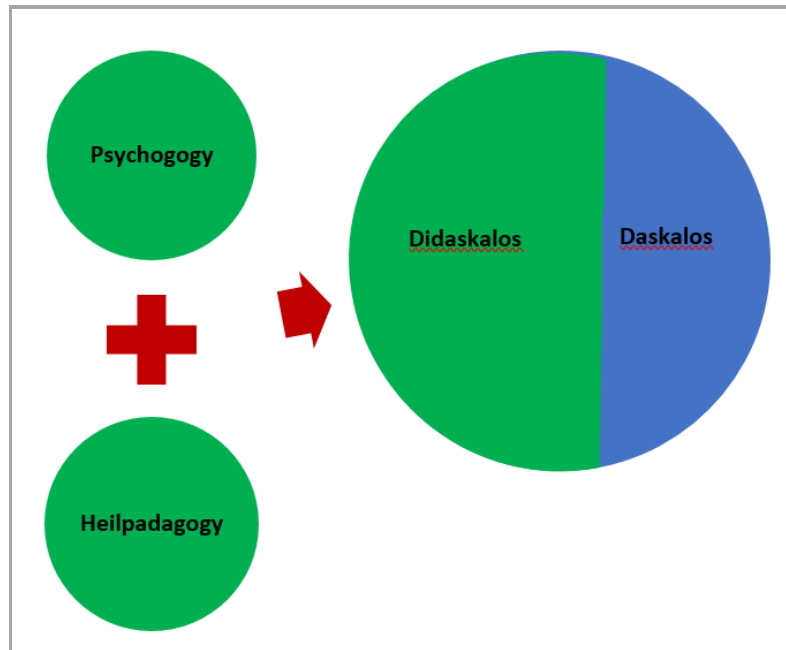


Figure 2: Two Forms of Teacher Support

- *Daskalos*: The teacher (including teacher aide, resource teacher and/or allied educator) plays the role of a support provider; and
- *Didaskalos*: Teaching (e.g., remedial teaching, diagnostic or clinical teaching) is modified into a form of supportive pedagogical provision. Under this teaching support, it can be further divided into (i) *Psychogogy*, i.e., literally, it means “to lead the mind of a learner”; and (ii) *Heilpadagogy* (originated from the German word *heilpadagogik*), i.e., literally translated, it means “to lead with assisted teaching.”

In *daskalos*, the teacher (including teacher aide and resource teacher) plays the role of a support provider to students with special needs by making access arrangement available and providing necessary assistance such as preparing worksheets in enlarged print for those who are visually impaired but not totally blind. There are two specialized teaching approaches that teachers (if they are trained in special needs education) and allied educators or paraprofessionals in education/special education can provide: The first approach is known as *psychogogy*, which means “to lead the mind of a learner” (see Chia, 2015a, for detail). The term “*psychogogy*” originated from East Germany and according to Chia and Ng (2011), they have defined it as “an instructive theory that includes psychological influence on a learner’s mind in terms of his/her learning and

thinking abilities, feelings and will to perform or act and whose behavioral traits interlinked by various senses through different sensory processes in order to establish his/her own perception and belief through interaction with others within a given sociocultural context" (para.2). In this approach, there is a need to consider the hierarchy of abilities and skills specific to the respective abilities. There are six levels in the hierarchy beginning from the foundation level #1 of innate abilities; next is the level #2 of sensory perceptuo-motor coordination abilities and skills; follows by level #3 of adaptive behavioral abilities and skills; next, level #4 of socio-emotional behavioral abilities and skills; level #5 of cognitive abilities and skills; and level #6 meta-cognitive abilities and skills (see Chia, 2008, for detail). It is not within the scope of this paper to delve into this topic. However, our concern is: Are our teachers properly equipped with adequate content knowledge and skills to handle students with special needs in their respective classrooms?

For *daskalos* to work successfully, it depends very much on the teacher's attitude in two ways: our first question is: *"Is the teacher inclusive?"* Our second question is: *"Is the teacher person-centered towards his/her treatment of a student with special needs?"*

To the first question, for a teacher at the individual level, being inclusive or to be inclusive, refers to his/her *"political actions and personal efforts but also, at the same time, the presence of inclusion practices in which people coming from different backgrounds possess with them different age, race and ethnicity, religion, gender, nationality, upbringing, sexual orientation, etc. that are socio-culturally accepted and welcomed, equally treated, etc. that are set up as an inviting context for everyone from all backgrounds as well as giving an equal opportunity for individuals to succeed in a way that works for them. Hence, for example, in terms of inclusive teaching, it means to make rooms for teachers from different backgrounds (e.g., experience, training and qualification) to actually create different definition of pedagogical success"* (Chia, 2016, p.143; cited in Ng & Chia, 2016).

To the second question, *"by person-centeredness, I refer to the way an individual with special needs is treated as a specific person with both unique strengths and needs that may result in some learning and/or behavioral concerns to be taken care of in this approach"* (Chia, 2015b, para.12). Can our teachers provide person-centered teaching/learning during lesson?

The second approach is *heilpadagogy*, which means *"to lead with assisted teaching,"* and in this approach, assistive technologies of different levels can be introduced or incorporated in the conventional teaching in a typical classroom. Heilpadagogy (originated from East Germany) also refers to assisted teaching or teaching for students with special needs. Loosely defined, it also refers to special needs education or special education. In the United States, it refers to educational therapy (Association of Educational Therapists) or special needs educational therapy (International Association of Counselors & Therapists). To elaborate further, educational therapy is defined as a

combination “of educational and therapeutic approaches for evaluation, remediation, case management, and communication or advocacy on behalf of children, adolescents and adults with learning disabilities or learning problems” (Association of Educational Therapists, 2002; rev. 2012, para.1). Often the approach is one educational therapist to one child. It has also incorporated the use of assistive technologies in the treatment for children with special needs. Is it possible for selected teachers or those teachers interested in educational therapy be trained in that specialized field to help students with special needs?

3. Collaboration between Teachers and Parents

In most mainstream schools in Malaysia and/or Singapore today, teachers and parents often come together to form some kind of Parent-Teacher Association (PTA) or even some specific parent-teacher support group to assist their children with special needs attending mainstream school which offer inclusive education. In such a case, teacher’s role is not only to teach, but also to educate, the child with special needs, while the parent is to play a supportive role to the teacher (e.g., as a volunteer to read to at-risk children in a weekly reading buddy program or as a voluntary teacher aide). Are teachers and parents ready to work collaboratively for the benefits of children with special needs attending their school?

4. Family Support for Children with Special Needs

When we talk about “family”, we need to ask ourselves, “*What is family by that term that we have been using so often?*” Family is a single word, with many different meanings. People have many ways of defining a family and what being a part of family means to them. Families differ in terms of economic, socio-cultural, religious faith, and many other facets, but what every family has in common is that the people who call it a family are making clear that those people are important in some way to the person calling them his/her family.

Here, we have chosen to adopt the typical (and generic) sociological definition of family: “*a fundamental social group in society typically consisting of one or two parents (father and mother) and their children*” (Blessing, n.d., para.2). We have proposed a more inclusive definition of family and it goes like this: Two or more people joined by a marital agreement to share goals and values, have long-term commitments to one another, with or without children, and reside usually in the same dwelling with or without other members from their respective families of origin living together. This

definition of family is a good starting point but there are several modern family structures that are excluded by this definition, such as childless couples or other variations on the family unit. There are so many types of family, e.g., single-parent family, adoptive/foster family, etc., and hence, we need to consider various factors if we want some kind of family support to be available for a child with special needs.

In family support, we have identified and categorized it into two types (see Figure 3):

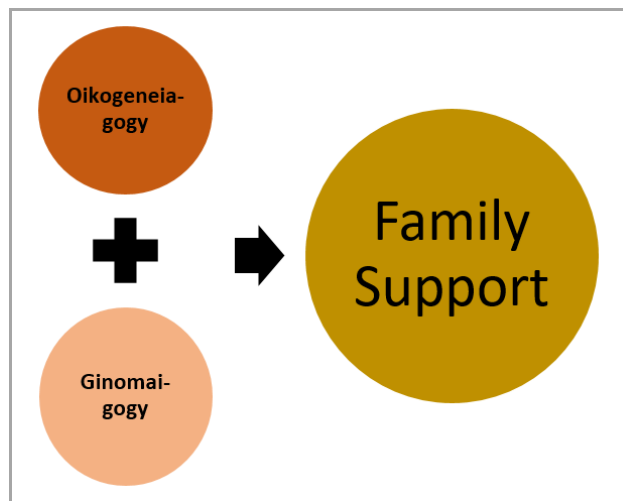


Figure 3: Two Types of Family Support

- *Oikogeneiagogy*: Literally translated from two Greek words *oikogeneia* (family) and *-gogy* ("to lead"), the term means to be family-led, and this is very much determined by the members (e.g., grandparents who are staying with the family, the maid employed to take care of the child with special needs, or any unmarried grown-up related to the family and lives with them) of the family that stay together. In this approach, the strength of support comes from everyone in the family especially when one of their family members is afflicted with special needs. For example, every responsible adult, including the maid employed by the family, takes turn to bring the child to school or for therapy session outside school.
- *Ginomaigogy*: Literally translated from two Greek words *ginomai* (parent) and *-gogy*, the term means, strictly speaking, to be parent-led (can be led by either father or mother or both), excluding the siblings of the child with special needs. This can be divided further into either paternal led or maternal led kind of support and more so for single-parent families. In this case, it can be a single-parent (divorcee, widow or widower) or a stay-home parent (while the other spouse has to work full-time) who is spending full-time to attend to the needs of

the child, e.g., bringing the child to school or therapy session, feeding and bathing the child, and so on.

In the first type of family support, it concerns more of sharing out the responsibility of looking after the child with special needs so that everyone contributes his/her effort and time to provide for the child concerned. This support also helps to reduce burnout for the primary caregiver. In the second type of family support, one parent plays the key role as the main caregiver. This is tough for the single parent, who may have to juggle between his/her part-time job and attending to the child with special needs. Normally, in this second family support, burnout and depression can be the consequences for these primary caregivers in what is known as caregiver stress syndrome (Chia, 2013). As a result, these single parents need some timeout for themselves to rest and pursue their own hobbies. Day care centers will provide such respite for them though it is not a long-term solution. Financial assistance for these single parents is very in need since they do not earn a lot to support themselves, not forgetting the school and therapy fees they need to pay. In most cases, counseling and social services provided by non-government welfare organizations will come in most helpful to them. What are services and resources available for single parents who have children with special needs? Where can they seek professional advice and/or assistance? If such services and resources are already available, are the parents aware or have they been told?

Lim (2015) has often stressed on the need to listen to parents (especially their woes coping with their children with special needs), where little has been done to formulate a conceptual framework for understanding how parents react to having a child with a disability or special needs. Using narrative accounts from parents to study the various psychological models (e.g., stage model, chronic sorrow, and personal construct) on their parenting experiences of children with disabilities, Lim (2015) argues that *“this in no way implies a pathological view of the family. In fact, many families cope very well, and more recent studies attempt to understand why some families adapt better than others”* (p.109)

4. Community Support for Children with Special Needs

Like teacher support and family support, we can also divide community support into two levels (see Figure 4):

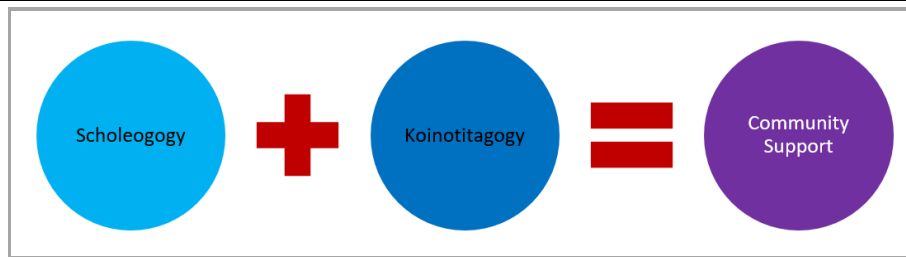


Figure 4: Two levels of Community Support

- School support, also known as *scholeogogy* (derived from two Greek words: *schole* means “school” and *-gogy* means “to lead”), refers to kind of school-led provision of services and resources and it works best if the educational institution adopts the principles of inclusion or inclusive education.
- Community or societal support, also known as *koinotitagogy* (derived from two Greek words: *koinotita* means “community” and *-gogy*), refers to provision of services and resources by community or society. The concept of *koinonia* embraces the concepts conveyed in the English terms community, communion, joint participation, sharing and intimacy ... and this is where community care and therapy originated from.

School itself is a sub-community within a bigger communal context. Its support for children with special needs is also known as *Scholeogogy*, i.e., led by school as an organization. *Scholeogogy* works best if the institution adopts the principles of inclusion or inclusive education. “*Inclusion (at the organizational level) ... refers to an organizational practice and its goal stemmed from the sociological notion of inclusiveness*” (Chia, 2016, p. 143; cited in Ng & Chia, 2016). Schools that adopt inclusive education often play an active role in training their teachers to be inclusive as well by preparing them how to reach out to children with diverse special needs, manage their behavioral challenges during lesson, and cope with unexpected issues that may arise from different types of disabilities and/or disorders. What kind of services and resources do inclusive schools provide to their students with special needs as well as their parents?

Community or societal support is also known as *koinotitagogy* or *koinoniagogy*, i.e., led by community or society. One good example is the special needs community therapy. Lim (2017) has defined special needs community therapy “*as a participatory community-based trans-disciplinary person-centered treatment (involving intervention, rehabilitation and/or management) to short-term (acute cases) and long-term (chronic cases) intellectual and developmental disabilities (see the IDEA 2004) done within a therapeutic residential context (i.e., therapeutic community home), where the clients and the therapists as well as some clients’ family members (depending on the policy of each community home) live and work together*” (para.1). Is such community therapy already available?

For school or community support to work well, we need to move away from the medical model of case management, which is multi-disciplinary, professionally directed and system-centered, to the social model of care management (Chia, 2015b, para.8). People naturally respond better to care and more so for individuals with special needs if care management approach is adopted. According to Chia (2015b), “[C]are management is more process-based, oriented towards personal well-being and personalized, adopting a service provider-to-customer relationship. This approach is not about what one does but who one is” (para.13). Have we moved away from case management to care management system? To what extent, if we do, have we gone into implementing the care management system?

Going back to what we have mentioned earlier in our paper, when we say, “*It takes a village to raise a child*”, this is exactly our emphasis, i.e., the responsibility of the community or society as a sociocultural entity to provide and nurture the child regardless of gender, race, socio-economic status, belief, and/or ability. It takes a village (or community) to keep our children safe when they are playing in our neighborhoods, parks and playgrounds. As neighbors, we keep an eye out for the children playing outside, we build friendships and relationships with our neighbors, and we work with the local police to keep our community safe. We send our children to a school in or close to our community such that we can recognize the school principal and the teachers there, and even partake in school-organized events. If a child who lives in that community is one with special needs, it should become a communal concern or an issue that the community should be interested, by determining how best the child can be helped, and pulling together its available services and resources, so that the child’s potential can be maximized to make him/her a useful member of the community, being an asset rather than becoming a liability.

This communal issue brings us to our next concern about the *Fabric of Life* (see HelloSoda, 2016, for detail) for an individual with special needs. The fabric of life refers to all the intertwining threads that make up a fabric, where the fabric is an individual with special needs, and the threads are everything that contributes to his/her life and character within the sociocultural context he grows and matures. These threads include the individual’s lifespan events from the time he/she was identified with special needs, his/her education and training, his/her family and friends, his/her personality, hobbies, lifestyle, where and when the individual spends his/her time, travels ... and, in fact, the list of things can be endless. That is why it is important to adopt the philosophy of person-centeredness to have an effective support service system because no two individuals with special needs are the same in every aspect. Also, since no individuals can function alone, they have to live with others in their community. This means we

have to bring in the *Fabric of Community* (or *Fabric of Society*). By *Fabric of Community* (or *Society*), we refer to the social customs, practices, habits, etiquette, protocols, and similar interactions comprise the core behavior of a particular community or society (adapted from Becksted, 2016). These could be formed from religious beliefs, laws, even weather, or “*always been that way*” (Becksted, 2016, para.2) attitude. In other words, for special needs community support to be effective, we have to keep the fabric of community in mind.

Finally, the way a community treats its members with special needs can tell us much about the progress of that community and it is best measured by the degree of progress which individuals with special needs are being included in every communal fabric of life.

However, the sad thing is that, in reality, people who have someone with special needs in their families or living with them tend to push the responsibility of providing for such an individual to someone else ... maybe a medical doctor, a priest or some religious figure, a teacher ... or they have the tendency to put the blame on the parents (especially, the poor woman who is the biological mother of the child born with special needs) with such bad genes ... or they cry out aloud that the social institutions (e.g., school, clinic, social welfare organization, temple, church) are not doing much to help, being unkind and not understanding towards someone with special needs. Lim and Chia (2017) have argued that “[P]laming and finger-pointing WON’T help at all. We MUST ACT on the current problem ... The question is how? Who should be involved? What can be done? Where to start? When should we begin? A list of questions can go on and on ...” (slide 21, para.1-2).

5. Conclusion

As alluded to earlier in this paper, we want to reiterate that the aim of our paper is to explore and question the kind of supports provided by teachers, families and the communities in which our children with special needs live. We do not presume to provide any solution to the issues we have brought up. More importantly, we want to raise the awareness among parents and teachers as well as within the schools and outside in the community at large: Are these supports already available or adequately provided for children with special needs? Whatever it is, as we are always told, there is still room for further improvement in the provision of services and resources for such children.

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