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Parental Advocacy for Students with Special Needs: A Systematic Review Study

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Abstract

This systematic survey study explores parental advocacy for students with special needs. Challenges, barriers and advocacy strategies are examined to understand how parents advocate. The SCOPUS and Web of Science (WoS) databases are used to find advocacy-related articles over the past 10 years from 2010 to 2021. A total of 80 articles with 60 studies from SCOPUS and 20 studies from WoS were identified through the PRISMA flow chart process. Findings revealed inadequate information, negative perceptions, language and cultural differences, insufficient knowledge, the presence of stereotypes and discrimination as well as differences in socioeconomic levels as barriers to parental advocacy. Some of the strategies adopted to advocate for the special children are communication with the special schools, the sharing of knowledge and purposes and provision of professional services to support the schools. Collaboration between parents and the school is identified to be the main medium that ensures the educational needs and rights of the students with special needs are met. A more conducive and meaningful learning environment for these students requires the involvement of multiple parties.

Keywords: Parent Advocacy, Students with Special Needs, Challenges, Obstacles, Strategies

Introduction

Advocacy is a form of support, encouragement and continuous help needed by this group to live their daily lives fully. It has been described as a key action that influences the development and implementation of a policy (Watson, 2015). Sama & Ali (2017) stated that advocacy can be a means of involving the community when resolving issues. One of the most important area where advocacy is mostly needed is education. Children with special needs have equal rights to education as that extended to typical children. Undeniably the challenges to the teachers and to the students themselves are immense but not insurmountable. Both parties require support. Consequently, more and more parents begin to realize the importance of advocacy in the effort to eliminate any form of discrimination towards the educational needs for this category of children. There are instances of parents who resort to the services of Special Education advocates to ensure the best standard of education (Burke & Goldman, 2017).

Parents of students with special needs play a key role as an advocate and the involvement of these parents is important to ensure that their children's education, mental and physical health and social needs are met. As parents, their unwavering commitment and

sacrifices for the well-being of their children with special needs makes them natural advocates (McCammon et al., 2001).

Understanding Advocacy

Advocacy is an action structured to address a problem aimed at influencing the attitudes of a group of individuals through the enactment of the law and implementing it until the desired goal is achieved (Holcomb-McCoy & Bryan, 2010). In other words, advocacy is seen as more of a formal in the context of social justice as emphasized by (Boshoff et al., 2016). In on that Trainor, (2010) Found Parental advocacy involves a nature that focuses on the concept of engagement and enforcement of special needs students. Therefore, there are various terms in the concept of advocacy and make it incompatible. There are inconsistencies in the definition of advocacy in the study conducted (Boshoff et al., 2016) and there is no clear terminology to denote the actual term of advocacy (Trainor, 2010).

In the context of Malaysia, the concept of advocacy is used in the form of gathering through the organization of non-governmental social organizations (NGOs). For example, an NGO was formed as a self-advocacy group against learning disabilities, to voice the right to learn independently, to make choices and to have a sense of responsibility in the community. Nuri, Ali and Salleh (2020) explain self-advocacy as an individual's ability to voice rights in communication relating to needs, goals, desires, knowledge and rights as a special needs individual. There are parents group who stress on the advocacy of parents by connecting parents and other advocators such as doctors, therapists, educators, and, activists to share experiences and information of a specific disability. There are also groups that focus on advocacy activities such as forums, lectures, support, as well as organizing courses among parents and the community.

Parents and Advocacy

Parents who support advocacy normally get themselves involved in planning effective strategies that promote good education for their children. It is the responsibility and the role of parents to identify their children's level of ability at an early age so that necessary interventions can be carried out. Kusrin et al (2020) suggest that to ensure the effectiveness of the intervention process, it must be implemented continuously by teachers and especially by parents to ensure for a positive outcome of the intervention. Krueger et al (2019) found that parents who adopt various advocacy strategies on their children are likely to be successful in their helping their children. They listed the strategies consist of the frequency of the advocacy, places and time that are conducive to advocate, parents attitudes and having achievable goals in the advocacy process. It has been identified that the most affective form of advocacy concerns the attitude of parents who devise a successful advocacy strategy by taking into account the ability and potential of their children with special needs (Besnoy et al., 2015).

Advocacy strategies are also employed through the use of professional advocator such as therapists and special education teachers (Burke et al., 2018). These professional advocators play an important role in helping parents to advocate regarding their children and to resolve problems faced in schools (Goldman, et al., 2020). Effective parental advocacy in schools can be realised through parents active participation in school activities such as Individual Education Plan meetings and Parents and Teachers Association Meetings.

Different parents define advocacy differently. There exists significant gap in advocacy practices among parents which justify the need to further explore and review these practices particularly the barriers that exist and the approaches the parents adopt within their respective context and strategies. Parents employing the advocacy process to secure their special children access to good education have identified several barriers that hinder advocacy. A study from Wright and Taylor (2014) revealed several parental advocacy barriers such as psychology, emotional experiences during advocacy implementation and cultural barrier. Cultural and language differences between parents and schools are also major barriers to good advocacy practices (Burke & Goldman, 2018). Parents who feel inferior may be reluctant to engage with advocacy (Resch et al., 2010). Parental advocacy is also hindered by poor funding as special education service facilities are normally expensive, preventing schools to provide facilities and services that are requested by parents (Goss, 2019). Poor communications and inadequate information are seen as the main causes of the lack of parental advocacy (Jefferson, 2015), while Hamzah et al (2021) expressed that parental challenges such as lack of information and knowledge, unstable emotions, lack of support from family members, negative public opinion and lack of support from professionals are the main causes of the lack of parental advocacy.

Different parents define advocacy differently. There exists significant gap in advocacy practices among parents which justify the need to further explore and review these practices particularly the barriers that exist and the approaches the parents adopt within their respective context and strategies. Therefore, this paper captures selected systematic research as a methodology for identifying issues that became the barriers for parental advocacy for their children with special needs.

Methodology

This study was conducted using a systematic literature review (SLR) method. According to Booth (2016) the SLR method enables a comprehensive, methodological and systematic approach towards attaining the research objectives. The method reduces the possibility of bias. The selection of articles is done based on several criteria that have been set by the researchers. The criteria set are necessary to establish a consistent approach in the selection of quality articles that are to be reviewed. The identified literature is from journal articles published around 2016 to 2021. The journal articles are related to parental advocacy for students with special needs. The researchers adopted the 8 steps proposed by Xiao and Watson (2019) in conducting the SLR namely: (1) formulating the problem, (2) expanding and validating the survey protocol, (3) article search, (4) screening criteria entry, (5) quality assessment, (6) data extracting, (7) data analysis and synthesis as well as (8) findings report.

This study also employed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) introduced by Moher et al. (2009) to explore the highlights in each step of the research process. PRISMA is a method and guideline for conducting a systematic review of works that produce good and accurate research by reporting what is done, the studies processes and the findings obtained (Page et al., 2021). It evolves around four phases namely: (1) the identification, (2) screening, (3) the qualifications) and (4) include. In the first phase of identification, article search was conducted. PRISMA is also used by researchers to strengthen the third to fifth steps as mentioned above of the SLR method.

In this systematic review, Scopus and Web of Sciences (WoS) became the two main databases in the search for journal articles related to parental advocacy for students with

special needs. Both of these databases were chosen because they are highly indexed databases and conform to the rulings set by the institutions of higher learning. Scopus permit access to the largest abstract and citation database while WoS permits access to articles that possess complete bibliographic data and cited references (Bergman, 2012). To identify the articles, the search is based on keywords which are ("advocacy" OR "collaboration" OR "involvement") AND "special education" AND ("challenge") by using Boolean operators. As a result of the search in these two databases, a total of 80 study articles namely 60 studies from Scopus and 20 studies from WoS were identified.

The second phase continued with a screening process in which 20 journal articles were removed from the list due to duplications. Further screening removed articles that did not meet the admission criteria set by the researcher as in Table 1.

Table 1: The inclusion and exclusion criteria in the article selection process.

Criteria	Admission	Exceptions
Year published	2010-2021	≤ 2015
Language	English	In addition to English
Document type	Journal articles	bibliography, book reviews
The focus of the study	Challenges, barriers and parental advocacy strategies for students with special needs	Effects of advocacy, self - advocacy, group advocacy
Type of study	Qualitative, quantitative, mixed studies, case studies	Dissertations, books, book reviews, program reviews

Twenty articles were removed because they did not meet the criteria set. The removed articles comprised of 10 studies published from 2010 to 2021 of which comprised of 5 journal articles, 2 related writings not in English and 3 articles with open access.

For the third phase of qualification, Xiao and Watson (2019) stated that the selected articles should be reviewed by two researchers in parallel and independently. Upon review, 47 full articles were screened again by focusing on the titles as well as the abstracts to obtain an overview of the respective article. From this process, a total of 30 articles were removed as it did not meet the established criteria. 6 articles were written in non-English, 19 articles were unrelated to parental advocacy and 5 articles commented on specific topics that were not in line with the research focus. In the final phase (the data inclusion phase), the researchers finally identified 17 articles that meet all the criteria set and qualify to be used as the samples for the study. The whole process of the PRISMA processes from identifying articles to determining to including the articles is shown in Figure 1.

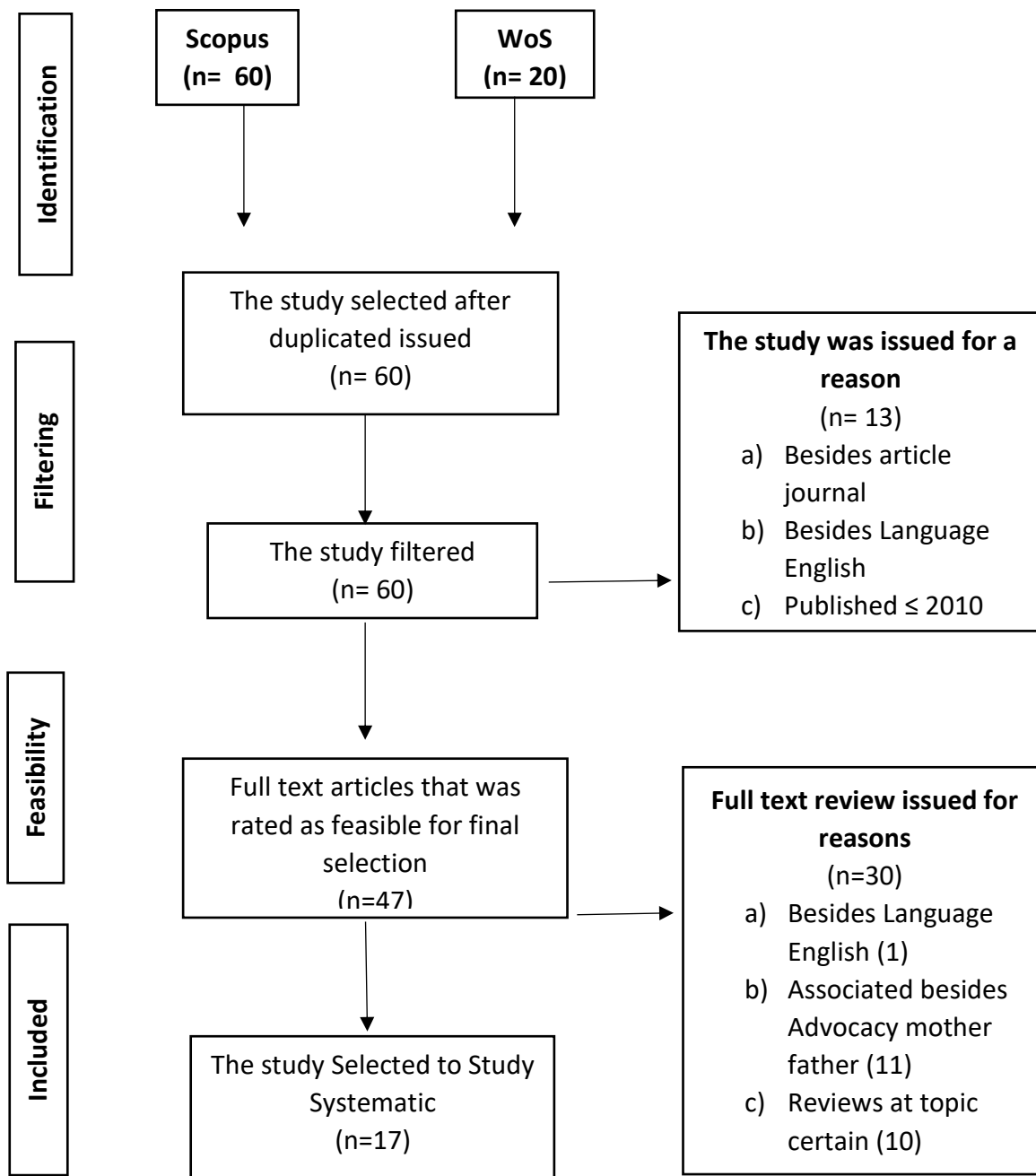


Figure 1: PRISMA flow chart for the article search process

Findings

The researchers confirmed that the selected studies are based on the set criteria and cover the scope of the research questions constructed by the researchers. Data were extracted from 17 selected articles based on a protocol constructed by the researchers and were matched based on three categories; research approach, barriers and challenges to parental advocacy and parental advocacy strategies.

Research Approach

Table 2 shows the 2 types of research approaches used in the studies in the selected articles. Of the total 17 articles, 15 of them were qualitative studies, and 2 were quantitative studies.

Research approach	Articles
Quantitative	Burke et al (2019); Wright & Taylor (2014)
Qualitative	Nagro et al (2019); Rossetti et al (2020); Glavan (2020); Goss (2019); Trainor (2010); Rehm et al (2013); Goldman & Burke (2020); Fogle et al (2020); Burke & Goldman (2018); Krueger et al (2019); Besnoy et al (2015); Burke et al (2018); Sauer & Lavvani (2017); Rossetti & Burke (2018); Mortier & Arias (2020); Burke & Sandman (2017)

Table 2: The research approach

Based on the analysis of the research approach, Table 2 shows that the qualitative approach is more dominant than the quantitative approach used by previous researchers. Asper & Corte (2019) explained that qualitative research is a process of improving understanding to approach the phenomenon to be studied.

Barriers and Challenges to Parental Advocacy

Parents who have children with special needs worry over how their children's education will be designed and developed. Ultimately as parents they are responsible to ensure that these children obtain the right level of education so as they could live a meaningful life within their respective abilities and capabilities. Dealing with the schools their children attend, parents hope that their advocacy can minimise issues like discrimination and neglect in the school settings. The search identified 7 forms of barriers and challenges as shown in Table 3.

Forms of barriers and challenges	Articles
a) Limited sources of information	Burke & Goldman (2018; Mortier & Arias (2020); Glavan (2020); Trainor (2010); Rossetti et al (2020)
b) Perception and system	
c) Language and cultural differences	
d) Lack of knowledge	Fogle et al (2020); Goss (2019)
e) Stereotypes and discrimination	Krueger et al (2019); Rossetti & Burke (2018); Nagro et al (2019)
f) Socioeconomic level	Rehm et al (2013); Besnoy et al (2015)
e) Transportation facilities	Rossetti & Burke (2018)

Table 3: Barriers and challenges of parental advocacy

There are 5 studies that highlighted limited sources of information on special education as well as the nature of the children's disabilities as form major barriers to advocacy. In addition, the perception of the community in general and the school in particular towards the students with special needs further reinforce the barrier to parental advocacy. Language and cultural differences also contribute as hindrances to advocacy. Interestingly, there are 2 studies that state the lack of knowledge of parents on special education as a barrier to the advocacy process. Three studies highlighted stereotyping and discrimination of parents of children with special needs as formidable challenges to parental advocacy. While the state of the socioeconomic level of parents involve only 2 studies. Finally, parents' transportation facilities

or the lack of it also contribute as challenges of parental advocacy for students with special needs.

Parental Advocacy Strategies

In realizing the intentions and goals of parents' advocacy for their children with special needs, parents need to formulate and plan good advocacy strategies. The advocacy strategies undertaken by these parents need to be seen in various contexts and roles.

Advocacy strategies	Articles
<ul style="list-style-type: none"> a) Bring support or materials b) Make a request c) Communication with the school d) Sharing knowledge e) Maximize access to parenting training 	Burke et al (2018); Wright & Taylor (2014); Mortier & Arias (2020); Rossetti & Burke (2018)
<ul style="list-style-type: none"> f) Frequency of advocacy g) Advocacy situation h) The purpose of advocacy i) Attitude j) The impact of advocacy 	Krueger et al (2019); Sauer & Lalvani (2017)
<ul style="list-style-type: none"> k) Get special help l) Obtain information m) Empowering Individual Education Plan (IEP) meetings n) Overcome language barriers by using a middleman 	Mortier & Arias (2020); Wright & Taylor (2014); Burke & Sandman (2017)

Table 4: Parental advocacy strategies

Table 4 shows the advocacy strategies undertaken by parents to ensure that the rights and educational needs of their children with special needs are met. There were 4 studies that emphasized on advocacy strategies such as bringing support or materials, executing requests with the school, trying to communicate with the school and sharing knowledge with other parents and maximizing access to parenting training. Two studies on parental advocacy strategies examine the frequency of advocacy, the time and space, purpose, attitude and impact. In addition, there is 1 study that discuss parental advocacy strategies in the areas of seeking and getting specific help and information on special education, how to empower Individual Education Plan (IEP) meetings as well as ways and means to overcome language and cultural barriers by using third parties as parental intermediaries.

Discussion

The discussion on the systematic literature review focuses on two main agenda which are forms of barriers and challenges to parental advocacy and parental advocacy strategies.

Forms of Barriers and Challenges to Parental Advocacy

Burke & Goldman (2018) stated that the form of barriers and challenges faced by parents mainly rest on the lack of information resources. Lack of sources of information on special education teachings as well as the nature of the children disabilities are major barriers to

parental advocacy within a string of several other factors. Among the factors that contribute to this barrier is the attitude of parents who do not emphasize the education of their children because they think that students with special needs do not have a bright future compared to typical children (Trainor, 2010). The findings of a study by Ismail & Ali (2020) emphasize that the most important challenge is that parents lack knowledge and information on special education and are in denial mode in respect of their children's condition.

In addition, according to Goldman (2020) the negative perception towards the relatively complicated education system is an obstacle to parental advocacy. This could be due to the school inability to handle the special needs and services that these students require and advocacy related support to the children's families. Researcher like Mortier & Arias, (2020) stressed on the form of challenges created by cultural differences among parents of the students. Cultural and linguistic differences are significant obstacles that prevents effective two-way communication between parents and schools (Kalyanpur et al., 2000).

A study by Fogle et al (2020) revealed that the lack of knowledge among parents and special education teachers towards the educational needs of students with special needs should be addressed quickly and effectively. When limited knowledge becomes a constraint, the relationship between parents and the school becomes stagnant and irrational. The fragility in parent-teacher relationships affects the delivery of special education programs (Goss, 2019). According to Rossetti et al (2021) there is an inconsistency of support from schools to parents when it comes to implementing advocacy. This has led to misunderstandings between parents and the schools where parents struggle to advocate for their children with no helping hand from the school. There are 3 studies describing the challenges of stereotyping and discrimination against parents. Krueger et al (2019b), explained that discrimination hinders awareness and failed to break barriers resulting in failure to meet the children's needs in accordance with their abilities and capabilities. Wright & Taylor (2014) explained that advocacy is essential to begin at the lowest level when the role of parents is at its most crucial stage when they require the most support, knowledge and skills to be effective advocates. Rossetti & Burke (2018); Nagro et al (2019) explained parental advocacy is hindered due to the school system that discriminates against certain races due to differences in skin color, culture and language. In addition, financial factors are also barriers to parental advocacy especially low-income parents who are unable to support their children to school and to choose the right mode of education that suit their children potential and aptitude. Transportation or the lack of it is also a factor that obstruct parental advocacy as explained by (Rossetti & Burke, 2018).

Parental advocacy strategies

Parental advocacy strategies as articulated by Burke et al (2018); Mortier & Arias (2020) mention of parental support to schools such as the provision of material support, accepting school request for aids, close communication with the school and the sharing of knowledge with the teachers. Extending support or the provision of teaching materials to schools are sometimes done through the engagement of individuals as their support representatives. Parents have also relied on the services of former special education teachers to attend Individual Education Plan (IEP) meetings at schools. This is due to parents who are less knowledgeable with special education and the use such services would aid in parental advocacy on their behalf.

Parents can request the schools for data and reports on their child's development (Burke et al., 2018) In addition, they can also request for IEP meetings where they can share

their experience and knowledge with other parents as well as with the school. The use of social media such as Facebook and Instagram provide platform for parents to share their experiences and share their insights on anything related to their children. Active parents also attend training and advocacy groups to further their special education knowledge as well as to collaborate with the school and enhance their advocacy efforts (Burke et al., 2019). Advocacy training with the participation of parents is a key component of successful special education services (Rooks et al., 2017) while Wright (2014) stated that the main thing in providing advocacy to these children involves maintaining contact with the school, face to face dialogue with teachers and parents who possess adequate knowledge on special education. All three of these factors provide a strong link to ensure the success of the advocacy taking place. Similarly, Rossetti & Burke (2018) stated that advocacy strategies should include multi language parenting training to accommodate multi linguistic parentage.

There are 5 additional parental advocacy strategies studied by Krueger et al (2019a) and Sauer & Lalvani (2017) who stated that the frequency of advocacy occurs depends on parental initiative. Parents advocate regardless of time and place for their children so that all the desired needs are met. Similarly, advocacy is most effective when the parents adopt the right the time and location that is most convenient to them and the children. For example, parents advocate in a variety of situations and contexts such as in a religious settings or during sessions with therapists. The purpose of advocacy also influences parents 'advocacy strategies where they seek specific desired outcomes such as involvement, acceptance, happiness and well-being for their children that include justice as well as equal opportunities. Meanwhile, parental attitudes or motivation levels are important factors in advocacy strategies. These factors influence their engagement in their child's activities, their expectation levels, their motivation to spread awareness in the community, their will to educate others, and many more. The participation of other stakeholders too contributes to the success of their parental advocacy.

Successful parental advocacy may enhance the children personal development and indirectly create other benefits. Through advocacy efforts such as communicating with others and exploring information on the internet, parents can expand their knowledge, thus allowing them to choose the best options for their children in therapy, interventions and other services. In addition, this effort not only benefits their children but also other children with similar special needs. Other advocacy strategies used in the study by Mortier & Arias (2020) relate to ways and means on how to obtain specific help and information. This refers to parents who share information and experiences about their children in advocacy groups. It also relates to how to seek and obtain legal advice when necessary. Next is an advocacy strategy through empowering Individual Education Plan (IEP) meetings. Mortier & Arias (2020) further emphasized parents are entitled to obtain written documents that have been drafted and planned by special education teachers for their children. This is to ensure that there is no discrimination by the school and all parties are involved in the decision making, thus ensuring a better quality of IEP. Similarly, the study highlighted by Wright & Taylor (2014) says that parenting strategies are entirely dependent on the efforts and initiatives of the parents themselves to seek as much information about their children especially educational rights and ancillary needs. Parents strive to collaborate with the school to establish good social relationships for the benefit of their children. Parental involvement with these schools will lead to positive changes to the school system. The study of Burke & Sandman (2017) states about getting specific assistance through legislation that can protect their children getting the right to proper education.

Conclusion

There are various strategies and challenges for parents in advocating for students with special needs. The strategies used by parents may not be the same depending on many aspects. Similarly, the barriers and challenges of advocacy are varied involving multiple factors. These barriers and challenges need to be minimised and overcome before an effective and successful advocacy is developed. In the meantime, a successful advocacy involves multi parties that include parents, schools, special education teachers, therapists and the general public. This collaboration enables the development of parental advocacy that is most beneficial to students with special needs. Therefore, it is pertinent that the said parties play their respective roles to ensure the rights and needs of students with special needs are achieved with optimum results.

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