

HOW PARENTS OF CHILDREN WITH VISUAL IMPAIRMENT AND MULTIPLE DISABILITIES SUPPORT EACH OTHER DURING THIS TIME OF THE PANDEMIC IN THE PHILIPPINES

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ABSTRACT

The global response to Coronavirus Disease 2019 (COVID-19) has changed daily life in many ways for many people. In the Philippines, schools remain closed and stay-at-home orders went into effect nationwide. The struggles faced by parents of children with visual impairment with or without multiple disabilities have amplified. Supporting the bond between parents or caregivers of these children is as important as ever. This discussion aims to answer the question about how parents of children with visual impairment with or without multiple disabilities from different parts of the Philippines, support each other as they learn to adapt and meet their children's needs as well as maintain their own mental health and relationships. We discussed the methods on how this support group, managed and run by parents themselves, build parent advocacy skills and self-efficacy skills as they cope during these times of the pandemic. We shared what activities were carried out despite the challenges this lockdown has brought and how these activities still allow families to regularly engage with each other and become present supporters of their children's development as they help them thrive and learn during this pandemic. We discussed the value of support groups and identify recommendations for support group design based on the experiences and feedback of the parents from the Philippines. Qualitative methods was used to examine the experiences of members of 1 parent-run support group. 30 parents were interviewed about the benefits and limitations of participation in support group. Information was collected by observing support group meetings, activities, and reviewing group documents. Interview, observation, and document data was analyzed to identify emerging themes. Results of the study indicated that the effects of belonging to a parent-led parent support group were substantial. Through these groups, parents gain increased skills, an increased sense of power and a sense of belonging. Participants are able to connect with each other and provide support and skills to deal with the day-to-day issues of raising a child with disabilities.

Keywords: parents of children with disabilities, children with multiple disabilities visual impairment (MDVI), support groups, empowerment, COVID-19

1. Introduction

Children with MDVI, are children who are blind and have additional disabilities. They may have physical challenges, speech and language problems, learning issues, and behavior problems. During the pandemic, these children are home all day without intervention and support. Many of them lose their routine, and they get bored and irritable. Parents struggle to keep up with the school modules sent home by the teachers and they are at a loss of how to teach their children.

There are no health services. Parents start to experience a constant fear of their own health, loss of a loved one, loss of finances, and also loss of relationships. Families members feel very isolated and many may be experiencing mental health problems. The struggles of raising a child with MDVI is very real, but this time, it is amplified.

In this paper, I discussed how Perkins International is supporting parents of children with multiple disabilities and visual impairment during this time of the pandemic in the Philippines. We will also discuss how parents are supporting each other. The activities that we are doing together to support families will be discussed as well as the outcomes of some of these activities. I shared with you some recommendations that was put to advice parents who want to start their own parent group or for those who want to support other parent groups. These recommendations came from our own experiences working together.

Perkins International's long-term partner in the Philippines, PAVIC is the one who made our work come to life. PAVIC stands for Parent Advocates for Visually Impaired Children. They are a group of 20 very active members, who reach out and recruit other parents of children with visual impairment. Now they have up to 800 members all around the country. As partners, our mission is very simple, it is to help parents become better parents for all children with visual impairment and for them to do whatever it takes to accomplish that. Qualitative methods was used to examine the experiences of members of 1 parent-run support group. 30 parents were interviewed about the benefits and limitations of participation in support group. Information was collected by observing support group meetings, activities, and reviewing group documents. Interview, observation, and document data was analyzed to identify emerging themes.

1.1 What Activities are Happening within the Parent Support Group During this Pandemic?

First, we have weekly support group sessions, where parents of children from different age group, log on every Fridays to meet each other, share parenting tips, ask questions, share happy moments as well as heart breaks. These parents are cheerleaders for each other during the best times as well as the toughest moments of raising a child with disabilities.

Second, parents build each other's self-confidence and self-efficacy skills by transferring their knowledge to others parents. They deliver free training in braille, or abacus and other topics to other parents.

Third, parents reach out to other professionals to help support them in topics related to their child, like occupational therapy, or topics for themselves, like how to practice mindfulness and have strong mental health. We also create webinars for parents as well as obtain low cost or no cost telehealth consultation for children.

Four, Parents nurture each other by celebrating holidays together with dancing contests, children's talent shows and many fun games.

Fifth, the parents also organize fitness activities for children and their families where they can exercise together as a community even if it is done online.

Sixth, these parents are hosting their national parent congress online. It's an amazing gathering of parents from all over the country and even internationally to feel the power and voices of parents as they brainstorm together with their local government on how they can continue to make changes to improve the quality of education and services for all children with visual impairment. It is a powerful event.

Aside from those mentioned above, parents are creating yoga classes online for blind children, they have very active online chat groups, international virtual team running relay, online fitness training with volunteer personal coaches, joined obstacle course races and outdoor experiences like mountain climbing and hiking. These are all amazing experiences for the whole family despite this time when life could be really tough and discouraging.

1.2 What is the Outcome of these Activities?

There are many beautiful stories and outcome from these activities. Three outcomes are highlighted here.

First outcome, parents learn that it's never too early nor too late to teach their child. From the parent support group, parents feel more confident that they can teach their child academic skills as well as daily living skills.

Second outcome, because the children are home, and the parents learn to enjoy this moment with them, the children participate in functional and meaningful activities at home, with their parents, grandparents, siblings and cousins.

Third outcome, parents believe in their child's power. They get to know their child better and appreciate them. When parents believe that their child can learn, they are naturally empowered to advocates for their child's inclusion in the community and get the support they know is right for them.

1.3 What did Parents Say about the Parent Support Group that is Valuable for them?

Parents also reported that the support group is valuable to them because...

- they are given the opportunity to give back to their community by sharing parenting tips and their stories to others.
- they are constantly reminded, that despite their busy life, they need to find time to devote to their child with disabilities.
- their children get to join activities with other children.
- they also get to receive consultation from professionals like physical therapists, occupational therapists, special educators, pediatricians, etc.
- One common thing that many parents shared is that listening to other parents' stories make them feel stronger and not alone.

1.4 What Recommendations and Suggestions are there to help form and Maintain Parent Support Groups?

As many of us know, getting people together is easy but keeping them together is not. Below are some recommendations that we have put together that can help create and maintain parent support groups.

1. Have a clear mission and purpose. A parent support group need to create their own mission and purpose for being together. This mission must be shared by all members of the group. It should be written out clearly, and often discussed as a group.

2. Build up from what works. Instead of planning huge things that require having to gather much resources from elsewhere, make an inventory of what you have. Use your resources and build up from there. Start from a place strength and available resource. Use internal resources instead of hiring someone else. For example, if Daddy Leo is a nutritionist in a local clinic. You can invite him to share his knowledge about proper nutrition for other families, instead of hiring someone from outside.
3. Stay in the “solution” frame. Parents often come exhausted, and they have difficulties with their kids’ and sometimes, conversations can be very heavy. The facilitators of parent groups need to know how to balance a time of when parents can share their burdens, but also to keep the group in a positive mindset. Always bring the group into thinking of solutions, alternate approaches or way of thinking together.
4. Understanding that parents are busy people. find a regular time for meetings that works for parents, perhaps after dinner, or when they put the children to bed.
5. Be very inclusive. Parents come from different walks of lives, different financial status, different educational background, male, female, etc.... As a leader, you need to make it loud and very clear, and be very inviting. Frequently reach out to parents to let them know how they BELONG to this group. That this group is for them and it’s got a seat with their name on it. Check in with parents as their situations always change. Clearly describe who this group is for and clearly point it out that this group is for them.
6. Build your network. You need to collaborate with your child’s teachers, school leaders, government leaders, health professionals, community health workers, neighbors, co-parents, relatives, family friends, church friends and everyone who can support you and your child. Go ahead and let them know your child, educate the community about your child and reach out to others openly as much as you think is best for you and your family.

2. Conclusion

It is an honour for us at Perkins International to be able to support and work together with these parents during the pandemic. Supporting parents of children with multiple disabilities and visual impairment has never been more vital than during this time of the pandemic when no appropriate support are being provide to the children and their families during this lockdown. The challenges that these families face day to day in raising a child with severe disabilities are amplified during this time. Many children are showing signs of regression and parents are showing signs of mental and emotional stress. This paper is able to show that when parents are supported, their confidence to engage with their children improves, thus giving children the opportunity to be an active participant in functional and meaningful activities at home. Parents get to know their children’s abilities more and form a strong belief that their child can learn. When parents are empowered, they learn to advocate for what their children need to reach their fullest potential.

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