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# EVALUATING THE EFFECTIVENESS OF SUPPORT PROGRAMME FOR SIBLINGS OF PERSONS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN SINGAPORE OVER A FIVE-YEAR PERIOD

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## **Abstract**

This research aims to assess the effectiveness of a siblings support programme conducted at a large intellectual disability service provider in Singapore. The organization provides a range of services to people with moderate to severe level of intellectual and developmental disabilities. Participants in the programme were siblings of these clients aged between 13 to 20 years old. Using quantitative data obtained from questionnaires administered to 59 participants and qualitative content analysis obtained from open-interview questions administered with 8 of the participants over a 5 year period from 2012 to 2016, the results were analysed to examine if the programme had met its intended objectives: 1. Create opportunities for siblings to obtain

peer support, 2. Encourage discussion among siblings about their own personal identities and emotions, and, 3. Enabling siblings to lead future support groups. Overall, the results showed that the siblings support programme had encouraged sharing among participants and allowed them to develop friendship bonds with one another. It is hoped that discussion of these findings would encourage more practitioners to focus on supporting the needs of these siblings.

**Keywords:** Intellectual Disability, Developmental Disability, Special Needs, Siblings Support, Programme, Peer Support

## Evaluating the effectiveness of support programme for siblings of persons with intellectual and developmental disabilities in Singapore over a five-year period

Families caring for persons with intellectual and developmental disabilities face challenges that place them at a higher risk of psychological difficulties (Paor & Strohm, 2009). Due to the reciprocal influences on other family members, this may increase the psychological stresses on the typically developing siblings (Brofenbrenner, 1979; as cited in Hannon, 2012). Hence, it is crucial that these siblings receive adequate support at an earlier developmental stage so as to allow them to cope with the complex roles that they can play as siblings. The availability of siblings support programmes have been identified as one option in

reaching out to these siblings.

This study examines the effectiveness of a siblings support programme initiated by social workers from a large intellectual disability service provider in Singapore in year 2010. For the purpose of this study, data have been retrieved over a five-year period from year 2012 to 2016.

### The Needs of Siblings

Individuals with intellectual and developmental disabilities often present with caregiving challenges that require extensive care and support. The multiple stressors that these families face may inadvertently contribute to significant parental distress or negative impact on the typically developing siblings' psychosocial functioning and later life outcomes (Mascha & Boucher, 2006; Penner, 2013; Benderix, Nordström, & Sivberg, 2004; as cited in Benderix & Sivberg, 2007). These siblings often grow up in an environment of immense stresses due to challenges arising from the relationships with their brother or sister with special needs. They experience different feelings, including guilt of their own ability and perceptions of being better than their siblings with special needs, fears that they may have caused the disability, or of becoming like their siblings in future, as well as feelings of embarrassment when being teased by their peers for having a sibling with special needs (Meyer & Vadasy, 2007). They may also experience other stresses that arise from having to take on secondary caregiving duties, such as attending to the daily care needs of their brother or sister, or having to fulfil parental expectations of undertaking future caregiving

responsibilities for their siblings with disabilities (Burke, Taylor, Urbano & Hodapp, 2012). These siblings may potentially face situations within their family that creates distress, yet may find themselves not having adequate understanding, emotional maturity and coping skills to deal with their experiences (Paior & Strohm, 2009). Without platforms to express such aberrant feelings, this may result in them being greatly affected by these experiences.

Looking from a lifespan perspective, it is important to ensure that siblings have access to support services at an early stage of their life (Strohm, 2002; Arnold, Heller & Kramer, 2012). This provides them with opportunities to better understand the circumstances they are in, and to equip them with the skills to deal with these experiences at an earlier stage of their lives as they continue to mature.

### **Effectiveness of Siblings Support Programmes Internationally**

Existing literature has shown the effects of siblings support programme on persons with special needs. In particular, siblings are able to gain a better understanding of their brother or sister with special needs, improve their relationship within the family and the way they cope and feel about themselves through attending such support programmes (Evans, Jones & Mansell, 2001, Conway & Meyer, 2008, as cited in Paior & Strohm, 2009; Naylor & Prescott, 2012).

Naylor and Prescott (2012) noted that siblings may find being a part of a support group to be therapeutic as it reduces their sense of isolation. These siblings

benefited from talking with others, receiving validation from other children with similar experiences, as well as being able to listen and relate to the challenges and rewards in living with their siblings with special needs (Strohm, 2002). Such programme help the siblings develop new coping strategies or improve on current coping strategies to improve the interactions they have with their siblings with special needs (Andrew, 2003; Conway & Meyer, 2008).

When siblings are well supported, this may also allow them to develop greater resilience in dealing with their difficult life experiences (Strohm, 2002). Through discussions that draws out the strengths and uniqueness of these siblings possess, it can potentially help them develop positive views of themselves and thereafter empower them to lead future support groups (Venegas, 2015).

### **The MINDS' Siblings Support Programme**

The siblings support programme was implemented in MINDS, a social service organisation in Singapore providing a range of services to people with moderate to severe level of intellectual disability. The siblings support programme reaches out to siblings of clients between 13 to 17 years old through year-end camps conducted in December. The siblings support programme started out with the following objectives: 1. Create opportunities for siblings to obtain peer support; 2. Encourage discussion among siblings about their own personal identities and emotions; 3. Enable siblings to lead future support groups.

Annual siblings support programme year-end camps

which took place between year 2012 to 2016 include the following: Camp Bond 2012 in Dec 2012, Power UP 2013 in Dec 2013, Dare to Dream II 2014 in Dec 2014, Ohana 2015 in Dec 2015 and I-to-We 2016 in Dec 2016.

## Method

### Participants

A questionnaire constructed in alignment to the objectives of the siblings support programme was administered to 59 participants aged 13 to 20 years old.

The participants include siblings who have participated in previous siblings support events, new siblings participating for the first time, and a few who had exceeded the age criteria but were active participants in previous events. All participants would need to have siblings who are currently receiving services in the organisation; however, an exception is made for siblings who had participated in previous siblings support programmes. Table 1 outlines the descriptive characteristics of the 8 participants in the siblings support programme who participated in the semi-structured interview.

**Table 1. Demographic Information and Profile of Participants.**

Gender	Age	Profile in Sibling Support Programme
Male	17 years old	Attended 2 siblings camps Appointed sibling leader in 2016
Female	16 years old	Attended 4 siblings camps Appointed sibling leader in 2016
Male	16 years old	Attended 4 siblings camps Appointed sibling leader in 2014
Female	19 years old	Attending 7 siblings camps Appointed sibling leader in 2013
Female	18 years old	Attended 3 siblings camps Appointed sibling leader in 2015
Female	16 years old	Attended 3 siblings camps Appointed sibling leader in 2016
Female	19 years old	Attending 5 siblings camps Appointed sibling leader in 2016
Male	16 years old	Attended 3 siblings camps Appointed sibling leader in 2016

## Procedure

Participants are asked to rate their responses for each question related to the objectives from a scale of ‘Strongly Agree’, ‘Agree’, ‘Neutral’, ‘Disagree’ and ‘Strongly Disagree’. Specifically for questions related to some objectives, participants are asked to rate their responses with ‘Yes’ or ‘No’. The results were analysed to examine if the programme had met its intended objectives. Additionally, eight participants also participated in a semi-structured, open-ended interview.

## Data Analysis

Data triangulation (Morse, 1991) was used by combining quantitative data through administration of questionnaires as well as qualitative data obtained from semi-structured interviews. The interview responses from the individual participant were transcribed and analysed for emergent key themes that were subsequently categorised and matched with the objectives of the siblings support programme. The study seeks to explore how the participants perceive the support programme and the extent to which the programme had met its intended objectives as a support platform for the siblings

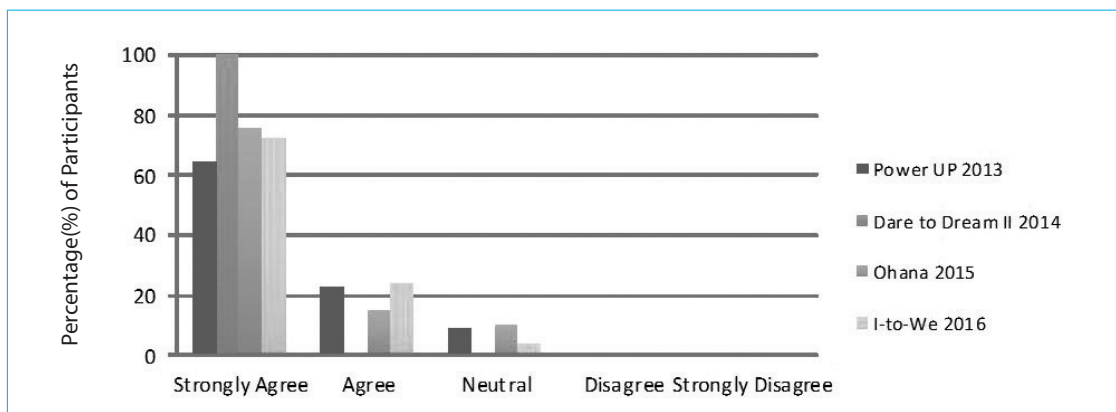
## Results

The study found that all objectives of the siblings support programme were achieved. Overall, results showed that the siblings support programme had provided opportunities for sharing among the participants and allowed them to create friendship and bonds with each other.

*Objective 1: Create opportunities for siblings to obtain peer support*

Findings from two questions in the questionnaire and participants’ responses from the interviews were analyzed to determine if the programme had met the intended objectives.

*Question: I have made new friends.* The findings in Figure 1 depicts that a large percentage of participants in the respective programmes had rated ‘Strongly Agree’ and ‘Agree’ when asked if they had formed new friendships. This is indicated through the positive responses of 87% in Power UP 2013, 100% in Dare To Dream II 2014, 90% in OHANA 2015 and 96% in I-To-We 2016.



**Figure 1. Responses from ‘I have made new friends’**

*Question: I would like to participate in the next Siblings Camp.* The findings in Figure 2 depicts that there were a significant number of participants who had repeatedly signed up for the siblings programme over the past years, with majority indicating that they would like to participate in future siblings camps. This is evidently reflected from their responses with 94% in Camp Bond 2012, 96% in Power UP 2013 and 100% for the camps from 2014 to 2016 all responding yes to their keen interest in participating in the future camps.

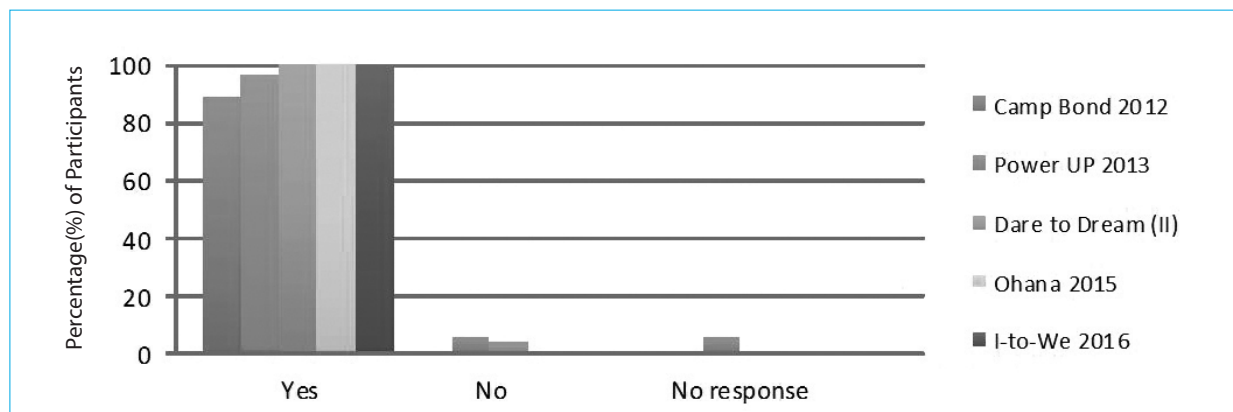
A sibling shared that siblings support programme had allowed her to obtain peer support based on their similar shared experiences and addressed her feelings of isolation: *"I made friends who understand my background and who are able to relate to my experiences. The siblings team gives me a platform to be able to share my thoughts and feelings with the others"*. Many siblings also identified that the activities organized during the programme served as a crucial aspect in creating opportunities for all siblings to build friendships and bonds with each other: *"These activities relied a lot on co-operation within the team, which I feel has further bonded us all..."*

One sibling saw the potential for the development of sustainable friendships and expressed his hopes for these bonds to develop further and outside of each event: *"I hope that it doesn't just end there and it will be great if all of them (the siblings) hang out with each other more to bond and support each other whenever they have problems - not just during camps and other social gatherings, but also other days whenever they feel lonely or when they're free."*

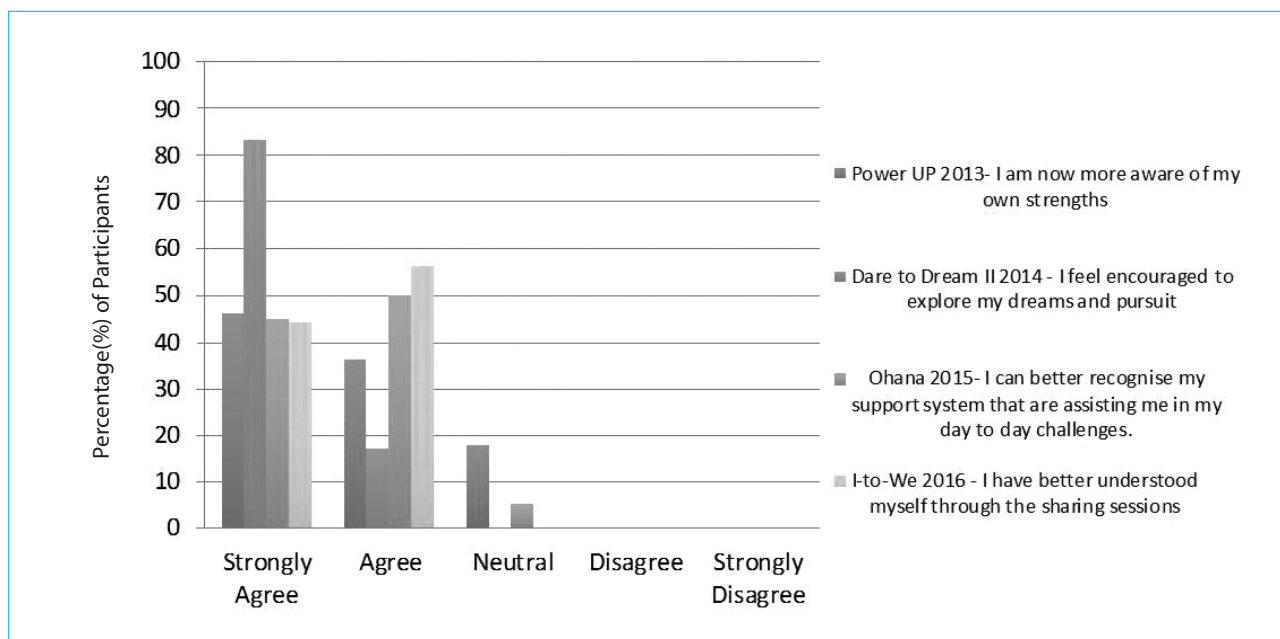
Objective 2: Encourage discussion among siblings about their own identities and emotions.

Various questions from the questionnaires administered at the respective camps that support this particular objective were identified. Additionally, the responses of another question that was commonly used across the five years and responses from the interviews were also used to examine if the programme had met its intended objective.

Figure 3 gives a summary of the responses of various questions from the questionnaires administered at the respective camps supporting this particular objective. The siblings support programme has incorporated various themes each year with the common aim of encouraging discussion among siblings about their own identities through the sharing sessions conducted.



**Figure 2. Responses from 'I would like to participate in the next Siblings Camp'**

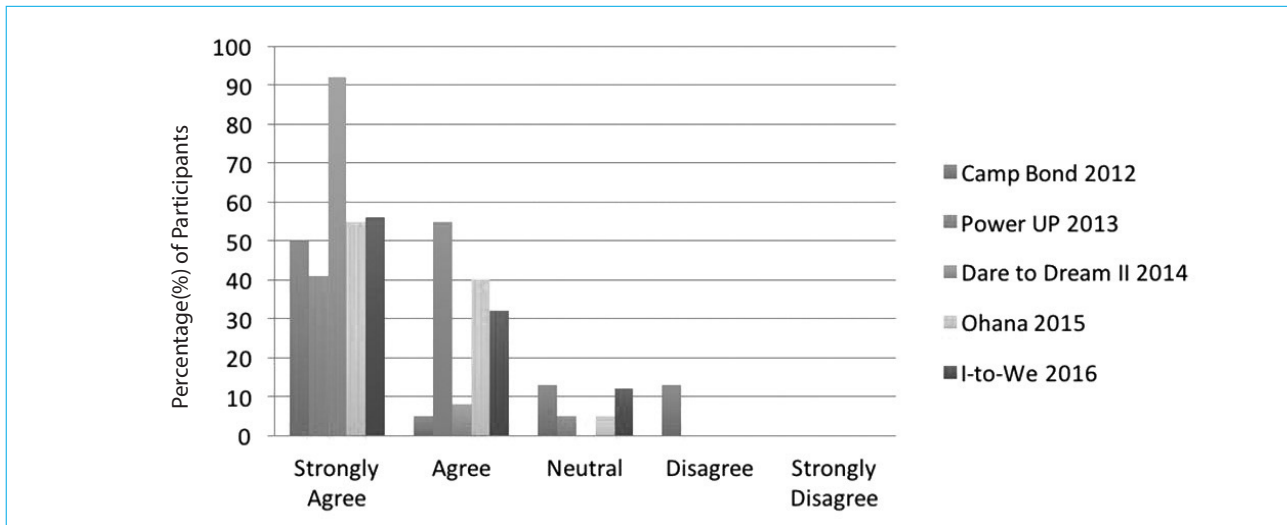


**Figure 3. Responses in relation to the objective: Encourage discussion among siblings about their own identities and emotions**

In Camp Bond 2012, as there is no question incorporated in the questionnaire related to the objective, this component was unable to be evaluated, making this a limitation. In Power UP 2013, emphasis was placed on helping participants to identify their strengths. 82% of participants rated ‘Strongly Agree’ and ‘Agree’ to the question, “I am now more aware of my own strengths”. In Dare to Dream II 2014, participants were being guided to explore their dreams. The responses were encouraging with 83% rating ‘Strongly Agree’ and 17% rating ‘Agree’ on the question, “I feel encouraged to explore my dreams and pursuit”. In OHANA 2015, the camp focus was on helping participants to develop

deeper awareness to themselves and to identify the various sources of support that are assisting them in their challenges. 95% participants rated ‘Strongly Agree’ and ‘Agree’ on the question, “I can better recognise my support systems that are assisting me in my day to day challenges”. In the subsequent I-To-We 2016 camp, it centered on the theme of cultivating self-identity in the adolescents and establishing a group identity among the siblings’ participants. When prompted if the camp had achieved the objective, “I have better understood myself through the sharing sessions”, 100% of the participants indicated a rating of ‘Strongly Agree’ and ‘Agree’.

*Question: I am able to share my feelings and challenges during the activities.* Responses in Figure 4



**Figure 4. Responses from 'I am able to share my feelings and challenges during the activities'**

illustrated that none of the camp participants from year 2013 to 2016 rated 'Disagree' to this question. In Camp Bond 2012, although 55% participants agreed that they had been able to share their feelings and challenges during the activities, 13% rated 'disagree' while 13% rated 'neutral'. Dare To Dream II 2014 received the highest positive feedback where 100% of participants had rated 'Strongly Agree' and 'Agree'. Hence, the activities did provide a platform on which they had been able to express their feelings and share their challenges.

One of the valuable gains for the siblings was recognizing that there are others who share similar experiences, and with whom they can relate to and share their feelings with: "...during sharing sessions, many of us opened up and I realised we had a lot in

*common, be it having siblings with special needs or the experiences we encounter with them...I used to think that I was the only one who had to deal with such a sibling and I couldn't share my emotions and experiences with my friends from school."*

One sibling also shared similar sentiments on how being a part of this programme have also allowed them to explore their experiences and mixed emotions towards their brothers and sisters with special needs within a supportive and safe setting and having their feelings acknowledged: *"I was able to talk to people that actually understands the struggles I have with my special needs sibling. With that, I realised that I'm not the only person in the world facing difficulties with my sibling."*

Overall, these siblings identified support from others as a valuable facet of their lives, and had appreciated



the opportunity to share their thoughts and feelings with other siblings who experienced similar experiences and challenges. Being part of the siblings programme is perceived to have broaden the personal boundaries of these siblings by providing a platform on which they were able to obtain support from other peers with similar experiences.

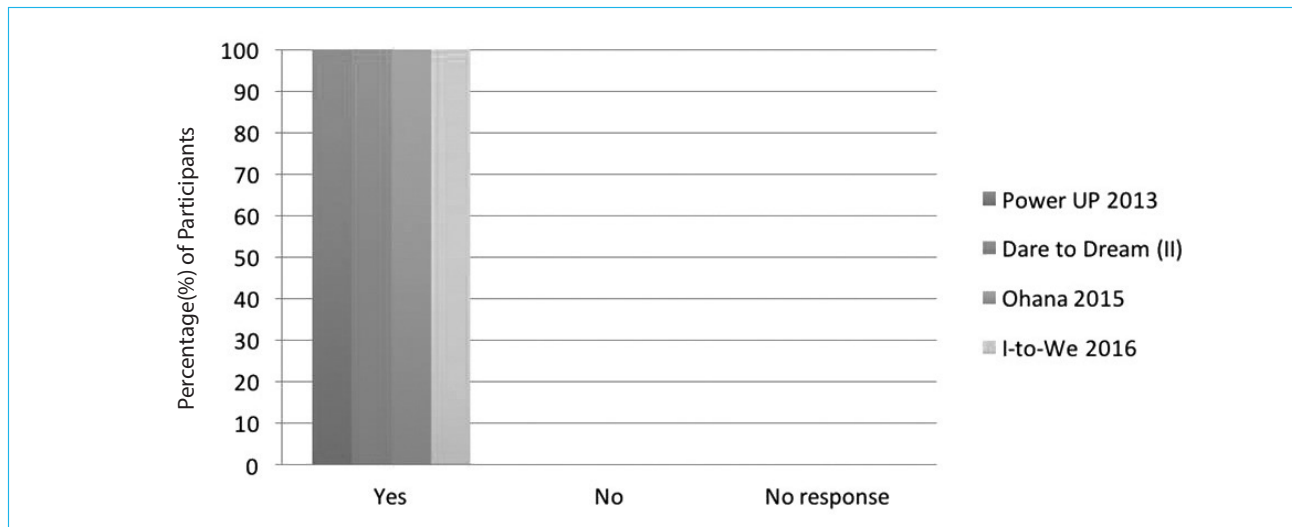
*Objective 3: Enabling siblings to lead future support groups.*

Responses from two questions administered in the questionnaire and participants’ responses from the interviews were analysed to determine if the programme had met its intended objective.

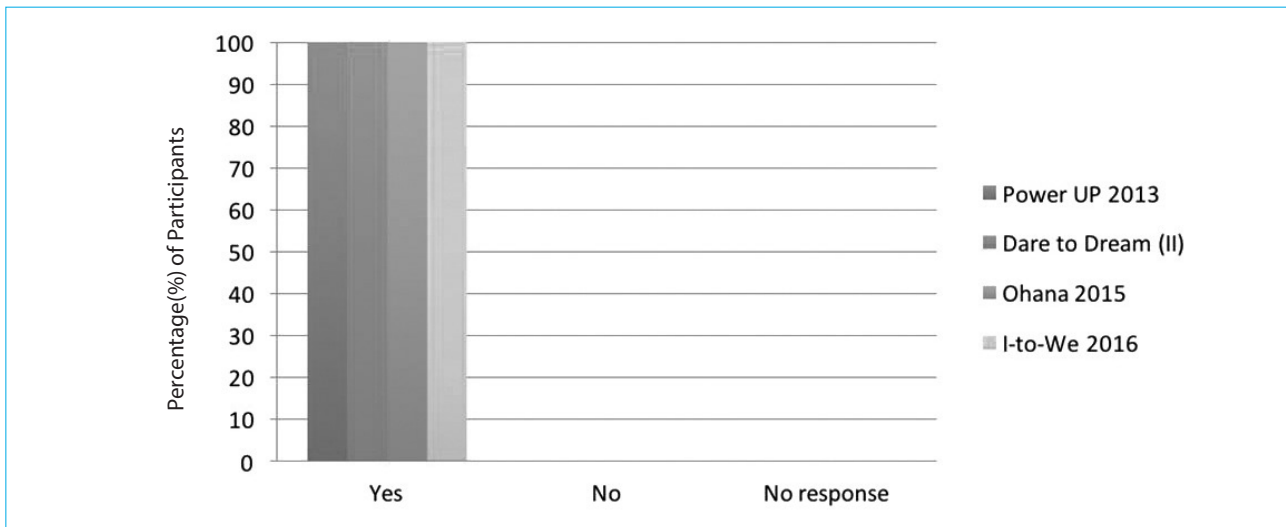
*Question: I would like to continue taking on the role as a sibling leader in the next siblings programme.*  
The social workers started to identify potential leaders amongst the sibling participants to assist in facilitating groups and taking ownership of activities such as

conducting ice breakers and bonding activities in year 2013. As of year 2016, there were eight sibling leaders who facilitated alongside the social workers in I-To-We 2016. As illustrated in Figure 5, there had been consistent positive responses from the sibling leaders over the four years from 2013 to 2016, with 100% indicating that they would like to continue taking on the role as a sibling leader in the next siblings support programme.

*Question 2: I would like to volunteer in the next Siblings' Camp.* Some siblings expressed their keen interest to volunteer and take on certain responsibilities in the subsequent siblings camp, as illustrated in Figure 6. The percentage was noted to have increased gradually over the years from 50% in Camp Bond 2012, to 59% in Power Up 2013, to 63% in Dare to Dream II 2015, and an outstanding 75% in OHANA 2015.



**Figure 5. Responses from ‘I would like to continue taking on the role as a sibling leader in the next siblings programme’**



**Figure 6. Responses from 'I would like to volunteer in the next Siblings' Camp'**

The siblings of older age range whom are sibling leaders perceived themselves to have experienced similar emotions and personal struggles as the siblings of younger age range. They felt that these experiences would be helpful in allowing them to relate to the myriad of emotions that these younger siblings were going through. This is evidenced from how these sibling leaders had shared their hopes on being able to support the younger siblings by addressing the difficult issues surrounding feelings of shame and embarrassment in having a sibling with special needs: *"I hope to teach other younger siblings that they do not have to be ashamed or embarrassed when it comes to talking about their special needs siblings"*

When prompted on what these participants hope to achieve in the future events as sibling leaders, many

of them shared on their aspirations to be of a positive influence for the other younger siblings: *"I hope to give that warm and support to new-comers so that they may be motivated to be positive despite the challenges."*

In addition, they also acknowledged that the importance of providing safe space was an important element that could allow siblings to express their feelings and open up to one another. One sibling leader shared on how she wanted to be the catalyst for change for the younger siblings: *"I hope I could set a good example or at least make the younger ones feel that there's a safe space for them to express how they feel without judgments. To be there as a listening ear and support and respect their choices in life"*.

Based on the general responses of all the sibling leaders, they had expressed interest in taking on more responsibilities in the siblings support programme:

*“when I started being a sibling leader, I felt a sense of responsibility. That I should guide my fellow peers in the group with their problems, and also advise them how to overcome it.”*

It is inferred that leadership roles have provided the participants with a heightened sense of responsibility for the other siblings in the programme, hence highlighting the need for the sibling leaders to be given continual opportunities in taking on the lead in future support groups and sibling programmes.

## Discussion

The findings provide a summative overview of the participants’ perceptions, views and feelings as derived from their individual experiences and participation in the respective camps. The results of the study indicated that the siblings support programme met its core objectives of create opportunities for siblings to obtain peer support, encouraging discussion among siblings about their own personal identities and emotions and enabling siblings to lead future support groups.

The effectiveness from the siblings support programme is reflected in the positive retention rates of participants who have repeatedly signed up for the camps and majority of participants expressing that they would wish to participate in future siblings’ camps. Hence, programme supporting these siblings are indeed valuable platforms that allow them to receive socio-emotional support, psychoeducation and be connected to a broader support network.

The siblings support programme provides participants with opportunities to form friendships with one another through a peer support setting. Due to the natural formation of cliques during the activities, it is likely that some participants may have an inclination to mingle with peers whom they may be more familiar and comfortable with. For participants who may be more passive or introverted, it is noted that these individuals may not have much chance to make new friends beyond their own team members, limiting their opportunities for new friendships.

Having a safe environment where participants are able to share their feelings and challenges is one objective that the sibling programme serves to achieve. Majority of participants agreed that they had been able to share their feelings and challenges during the activities, hence indicating the effectiveness of the support programme in allowing siblings to be able to share their difficult experiences or emotions within a safe and supportive context.

One crucial aspect for further consideration of the siblings support programme in the organisation would be in the area of conducting continual outreach work to reach out to more siblings. As participation in the sibling support group is solely voluntary, it can therefore be inferred that siblings who choose to enroll and participate in the sibling programme would have had some level of willingness and pre-motivation that prompts their decision to enroll and participate in the programme. Another contributing factor to their participation may be that their families recognise the value of enrolling their typically developed child for

such support programmes. As such, for siblings who are not in these categories, this group would tend to fall between the gaps of support. This further highlights the role in which parents and professionals have towards providing the needed support, understanding and attention to the siblings.

The results showed that all the siblings leaders had indicated a strong inclination to continue taking on this role, hence it is proposed that they will continue to receive the necessary support to take on leadership roles, and eventually to facilitate and manage their own future support groups. Through positive role modelling, this would not only increase their self-esteem and personal competency, but also serve to motivate their other peers to volunteer in subsequent programmes. Nonetheless, it would still be necessary for the siblings programme to continue being supported by the professionals who work directly with special needs students and families (e.g. social workers of disability services) so as to facilitate outreach and ensure appropriate intervention structures to support siblings through their respective experiences and challenges related to having a sibling with special needs.

### **Practice implications**

This study reinforces the need for practitioners to focus on the needs of siblings of person with special needs, as family members and at times practitioners are often too focused on caring for or providing interventions for the person with special needs that they may inadvertently neglect the other “invisible child” who may also be experiencing difficulties. This study also

highlights the need to provide a platform for this group of siblings to be heard and for outreach efforts to more siblings. Hence, resources should be strengthened to form a stronger supportive network that reaches out in supporting more siblings of persons of special needs. In the current society, there is a lack of siblings’ programme available. Hence, the encouraging results in this research show that development of permanent siblings support groups in different agencies is essential in ensuring sustainability and frequency of siblings’ work.

Although this research highlights the importance of the siblings support programme in supporting them in their journey with their siblings, it has also highlighted the siblings’ need for attention, continual support, and understanding within their respective families, communities and the society as a whole. As reflected in the positive outcomes as derived from this evaluative study, it has evidently reflected the need for sibling support groups to be established as a crucial component within the special schools and to be incorporated as part of a whole-family approach.

Future studies could consider including participants who are not sibling leaders and those who did not return for subsequent camps in the qualitative interviews to understand their concerns for future programme planning.

## **Conclusion**

Findings of this siblings support programme were consistent with previous research

literatures highlighting how these programmes are helpful in allowing these siblings to obtain peer support from one another, and feeling supported when dealing with concerns that may arise as they grow up with a sibling with special needs. The programme had also enabled participants to take on leadership roles, enabling them further to run their own future support groups. The high retention rate of participants over the five years period have positively reflected the value of the programme in reaching out to these siblings and providing them with the necessary support in mitigating their challenges and addressing their needs. It is hoped that findings from this study can contribute in encouraging more practitioners to recognize the importance and value of siblings support programme and in supporting the needs of these siblings.

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