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Preparing adolescent siblings of brothers and sisters with intellectual and developmental disabilities for potential caregiving in future

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Abstract

The presence of a person with intellectual disabilities (I/DD) within the family creates considerable stress and burden to all family members, including the typically developing siblings. These siblings of persons with ID are likely to take on the role as future caregivers when their parents aged. This study using a qualitative research design focused on nine adolescent siblings between the age group of 16 to 21 years old who have a brother and sister with ID to understand their feelings and concerns of future caregiving as well as factors that could better prepare siblings for future caregiving. Semi-structured, in-depth, face-to-face interviews were employed. Results of the study illustrated that siblings largely have favourable views towards future sibling

caregiving, if there are support services and planning in place to help siblings and families prepare for the future care and support needs. Siblings' views of being potential future caregivers for their siblings with I/DD are consistent with the model of sibling attachment, illustrating that there are more acceptance among the eldest and only sibling and worries would be more for those without siblings support. Future sibling caregiving could likely impact on their current and future life priorities, yet their positive thoughts keep them going.

Keywords: Intellectual Disability, Developmental Disability, Special Needs, Siblings, Potential Caregiving

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In Singapore, the number of children diagnosed with developmental issues had increased and there is a longer life expectancy of persons with disabilities (National Council of Social Service, 2017). This growing number would mean that many persons with disabilities would necessitate the need for extended family caregiving (Saxena, 2015) and the role of siblings would become increasingly relevant (Burke et al., 2012 as cited in Jacobs & MacMahon, 2017). The presence of a person with intellectual and developmental disabilities (I/DD) within the family creates considerable stresses and challenges to all family members, including their siblings without special needs. As sibling relationship is one of the most enduring relationships of one's life and that they play significant roles in the lives of the brothers and

sisters with disabilities, there is a need to support these siblings.

Adolescence appears to be the transition point that these siblings start to become increasingly aware of the future caregiving responsibilities they may have in looking after their brothers and sisters with special needs (Jacobs & MacMahon, 2017; Grabowski, 2016). They witness how their parents care for their siblings with special needs and start thinking of the roles they may play in future. These siblings of persons with I/DD are also likely to take on the role as future caregivers when their ageing parents are no longer able to continue as the primary caregiver of the person with I/DD in future (Saxena, 2015). Having conversations on their feelings and concerns about being potential future caregivers for their siblings with I/DD is thus necessary for practitioners to provide early intervention to address these issues.

Given the lack of available studies on adolescent siblings, this study would focus on adolescent siblings between the age group of 16 to 21 years old who have a brother or sister with I/DD to understand their feelings and concerns of future caregiving as well as factors that could prepare these siblings for future caregiving.

Literature Review

Having a sibling with Intellectual and Developmental Disability

Siblings often grow up in an environment of immense stress due to the challenges arising from the relationships with their brother or sister with I/DD. Literature

reviewed that these siblings often experience different feelings as they are growing up, 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 and being teased by their peers for having a sibling with special needs, hence resulting in feelings of embarrassment (Meyer & Vadasy, 2007). Adolescent siblings may feel a stigma associated with having a sibling with special needs, experiencing rejection in certain friendships or dating relationships for this reason (Cicirelli, 1995).

Adolescence is a time when autonomy, identity and independence are developed and the time when siblings are beginning to plan their own future including their education and career pathways (Grabowski, 2016). For those with a sibling with I/DD, they become more aware of future caregiving responsibilities (Jacobs & MacMahon, 2017) and ask to be included in family discussions (Mchugh, 2003). While they are dealing with the above feelings, they may have a greater concern as they deliberate how their siblings may be considered alongside with their future plans at this stage (Cicirelli, 1995; Seligman & Darling, 2007; Petalas, 2012). Grabowski (2016) reviewed that the natural trajectory of sibling caregiving responsibilities may be shifted due to having a sibling with special needs, particularly reflecting on how they could care yet pursue their aspirations in life. These feelings are experienced more strongly by siblings who have more positive relationships and are in close contact during childhood with their siblings with special needs, further expectations from their parents as

well as their self-imposed expectations to provide future caregiving for their siblings (Bigby, 1996; Griffiths & Unger, 1994 as cited in Saxena, 2015).

Future concerns of these siblings

Adolescent siblings, especially female siblings, expressed concerns over caregiving of their siblings with I/DD in future, particularly worries and anxieties when the parents are no longer available to fulfill that primary responsibility in the future (Damiani, 1999; Seligman & Darling, 2007). This is similarly reported in those who are likely to care their siblings with special needs due to their love and commitment towards them (Degeneffe, 2015).

These worries and anxieties could be a result of observing the stresses that their parents are going through, having thoughts that they would never be able to care similarly as their parents predominantly due to the lack of competence they have for such caregiving responsibilities (Degeneffe, 2015). These fears about the future caregiving are further exacerbated when their siblings have more severe disability conditions, requiring more intensive supervision and lifelong care (Seligman & Darling, 2007). The concerns about having insufficient financial resources, poor physical and emotional health as well as having to manage their future spouses could also aggravate their worries and complicate their thoughts about future caregiving for their siblings with special needs (Seligman & Darling, 2007; Degeneffe, 2015; Saxena, 2015). They may also be worried about how these future caregiving tasks could impact their decisions that need to be made in future years including

their marriage, career and plans to have children (Davys, Mitchell, & Haigh, 2016).

Factors influencing future caregiving of these siblings

Though the adolescent siblings have such concerns, the family may not encourage these discussions of future caregiving of their siblings with special needs, leading to feeling of loneliness (Seligman & Darling, 2007) and increased distress about caregiving among siblings when they are called upon in future (Griffiths & Unger, 1994 as cited in Saxena, 2015). These conversations concerning care for their siblings with a disability are usually held only when parents are no longer able to provide such care (Turnbull et al., 2006 as cited in Seligman & Darling, 2007). This could be possibly since family members are already pre-occupied with the daily demands of caring for the siblings with special needs as well as the inability and difficulty to share information with these siblings, resulting in a lack of preparation by the whole family (Degeneffe, 2015; Turnbull et al., 2006 as cited in Seligman & Darling, 2007).

Early intervention and planning for the future could help to improve the lives of the person with I/DD and their siblings. With preparation for future caregiving, they would be able to respond appropriately and adequately in circumstances of crisis (Saxena, 2015). One way would be through siblings support groups that can help them develop effective caregiving skills (Saxena, 2015), as reflected by adult siblings who expressed hopes that they could have met other siblings with similar situation in their earlier years to discuss

about their challenges and help them cope with the current situations they experience (Strohm, 2008). These strong emotional and social support formed from earlier years lasting into later years may help siblings to continue to provide caregiving (Saxena, 2015), knowing that they are not alone in this caregiving journey.

The families play an important role in the life of these siblings in the earlier years, influencing the siblings' involvement in the planning and expectation of future caregiving for those siblings with I/DD. Caregiving conversation that is done openly in the family with the sibling during adolescence allows them to consider the needs of their brother or sister with I/DD while making their own plans for the future (Grabowski, 2016). Professionals could also facilitate this aspect by providing platforms to openly discuss concerns about their siblings' future, especially at the adolescence stage when information are needed by these siblings (Seligman & Darling, 2007).

The socio-economic status of the family could influence a sibling's ability to care for their sibling with special needs in future (Seligman & Darling, 2007). The caregiving could be especially tough for those with fewer financial resources to support their siblings with special needs (Smith et al., 2007). Planning ahead among these adolescent siblings to have their own lives through making independent decisions and being financially independent would mediate future caregiving concerns (Seligman & Darling, 2007).

Guiding Theories and Conceptual Framework

According to Erikson's (1959) theory of psychosocial

development, one undergoes eight psychosocial crises throughout a lifespan, with each crisis phrased as a struggle between two opposite or conflicting personality characteristics (Thomas, 1992). At the adolescence stage of development, Erikson states that one would go through the psychosocial stage of identity versus role confusion. Adolescents at this stage would search for sense of self and personal identity through exploring their personal values, beliefs and goals (Newman & Newman, 2009). Those who receive proper encouragement through personal exploration will have a better sense of self and feeling of control (Newman & Newman, 2009). Hence, adolescent siblings who are prepared for future caregiving at this stage would possibly feel more in control of their own lives.

Looking from a lifespan perspective, it is important to ensure that these siblings have access to support

services at an early stage of their life (Strohm, 2002). 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. Hence, instead of looking at the factors that enhance or complicate siblings in taking on caregiving role only at the adulthood stage, it is important to plan beforehand and explore the perspective of adolescents on future caregiving.

Based on the guiding theories and existing literatures, a conceptual framework (Figure 1) is formulated for this study. Risk and protective factors relating to sibling with I/DD, adolescent sibling and family all have an impact on the thoughts, feelings and concerns of adolescent sibling assuming future caregiving of their sibling with I/DD.

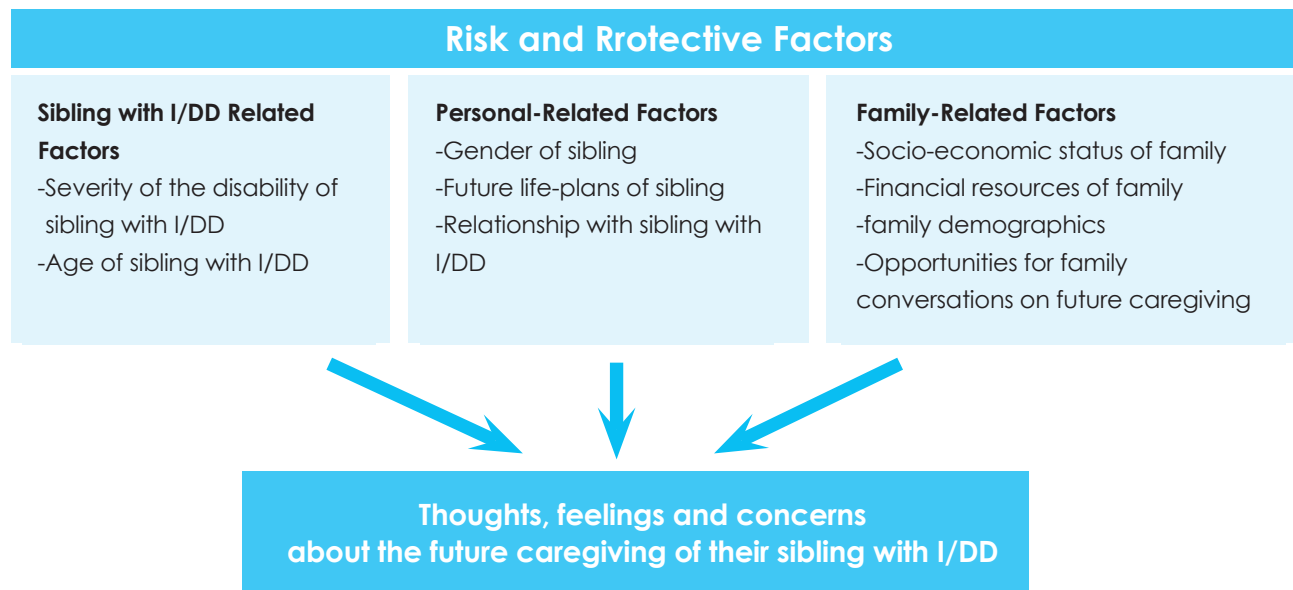


Figure 1. Conceptual framework guiding the study.

Purpose of Study

Implications for the Current Proposed Study

Existing literatures, relating to factors that influence siblings caring for their brothers and sisters with I/DD, are often related to that of adult siblings. Yet, lifespan developmental approach reviewed that the readiness in future caregiving of these siblings at an early stage would be helpful in them dealing with issues at the later stage. In addition, current literature focused majority of studies on caregiving experiences of adolescent primary caregivers, and not those siblings that have potential to care in future. Thus, a new perspective may emerge by conducting a study on siblings belonging to a younger age group, and are potential future caregivers.

Research Questions

This study seeks to address the following research questions:

- 1) What are the siblings' feelings about assuming future caregiving of their brothers and sisters with I/DD?
- 2) What are the hopes and concerns these siblings have regarding future caregiving?
- 3) What are the factors that could prepare these siblings for future caregiving?

Methodology

Research Design

This study being an exploratory study attempted to investigate a relatively under-explored area in the local

context. A qualitative research design was chosen as it offers "a deeper and richer understanding of people's lives and behaviour, including some knowledge of their subjective experiences" (Monette, Sullivan, & DeJong, 2005).

To do so, semi-structured, in-depth, face-to-face interviews were employed to ensure the richness of information from these siblings. Open-ended questions were used to give siblings the space to express their feelings and relate experiences that are unique to them by the researcher (Jacobs & MacMahon, 2017).

Sampling and Sample Characteristics

Purposive sampling, "a deliberate process of selecting respondents based on their ability to provide the needed information" (Padgett, 2008) was utilized. The sample size included eight to ten participants to get a range of inputs for comparison.

Participants were eligible if they are (1) siblings of brothers and sisters with I/DD, (2) adolescents between the age of 16 to 21 years old and (3) parents are the main caregivers of the sibling with I/DD. According to the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013), Intellectual Disability or Intellectual Developmental Disorder is a disorder beginning during the developmental period which includes both intellectual and adaptive functioning deficits in conceptual, social, and practical areas (American Psychiatric Association, 2013). The term 'caregiving' in this study includes time and energy spent in providing emotional, personal, and social care and support on a daily or intermittent basis (Saxena, 2015).

There is no age criterion for the age of the siblings with I/DD, as it is assumed that it would not affect the results of the study.

Participants were excluded from the study if the typically developing siblings have (1) presence of any psychiatric morbidity or form of disability e.g. physical disability, and (2) presence of other siblings in the family who are caregiving for the person with disabilities. As siblings with a form of psychiatric morbidity or disability may complicate the results of this study, this group was excluded from this study. Siblings who have witnessed their own siblings caring for their siblings with I/DD may have preconceived notion about caregiving duties, thus complicating the results. Hence, they are also excluded from this study.

Instrument

An interview guide which consists of key questions addressing this study was developed. This interview guide was done through the assistance of inputs from literature review and reflected through the conceptual framework.

The principal investigator allowed participants the option of responding that he/she would avoid or choose not to be a caregiver. In such instances, when participant responded that he/she would avoid or choose not to be a caregiver, the principal investigator directed the interview by asking participant to imagine if they are still being chosen by others e.g. their parents to be a caregiver for their sibling with I/DD in future.

Data Collection

The participants were recruited through contacts of a social service organisation that offers services to clients with I/DD. Social workers first contacted the parents of the siblings who met the sampling criteria and explained the purpose of the research. Once the parents and the siblings indicated interest in participating and granted permission to provide the parent's and/or sibling's contact information, the principal investigator then arranged an interview at the sibling's place of convenience.

Moyson & Roeyers (2012) reviewed that quality of the study would be largely influenced by the degree to which the siblings felt at ease during the research in general and during the interviews in particular. To attain trust between the principal investigator and the siblings, the interviews took place in locations that would make siblings feel comfortable and share openly. The interview was only conducted after the siblings had understood the nature of the study and given their informed consent along with their parental consent (for those below 21 years old), indicated by both their signatures in the Participant Information Sheet/ Consent Form. The semi-structured interviews were audio recorded with the participants' written consent, then transcribed. Questions may not be asked in accordance and depended on the flow of the conversation between the principal investigator and the sibling. Each interview was kept at a maximum duration of one and a half hours.

Data Analysis

The audio-recorded interviews were transcribed by the principal investigator in order to facilitate data analysis.

Coding was used to reduce the data and categorize them into themes. Open coding through the assignment of initial codes and labels was then carried out on the raw data. Subsequently, focused coding was used to expose the core concepts and categories and the relationships among them that emerge from the data (Monette, Sullivan, & DeJong, 2005). Labels were derived from the data (e.g. 'finding the positive'), previous studies (e.g. 'family caregiving conversations') or simply using phrases that represent a set of ideas (e.g. 'lack of competence affecting the care of their siblings').

After the initial stage of coding, a discussion was held between the principal investigator and the supervisor, whereby the codes were cross-examined by her, to prevent subjective bias of these codes. The coding process was not a linear one, as re-visitation of data and themes were done after the discussion to regroup the themes into its current format.

Ethical Considerations

Ethical approval was sought from the National University of Singapore Institutional Review Board (NUS-IRB). Parental consent was sought from all participants under the age of 21.

Background of the study and the methods used were clearly explained to the siblings and confidentiality is assured. Participants were also allowed to withdraw from the study at any time. Interview did not proceed if

the parent or participant did not give consent.

At the end of the interview, the principal investigator checked with each participant to see if he or she is experiencing any negative feelings or require counseling. Upon the completion of each interview, the principal investigator informed the social worker in-charge that the interview had ended and sought collaboration with the social worker to contact the participants three to five working days after the interview to gather feedback in regards to positive or negative experiences resulted from the interview. Since the discussion about future caregiving for their sibling with I/DD may be an emotional experience for these siblings, these conversations ensured that any negative occurrences were addressed in a prompt and timely manner to avoid adverse outcomes on the participant.

Findings

Nine siblings who matched the sample criteria participated in the study. Their demographic information is listed in Table 1. Seven out of nine participants were female. The age range of the total number of five Chinese, three Malays and one Indian participants ranged from 16 to 21. The age range of the siblings with I/DD ranged from 9 to 22. Three siblings with I/DD require higher level of care while five siblings require moderate level of care. One sibling requires low level of care, considering that she is able to travel independently without supervision and perform activities of daily living on her own.

Table 1. Demographic Information of Participants.

Respondent's Age and Gender	Race	Sibling's Age and Gender	Siblings' Diagnosis	Siblings' position in the family	Sibling's level of care required
21 (F)	Chinese	16 (M)	Down Syndrome	Third among 4 siblings	Moderate
18 (M)	Malay	22 (M)	Global Developmental Delay	Eldest among 2 siblings	High
20 (F)	Chinese	17 (M)	Down Syndrome	Youngest among 2 siblings	Moderate
17 (F)	Chinese	11 (M)	Autism Spectrum Disorder	Youngest among 2 siblings	Moderate
18 (F)	Malay	9 (M)	Autism Spectrum Disorder	Youngest among 4 siblings	Moderate
18 (F)	Chinese	16 (F)	Down Syndrome	Third among 4 siblings	Moderate
16 (M)	Chinese	16 (F)	Global Developmental Delay	Twin sibling	High
21 (F)	Indian	17 (F)	Down Syndrome	Youngest among 2 siblings	Low
16 (F)	Malay	15 (F)	Intellectual Disability and Epilepsy	Second among 4 siblings	High

The themes that represent the responses of the siblings are illustrated below with representative quotes that demonstrated the emerging theme. Pseudonyms were used throughout analysis to maintain anonymity.

Siblings' Feelings of Assuming Future Caregiving Role

Generally, siblings experience positive and negative feelings when they were asked to assume future caregiving role of their siblings with I/DD, with one

participant experiencing mixed feelings. The themes within the categories are listed in Table 2.

Positive feelings. With a number of siblings, the choice to assume future caregiving role of their siblings with I/DD largely resulted from positive feelings of 'acceptance' from their love and commitment towards their siblings with I/DD: *"If everyone is gone, and it is just me and my brother, I would still take care of him... I will still love him no matter what."* Some siblings are also willing to assume a greater caregiving role in future years if they are the

Table 2. Categories and themes of feelings of siblings.

Category	Theme	No of times theme found
Positive	Accepting	10
	Confident	2
Negative	Pressured	2
	Uncertain	3
	Fearful	3
	Sorry	1
Mixed	Positive yet Negative	1

only sibling or the eldest child in the family, *“sometimes I still feel happy at least I mean he is not normal but I have a brother and I have a sibling... I don’t mind helping him, my role here is to provide care for him.”*

There are two siblings who indicated that they are presently confident to adequately care for their sibling with I/DD in future: *“I will just hope that she (my mum) understands that I am eligible enough to look after and take care of (Z), when my father is gone, my mum is gone”.*

Negative feelings. Despite so, majority of the siblings experienced negative feelings. Some feel pressured being the only sibling caring for the sibling with I/DD due to a lack of support and the unpredictability of their own future: *“I feel very pressured... I worry a lot about the future. I am not sure if I am able to make it in life. So how am I going to provide for my brother, if I can’t find a good job in future? How am I going to provide for my family if I have this chance of not doing well?”*

Some feel uncertain about the required care of their siblings in future: *“I won’t know how to manage all his*

stuff, like his daily care” as well as being fearful about the uncertainty of what it takes to be caregiver and the plans in place for the sibling with I/DD: *“If I were to look after him as a full time caregiver what to expect... What are the challenges I’m going to face?... So it’s like what to expect, like how tough is it going to be... It’s like going to be a bit scared...”*

There was one sibling who felt sorry for the sibling with I/DD when talking about future caregiving as the sibling would never be able to be as independent as her: *“(J) has to depend on us and cannot be independent. Being independent is very important to me and he doesn’t have it and you feel sad for him”.*

Mixed Feelings. One sibling experiences ambivalent feelings though more positive when asked to assume future caregiving role of his siblings with I/DD, as his feelings are largely dependent on the siblings’ behavior: *“I feel kind of mixed, slightly to the positive side. Like it is nice to have him around when he is happy. When he is angry, ... everyone will get pissed off cause he would be throwing things and slamming the door.”*

Table 3. Categories and themes of hopes and concerns of siblings.

Category		Theme	No of times theme found
Siblings with I/DD	Hope	Improve and be independent	20
		Be meaningfully occupied	2
		Have a satisfied well-being	4
		Be spiritually connected	1
	Concern	Inability to hold a job	6
		Healthcare needs	3
Adolescent Siblings (Self)	Hope	Succeed as a person	3
	Concern	Management of finances	10
		Ability to attend to other life roles and responsibilities	12
		Ability to meet the daily challenges of high support needs of sibling with I/DD	13
		Lack of competence affecting the care of sibling with I/DD	7
		Personal grief if sibling with I/DD passed on first	1
Support around the siblings	Hope	Presence of other siblings' support	14
		Good relationships with future spouse and future family members	9
		Presence of formal support	9
	Concern	Having children	1
Government and society	Hope	Government to provide financial support	2
	Concern	Public reactions towards siblings with I/DD	4

Siblings' hopes and concerns of future caregiving

The hopes and concerns of siblings if they are to take on future caregiving of their siblings with I/DD include those for their siblings I/DD, themselves, their support

networks and lastly, the larger macrosystem. The themes within the categories are listed in Table 3.

Siblings with I/DD. Seven siblings expressed their hopes for their siblings with I/DD to improve and be

more independent to lessen their future caregiving responsibilities. These include seeing improvement in their siblings' money management skills, daily living skills, travelling skills and behavioural issues. They also articulated hopes for their parents to change their parenting style towards their sibling with I/DD to be more authoritarian, instead of giving in mostly in the early years. They felt that this would encourage independence of their sibling and lessen their future caregiving responsibilities. With these concerns about the lack of independence and maturity of their siblings with I/DD, the siblings articulated worries about their sibling with I/DD having the ability to hold a job and do well in their future job, which may possibly lead to increasing future caregiving responsibilities: "Is he able to work? If not his days would be spent doing nothing and it would not be good... *is he able to work, is he able to handle his future workplace, how is he going to be with his future colleagues? Is he going to still be like so immature, like a child?*"

Besides having hopes for their siblings with I/DD to be more independent, some expressed for their sibling to continue to be meaningfully occupied through opportunities for leisure activities and having satisfying well-being: "... *I want to see him happy...*" and "*I think if I got a house I would make like one room for her. She must be very comfortable*". There was one sibling who expressed hopes for the siblings with I/DD to be more spiritually connected in future: "... *hope (J) will understand more significantly about god cause my family is quite religious*".

Some siblings with I/DD have current medical

conditions including epilepsy and are more susceptible to common illnesses. This led to worries among potential siblings caregivers since they are concerned about their future healthcare needs including the type of medication their sibling could consume and having the necessary knowledge to manage their healthcare needs: "*I really don't want any chronic condition. Because chronic right, they mostly do not have oral suspension... And next time if he were to or anything happen to him or what... I can take tablets but he cannot take tablets.*"

Adolescent siblings (Self). Apart from having hopes for their siblings with I/DD, potential siblings caregivers themselves have hopes for their own selves. Some hope to be successful especially having a well-paid job, in order to better care for their siblings with I/DD in future: "*I always have this mindset that I won't do well and how am I going to take care of him, because my parents will grow old and we have him... I'm actually aiming to get a high pay job so I won't have any financial problems in the future... I'm actually hoping that I can make it as a person*"

Many mentioned about the concerns of being unable to balance the demands of their immediate family and job in future, which is largely linked to them having to attend to other life roles and responsibilities while caring for their siblings with I/DD in future. There were two siblings who expressed that they are willing to give up life priorities including marriage ("*I have to see how she maintain herself. If she is perfectly alright then I can go and look for my own life. If that is not the case, then I will be single all the way...*") and going overseas for job opportunities ("*but I just thought of what if I have*

to go overseas. Like how to balance work, friends and taking care of him...”), if their siblings with I/DD are not independent enough for them to achieve these.

Some mentioned about their inability in meeting the daily challenges of high support needs of their sibling with I/DD, especially the close supervision required by their siblings. This is similar across siblings requiring different levels of care. For those requiring low level of care, potential sibling caregivers are concerned about the sibling with I/DD having lack of stranger awareness (“trust people easily”) and inability to protect themselves when at work (“getting clingy to guys at work”). While for those requiring high level of care, they are concerned about them engaging in dangerous behavior when left alone at home (“cutting their own hair” and “going out on their own and losing their way”).

Seven participants mentioned concerns about management of future finances for their siblings with I/DD, including one whom the parents had put aside money at present for the future caregiving finances of the siblings with I/DD. These include concerns about having insufficient money for their medical bills, daily living expenses and hiring a foreign domestic helper to look into the needs of their siblings with I/DD in future. These concerns are also raised as many felt that their siblings with I/DD are either unable to work in future or would be holding lowly paid jobs, leaving them to support them financially. They also mentioned that their worries are greater when the socio-economic statuses of their family of origins are underprivileged: *“I worry a lot, as my family compared to my friends, their families has higher income... So for myself I just have to study*

hard and get a good job and then have a lot of money. I think money is the main issue here.”

Siblings largely spoke about their lack of competence, expressing a belief that they do not possess the relevant knowledge or capacity to adequately manage the tantrums and the daily care of their siblings with I/DD as compared to their parents, affecting how they care for their siblings in future. They foresee that it would be more challenging to manage the tantrums of their siblings as they grow older: *“As he grows he will get stronger...whenever he tries to throw tantrums, we can still stop him now. I’m scared that if he gets older and stronger, we won’t be able to stop him as much as now. Then he will start hitting us...”* One sibling shared that gender differences between her and her elder brother with I/DD make her worry about his future caregiving: *“Can I provide for him and provide him the necessities, especially since he is a boy? Since he is a boy, it could be more difficult...”*

Lastly, one sibling mentioned about her concerns of having to deal with her personal grief in future, if her siblings with I/DD passed on first while providing caregiving: *“I heard somewhere that Down syndrome people don’t live very long and will die earlier. So I am just worried that if he dies before me, will I be able to take it?”*

Support around the siblings. Siblings who have other siblings present in the family system hope to have their siblings’ support in future. They perceived emotional, practical and social support from their siblings as a buffer to the stresses involved in the future caregiving of their siblings with I/DD. Yet, they also

recognize future limitations of their siblings, especially if they have other life responsibilities in future: *“Scared that maybe one of them haven get married or never get a proper job, it would also be a struggle to them. Cause they have to take care of the little brother, they also have to find a job to support themselves or maybe they themselves are not so abled. I am worried that my little brother may get ignored and may not get proper care.”*

In addition, there was one respondent who shared that she being the eldest sibling would prefer to take the sole responsibility of future caregiving in order to not distress her younger siblings: *“I don’t want any of my other siblings to be affected by her and be stressed. If they want to be stressed, they should only be stressed about their own problem and not my sister.”* Similarly for those without other sibling apart from the siblings with I/DD, they mentioned increased future caregiving burden since there is no alternative support to turn to and share the caregiving responsibilities: *“I only got myself… it makes a very big difference because you are like the only one that has to support him, cannot be others”.*

Siblings mentioned that they hope to have positive relationships with their future spouses and in-laws, even when they are caring for their siblings with I/DD. They were also conscious about the need to choose a future life partner that could accept their siblings with I/DD, accommodating them in their home: *“My partner would have to be… I am not sure if he can be 100% accepting of (S) but at least he has to be generous enough to allow him to stay with the sisters…”* However, many do not have expectation on their future spouse to look after their siblings with I/DD and prefer to manage on their own.

One respondent mentioned her worries of having her own children in future, as she is concerned when having to balance the care of their own child and a sibling with I/DD: *“how are they going to react to their uncle having down syndrome? Are they going to be like mean to him, cause they don’t understand him?... I am scared that if in future I have children, will they be nice to him or mean to him?”*

Siblings hope to receive formal support in future to support the care of their sibling with I/DD while they are at work, as they recognise caregiving could result in conflict between work and these duties. Having services in place (e.g. day activity centre or foreign domestic helper) allows their sibling with I/DD to be supervised and meaningfully occupied while they focus on work. Yet, one respondent was concerned about the quality of services being provided: *“…really afraid that she is going to other centres too. You know nowadays people cannot be trusted right. They may beat the person when they can’t control their emotion… I wish I am in a job I can also take care of her, because I don’t want like other people to be stressed taking care of my sister also…”*

Government and Society. Siblings expressed concern about the negative reactions from the public about their sibling with I/DD, and hope they could improve their perceptions and reactions towards them: *“… even the people in public. Cause he goes for bowling sessions by himself … Sometimes people can be a bit mean to him on the train.”* They felt that positive societal perceptions would reduce their future caregiving stresses.

They also expressed hope to receive more government support when caring for the siblings with

I/DD in future, in particular having subsidies for medical fees: “... think the government don’t really acknowledge autism or disability. It is like knowing my brother’s condition, there isn’t much subsidy though my dad is earning”

Factors influencing future caregiving of these siblings

Siblings expressed that factors cutting across personal characteristics of potential siblings caregivers, sibling relationships between the sibling and the sibling with I/DD as well as presence of current and future familial and outside support, could prepare them for future caregiving. The themes within the categories are listed in Table 4.

Personal characteristics. Siblings expressed that finding the positives would help them to prepare themselves for future caregiving, though there are much challenges they would face. Some have positive thinking believing that the solution would come for any difficulties they face when caring for their sibling with I/DD: “need to have a good mindset. You know you have this type of sibling you must be responsible as well. Don’t try to hate them and show them the hatred... be more considerate and concerned towards them and show them that you are my everything.”

Sibling with I/DD and sibling. Siblings who presently have had more contact with their siblings

Table 4. Themes of factors influencing future caregiving of potential sibling caregivers

Category	Theme	No of times theme found
Personal characteristics of adolescent sibling (self)	Finding the positives	8
Sibling with I/DD and sibling	Present-sibling caregiving opportunities	8
Family-related factors	Having early family conversations on future caregiving	9
	Importance of parent’s role	9
Community resources and support	Increased current knowledge from external parties	5
	Awareness about the future services of siblings with special needs and the challenges of future caregiver	5
	Adolescent sibling support	3

with I/DD (e.g. bringing them out, teaching them, providing instrumental care duties) as well as taking on certain responsibilities to reduce parental stress and share parents' obligations are similarly more prepared to provide future caregiving: *"After school, if I see him, sometimes if I am free I will pick him up from downstairs at his school bus stop area there then I will bring him up and after he is done bathing and eating, I am the person who teaches him to study at home."* Though parents primarily performed these tasks, siblings who sometimes take care of their siblings would enhance their ability to be a more confident caregiver with these early experiences.

Family-related factors. Having early family conversations on future caregiving would be a fundamental precursor to future caregiving. Seven respondents shared that their parents had spoken to them about future caregiving of their siblings with I/DD, and felt that having these family conversations allow them to start thinking about future care plans and have a clearer understanding about potential caregiving. Parents, usually mothers, who had encouraged open communication with the siblings about future caregiving, make the future caregiving process to be less complicated for the sibling. Yet, some shared discussing about this subject made them worried: *"My mum said ... they will leave a sum of money for my brother to go to Day Care. She say like they will get a maid to help him, but ask me to also spend time with him... She said like you still have to take care of him even though there's like maid and day care. Then we started talking about the maid prices which is quite expensive... feel pressured"*

Parents are especially important in preparing siblings for future caregiving of their siblings with I/DD. Parents who gave advices, information and opportunities to siblings to gain understanding on their siblings with I/DD, allow them to feel more secure about potential caregiving. As mentioned above, some siblings are unprepared and anxious about this subject matter. By learning and witnessing their parents' ways of caring for their siblings with special needs through day-to-day experiences, these enhanced their abilities be a potential future caregiver: *"... have to depend on myself what to do and remember what my mother always do with my brother ... so I can take over my mother immediately"*.

Community resources and support. Siblings felt that there is a need to broaden their current knowledge of the sibling with I/DD through attending talks and workshops from social service agencies. This includes learning skills to manage the tantrums and instrumental care activities of their siblings with I/DD, coping with future family dynamics and understanding about the health condition of their siblings. One respondent mentioned that it would be helpful if the talks that their parents attend are offered to adolescent siblings so they acquire the knowledge too: *"talks that my parents attend are useful and it would be good if they extend to the siblings...Then we can learn those information. During those talks, they talk about techniques and stuff and it would be good for us to know also...about how to handle (S)..."*

Siblings also mentioned the importance of being aware about the future services of siblings with I/DD and understanding the challenges of future caregiver, to prepare them as future potential caregivers. Many

siblings mentioned that they do not know the post-school options for their siblings with I/DD and are concerned there is no formal service available for their siblings while they are at work: *“knowing what to expect, Like what can he do in future in terms of job or anything? And also like what can I do to prepare (I)...”*. With the uncertainties of being a caregiver, one respondent hopes to understand the daily challenges they may face when meeting the support needs of their siblings and ways to deal with these future difficulties: *“now I don’t look after him full time, Like what happens if it’s like my turn, It’s like going to be a bit scared... just advice, How am I gonna handle, what am I gonna be dealing, how much stressed out I’m going to be...”*

Siblings felt that their present involvement in adolescent siblings support group is useful as they learn from others about their siblings with I/DD, preparing them for future caregiving. These groups also allow connections with other siblings who also have brothers and sisters with special needs, *“I think even though they don’t share the burden, but just knowing that there are other people going through the same thing, it helps a lot even though the problem is not solved... I mean the difficulties”*.

Discussion

The findings largely highlighted siblings’ favourable views towards future sibling caregiving, if there are support services and planning from different levels in place to help siblings and families prepare for the future care and support needs of the siblings with I/DD.

Siblings’ ascribed roles as future primary caregivers

Though siblings are largely accepting and committed to care for their sibling with I/DD in future due to their love and acceptance towards them, there were also negative feelings about future caregiving largely due to concerns cutting across those for their siblings with I/DD, themselves, their support networks and the larger macrosystem. These siblings’ views of being potential future caregivers for their siblings with I/DD are consistent with the model of sibling attachment (Bowlby, 1969 as cited in Jacobs & MacMahon, 2017) which described the function of the sibling relationship as preserving parental/ family values and goals of their ascribed role to be a future primary caregiver for their sibling with I/DD. These feelings of acceptance are especially prominent among those who are the eldest and only sibling in the family, relating to greater caregiving responsibilities be it male or female sibling looking after the siblings with I/DD. Besides that, the worries and anxieties are particularly noticeable among those without presence of other sibling support to buffer the future caregiving stresses (Saxena, 2015).

How family impacts future caregiving

Contrary to other literatures illustrating families may not encourage discussions of future caregiving of siblings with I/DD with their typically developing child (Seligman & Darling, 2007), majority of the participants had some form of family conversations on future caregiving of siblings with I/DD with their parents. This is possibly linked to Singapore government philosophy on ‘family being the first line of support’ (Ong, 2010)

and it is the family members' responsibility to look after the sibling with I/DD. Though early family discussions prepare siblings to be future caregivers for their sibling with I/DD, there need to be deeper discussions and plans relating to other concerns that their potential sibling caregiver may experience and increase their knowledge to care for their sibling with special needs. It would be helpful to complement these discussions with present caregiving opportunities concerning the siblings with I/DD to increase their confidence and competence, besides knowing what to expect if their caregiving roles are to increase in future years.

Impacts on siblings' life priorities

Many siblings recognise that future sibling caregiving could likely impact on their current and future life priorities, yet their positive thoughts keep them going. These life priorities include working hard at present to have a well-paid job, their decision to have their own families, and changes of the nature of their relationships with their future spouse, members of their extended families and children. Their individual goals to be financially capable are possibly linked to concerns that their sibling with I/DD would not be able to have jobs that could sustain themselves financially and the high costs of having to support their sibling with I/DD. Similar to literatures, these adolescent siblings are considering their sibling with I/DD alongside their future plans (Cicirelli, 1995; Seligman & Darling, 2007; Petalas, 2012), and some had intentions to compromise certain personal interests in future to be more involved in sibling caregiving. This reflects on the valuable role

that these sibling play as potential future caregivers, and having direct services such as Day Activity Centres and government financial support could help relieve them from some responsibilities.

Revised conceptual framework

The findings illustrated that apart from the protective and risk factors concerning future caregiving relating to sibling with I/DD, adolescent sibling and family, the conceptual framework should extend beyond and include factors relating to the mesosystem, exo-system and macrosystem. Figure 2 illustrates the revised conceptual framework that has emerged from this study, incorporating the ecological model (Bronfenbrenner, 1977, 1979) which illustrates that future caregiving of a sibling with I/DD is influenced not only by interactions within the microsystem but also by its interactions with other levels of the entire social system: mesosystem, exo-system and macrosystem (Hornby, 1994). These findings highlighted the need for intervention from different levels to help siblings and families prepare for the future care and support needs of the siblings with I/DD and that the term 'caregiver' could be incorporated to include these potential future sibling caregivers (Heller, 2008). The presence of protective factors cutting across different levels could prepare the siblings to care for their siblings with I/DD in future.

Implications to social work practice

The existing gaps and future services could be addressed and developed across the four levels to enhance the contribution of potential future siblings caregivers.

Protective Factors influencing future caregiving of siblings with I/DD

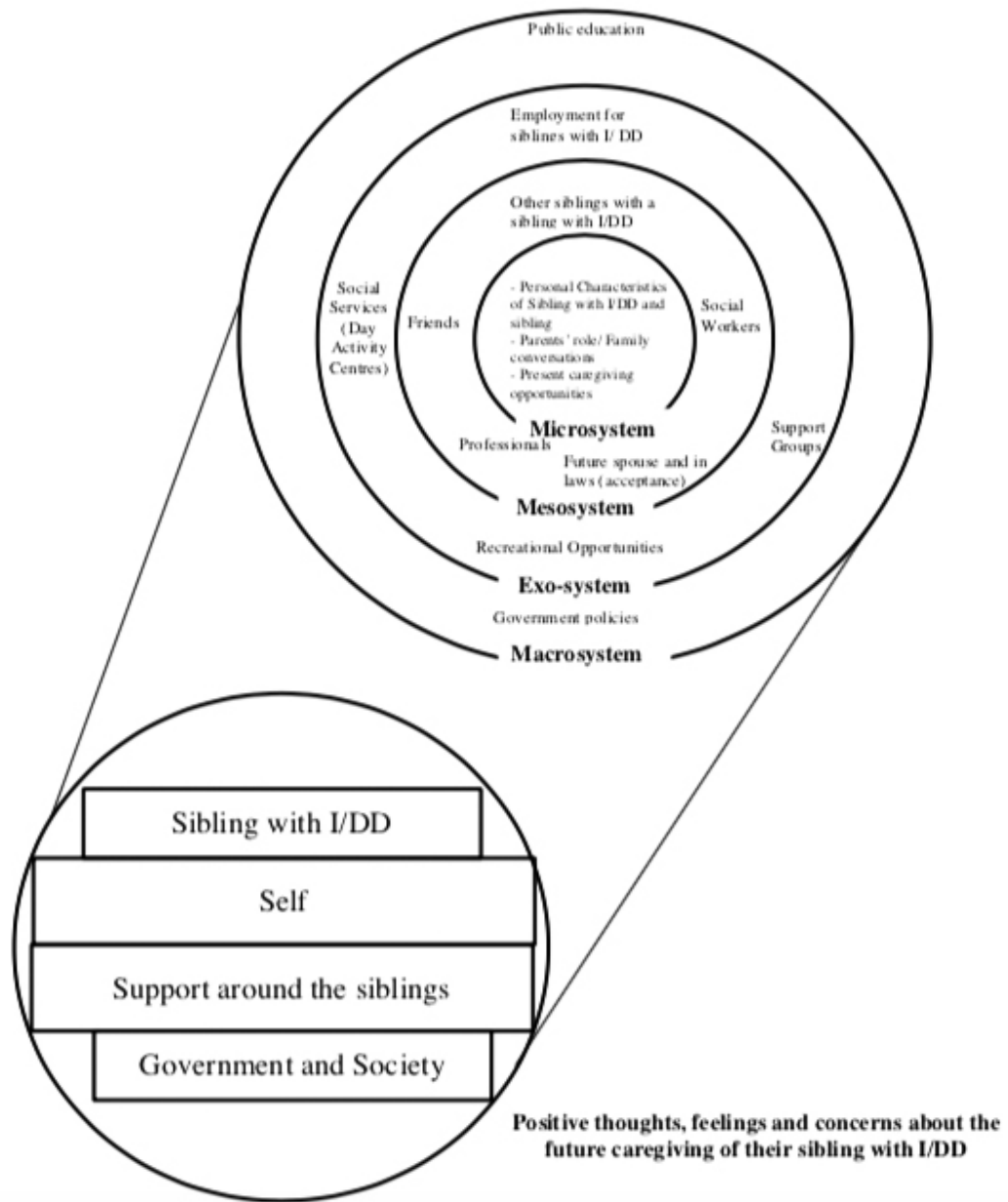


Figure 2. Revised conceptual framework emerged from this study.

From a *microsystem* perspective, parents play an important role in educating and preparing these siblings about future caregiving of siblings with I/DD (Grabowski, 2016). Hence, professionals could encourage more conversations on future caregiving with all family members present.

From a *mesosystem* perspective, the range of settings in which the siblings actively participated in (Hornby, 1994) has an influence on potential sibling caregivers. Professionals such as social workers could increase awareness about future caregiving and improve the current knowledge of these siblings including handling future family dynamics, knowledge on future services for their siblings with I/DD and competencies in managing siblings with I/DD to further their knowledge on future caregiving. Such preventive interventions could allow these siblings to respond more appropriately about future caregiving (Saxena, 2015; Strohm, 2008).

From a *exosystem* perspective, increased opportunities for employment of their siblings with I/DD who are work-capable would enable them to be independent, minimising the siblings' concerns of management of finances. Presence of appropriate recreational opportunities enable sibling with I/DD to be meaningfully occupied. Having support groups planned from an adolescence stage is useful as these siblings, especially those without other siblings, allow them to receive validation from other children with similar experiences, and potentially develop greater resilience in dealing with their difficult experiences including future caregiving (Strohm, 2002).

From a *macrosystem* perspective, the presence of

appropriate government schemes to address the cost of caregiving, and public education on person with special needs aiming to improve societal perception could mediate the siblings' concerns of future caregiving. Social workers play a key role in advocating for such initiatives and organizing public education campaigns.

Limitations and recommendations for future research

Due to the small non-random sample size and participants from solely one organisation, it does not permit generalizability of the results to the wider population.

Further research should consider expanding the sample to validate the findings and enhance understanding of this topic. Alternatively, this research could be replicated at another level when siblings' views on potential future caregiving are explored on a longitudinal approach, since it would take into account the changes in roles and responsibilities over time using a life course approach (Davys, Mitchell, & Haigh, 2016).

Conclusion

The specific aim of this study is to find out about the feelings and concerns of future caregiving and the factors that could prepare adolescent siblings for future caregiving of their sibling with I/DD. From this qualitative research, it presented a snapshot of common hopes and concerns that these siblings have and the protective factors cutting across different levels that

could prepare adolescent siblings to care in future. It is hoped that social service professionals would place more attention on engaging families, communities and the society in future care planning of the sibling with I/DD and to prepare adolescent siblings on potential future caregiving of their sibling, in view of the valuable role they play. Furthermore, practitioners could play a

key function in advocating for social policies for these potential sibling caregivers to enable them to cope well with these future caregiving. Lastly, it is hoped that this study would act as a springboard for more future researches to be conducted on this population: potential sibling caregivers.

Reference

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Washington, D.C: American Psychiatric Association.
- Bigby, C. (1996). Transferring responsibility: The nature and effectiveness of parental planning for the future of adults with intellectual disability who remain at home until mid-life. *Journal of Intellectual and Developmental Disabilities, 21*, 295–312.
- Cicarelli, V. (2013). *Sibling relationships across the life span*. Springer Science & Business Media.
- Damiani, V. B. (1999). Responsibility and adjustment in siblings of children with disabilities: Update and review. *Families In Society, 80*(1), 34-40.
- Davys, D., Mitchell, D., & Haigh, C. (2016). Adult siblings consider the future: Emergent themes. *Journal of Applied Research in Intellectual Disabilities, 29*(3), 220-230.
- Degeneffe, C. E. (2015). Planning for an uncertain future: Sibling and parent perspectives on future caregiving for persons with acquired brain injury. *Journal of Rehabilitation, 81*(4), 5.
- Grabowski, M. (2016). *The Relationship between Siblings with a Brother or Sister Diagnosed with Autism Spectrum Disorder and Anticipated Caregiving* (Doctoral dissertation, William James College).
- Hornby, G. (1994). *Counselling in child disability: Skills for working with parents*. Nelson Thornes.
- Heller, T., Kaiser, A., Meyer, D., Fish, T., Kramer, J., & Dufresne, D. (2008). The sibling leadership network: recommendations for research, advocacy, and supports relating to siblings of people with developmental disabilities. Paper presented at the Sibling Leadership Network Meeting. Retrieved from https://www.researchgate.net/publication/237519507_The_Sibling_Leadership_Network_Recommendations_for_Research_Advocacy_and_Supports_Relating_to_Siblings_of_People_with_Developmental_Disabilities
- Jacobs, P., & MacMahon, K. (2017). 'It's different, but it's the same': perspectives of young adults with siblings with intellectual disabilities

- in residential care. *British Journal of Learning Disabilities*, 45(1), 12-20.
- McHugh, M. (2003). *Special siblings: growing up with someone with a disability* (revised ed.). Belmont: Brooks/Cole.
- Meyer, D. and Vadasy, P. (2007). *Sibshops: workshops for siblings of children with special needs* (revised ed.). Baltimore, MD: Paul H. Brookes.
- Monette, D. R., Sullivan, T. J., & DeJong, C. R. (2005). *Applied social research: a tool for the human services* (6th ed.). Belmont: Brooks/Cole.
- Moyson, T., & Roeyers, H. (2012). 'The overall quality of my life as a sibling is all right, but of course, it could always be better'. Quality of life of siblings of children with intellectual disability: the siblings' perspectives. *Journal of Intellectual Disability Research*, 56(1), 87-101.
- National Council of Social Service (NCSS). (2017). *3rd Enabling Masterplan 2017 – 2021: Caring nation, inclusive society*. Retrieved from https://www.ncss.gov.sg/NCSS/media/NCSS-Documents-and-Forms/EM3-Final_Report_20161219.pdf
- Newman, Barbara M. & Newman, Philip R (2009). *Development Through Life: A Psychosocial Approach* (10th ed.). Wadsworth, Cengage Learning, Belmont, CA.
- Ong, K. Y. (2010). *Singapore's Social Policies: Vision, Accomplishments, and Challenges*. Retrieved from http://lkyspp2.nus.edu.sg/ips/wp-content/uploads/sites/2/2013/06/sp_oky_The-Centre-for-Social-Development-Asia-Conference_080610-1.pdf
- Padgett, D. K. (2008). *Qualitative methods in social work research* (2nd ed.). New York: Sage.
- Petalas, M. A., Hastings, R. P., Nash, S., Reilly, D., & Dowey, A. (2012). The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder. *Journal of Intellectual and Developmental Disability*, 37(4), 303-314.
- Saxena, M. (2015). Variables that can enhance and complicate sibling caregiving of individuals with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 12(3), 210-219.
- Seligman, M., & Darling, R. B. (2007). *Ordinary families, special children* (3rd ed.). Guilford Press; New York.
- Smith, M., Greenberg, J. S., & Seltzer, M., (2007) Siblings of adults with schizophrenia: expectations about future caregiving roles. *American Journal Of Orthopsychiatry*. 77(1): 29-37.
- Stroh, K. (2002). *Siblings: Brothers and sisters of children with special needs*. Kent Town, Australia: Wakefield Press.
- Stroh, K. (2008). Guest Editorial: Too important to ignore: Siblings of children with special needs. *Australian e-Journal for the Advancement of Mental Health*, 7(2), 78-83.
- Thomas, R. (1992). *Comparing Theories of Child Development* (3rd ed.). Belmont: Wadsworth Publishing Company.

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