

A Study of Lived Experiences of Parents of Children with Down Syndrome on Activities of Daily Living

Darsyanah Nadarajan^a, Dr Faridah Serajul Haq^b

^a Faculty of Education, SEGi University, 47810 Petaling Jaya,
Selangor

^b Faculty of Education, SEGi University, 47810 Petaling Jaya,
Selangor

ABSTRACT

Activities of Daily Living (ADL) are often overlooked especially when children are in their beginning years of development. This especially can be a challenge for parents of children with Down syndrome due to the varying levels of progress of their child's development in the areas of: a) socio-emotional, b) communication, c) motor, d) cognitive and e) self-help skills. Thus, Vygotsky's Sociocultural Theory was applied to theoretically study the lived experiences of parents of children with Down syndrome on Activities of Daily Living (ADL). The objectives of the study are: a) to explore how parents teach Activities of Daily Living to their children with Down syndrome, b) to determine how parents perceive the importance of Activities of Daily Living for their children, and c) to identify the challenges parents faced in teaching their children with Down syndrome on Activities of Daily Living. A qualitative approach using semi-structured interviews and journals were adopted and 3 parents participated in this study. For the first research question on how parents teach their children ADL, two themes emerged from the findings; one, modeling via the More Knowledgeable Other (MKO), two, encouragement using tools or signs. For the second research question on how parents perceive the

* Corresponding author:
Email address: faridahhaq@segi.edu.my
Affiliation: Faculty of Education, SEGi University

importance of ADL, one key theme manifested: important in promoting independence. Finally, for the third research question on the challenges parents face in teaching their children ADL, two major themes were identified; first, behavioral challenges of children and second, parent's emotions. Future researchers may conduct a study by looking at both parents' perspectives to obtain a more rich and in-depth study on their child's ADL.

Keywords: *Activities of Daily Living, Down syndrome, lived experiences, parents*

1. Introduction

The importance of educating functional skills to individuals with disabilities has long been established by scholars and practitioners (Ayers et al. 2011; Brown et al., 1979). These functional skills, otherwise known as Activities of Daily Living (ADL), encompass day-to-day routine such as, brushing teeth, bathing, dressing, grooming, eating, toileting to ambulating as it forms an essential part of our lives. ADL is usually introduced by parents or carers transitioning from dependence to complete independence at a very young age. Typically, parents or carers bring along rich experiences that were amassed from their values, disposition, beliefs, attitude, and knowledge, gained over the years (test, Aspel and Everson, 2006; Volkmar and Wiesner, 2009). This fundamental aspect of daily living activities involves many skills that are essential for the successful execution of tasks. However, due to a genetic disorder that affects children with Down syndrome, many of the skills that are required in accomplishing ADL in the developmental trajectory are delayed by approximately three months (Van Herwegen, Rundblad, Davelaar, and Annaz, 2011; Sugden, and Wade, 2013).

Down syndrome which is one of the most prevalent and readily identifiable chromosomal conditions is an intellectual disability that appears in about 1 in 400 to 1500 newborns (Capone, Grados,

Kaufmann, Bernad- Ripoll, and Jewell, 2005). Due to an extra copy of the 21st chromosome, the genetic mutation results in gene overexpression (Roizen and Patterson, 2003). Among the common phenotypic characteristics that are usually visible in children with Down syndrome are low muscle tone, single deep crease across the centre of their palm, small stature and upward slant of the eyes (Chapman and Hesketh, 2000). Nonetheless, each child is unique in his or her own way and their characteristics would differ from one person to another, or in certain cases, may not even be present (Skallerup, 2008). Most children who are born with Down syndrome tend to develop motor and cognitive skills at a much slower rate as compared to typically developing children (Malak, Kostiukow, Krawczyk-Wasielewska, Mojs, and Samborski, 2015; Moore, Oates, Hobson, and Goodwin, 2002). A task that may appear as simple as holding a cup can a great challenge to children with Down syndrome due to the characteristics that they may possess.

For as long as children rely on parents to carry out ADL for them, the information parents share of their teaching and demonstrating ADL to their children for the benefit of many researchers and parents of children with Down syndrome will be vital.

When it comes to Activities of Daily Living (ADL), children without disabilities are able to grasp the skills that are taught to them with ease. However, due to a slower development in their motor and cognitive development, children with Down syndrome require relatively more time to process the skills that are taught to them (Hallahan, Kauffman, and Pullen, 2012). Children with Down syndrome have shifting degrees of learning and language inability, in addition to poor functioning motor skills, varying from mild to severe. They likewise develop at a slower pace emotionally, socially, and cognitively (Kazemi, Salehi, and Kheirolah, 2016).

Since ADL is a necessity that needs to be carried out by every individual, the researcher intends to look at parents' experiences on carrying out ADL with their children with Down syndrome. ADL which is the basic unit of activities of daily living can be defined skills which covers basic physical areas in a person's everyday life such as "grooming/personal hygiene, dressing, toileting/continence, transferring/ ambulating, and eating" (Mlinac and Feng, 2016). The current study examined the lived experiences of parents of children with Down syndrome on Activities of Daily Living (ADL), namely, of toddlers of the ages 3 years old.

These toddlers who are still in their beginning years are still in the starting stages of learning the fundamentals of ADL. The researcher takes this opportunity to delve into the lives of parents who are carrying out the ADLs on a daily basis and give voice to the experiences through interviews and one-week of journal writing by putting pen to paper of the minute details of the experiences with their child.

2. Literature Review

Concept of Activities of Daily Living (ADL)

King, Okodogbe, Burke, McCarron, McCallion, and O'Donovan, (2016) looked into the areas of Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) performance which includes "dressing, walking, moving around the home, bathing and showering, oral hygiene, eating, drinking, bed mobility, toileting, medication management, meal preparation, grocery shopping, telephone use, money management and domestic tasks such as laundry and cleaning." However, the age group chosen for this research was adults with Down syndrome who were 40 years and above. In another study conducted by Green and Carter, (2011), they defined Daily Living Skills (DLS) as an "age-appropriate, self-care activities needed to function at home and in the community, and which includes behaviors such as washing, dressing, following

safety rules and completing household chores.” This study carried out by Green and Carter looked specifically on toddlers with Autism Spectrum Disorder (ASD).

A recent quantitative study conducted in 2018 by Matthews, Allain, Matthews, Mitchell, Santoro, and Cohen (2018) examined the health, social, communication and daily living skills. Matthews et al. looked into everyday tasks such as drinking, moving about in and out of the house, eating, dressing, toileting, grooming, bathing, carrying out domestic activities, managing finances and using technology. The surveys were given out only to parents or legal guardians, grandparents, adult siblings, other family members or caregivers of an adult with Down syndrome who was at least 20 years of age (Bal, Kim, Cheong and Lord, 2015).

Methods parent use to teach ADL

A considerable amount of literature has been published on methods of teaching ADL. Surveys such as that conducted by Shepley, Spriggs, Samudre and Elliot have shown that middle school students with intellectual disability were able to independently initiate and navigate the mobile device during technology training using video activity schedules. Three of the students were able to self-instruct in order to independently prepare a snack (2017).

A study by Hayton, Wall and Dimitriou (2018) examined the development of independent living skills of dressing (ILSD) in two clinical groups. Young children with Visual Impairment (VI) and Down syndrome (DS) were compared to Typically Developing (TD) children. It appeared that comprehensible and structured verbal instructions paired with motor activities were useful in giving support for ILSD.

Previous research findings suggested that instructional video modeling was effective in promoting daily living skills across three

children with autism of the ages 5 years (Shipley-Benamou, Lutzker, and Taubman, 2002). In another study conducted by Cannella-Malone et al. (2011), the researchers compared the effects of video prompting to video modeling to teach seven students with severe intellectual disabilities to do laundry and wash dishes. It was discovered that video prompting appeared to be more effective than video modeling in teaching the two daily living skills (Cannella-Malone et al., 2011).

Findings from a study by Biederman, Fairhall, Raven and Davey (1998) believed that teaching children through passive modeling was more significantly effective than hand-over-hand modeling and with passive response-contingent verbal prompting. According to Will, Caravella, Hahn, Fidler, and Roberts (2018), there was only one study conducted on adaptive behavior in Down syndrome that examined the adaptive skills, which includes daily living skills, of toddlers with Down syndrome.

Perception of parents on ADL

A study conducted by Docherty and Reid (2009) identified that parents often provide assistance in the activities for their children and view themselves as “gatekeepers” during their transition as well as activities. Independence is often the ultimate goal for their children and that in future they would be able to take care of themselves.

A study on exploring parental perspectives of participation in children with Down syndrome carried out by Lyons, Brennan and Carroll (2015) resulted in two main themes and seven sub-themes. The first theme that was identified was the value of participation which promoted their sense belonging and well-being, meanwhile, the second theme, ‘barriers and facilitators of participation’, had more sub-themes such as the child factors, attitudes and perceptions of others, adaptation to the environment and logistics issues.

In the Malaysian context, Chan, Lim, and Ling (2014) examined the experiences of mothers caring for a child with Down syndrome in Sarawak. The major themes that were highlighted in this study were children's health, developmental delays, daily needs and behavioral issues. The age group for this particular study looked at children with Down syndrome aged 18 years and below.

While the Malaysian syllabus for Special Needs Education only contains one chapter on self-management (*pengurusan diri*) (Bahagian Pembangunan Kurikulum, 2011; Bahagian Pendidikan Khas, 2011) it does not contain parents' involvement to work closely with the teachers to teach their child in the best possible way. Working hand-in-hand with the teachers, parents are able to play an active role for further development of ADL.

Challenges faced by parents in teaching their child

A study conducted by Spiker (1982) almost four decades ago on 25 mothers' experiences in early intervention activities with their children with Down syndrome displayed challenges due to the lack of time. Parents appeared to play an active role during their child's infancy which slowed down during their child's preschool years due to time constraints.

In another study by Smith, Maenner, and Seltzer (2012) to examine the changes in the individual's with Autism Spectrum Disorder (ASD) and Down syndrome, it appeared that individuals with Down syndrome were associated with lower initial levels of daily living skills and had a deliberate change gradually. No significant curvature appeared for these individuals although they achieved daily living skills in due course (Smith, Maenner, and Seltzer, 2012).

A recent study on adaptive behavior in infants and toddlers with

Down syndrome and fragile X syndrome revealed the importance of incorporating adaptive behavior which includes daily living skills in children's early years as they have poor motor functioning (Will, Caravella, Hahn, Fidler, and Roberts, 2018). Children with Down syndrome showed more evident impairment in motor functioning from 12 months up to 3 years of age (Will et al., 2018).

While there are other studies on how the areas of development of a child with Down syndrome can be a challenge to the family, not many studies are conducted to specifically determine the challenges parents face when teaching their child ADL. Generally, however, parents of children with Down syndrome appeared to have more stress as compared to parents with children who are typically developing (Sanders and Morgan, 1997). This is due to the greater health care needs that most children with Down syndrome have (Schieve, Boulet, Kogan, Van Naarden-Braun, and Boyle, 2011).

On the other hand, past studies that have been carried out by Chi-Wen, Sylvia, Jodie, Grace and Saitlin (2016) has shown that children who have Sensory Processing Disorder (SPD) have challenges in carrying out daily living skills as children with SPD are unable to process information received in their daily life causing them to be 'extra sensitive' to the processed information. Children with Down syndrome that have SPD are unable to carry out daily living skills as other children with Down syndrome due to the inability of the brain to process the information received from their parents. When this situation arises, children with Down syndrome that has SPD would throw tantrums or would not respond in an appropriate manner when they are being taught ADL (Bar-Shalita, Vatine, Parush, 2008; Engel-Yeger, 2008).

Van Dijk and Lipke-Steenbeek (2018), reported that 80 percent of children with Down syndrome below the age of 7 years have problems with eating. This is due to their physiological and

anatomical irregularity such as small upper jaw, lip tension, and stronger tension of their tongue. Due to this, children with Down syndrome would not be able to chew effectively causing the food to be expelled because of their protrusion of tongue.

Similar study conducted by Spender, et al. (2008) explored the feeding difficulties of oral-motor function and discovered that children with Down syndrome specifically had challenges particularly on the areas of their jaw and tongue resulting in a poor feeding task. Parents appeared to be more controlling and would not immediately disclose about their child's feeding issues unless observed during feeding session.

Theoretical Framework

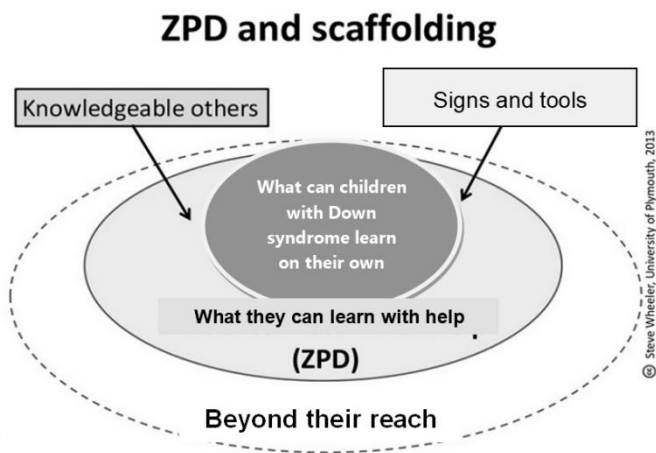


Figure 2.1 Theoretical Framework of Vygotsky's Sociocultural Theory adapted from McLeod, S. A. (2018, Aug 05).

This study will be described within the theoretical context of Vygotsky's Sociocultural Theory of Cognitive Development. The child's cognitive development takes place through social interaction based on two levels; first, through interaction with other individuals

and second, a child's cognitive development is based on the Zone of Proximal Development (ZPD) the child is currently in. The cultural context of this theory is transmitted by parents and other members of society in the child's life. Vygotsky (1978) proposed that a child's cognitive development is shaped by the culture in which the child is brought up (Lalvani, 2008). The environment which the child is brought up is often influenced by cultural beliefs of the child's parents or the individuals that play a role in the child's life and that have a major impact on the child's cognitive development (Vygotsky, 1978). Sociocultural Theory addresses how children are able to develop cognitively from the interactions of the adults around them and together with the cultural aspect determining when, where and how these interactions will take place. In teaching ADL to their children, parents play a role in providing an environment that best suit the child's learning of ADL to take place. The interaction of parents on how ADL is taught to the child is based on the cultural upbringing of the child (Vygotsky, 1978).

ADL is viewed to be most productive within the ZPD. ZPD is understood as the 'distance between the learner's actual development and the learner's potential development' (Wertsch, 1984). It is the zone in which the child is fully prepared cognitively but requires assistance and interactions in order to fully manifest the ability to perform a task (Vygotsky, 1978). In ADL, this zone can be interpreted as the distance between the child's basic knowledge in ADL and the extent to which the learner can advance or reach a higher skill of ADL. It is believed that within this ZPD that effective learning takes place with the assistance of others who acts as mediators, also known as the More Knowledgeable Other (MKO), that are the parents of children with Down syndrome.

The parents of children with Down syndrome who are the MKO will play a huge role in guiding their child in the ZPD to a higher level of ADL. The knowledge imparted to their children through

modeling or scaffolding are some of the examples in which it facilitates the learning of the child (Vygotsky, 1978; Papalia et al., 1998). There are many tools used on imparting knowledge to children in the ZPD, however, the vital role of the MKO is to facilitate the child's learning towards independence in ADL (Bodrova, 1997).

Parents provide children with various methods as well as assistance of teaching their child during parent-child interaction in order to facilitate their child's learning in ADL. This is known as scaffolding which is defined as the ability of an adult to structure the environment and teach them through assistance in order for children to solve skills which are deemed suitable for their level (Robinson, Burns, and Davis, 2009; Vygotsky 1978), in this context, Activities of Daily Living. The process of scaffolding is known to increase the developmental area of a child's cognition (Wood, Bruner & Ross, 1976). When parents scaffold ADL such as toileting, eating, grooming or dressing, children are able to understand the concept of ADL and gradually as they develop and are able solve the activities independently, parents can decrease the scaffolding. The role of the parents then changes from someone who helped them carry out the activities to one who provides encouragement, help and criticism (Wood, Bruner, and Ross, 1976).

Parents may be faced with challenges teaching their child on ADL when they are not able to provide a supportive learning environment for their child or if parents instruct their child to carry out a task beyond their reach. If the environment is not conducive for the child's learning to take place, parents would be faced with challenges on teaching them the daily living skills.

3. Methodology

The data collected through semi-structured interviews and journals were qualitatively analyzed. The data analysis was carried out

through coding for both the pre-interview and post-interview as well as for the journals. That is, the researcher began by establishing a set of categories for the data collected, then refined the categories and organized them in different ways in order to account for the data (Flowerdew, 2002). This was carried out in order to triangulate and validate the results.

The research aimed to answer the following research questions:

- I. How do parents teach Activities of Daily Living to their children with Down syndrome?
- II. How do parents perceive the importance of Activities of Daily Living for their children?
- III. What are the challenges parents faced in teaching their children with Down syndrome on Activities of Daily Living?

Central to this study is the need to select a feasible research paradigm to explore, deconstruct, and understand the multiple realities and lived experiences of the three parents. Husen (1999) offers the view that a “paradigm determines the criteria according to which one selects and defines problems for inquiry and how one approaches them theoretically and methodologically” (p.31). A paradigm theoretically anchors the research by illuminating fundamental assumptions about the nature of reality (Patton, 2002, p.39) based on the researcher’s worldview in terms of ontological and epistemological positions. In this study, an interpretive lens was employed to underpin the methods used and the subsequent analysis of the data. An interpretive paradigm proposes the existence of multiple realities within the social world of the parents. These realities are thus value-laden, multifaceted, subjective, abstract, and contextually-bound (Guba and Lincoln, 1994). Importantly, reality is fluid, “multi-dimensional and ever changing” (Merriam, 1998, p.202) which shapes its interpretation. Therefore, this research is not concerned with the search of a single ‘truth’ that often

characterizes positivist research; rather, it is a quest to understand the lived experiences of parents from the different ethnic, age, and socio-economic groups and how they view ADL.

This concern for an emic point of view, or in other words, for the parents' points of view hinges on the belief that the world of lived and multiple realities is socially and constructed by the individual (Guba and Lincoln, 1994). The approach taken in this study was also grounded on hermeneutical and dialectical principles, in that, conventional hermeneutical techniques were used to elicit and gather data. The interpretations that manifested in the interactions between the researcher and the parents were compared and contrasted through a dialectical interplay while the journal entries permitted a more nuanced and reflective interpretation that were based on the social realities of the parents (Guba and Lincoln, 1994).

4. Data Analysis

RQ 1: The Ways in Which Parents Teach Their Child about ADL Modeling

The first objective of this research was to explore how parents teach ADL to their children with Down syndrome. One of the common themes that were identified from the interviews and journals is modeling. All three parents agreed that modeling was indeed a key method of teaching their children. Parent A, for instance, mentioned;

“It is more of self-help like I am getting him to vacuum, hang clothes and all these additional things because for feeding he has already mastered; he can already be able to feed himself. Dressing is slowly also, you know like we are doing it but not much change as I see, the basic things that are carried out on a day-to-day basis, I will do then try to get him to

see what I am doing. Sometimes it can be slightly frustrating but I try my best." (Parent A, post-interview, November 19th, 2018)

She mentioned how her son, Arthur, was able to carry out other tasks of ADL such as eating and toileting with less to no assistance. However, when it came to 'dressing', there was only a little change and concluded by saying that she will continue using modeling as a method to teach him so that he will be able to reproduce the desired behavior in the future. Another parent mentioned in the journal that modeling was done through Brenda's sister with one of the journal entries stating,

"we will give her breakfast (will follow her sister to eat on her own)" (Parent B, journal entry, November 15th, 2018)

This way, modeling was done without Brenda's sister being aware on how her actions has contributed to Brenda's learning. In this sense, Brenda's sister unwittingly became the More Knowledgeable Other (MKO) to Brenda resulting in learning.

Additionally, Parent C, in her interview added that she would usually model to her child on how to pass motion by doing it in front of her. According to Parent C, her daughter has been said to have a 'defensive behavior' and 'sensory processing disorder of being hypersensitive'. During our first interview, she said,

"so when there's toilet training, it's a problem for her because she feels disgusted at things that are sticky, things that she's not used to or is new to her...she's scared and disgusted. So for instance when she went to the toilet when she was younger, when we taught her toilet training and when the urine accidentally splashed on her feet, she would become disgusted and

scared and so she would squirm and climb on my body” (Parent C, pre-interview, November 14th, 2018)

Her ‘hypersensitivity’ was resolved to a certain extent after continuous modeling paired with immediate hands-on practice. When Parent C sensed that her daughter was about to pass motion, she would immediately bring her to the toilet and make her squat. The toilet at Parent C’s home is a squat toilet which generates fear in her daughter. Parent C would constantly instill positivity in her daughter by modeling and showing her that there are no negative consequences in using the squat toilet to pass motion and would then show her how it is used. After constantly modeling the toileting etiquette, from letting her pass motion in her diapers near the door, to bringing her closer to the toilet each time, her daughter’s fear subsided gradually for both, the squat toilet and to pass motion;

“Previously, she used to run away...I’ll close the door and she’ll run away. When I’m defecating too she’ll be afraid and will start squirming. I’ll have to reassure her and say ‘it’s okay, it’s urine and stool...it’s okay’ and I had to do it many times...like 5 to 10 times...like many times, 5-10 times and now she’s used to it. When she sees me going to urine and defecating and there’s nothing wrong with it, she will be okay.” (Parent C, pre-interview, November 14th, 2018)

According to Vygotsky’s Sociocultural Theory, children who are in the ZPD, require scaffolding from a MKO. Contextualized in this study, it was evident that parents played the role of a MKO (Vygotsky, 1978) in helping their children achieve the desired behaviour. All three parents concurred that they taught ADL through modeling as it was the easier to demonstrate the desired behavior than to verbally explain it to them. Through constant repetition and

hands-on practice, parents were able to notice changes in how the children accepted the new behavior. Parents play the role in bridging the gap between what the children do not know to what the child knows and supposed to know. When children are in the ZPD, they would require scaffolding from a MKO and after the children have begun to understand the concept of ADL for specific tasks, scaffolding can be reduced accordingly (Pratt, Kerig, Cowan, and Cowan, 1988; Sun, and Rao, 2012; Vygotsky, 1978).

Encouragement

Another common theme that emerged from the coding was the use of encouragement in teaching their child ADL. Encouragement took the form of verbal compliments, and rewards for instance, being allowed to watch cartoons or nursery rhymes, dancing. Parent A revealed in the interview,

“I would tell him after you finish eating, I would let you watch TV. They would have some motivation and along the way we would encourage them by praising them.” (Parent A, pre-interview, November 13th, 2018)

When prompted with a question on the types of reward she would give him, parent A believed that encouraging her son through verbal praises would suffice because at this age, they do not require as much material rewards. Encouragement in the form of praises, dancing and singing are viewed as more significant than tangible rewards;

“Yeah basically it would be praises or I would dance for him or get him to sing some song. I think need a little bit more encouragement and it would help a lot for them. Because at this age they don’t really need a lot of rewards, just praises would be enough like

'Good Job!'” (Parent A, pre-interview, November 19th, 2018).

Parent C, on the other hand, faces challenges when getting her child to pass motion as her daughter gets disgusted with her own stool and is afraid to go to the toilet. However, parent C uses encouragement to shift her fear into something positive,

When it's time to wash, I'll remove her diapers and wash her while saying, 'Good Job, Cynthia, you managed to pass motion! See, look, this is your stool. Good job, Cynthia! Next time you pass motion, you won't have to use diapers.' (Parent C, pre-interview, November 14th, 2018)

Parent B, shared similar views on encouraging his child when carrying out ADL,

“as I mentioned is going to be like reinforcing on what she needs to do and telling what to do and all that. So that is the only way I see that we normally would approach her with. I think positive reinforcement will be the first point of our approach rather than wait and seeing or hoping that she will do as she is still young.” (Parent B, post-interview, November 18th, 2018)

Past studies have reported that due to the developmental delay in children with down syndrome (Malak, Kostiukow, Krawczyk-Wasielewska, Mojs, and Samborski, 2015), parents opt to other methods such as encouragement in order to promote ADL.

Using Tools or Signs

One of the concepts under Vygotsky's Theory (Vygotsky, 1978,

1997; Luria, 1976) entails using symbolic tools or signs for the development of the child. This was conceptualized from the interview with the parents. Two parents shared similar opinions on using tools, objects or signs in order to provide meaning to the tasks.

Parent A, for instance, is making an effort to teach her son the concept of toileting outside of her home environment by using sign language. By creating the ‘opportunity’, she is providing the platform for her child to internalize and form the ‘familiarity’ of toilets, not specific to her home through sign language.

“Even here, before going for swimming I will sign and tell him to go to toilet, then he will go. But sometimes it is difficult maybe they don’t want to do it. He needs familiarity and encouragement; give them opportunity so that they will do it.” (Parent A, pre-interview, November 13th, 2018)

On the second day of the journal entry by parent A, she stated that,

“Today I’ve also borrowed a tool set from the library which includes hammer, spanna, screwdriver, pliers, a pipe wrench, wire cutters and assortment of fasteners. Tonite we are going to fix things up in the house... Arthur will also learn to master the skills of each tool. This will be important for him to be independently fix things up when he grows.” (Parent A, journal entry, November 14th, 2018)

This extract from the journal entry shows how parent A perceives ADL to be. Her concept of ADL involves carrying out activities that would be useful in future when it involves ‘fixing something up’. Her understanding of ADL when teaching him about the different tools is for him to be a ‘reliable mechanic and contractor’. By

providing him with different avenues to carry out tasks, she is also providing him with choices that he can make in future.

In the post-interview session that was carried out with parent A, she highlighted how she is establishing a connection between what the child has learnt and bringing him to the outside world to teach him the meaning of what he has learnt. In her case, tools that were used to teach him was books and when she brought him to the supermarket,

“The thing I have added in was to reinforce everything we have done. For example, I have shared with you how we have done shopping in the school and when I went back, I reinforced it by reading books to him about supermarket and also bring him out to the real world to start buying and paying stuff.”
(Parent A, post-interview, November 19th, 2018)

Another parent associates signs to carry out a specific task such as going to toilet or to practice combing her hair she would use the mirror and a doll as tools to establish the connection between the doll's hair and her child's hair in order to relate it to the task of combing hair.

“I associate defecating by holding my nose to imply smelly and squat to show her the method of defecating, I'll hold her hand and push together with her.” (Parent C, pre-interview, November 14th, 2018)

“We have a mirror near the stove in the kitchen and I have allocated that space for combing hair; there's also a doll there for her to comb her hair, she can go there which is at her level.” (Parent C, pre-interview, November 14th, 2018)

Due to developmental delay in children's language, parents use other means to communicate with their children. For instance, they use sign language or external tools such as books when communicating with their children. Some children with Down syndrome acquire speech at a delayed period and in order to bridge that communication gap, parents use tools and signs in order to facilitate the understanding of ADL for their child (Caselli, et al. 1998; Chapman, Seung, Schwartz, and Kay-Raining, 1998; Gindis, 2003; Miller, 1999; Sigman, 1999).

RQ 2: Parents' Perception on the Importance of ADL

All the parents expressed their perception towards ADL and they equally felt that ADL is an important aspect in their child's life. They believed that ADL would play a vital role in promoting independence and one of the ways it can be achieved is through a fixed schedule, which two parents concurred on.

Important in Promoting Independence

Three of the parents equally felt that ADL plays an important role in their child's life. This was mainly due to the fact that ADL acts as a means to promote independence to their child. Below are the excerpts from the interview with parent A, B and C when asked their perception on ADL.

"Of course it is very very important, he is doing quite well and is important for them to be independent and to take care of themselves." (Parent A, pre-interview, November 13th, 2018)

"Of course it is important because this will teach her to be independent not to be dependent on us at all. We are growing older and she will need to become more and more independent on her own." (Parent B, pre-interview, November 12th, 2018)

“Yes, it is most definitely important so that they will be independent and able to practice living on their own as well as help others.” (Parent C, pre-interview, November 14th, 2018)

Past studies have shown that parents are intent on teaching their children ADL in order to promote independence to their children from early stages (Resch et al., 2010; Shepley, Spriggs, Samudre, and Elliot, 2017; Van Riper, 1999; Docherty and Reid, 2009).

Schedule

All the parents did express the importance of ADL for their child, however, when it came to having a specific schedule on ADL for their child, two of the parents felt having a fixed schedule would strengthen their daily living skills while another parent who wanted to put ADL as the ‘top priority’ was more lenient on his child’s schedule for ADL as he felt that ‘she is still anyway 3 years old and it was the ‘school holidays’ Parent A and C both felt that having a fixed schedule for their children would further improve their daily living skills.

“Consistency and repetition is the key for ADL... encouraging them a lot and of course a fixed schedule from the very beginning.” (Parent A, pre-interview, November 13th, 2018)

“She knows that when we give instructions, we will be firm with her that no matter what she will still have to complete the task given... she understands instructions and knows her daily schedule.” (Parent C, post-interview, November 20th, 2018)

Parent B mentioned that there was no specific schedule when it came to ADL as she is still young and it is the school holidays and

so his other children would also be around and that they would be occupied playing.

“I would like to prioritize that, I will give it a top priority for it but she is still anyway 3 years old... She tends to go to bed later than usual because the other kids are around playing... routine is a bit here and there for food time and all that because it's the holiday ...” (Parent B, post-interview, November 18th, 2018)

RQ 3: Challenges Faced by Parents when Teaching ADL Degree of Child's Capacity of Learning

Many challenges arise when involving degree of child's learning, namely; lack of concentration, impatient, carrying out many tasks all at once or having one's own way of doing it and finally, the variety of emotions of the child that accompanies when teaching them.

Parent A felt that one of her challenges in teaching her son ADL was how her son would carry out many tasks all at once, being impatient and stubborn.

“He needs constant reminder and sometimes he is not patient, even any other kids would be in the same situation. They would want to find the easy way, we feed them and they eat.... and at times he will be stubborn and even during feeding, sometimes he would not want to eat himself, sometimes he has no problem and can finish on his own.... Sometimes it is not that they cannot do it, they just tend to not do it by throwing tantrum or being ‘manja’” (Parent A, post-interview, November 19th, 2018)

“She gets distracted with other things at times and we would have to remind her. She would tend to want to do it her own way at times...It is either distracted or she would want to do it her own way or if you woke up from the wrong side of the bed, then your mood will be out, same goes for her.” (Parent B, post-interview, November 18th, 2018)

“So I think patience is the key for me, even for anyone if their patience is being tested they would be arghh, you know very angry. But I try to just walk out and do something and then come back to him.” (Parent A, pre-interview, November 13th, 2018)

“Sometimes it can be slightly frustrating but I try my best.” (Parent A, post-interview, November 19th, 2018)

In the pre-interview session with parent A, she describes how she feels when her child ‘tests her patience’ when teaching him ADL. As a result, she leaves momentarily to cool off and then come back to continue where she left off. In the literature on families with children with disabilities, parents resort to making positive meanings to the situation they are in and try to ‘regain a sense of control’ by making the situation seem manageable (King et al. 2006; Summers, Behr, and Turnbull, 1989; Patterson 1991; Barnett, and Boyce, 1995; Resch et al., 2010). During the post-interview session, as shown in the last excerpt, parent A shared her frustration regarding dressing. She revealed how her son is able to accomplish other task at ease, however, when it came to dressing, there seems to be no changes in his progress.

Sensory Processing Disorder

Parent C felt that the main challenge she faced when teaching ADL

was the Sensory Processing Disorder (SPD). According to this parent, she described her daughter as being ‘hypersensitive’ and due to this, she finds it challenging to teach her child feeding, toileting or grooming. For feeding, she mentioned,

“she’s hypersensitive and picky eater, just like sensory so she’s afraid of squishy, hard food, even when she was a baby, she would be afraid to have a taste of anything... She’s still not good in opening and closing her mouth muscles. Also, Cynthia has ‘lip tie’ inside her mouth, so when she wants to close her mouth, it’s difficult for her because it’s painful right?... from small we taught her to use cup, just holding the cup handle can be a huge challenge to her. Because she’s afraid of things that she holds, sensory right, so when we ask her to hold the cup, she would throw it away. New things that she holds would be a challenge.”
(Parent C, pre-interview, November 14th, 2018).

Many challenges arise for this particular parent due to her daughter’s oversensitivity in SPD. Past literatures (Chi-Wen et al., 2016; Koenig and Rudney, 2010; Ahn, Miller, Milberger, and McIntosh, 2004) believe that having Sensory Processing Disorder can affect an individual from carrying out ADL as it involves both fine and gross motor skills for completing a task (Bruni, Cameron, Dua, and Noy, 2010).

Parents’ Feelings

When prompted parent A about her feelings when she is teaching her son dressing, she mentioned,

“Sometimes it can be slightly frustrating but I try my best.” (Parent A, post-interview, November 19th, 2018)

Without elaborating, she moved on to mention on how she would reinforce when teaching her son ADL.

Parent C was prompted on how she feels when teaching her daughter due to the challenges she face. In the interview she said,

“Yes, it can be tiring at times, sometimes I just want to lie down on the bed and take a break but I know she is capable of many things, so if I don’t try to even provide it for her, how will she reach those goals. I want to provide the best...she has to be independent without me when that time comes.” (Parent C, post-interview, November 20th, 2018)

This can be said that due to the many challenges this parent faces due to her daughter’s ‘hypersensitivity’, she remains high-spirited to provide the best for her daughter. In the future, she views her daughter as an independent individual who would not have to rely on anyone and able to carry out tasks on her own.

Overall, for the first research question, the data from the interviews and journals revealed that there were three ways in which parents use to teach their children ADL, namely; through modeling, encouragement and by using real objects and signs.

Whereas for the second research question of how parents perceive the importance of ADL for their children, all the parents felt that ADL played an important role in promoting independence and autonomy for their children. Two parents expressed that they have a fixed schedule for their child to follow while another parent was lenient in the child’s schedule. Despite these marked differences in their scheduling, all three parents concurred with the significance of ADL in their children’s lives as it allowed some form of structure and regime that was essential in reproducing the desired behavior.

Lastly, in relation to the final research question, parents believed that the varying degree of their child's learning and the combination of Sensory Processing Disorder resulted in delayed learning or hindered any real progress, and this was seen as a primary challenge for the parents. Further, all three parents agreed that the children's erratic and often, fluctuating behavior disrupted the teaching of ADL. The frustration from watching their children progress slowly and their unpredictable emotions were also some of the reported challenges that they felt.

5. Conclusions and Recommendations

This study explored the lived experiences of parents of children with Down on ADL and was theoretically analyzed through Vygotsky's Sociocultural Theory. All in all, the findings of this study can be summarized as follow; for the first research question on how parents teach their children ADL, two themes emerged from the findings; one, modeling via the More Knowledgeable Other (MKO), two, encouragement using tools or signs. For the second research question on how parents perceive the importance of ADL, one key theme was evident: important in promoting independence. Finally, for the third research question on the challenges parents face in teaching their children ADL, two major themes were identified; one, behavioral challenges of children and two, parent's emotions.

The findings from this research will be able to benefit other parents of children with Down syndrome, teachers and researchers. Based on the findings, teachers can use the information that have been manifested in many ways. One of it is through Parent-Teacher meetings in the centers. At the end of the year during Parent-Teacher meeting in this particular center, parents will have to attend their child's Progress Report Day. Since this center follows closely with the Robert Deller Curriculum and the Hawaiian Early Learning Profile (HELP), six areas of the child's development will

be discussed on that day. One of the areas of development being self-help skills which covers the child's ADL can be discussed further in a more in-depth manner. Parents and teachers can work closely to provide the best teaching and learning experience for both the parent and the child.

Secondly, the Ministry of Education (MOE) of the Special Education Division can further develop their curriculum to provide a more active parental involvement with the teachers on their child's ADL. Seeing how ADL is a daily task which involves the motor and coordination skills that is required to be carried out by every individual on a daily basis, the Special Education Division of the MOE can further develop their curriculum to involve parents and teachers on their child's development. The government schools can inculcate ADL from beginning years of the child's development which is in the child's National Special Education Pre-school years (*Pra-Sekolah Pendidikan Khas Kebangsaan*).

Future researchers may conduct a study by looking at both parents' perspectives to obtain a more rich and in-depth study on their child's ADL. Researchers can explore perspectives of both parents of the child to get a more unyielding data. Looking at both points of views of the parents can provide information which the other parents may not be able to provide due to many factors such as time spent with the child, various environmental factors, different events in the child's life. By looking at both perspectives of the parents, data obtained from two points of view can provide rich information about the child's everyday routine which will not be the same from both parents. More questions can be prompted from the interviews for the parent who spends more time with the child.

6. References

- Ahn, R. R., Miller, L. J., Milberger, S., & McIntosh, D. N. (2004).
Prevalence of parents' perceptions of sensory processing

disorders among kindergarten children. *The American Journal of Occupational Therapy*, 58(3), 287-293. Retrieved from <http://spdnetwork.com/pdf/Prevalence-of-Parents-Perceptions-of-SPD-2004.pdf>

Allen, S., & Casey, J. (2017). Developmental coordination disorders and sensory processing and integration: Incidence, associations and co-morbidities. *British Journal of Occupational Therapy*, 80(9), 549–557. doi:10.1177/0308022617709183

Ayers, K. M., Lowery, K. A., Douglas, K. H., & Sievers, C. (2011). I can identify Saturn but I can't brush my teeth: What happens when the curricular focus for students with severe disabilities shifts. *Education and Training in Autism and Developmental Disabilities*, 46(1), 11-21.

Bahagian Pembangunan Kurikulum, K. P. M. (2011). *Kurikulum standard prasekolah pendidikan khas kebangsaan (masalah pembelajaran)*. (Bahagian Pembangunan Kurikulum, Ed.). Putrajaya: Kementerian Pelajaran Malaysia.

Bahagian Pendidikan Khas, K. P. M. (2011). *Prasekolah pendidikan khas*. (B. P. Khas, Ed.). Putrajaya.

Bal, V. H., Kim, S. H., Cheong, D., & Lord, C. (2015). Daily living skills individuals with autism spectrum disorder from 2 to 21 years of age. *Autism*, 19(7), 774-784.

Bar-Shalita T, Vatine JJ, Parush S. (2008). Sensory modulation disorder: A risk factor for participation in daily life activities. *Developmental Medicine and Child Neurology* 50;932–937.

Barnett, W. S., & Boyce, G. C. (1995). Effects of children with Down syndrome on parents' activities. *American Journal of*

Mental Retardation, 100(2), 115-127.

Berger, J. & Cunningham, C. (1986). Aspects of early social smiling by infants with Down's syndrome. *Child Care, Health and Development*, 12, 13-24.

Biederman, G. B., Fairhall, J. L., Raven, K. A., & Davey, V. A. (1998). Verbal Prompting, Hand-over-Hand Instruction, and Passive Observation in Teaching Children with Developmental Disabilities. *Exceptional Children*, 64(4), 503–511. doi:10.1177/001440299806400406

Bodrova, E. (1997). Key Concepts of Vygotsky's Theory of Learning and Development. *Journal of Early Childhood Teacher Education*, 18(2), 16–22. doi:10.1080/1090102970180205

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <http://dx.doi.org/10.1191/1478088706qp063oa>

Brown, L., Branston, M. B., Hamre-Nietupski, S., Pumpian, I., Certo, N., & Gruenewald, L. (1979). A strategy for developing chronological-age-appropriate and functional curricular content for severely handicapped adolescents and young adults. *Journal of Special Education*, 13, 81-90.

Bruni, M., Cameron, D., Dua, S., & Noy, S. (2010). Reported Sensory Processing of Children with Down Syndrome. *Physical & Occupational Therapy In Pediatrics*, 30(4), 280–293. doi:10.3109/01942638.2010.486962

Cannella-Malone, H. I., Fleming, C., Chung, Y.-C., Wheeler, G. M., Basbagill, A. R., & Singh, A. H. (2011). Teaching Daily Living

Skills to Seven Individuals With Severe Intellectual Disabilities: A Comparison of Video Prompting to Video Modeling. *Journal of Positive Behavior Interventions*, 13(3), 144–153. doi:10.1177/1098300710366593

Caselli, M. C., Vicari, S., Longobardi, E., Lami, L., Pizzoli, C., & Stella, G. (1998). Gestures and words in early development of children with Down syndrome. *Journal of Speech, Language, and Hearing Research*, 41, 1125-1135.

Chan, K. G., Lim, K. A., & Ling, H. K. (2014). Care demands on mothers caring for a child with Down syndrome: Malaysian (Sarawak) mothers' perspectives. *International Journal of Nursing Practice*, 21(5), 522–531. doi:10.1111/ijn.12275

Chapman, R. S., Seung, H. K., Schwartz, S. E., & Kay-Raining Bird, E. (1998). Language skills of children and adolescents with Down syndrome: II. Production deficits. *Journal of Speech, Language, and Hearing Research*, 41, 861-873.

Chapman R.S. and Hesketh L.J. (2000) Behavioral phenotypes of individuals with Down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews* 6(2): 84–95

Chi-Wen Chien, Sylvia Rodger, Jodie Copley, Grace Branjerdporn & Caitlin Taggart (2016) Sensory Processing and Its Relationship with Children's Daily Life Participation, *Physical & Occupational Therapy In Pediatrics*, 36:1, 73-87, DOI: 10.3109/01942638.2015.1040573

Cohen, L., Manion, L., & Morrison, K. (2018). *Research Methods in Education* (8th ed.). London: Routledge.

Docherty, J. & Reid, K. (2009). What's the next stage?' mothers of

young Adults with Down syndrome explore the path to independence: A qualitative investigation. *Journal of Applied Research in Intellectual Disabilities*. 22, 458–467.

Engel-Yeger B. (2008). Sensory processing patterns and daily activity preferences of Israeli children. *Canadian Journal of Occupational Therapy* 75.

Ferguson, H., Myles, B. S., & Hagiwara, T. (2005). Using a personal digital assistant to enhance the independence of an adolescent with Asperger syndrome. *Education and Training in Developmental Disabilities*, 40(1), 60-67.

Fidler, D., Hepburn, S., & Rogers, S. (2006). Early learning and adaptive behaviour in toddlers with Down syndrome: Evidence for an emerging behavioural phenotype? *Down Syndrome Research and Practice*, 9(3), 37–44.

Flowerdew, L. (2002) ‘Corpus-Based Analyses in EAP’, in L. Flowerdew, *Academic Discourse*. Harlow: Longman: 95-115

Fraenkel, J. R., Wallen, N. E., & Hyun, H. H. (2012). *How to design and evaluate research in education* (8th ed.). New York: McGraw-Hill.

Gindis, B. (2003). Remediation through education: Sociocultural theory and children with special needs. In *Vygotsky's educational theory in cultural context*. (pp.200- 221). Cambridge, NY: Cambridge University Press.

Green, S. A., & Carter, A. S. (2011). Predictors and Course of Daily Living Skills Development in Toddlers with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 44(2), 256–263. doi:10.1007/s10803-011-1275-0

- Guba, E. G., & Lincoln, Y. S. (1994). *Handbook of qualitative research*. Thousand Oaks, CA: Sage.
- Hallahan, D., Kauffman, J., & Pullen. (2012). *Exceptional learners: An introduction to special education*. (12th ed.). Upper Saddle River, NJ: Pearson Education Inc.
- Hayton, J., Wall, K., & Dimitriou, D. (2018). Get your coat: examining the development of independent dressing skills in young children with visual impairment, Down syndrome and typically developing children. *International Journal of Inclusive Education*, 1–16. doi:10.1080/13603116.2018.1456568
- Hennink, M., Hutter, I., and Bailey, A. (2011) *Qualitative Research Methods*, London: Sage.
- Huiracocha, L., Almeida, C., Huiracocha, K., Arteaga, J., Arteaga, A., & Blume, S. (2017). Parenting children with Down syndrome: Societal influences. *Journal of Child Health Care*, 21(4), 488–497. doi:10.1177/1367493517727131
- Husen, T. (1999). Research paradigms in education. In J. P. Keeves & G. Lakomski (Eds.), *Issues in educational research* (1st ed., pp. 31-39). New York: Pergamon.
- Jacelon, C. S., & Imperio, K. (2005). Participant Diaries as a Source of Data in Research With Older Adults. *Qualitative Health Research*, 15(7), 991–997. doi:10.1177/1049732305278603
- Jenkins, C. (1993). Expressive language delay in children with Down's syndrome: A specific cause for concern. *Down Syndrome Research and Practice*, 1, 1-14.

- Jones, S. (2014). Effect of motor skills and cognition on activities of daily living in children with Down syndrome (Doctoral dissertation, Texas Christian University Fort Worth, Texas).
- Kazemi M, Salehi M, Kheirolah M. (2016), Down Syndrome: Current Status, Challenges and Future Perspectives. *Int J Mol Cell Med.* 2016; 5 (3) :125-133
- Koenig, K.P., & Rudney, S.G. (2010). Performance challenges for children and adolescents with difficulty processing and integrating sensory information: a systematic review. *The American journal of occupational therapy: official publication of the American Occupational Therapy Association*, 64 3, 430-42.
- King, E., Okodogbe, T., Burke, E., McCarron, M., McCallion, P., & O'Donovan, M. A. (2016). Activities of daily living and transition to community living for adults with intellectual disabilities. *Scandinavian Journal of Occupational Therapy*, 24(5), 357–365. doi:10.1080/11038128.2016.1227369
- King, G. A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P., & Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child: Care, Health and Development*, 32(3), 353–369. doi:10.1111/j.1365-2214.2006.00571.x
- Lalvani P (2008) Mothers of children with Down syndrome: constructing the sociocultural meaning of disability. *Intellectual and Developmental Disabilities* 46(6): 436–445.
- Lewis E and Kritzinger A. (2004) Parental experiences of feeding problems in their infants with Down syndrome. *Down Syndrome Research and Practice*; 9: 45-52.

- Lichtman, M. (2006). *Qualitative research in education: A user's guide*. Thousand Oaks, CA: Sage.
- Luria, A. R. (1976). *Cognitive development: Its cultural and social foundations*. Cambridge, MA: Harvard University Press.
- Lyons, R., Brennan, S., & Carroll, C. (2015). Exploring parental perspectives of participation in children with Down Syndrome. *Child Language Teaching and Therapy*, 32(1), 79–93. doi:10.1177/0265659015569549
- Mahoney, G., Robinson, C., & Fewell, R.R. (2001). The effects of early motor intervention on children with down syndrome or cerebral palsy: a field-based study. *Developmental and Behavioral Pediatrics*.
- Malak, R., Kostiukow, A., Krawczyk-Wasielewska, A., Mojs, E., & Samborski, W. (2015). Delays in Motor Development in Children with Down Syndrome. *Medical Science Monitor*, 21. doi:10.12659/msm.893377
- Matthews, T. J., Allain, D. C., Matthews, A. L., Mitchell, A., Santoro, S. L., & Cohen, L. (2018). An assessment of health, social, communication, and daily living skills of adults with Down syndrome. *American Journal of Medical Genetics Part A*, 176(6), 1389–1397. doi:10.1002/ajmg.a.38721
- McLeod, S. A. (2018, Aug 05). *Lev Vygotsky*. Retrieved from <https://www.simplypsychology.org/vygotsky.html>
- McWilliam, R. A. (2010). *What Works for Special-Needs Learners : Working with Families of Young Children with Special Needs*. Publisher: Guilford Press.

- Merriam, S.B. (1998). *Qualitative research and Case study applications in education*. San Francisco, CA: Jossey-Bass
- Merriam. S. B. (Ed.). (2002). *Qualitative research in practice: Examples for discussion and analysis*. San Francisco: Jossey-Bass.
- Miller, J. F. (1999). Profiles of language development in children with Down syndrome. In J. F. Miller, M. L.
- Leddy, & L. A. Leavitt (Eds.), *Improving the Communication of People with Down Syndrome*. (pp. 11-39). Baltimore: Paul H. Brooks Publishing.
- Mlinac, M. E., & Feng, M. C. (2016). Assessment of Activities of Daily Living, Self-Care, and Independence. *Archives of Clinical Neuropsychology*, 31(6), 506–516. doi:10.1093/arclin/acw049
- Moore N. (2012) The politics and ethics of naming: questioning anonymisation in (archival) research. *International Journal of Social Research Methodology* 15(4): 332.
- Moore, D, Oates, J, Hobson, R, and Goodwin, J. (2002) Cognitive and social factors in the development of infants with Down syndrome. *Down Syndrome Research and Practice*, 8(2), 43-52. doi:10.3104/reviews.129
- Papalia, Diane E., et al. (1998). *Human Development*: Boston: McGraw Hill Companies, Inc. 7th Edition.
- Patton, M. (2002). *Qualitative Evaluation and Research Methods* (2nd ed.). Newbury Park, CA: Sage Publications, Inc.

- Patterson, J. M. (1991) Family resilience to the challenge of a child's disability. *Pediatric Annals*, 20, 491–499.
- Pratt, M.W., Kerig, P., Cowan, P.A. and Cowan, C.P. (1988) Mothers and fathers teaching 3-year-olds: Authoritative parenting and adult scaffolding of young children's learning. *Developmental Psychology*, 24: 832-839
- Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology*, 55(2), 139–150. doi:10.1037/a0019473
- Robinson, J. B., Burns, B. M., & Davis, D. (2009). Maternal scaffolding and attention regulation in children living in poverty. *Journal of Applied Developmental Psychology*, 30, 82–91.
- Roizen, N. J., & Patterson, D. (2003). Down's syndrome. *The Lancet*, 361, 1281–1289.
- Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for Intervention. *Child & Family Behavior Therapy*, 19(4), 15-32. doi: 10.1300/J019v19n04_02
- Schieve, L. A., Boulet, S. L., Kogan, M. D., Van Naarden-Braun, K., & Boyle, C. A. (2011). A population-based assessment of the health, functional status, and consequent family impact among children with Down syndrome. *Disability and Health Journal*, 4(2), 68-77. doi: 10.1016/j.dhjo.2010.06.001

- Shepley, S. B., Spriggs, A. D., Samudre, M., & Elliot, M. (2017). Increasing Daily Living Independence Using Video Activity Schedules in Middle School Students With Intellectual Disability. *Journal of Special Education Technology*, 33(2), 71–82. doi:10.1177/0162643417732294
- Shipley-Benamou, R., Lutzker, J. R., & Taubman, M. (2002). Teaching Daily Living Skills to Children with Autism Through Instructional Video Modeling. *Journal of Positive Behavior Interventions*, 4(3), 166–177. doi:10.1177/10983007020040030501
- Sigman, M. (1999). Developmental deficits in children with Down syndrome. In H. Tager-Flusberg (ed.), *Neurodevelopmental Disorders*. (pp. 179-195). MIT press, Cambridge.
- Skallerup, S. (Ed.). (2008). *Babies with Down Syndrome: A New Parents' Guide* (3rd ed.). Bethesda, MD: Woodbine House.
- Skotko, B. G., Levine, S. P., & Goldstein, R. (2011). Having a son or daughter with Down syndrome: perspectives from mothers and fathers. *American Journal of Medical Genetics Part A*, 155A(10), 2335-2347. doi: 10.1002/ajmg.a.34293
- Smith, L. E., Maenner, M. J., & Seltzer, M. M. (2012). Developmental Trajectories in Adolescents and Adults With Autism: The Case of Daily Living Skills. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(6), 622–631. doi:10.1016/j.jaac.2012.03.001
- Spender, Q., Stein, A., Dennis, J., Reilly, S., Percy, E., & Cave, D. (2008). An Exploration Of Feeding Difficulties In Children With Down Syndrome. *Developmental Medicine & Child Neurology*, 38(8), 681–694.

doi:10.1111/j.1469-8749.1996.tb12138.x

Spiker, D. (1982). Parent Involvement in Early Intervention Activities with Their Children with Down's Syndrome. *Education and Training of the Mentally Retarded*, 17(1), 24-29. Retrieved from <http://www.jstor.org/stable/23877086>

Stake, R. E. (2010). *Qualitative research: Studying how things work*. New York: The Guilford Press.

Sugden, D., & Wade, M. (2013). *Typical and Atypical Motor Development*. London: Mac Keith Press.

Summers, J. A., Behr, S. K. & Turnbull, A. P. (1989) Positive adaptation and coping strengths of families who have children with disabilities. In: *Support for Caregiving Families: Enabling Positive Adaptations to Disability* (eds G. H. S. Singer & L. K. Irvin), pp. 27– 40. Paul Brookes, Baltimore, MD, USA.

Sun, J. & Rao, N. (2012) Scaffolding preschool children's problem solving: A comparison between Chinese mothers and teachers across multiple tasks. *Journal of Early Childhood Research*, 10: 1-21

Test, D. W., Aspel, N. P., & Everson, J. M. (2006). *Transition methods for youth with disabilities*. Upper Saddle River: Pearson Prentice Hall.

Van der Veer, R., & Valsiner, J. (1991). *Understanding Vygotsky*. Cambridge, MA: Basil Blackwell.

Van Dijk, M., & Lipke-Steenbeek, W. (2018). Measuring feeding

- difficulties in toddlers with Down syndrome. *Appetite*, 126, 61–65. doi:10.1016/j.appet.2018.03.018
- Van Herwegen, J., Rundblad, G., Davelaar, E. J., & Annaz, D. (2011). Variability and standardized test profiles in typically developing children and children with Williams Syndrome. *British Journal of Developmental Psychology*, 29(4), 883–894. doi:10.1111/j.2044-835x.2010.02015.x
- Van Riper, M. (1999). Maternal perceptions of family-provider relationships and well-being in families of children with Down syndrome. *Research in Nursing & Health*, (22), 357–368.
- Volkmar, F. R., & Wiesner, L. A. (2009). *A practical guide to autism: What every parent, family member, and teacher needs to know*. Hoboken: John Wiley & Sons, Inc.
- Vygotsky, L. S. (1978). *Mind in society: The development of higher psychological processes*. Cambridge, Mass.: Harvard University Press.
- Vygotsky, L. S. (1997). *The History of development of higher mental functions*. New York: Plenum Press.
- Vygotsky, L. S. (1998). *Child psychology*. New York: Plenum Press
- Wagner, S., Ganiban, J. M., & Cicchetti, D. (1990) Attention, memory, and perception in infants with Down syndrome: a review and commentary. In D. Cicchetti & M. Beeghly (eds.), *Children with Down syndrome: A Developmental Perspective*. (pp 147-179). Cambridge University Press, Cambridge.
- Wertsch, J. V. (1984). The zone of proximal development: Some conceptual issues. *New Directions for Child Development*, 23,

7-18. <http://dx.doi.org/10.1002/cd>.

Will, E. A., Caravella, K. E., Hahn, L. J., Fidler, D. J., & Roberts, J. E. (2018). Adaptive behavior in infants and toddlers with Down syndrome and fragile X syndrome. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics*, 177(3), 358–368. doi:10.1002/ajmg.b.32619

Wood, D., Bruner, J.S., & Ross, G. (1976). The role of tutoring in problem solving. *Journal of Child Psychology and Psychiatry*, 17, 80-100

Yin, R. K. (2016). *Qualitative research from start to finish*. New York, NY: Guilford Press.

Zimmerman, D. H., & Wieder, D. L. (1977). The diary interview method. *Urban Life*, 5(4), 479-499.