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The upside to Down syndrome: an educational manual for parents

Brittany Larson  
*University of North Dakota*

Seth Luoma  
*University of North Dakota*

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THE UPSIDE TO DOWN SYNDROME: AN EDUCATIONAL MANUAL FOR PARENTS

By

Brittany Larson, MOTS
Seth Luoma, MOTS
Advisor: Gail Bass, Ph.D., OTR/L

A Scholarly Project
Submitted to the Occupational Therapy Department
of the
University of North Dakota
In partial fulfillment of the requirements
for the degree of
Master’s of Occupational Therapy

Grand Forks, North Dakota
May 14, 2011
This Scholarly Project is dedicated to my mother
For always encouraging me to do great things
And providing constant support along the way.
This Scholarly Project Paper, submitted by Brittany Larson and Seth Luoma in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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Title The Upside to Down Syndrome: An Educational Manual for Parents

Department Occupational Therapy

Degree Master’s of Occupational Therapy

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Signature Brittany Larson Date 4/21/11

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ABSTRACT

Parents of children with Down syndrome want their child to be as successful as other children in areas of development, specifically play. Play is crucial to a child’s development as it assists with the progression through childhood developmental stages. This can help lay a foundation for learning daily life skills such as dressing, feeding, and social interaction. For children with Down syndrome, performing daily living tasks may be more difficult as fine and gross motor skills are affected by low-tone, cognition level, and coordination. Providing children with a variety of play activities to build both fine and gross motor skills can help increase independence and support development.

Throughout the literature review, it was noted that there is currently an abundance of research regarding typically developing children and the benefits of play. There is a lack in literature focused on children with Down syndrome and how play can support development within this population. A common theme arising in the literature is parental perceptions about the uncertainty involved in raising a child with Down syndrome. Parents felt as if they do not have enough information on what they can do at home to encourage fine and gross motor skill development and have few resources they may utilize. Some parents reported receiving information from their child’s occupational therapist, however, parents felt as if more information is necessary (Menear, 2007). The few parental resources currently available contained language that may decrease user-friendliness and negatively impact the use of some resources. Current literature also described parental concerns about keeping their child active in order to maintain health.
while providing activities that allow their child to be successful. Occupational therapists can help bridge the gap between activity and success by providing parents with education and suggestions as to what activities can help their child build fine and gross motor skills while using play as the basis for activity.

The methodology of this scholarly project included a review of literature regarding play and the impact on the development of children with Down syndrome as well as typically developing children. Local bookstores and internet websites were also explored to determine the availability of resources for parents of children with Down syndrome.

To address motor goals through play and structured developmental activities, an educational manual was developed for parents of children with Down syndrome and it is designed to be used under the guidance of an occupational therapist. The manual addresses two types of play; active, which involves gross motor activities such as running and jumping and quiet play which encourages fine motor skills through table-top activities such as coloring, drawing, and using hands to manipulate objects. Parents are able to choose activities which are suitable for their child based on the resources available at home and the energy level of the child.
CHAPTER I

INTRODUCTION

Children can benefit from the various interventions occupational therapists provide. Based on the Chapter II literature review, there are better outcomes for children with Down syndrome and their parents with intervention from Occupational Therapists (OTs). Therapists are able to help children with Down syndrome through their knowledge of intervention in areas of self-care skills, fine and gross motor skills, school related skills, and play (Bruni, 2006). Occupational therapists can also assist families with activities that allow a child with Down syndrome to increase early motor development and praxis skills. As stated by Case-Smith (2001), therapists use interventions that are designed to support the development and functional activity performance in the areas of greatest concern. According to Palisano et al. (2001), children with Down syndrome may successfully achieve motor goals through play and structured developmental activities. Some of the literature and research reviewed for Chapter II also indicated that if parents have the appropriate resources to facilitate home programs that the outcomes for their children with Down syndrome are more positive.
Problem Statement

The literature reviewed in Chapter II also revealed that there is a need for structured home-based interventions for children with Down syndrome. Parents of children with Down syndrome expressed their concern with the lack of structured programs for their children (Menear, 2007). Play is how a child learns about the world and themselves; as children grow, the types of play they engage in changes as it reflects their development. Starting at infancy children learn about their bodies, cause/effect, objects, and people within their environment (Knox, 2005). Occupational therapists are in a key position to help parents with this because therapists can guide the intervention towards developing fine and gross motor skills through play activities. According to Palisano et al. (2001), children with Down syndrome may successfully achieve motor goals through play and structured developmental activities.

Purpose of the Product

In order to address this need, the manual, developed as a part of this scholarly project, is to be used in conjunction with interventions specifically developed by OTs for children with Down syndrome as it addresses underlying developmental delays. The manual offers variations of play activities as each child is an individual and one variation may not be appropriate for all. With input from the OT, parents can adjust the play activities depending on the level of performance capacity of their child. Play activities are adapted which enables children to successfully participate in activities by grading the activity to their individual needs.
Theoretical Model

The development of the manual was guided by the literature review in Chapter II, and the authors chose the Model of Human Occupation (MOHO) (Kielhofner, 2002) for the theoretical base. MOHO addresses three aspects of an individual: volition, habituation, and performance capacity (Cole & Tufano, 2008). Volition is one’s motivation to participate in an occupation. Habituation is the process in which occupation is organized into patterns and routines. Performance capacity takes into account the physical and mental abilities that underlie skilled performance with an activity (Cole & Tufano, 2008). According to Cole and Tufano (2008), MOHO addresses subsystems of the child and how he/she interacts with the environment based on opportunities and/or barriers. The manual developed as the product of this project helps parents of children with Down syndrome to successfully facilitate their child’s interactions within their environment.

A child’s main occupation is play. A child’s role and routine is made up of play activities which they choose to participate in. An occupational therapist using MOHO as a model will attend to the performance capacity factors and how those interact with the child’s habituation and volition. As a child prefers different types of play during development, new skills are acquired through play activity. Throughout development, children move through different stages of development and display different behaviors during different types of play (Kuhanek, Spitzer & Miller, 2010).

Summary

Chapter II of this document contains a summary of the literature reviewed for the development of this product. Materials reviewed included scholarly research articles and
books discussing the association of childhood play and development. Chapter III is a
description of the methodology used in the development of the manual and Chapter IV
includes the parent manual in its entirety. Chapter V addresses the clinical strengths to
the product, limitations, and recommendations for those limitations. The final chapter
also addresses how the product will be used and how outcomes will be measured.
CHAPTER II

Overview of Down Syndrome

Occurring one in every 733 live births (National Down Syndrome Society, 2010), Down syndrome is the most common inherited genetic syndrome. Down syndrome occurs when there is a third copy of the 21st chromosome instead of the usual two chromosomes. This is the case with all individuals diagnosed with Down syndrome; however, what happens to the extra chromosome indicates the type of Down syndrome. There are three types of Down syndrome: mosaicism, translocation, and trisomy 21. Mosaicism accounts for 1% of all individuals with Down syndrome and occurs when there is a mixture of two types of cells during cell division. Some cells contain 46 chromosomes while others contain 47; those containing 47 chromosomes contain an extra chromosome 21. Individuals with Mosaicism may have fewer characteristics of Down syndrome than other types. The second type, translocation, makes up 4% of all cases of Down syndrome. Translocation is defined by part of the 21st chromosome breaking off during cell division and attaching itself to chromosome 14; it is the extra part of chromosome 21 that causes characteristics of Down syndrome in translocation. Lastly, trisomy 21 accounts for 95% all cases of Down syndrome; this is caused by a cell division error that results in an embryo having three copies of chromosome 21 instead of two. Throughout development of the embryo, the extra chromosome is duplicated in all cells of the body, resulting in Down syndrome (National Down Syndrome Society, 2010).
Upon birth, children with Down syndrome exhibit physical characteristics such as wide-set, upward slant to the eyes, low muscle tone, flat facial profile, small nose, small head circumference, low birth weight and short length (National Down Syndrome Society, 2010). According to Davidson (2008), throughout infancy and early childhood, individuals with Down syndrome show delays with developmental milestones such as sitting, crawling and walking; these milestones can emerge at twice the age of typically developing children.

Congenital health conditions such as: heart disease, anomaly of the gastrointestinal tract, ear infections, sinus and nasal problems, tracheomalacea, vision problems, immune dysfunction, orthopedic issues such as joint laxity, thyroid abnormalities and atlantoaxial instability can also affect children with Down syndrome (Davidson, 2008). The National Down Syndrome Society cautions parents that precautions should be taken regarding atlantoaxial instability as this joint connects the first and second cervical vertebrae. If broken, this can have severe outcomes such as paraplegia, hemiplegia, quadraplegia or even death. The National Down Syndrome Society states that in addition to physical health conditions, cognitive delays range from mild to moderate; however, this alone does not define what an individual with Down syndrome is capable of. Poor oral motor skills are prominent in an individual with Down syndrome due to low muscle tone; oral motor issues cause difficulty with eating and more prominently, language (Kumin, 1996).

Another aspect of childhood development that has an impact on children with Down syndrome is the acquisition of fine and gross motor skills which help build a foundation for life-skills development and proficiency in daily activities (Fidler,
Hepburn, Mankin & Rogers, 2005). Through play, children are able to develop these skills and progress through developmental stages. Children with Down syndrome may encounter difficulty with these tasks due to low muscle tone, poor motor planning, and delayed cognition which are important aspects of participating in play; however, it is important to note that each child is different in the sense that the level of skill development varies. During childhood, parents play a fundamental role in helping their child learn through play and they may not think about the different skills necessary for a child to participate in play (de Falco, Esposito, Venuti, & Bornstein, 2008). Parents who have a child with Down syndrome often have questions regarding function relating to daily activities (i.e. dressing, self-cares, play) and how to interact with their child who has special needs (Dolva, Coster & Lilja, 2004).

Parental Perceptions

Parents may feel unprepared for the impact that a child with Down syndrome may have on their lives and they may experience a wide range of emotions while raising a child with Down syndrome (Eaves, Ho, Laird, & Dickson, 1996). Perceptions have an impact on how parents raise their children, regardless of the child’s abilities. It has been found through studies that parents of children with Down syndrome experience different types of perceptions about their children. Some of the perceptions reported by parents include understanding how their child interacts in social situations, increased stress levels while raising a child with an intellectual disability, doubts regarding parenting abilities, and concerns about development when compared to typically developing children (de Falco, Esposito, Venuti & Bornstein, 2008; Fidler, Most, Booth-Laforce & Kelly, 2008; Menear, 2004). A study by Menear (2004), suggests that parents believe their children
with Down syndrome participate in activities mainly for social reasons. To support this, social strengths of individuals with Down syndrome have been researched and findings show that the social strengths may be so great that they interfere with other aspects of development such as orientation/engagement, emotional regulation and motor skills (Fidler, Most, Booth-Laforce & Kelly, 2008). Parents’ interactions with their children play a part in helping them acquire social skills necessary for interaction. Parents who play with their children have an effect on the child’s psychological growth and adaptation (de Falco, Esposito, Venuti & Bornstein, 2008). It is hypothesized that fathers who play with their child adjust their behaviors according to the level of their child’s abilities and interests. By changing their behaviors, fathers have a mutual attunement with their child because children with Down syndrome respond to how their fathers behave (de Falco, Esposito, Venuti & Bornstein, 2008).

Parents are worried about their children because of the big gaps between them and their peers, specifically in the areas of motor-skills and cognitive functioning. When children with Down syndrome are growing up, they take a longer time to develop motor skills essential for walking and talking (Menear, 2004). This delay at a young age widens the gap as they become teenagers and separates them from their peers when compared by mental-age match and development. Children with Down syndrome require more time to develop motor movements as they become more complex (Palisano et al., 2001). A majority of parents want their children to be able to participate and play with all peers of the same age regardless of functioning level. Not only do motor skills impact the level of participation among children with Down syndrome and their peers, but cognitive development is also an issue. Cognitive functions affect skills necessary for activity
performance and for individuals with Down syndrome; the cognitive limitations have a
direct correlation between the individual’s IQ and areas of function (Rihtman et al.,
2010). The data from the study conducted by Rihtman et al. (2010) also indicated that
the functional profile of individuals with Down syndrome does indeed improve with age
and does not plateau as previously believed. Thus, it is imperative that parents do not
limit their perceptions and expectations about their children.

In a study of 57 mothers of a child with an intellectual disability researchers
explored parental perceptions regarding parenting experiences and stress levels. Griffith,
Hastings, Nash and Hill (2009), found that mother’s perceptions were positive when
addressing factors that the child has brought to them; happiness and fulfillment, helped
them learn patience, gave them a new perspective on life, and brought their family closer
together. Mothers in this study also reported life satisfaction and positive affect because
of the joys their child has brought them. Parents’ perceived efficacy in raising a child
with Down syndrome was surveyed in a study completed by Al-Kandari and Al-Qashan
(2009). Mothers in the study perceived their abilities to raise their children as negative.
They believed that they did not have the skills necessary to raise a child with intellectual
disabilities and to meet their basic needs. The study data also indicated that mothers lack
information on how to deal with their child’s behaviors and they lack efficacy on
behavior management, thus, the more knowledgeable and skilled the mothers are, the
higher the reported efficacy rating.
Parental Stressors

In a study by Lam and Mackenzie (2002) research data indicated that parents of children with an intellectual disability generally feel greater levels of stress regarding childhood development and have day to day uncertainties associated with their child’s needs. The initial stressor occurs when a mother gives birth to a child who does not meet their expectations. The participants in this study reported feeling grief, and having to progress through different stages of grief when learning that their child was diagnosed with a condition that is not curable. However, participants were also in agreement that raising a child with an intellectual disability is not an entirely negative experience. While stress still remains noteworthy among parents, the levels of stress are not as high as once thought (Van Der Veek, Kraaij & Garnefski, 2009). Parents must teach their children daily living skills, deal with behavioral issues, and manage health concerns that are associated with the diagnosis of Down syndrome. Studies by Van Der Veek, Kraaij and Garnefski (2009) and Dabrowska and Pisula (2010) explored families’ experiences raising a child with Down syndrome and have found that generally there are increased feelings of depression, decreased self-esteem, and self-blaming which ultimately affect the role as a parent. The stresses are particularly significant regarding emotional, behavioral and communication problems. Dabrowska and Pisula (2010) found that this was due to stigma of society and other family members who may not fully understand the child’s diagnosis, which causes parents to feel stress as to how they handle their children and who they seek support from. The way parents cope with stressors relating to their child’s diagnosis is important, as this can influence the types of services sought for their child, and can have an impact on overall development (Head & Abeduto, 2007).
Dabrowska & Pisula (2010) proposed the idea that coping strategies directly affect factors describing individual parental stress. Parents who engage in self-blame and ruminating coping strategies were positively correlated with depressive symptoms whereas positive reappraisal strategies were correlated to a positive affect (Van Der Veek, Kraaij & Garnefski, 2009). Dabrowska and Pisula (2010) explain a study by Hastings et al. in 2005 that indicates that parents use active avoidance coping which is associated with high stress levels of both mothers and fathers. Religious coping is another way of dealing with stressors of raising a child with Down syndrome; however, this coping mechanism suggests that this produces a high level of stress. Successful approaches using coping skills can reduce the amount of stress experienced by families and leads to successes in raising children with Down syndrome. Low-level stress coping mechanisms are related to seeking informal support, problem-oriented coping and coping by focusing on family integration and cooperation (Dabrowska & Pisula, 2010).

Social Skills

One of the issues parents of children with an intellectual disability face is the inclusion of their child in peer-related activities; as a result of language barriers and skill deficits a child with an intellectual disability is at risk of becoming socially isolated from peers. Parents play an integral part in preventing social isolation as they are able to arrange social situations for their child and promote learning experiences (Guralnick, 2002), however, recent research has shown that parents are less likely to arrange play opportunities for their child with an intellectual disability versus parents of typically developing children. One-third of all children with Down syndrome are without play contacts, thus explaining social isolation and decreased ability to engage in the
environment. Parents may have difficulties initiating social play with their child leading the child to demonstrate difficulty interacting socially with peers (Guralnick, 2002).

Language difficulties present a challenge between an individual with Down syndrome and whomever they are speaking with. Many individuals with Down syndrome have some sort of hearing disability, articulation difficulty, and expressive and receptive language impairment (Hick, Botting & Conti-Ramsden, 2005). Children with Down syndrome have an especially difficult time with expressive language when compared to their listening comprehension and non-verbal cognition. Parents may find it difficult to interact with their children due to the language barrier, thus, suggesting that in order for parents to communicate and play with their children, they need to adjust their vocabulary to meet the needs of their children (Johnson-Glenberg & Chapman, 2004). Johnson-Glenberg and Chapman (2004) discovered that parents tuned their vocabulary to match the lexicon of their children. By adjusting their language to match that of their children, parents are able to bond with them. Bonding during play is a crucial time for both parents and their children because it helps to develop their relationship. The importance of parental/child language interaction is that further along in their lives, when these children are teenagers, their vocabulary comprehension skills are greater than one would predict at that age.

How parents interact with their child may be based on cultural beliefs, however, a commonality between cultures includes the impact parental involvement may have on learning and development (McCollum & Chen, 2003). The study conducted by McCollum and Chen (2003) attempted to gain an understanding of cultural differences in how Taiwanese mothers interact with their child diagnosed with Down syndrome and the
mothers’ beliefs that contribute to their child’s development. Having a positive versus negative attitude about raising a child with a disability impacted how mothers interacted with their babies. One of the participants stated she has few interactions with her child due to the fact her child’s developmental milestones (i.e. crawling, talking) are delayed when compared to her peer’s milestones. Because her daughter is currently unable to perform those activities the mother states she is unable to interact. On the contrary, the absence of certain developmental milestones encouraged another mother to become more observant about how her child interacted with objects around her and as a result, the mother provided experiences individualized to her baby’s needs. Play is a way for parents to interact socially with their children.

Play

According to the Occupational Therapy Practice Framework: Domain & Process 2nd edition (American Occupational Therapy Association, 2008), play is defined as “any spontaneous or organized activity that provides enjoyment, entertainment, amusement or diversion” (p. 632). Play is how a child learns about the world and themselves; as children grow, the types of play they engage in changes as it reflects their development. Starting at infancy children learn about their bodies, cause/effect, objects, and people within their environment (Knox, 2005). As a child prefers different types of play during development, new skills are acquired through play activity. Throughout development children move through different stages of development and display different behaviors during different types of play (Kuhanek, Spitzer & Miller, 2010). There have been several theories regarding play and how play evolves throughout childhood. Piaget proposed there are particular stages regarding play; sensorimotor stage, preoperational
stage, concrete operations stage, and the stage of formal operations. In the sensorimotor stage, children exhibit different reflexes which eventually help the child to be independent with relating to the environment. As a child grows, interaction with the environment becomes less about exploration and becomes more play-oriented. Upon this differentiation a child incorporates objects and different movements of body parts to figure out play activities they find enjoyable (Kuhanek, Spitzer, and Miller, 2010).

One may wonder why play is so important to the development of children; from a physiological aspect, movement that takes place in the form of play and exploration is beneficial for children as it helps to support the functionality of the vestibular system (Kuhanek, Spitzer & Miller, 2010). Kuhanek, Spitzer and Miller (2010) mention that theorists suggest play may create a more flexible brain and ability to respond creatively to adaptable situations. Motor skills are built through play activities such as balance, skipping, and hopping. Currently, children are spending increased amounts of time in sedentary activities such as watching TV and playing video games as opposed to participating in physical activity, which may delay the acquisition of motor skills. While children move through stages of play it is important to understand that some may progress at a slower rate and at different ages; this is common for children with disabilities (Kuhanek, Spitzer & Miller, 2010). The sensation gained from play reflects sensory experiences and an individual’s need for sensory input (Kuhanek, Spitzer & Miller, 2010).

Individuals with Down syndrome typically present with hypotonicity (low tone), low fitness levels, and obesity. This is caused in part by sedentary lifestyles, low motivation, and a lack of recreational opportunities for children within the community.
Support from parents to be physically active may play a crucial role in the physical capacity of their children, ultimately influencing overall wellness of their child. In a study by Menear (2007), it was found that parents of children with Down syndrome hold perceptions about physical fitness and the importance of being active during childhood. Parents in the study believed that physical fitness has long-lasting, positive benefits on health and that their child could be more physically active. Secondly, the parents believed that their child participates in physical activity due to social reasons. Ultimately, parents felt they would benefit from specialized services to gain a better understanding through parental education about physical activity and home-based activities that could promote a healthy lifestyle for their child. Recent studies of individuals with Down syndrome who participated in the Special Olympics found that those who are physically active on average of five hours per week for one year have a higher aerobic capacity, greater strength, and power. Additionally, balance improved for individuals with Down syndrome who participated in physical activity. Parents also wished they had prepared their children to be more physically active when they were younger (Menear, 2007). All children require basic motor control in order to participate in play and recreational activities. Some skills that play is dependent upon include weight support, balance, and posture. This may present as a challenge for children with Down syndrome because they exhibit hypotonicity, which affects posture. Children need this type of support in order to transition from sitting to crawling to walking allowing them to become an active participant in their environment. As movement activities become more complex, children with Down syndrome require additional time to learn these movements (Palisano et al., 2001). Complex activities, such as stepping with balance, hand
manipulation, and core exercises require praxis skills, the precise movement of limbs. Children with Down syndrome have difficulty executing precise movements which are required for many daily activities and play. (Fidler, Hepburn, Mankin, & Rogers 2005).

Occupational Therapist Role

Children can benefit from the various services occupational therapists provide. Therapists can contribute their services by helping children with Down syndrome in areas of self-care skills, fine and gross motor skills, school related skills, and play (Bruni, 2006). The delay in motor development and praxis that is key to play has implications on how occupational therapists direct intervention. One suggestion by Fidler, Hepburn, Mankin, and Rogers (2005) was that occupational therapists can devise intervention plans that include approaches to errorless learning techniques which remove failure from learning trials. This technique, known as “just the right challenge” allows the child to experience success and diminishes task abandonment. Also, the “top down” approach was utilized to evaluate specific limitations in activities and to determine the limitations that impact successful participation (Rogers, Holm, & Stone, 1997). OTs can modify or adapt a child’s environment relating to the specific limitation. For example, an environment can be modified by limiting distractions, adding sufficient amount of light, adding body supports, etc. By modifying or adapting the child’s environment, that child can become more successful and/or independent (Bruni, 2006).

Occupational therapists have knowledge of targeting areas of strength and for individuals with Down syndrome those areas are social functioning and visual-spatial processing (Fidler, Hepburn, Mankin & Rogers, 2005). By targeting the areas of strength, therapists can assist families with activities that allow the child with Down
syndrome to increase early motor development and praxis skills. As stated by Case-Smith (2001), therapists lead interventions that are designed to support the development and functional activity performance in the areas of greatest concern. According to Palisano et al. (2001), children with Down syndrome may successfully achieve motor goals through play and structured developmental activities. Additional therapy interventions may also be directed towards other areas of development. Fidler, Hepburn, Mankin and Rogers (2005) also recommended that practitioners may guide interventions that are time-sensitive and prevent or offset future delays. In a focus group made up of parents, a need for home-based interventions was identified by the authors. One suggestion given by a member of the parent focus group was that they wanted to have activities at home that could be individualized for their child, that contained complete descriptions and illustrations that are easy to follow, and that allow for flexibility with the resources they have at home (Menear, 2007).

Occupational therapists also play a role in providing structure for families of children with Down syndrome. In a previously mentioned study by Menear (2007) that addressed parents' perceptions of health and physical activities of children with Down syndrome, one mother suggested, "It would be nice if we had some kind of structured program..." (p. 62). This message was reciprocated by other mothers who stressed the need for organized programs and activities led by professionals. The need for occupational therapists to set up a home-based intervention plan is justified by the fact that a therapist can relate the activities to special education goals and objectives set by the school. The therapist can also include the school's physical education curriculum in the home-based program (Menear, 2007). It is important that the intervention program is
structured by a professional who understands and knows the importance of physical activity. Patient and family education is crucial when trying to adopt a program for home. In Menear’s (2007) article, parents explained their need for parent education regarding the home-based program and this is exactly what occupational therapists can provide. Home-based program interventions have been successful as described by one focus group in the Menear (2007) study.

Home-based physical activity interventions have been found effective with 7- to 14-year-old children with cystic fibrosis, children with mental retardation, and infants and toddlers with Down syndrome. Programmes that are guided by family systems theory hold much potential for immediate and long-term success (p. 66). The success of these programs is impacted by families and therapists working together to create a home program that meets the needs of the child. Parents’ perceptions of the amount of activity engaged in by their children with Down syndrome relates to how much a sibling encourages interaction (Menear, 2007). Parents believe that their child with Down syndrome will remain sedentary unless provoked by a sibling. One mother explained, “I think they are very visual and they are very present. It’s this moment and what I see” (Menear, 2007, p. 63). This statement indicates the need for structured activity and interventions led by occupational therapists. In a study by Eaves, Ho, Laird and Dickinson (1996), only 33% of 200 caregivers of persons with Down syndrome reported having excellent resources on information about how to support the development of their children. Most reported having to seek information on their own and this is where occupational therapy can fill that void.

Active play vs. Quiet play

The purpose of the manual is to provide parents with active and quiet play activities for children. Active play consists of activity that requires exerting more energy
than quiet activity, and is commonly associated with social activities (i.e. soccer).

Generally, active play is consistent with regards to no rules or organization. Active play presents opportunities for children to engage and interact with peers (Virginia Department of Health, 2010). These activities are geared towards gross motor functioning and using larger muscle groups, such as running and jumping. Active play can increase muscle and bone strength, help maintain weight, augment psychosocial well-being and may improve mood (Bayley, N., 1969). Also, children may figure out ways to solve problems and think independently while participating in play (Virginia Department of Health, 2010). Quiet play consists of activities that can be performed in a quiet environment and promote fine-motor skills for activities such as cutting and writing. Quiet play can be especially useful for parents when they need an activity to keep their child occupied. Children can play in a relaxed atmosphere with no questions from parents or rules to govern their exploration.

Summary

Play is how a child learns about the world and themselves; as a child grows, the types of play they engage in changes as it reflects their development. Play is the primary occupation of children (Knox, 2005), through play children are able to learn new simple and complex skills that are necessary to perform functional daily living tasks. These skills include core strength, balance, and motor control (Palisano et al., 2001). These skills allow a child to become more independent in other areas of life including school, self-care, play, leisure, and social involvement (Bruni, 2006). A child with Down syndrome requires more time to learn and develop these skills due to varying levels of cognitive and fine and gross motor impairments. When these skills are delayed, it interferes with the
development that takes place through play. Some parents of children with a disability are unsure of how to interact with their child because of their specific needs; this is where occupational therapy can help. Occupational therapists are knowledgeable about childhood development and the specific issues commonly associated with Down syndrome (Knox, 2005).

Occupational therapists can educate parents on different techniques to use with their child during play to support their individual needs. Parents play a crucial role in their child’s development by participating with them in play activities (de Falco, Venuti, Esposito & Bornstein, 2008). Recent findings from a parent focus group suggest that home based intervention programs led by parents would be beneficial (Menear, 2007).

According to Kuhaneck, Spitzer and Miller (2010), there is a minimal amount of literature about the play of children with disabilities when compared to literature about typical play development. The purpose of this scholarly project was to develop a manual for parents of a child with Down syndrome that includes different types of play activities that can facilitate and support their child’s development. The manual was designed to provide parents with descriptions of play activities and why each activity helps to support development. The manual also includes ideas to modify each play activity. Each activity will be broken down through activity analysis to increase user-friendliness. The manual fills the need for structured play activities at home which can help children with Down syndrome develop skills necessary for play and development.
CHAPTER III
METHODOLOGY

The purpose of this scholarly project was to develop a manual for parents of a child with Down syndrome that includes different types of play activities that can facilitate and support their child’s development. The manual was designed to provide parents with descriptions of play activities and why each activity helps to support development. The manual also includes ideas to modify each play activity. Each activity is broken down through activity analysis to increase user-friendliness. The manual fills the need for structured play activities at home which can help children with Down syndrome develop skills necessary for play and development. The manual was designed to be used under the guidance of an occupational therapist. Input was received from two practicing occupational therapists that expressed an interest in the idea of the manual because they are unable to find a product similar to this one.

The literature reviewed in Chapter II revealed that there is a need for structured home-based interventions for children with Down syndrome. Parents of children with Down syndrome expressed their concern of the lack of structured programs provided for their children (Menear, 2007). Play is how a child learns about the world and themselves; as children grow, the types of play they engage in changes as it reflects their development. Starting at infancy children learn about their bodies, cause/effect, objects, and people within their environment (Knox, 2005). Occupational therapists are in key position to help parents with this because therapists can guide the intervention towards
developing fine and gross motor skills through play activities. According to Palisano et al. (2001), children with Down syndrome may successfully achieve motor goals through play and structured developmental activities.

The process for gathering information to develop the product started out with a literature review to find information regarding parents’ perceptions about their children with Down syndrome. The search then continued with topics such as “play and Down syndrome” and “play characteristics of typically developing children”. The authors researched to find current materials on Down syndrome that have a similar purpose as the developing product. It was discovered through the literature review that there is currently minimal literature regarding children with Down syndrome and play activities.

The authors searched databases and book stores to find materials that were relevant to developing the product and a few were found but was not utilized. Three books were provided by the advisor which were incorporated into the literature review and development of the product. One book was found by the authors that was used in conjunction with developing the product. The books provided the authors with different layout formats and types of activities to use.

The authors collaborated with their advisor on a weekly basis to obtain comments and suggestions regarding the literature review and the development of the product. Development of the product started once the literature review was in the final stages of review. Ideas were discussed about what the product should contain and how it should look. A list of activities was generated and divided into “active play” and “quiet play”. Print Shop 2.0© was used to create the pages of the manual which included layout design, backgrounds, and clip art. The authors obtained permission from parents of
children with Down syndrome to allow them to use pictures of them participating in play activities throughout the manual (see appendix). Chapter IV includes the parent manual in its entirety. Chapter V addresses the clinical strengths to the product, limitations, and recommendations for those limitations. The final chapter also addresses how the product will be used and how outcomes will be measured.
CHAPTER IV

PRODUCT

The purpose of this scholarly project was to develop a manual for parents of a child with Down syndrome that includes different types of play activities that can facilitate and support their child’s development. The manual is designed to provide parents with descriptions of play activities and why each activity helps to support development. The manual also includes ideas to modify each play activity. Each activity is broken down through activity analysis to increase user-friendliness. The manual fills the need for structured play activities at home which can help children with Down syndrome develop skills necessary for play and development. The manual was designed to be used under the guidance of an occupational therapist.

The development of the manual was guided by the literature review in Chapter II, and the authors chose the Model of Human Occupation (MOHO) (Kielhofner, 2002) for the theoretical base. MOHO addresses performance capacities such as physical and mental abilities that underlie skilled performance with an activity (Cole & Tufano, 2008). According to Cole and Tufano (2008), MOHO addresses subsystems of the child and how he/she interacts with the environment based on opportunities and/or barriers. The manual developed as the product of this project helps parents of children with Down syndrome to successfully facilitate their child’s interactions within their environment.
Occupational Therapy

The American Occupational Therapy Association (AOTA) states that the occupational therapist’s contribution is to “promote the health and participation of people, organizations, and populations through engagement in occupation” (AOTA, 2008, p.626). Occupations are daily activities that people engage in on a day-to-day basis. Occupational therapists provide interventions to individuals who experience a physical, intellectual, or developmental disability so they can participate in occupations that are meaningful to them (Hinojosa, 2003). Occupational therapists provide services in school settings, nursing homes, hospitals, clinics, community setting, or homes. The primary occupation of a child is play (Knox, 2005). Through play children are able to learn new simple and complex skills that are necessary to perform functional daily living tasks.

Occupational therapists have the knowledge and skills to assess the underlying factors regarding play activities. A child with Down syndrome requires more time to learn and develop skills due to varying levels of cognitive and fine and gross motor impairments. When these skills are delayed, it interferes with the development that takes place through play. Occupational therapists are knowledgeable about childhood development and the specific issues commonly associated with Down syndrome (Knox, 2005). OT’s work closely with parents and their children with Down syndrome by guiding interventions that focuses on play and the product of this project is a tool that the therapist can use to help parents work with their child at home. The activities are designed to fit within family routines.
The Upside to Down Syndrome

An educational manual for parents of children with Down syndrome

Brittany Larson, MOTS
Seth Luoma, MOTS
Advisor: Gail Bass, Ph.D OTR/L
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Introduction

This manual was designed to provide you as a parent(s) of a child with Down syndrome descriptions of play activities that you can do with your child in your home environment. The manual is to be used under the guidance of your OT as part of an intervention program that addresses developmental skills. The manual is designed to provide you with descriptions of play activities and why each activity helps to support your child’s development. The manual also includes ideas to modify each play activity to better meet your child’s developmental needs.

What can an OT do to help children?

Therapists are able to help children with Down syndrome through their knowledge of intervention in areas of self-care skills, fine and gross motor skills, school related skills, and play (Bruni, 2006). Occupational therapists have the knowledge and skills to assess the underlying factors regarding play activities. A child with Down syndrome requires more time to learn and develop skills due to varying levels of cognitive and fine and gross motor impairments. When these skills are delayed, it interferes with the development that takes place through play. Occupational therapists are knowledgeable about childhood development and the specific issues commonly associated with Down syndrome (Knox, 2005). Your OT will work closely with you as a parent(s) by helping you use play activities that support your child’s development and also fit into your daily routine.
Why is play important?

Play is how a child learns about the world and themselves; as children grow, the types of play they engage in changes as it reflects their development. Starting at infancy children learn about their bodies, cause/effect, objects, and people within their environment (Knox, 2005). Throughout development children move through different stages of development and display different behaviors during different types of play (Kuhanek, Spitzer & Miller, 2010). According to Bateson (2005), a child’s greatest benefit of play is to promote creativity and flexibility.

Layout of Manual

You will find in this manual a cover page for each activity that describes the basic activity. The activity page will have a description of the benefits of the play activity and ideas to modify the activity to meet your child’s needs. If you wish to focus on a certain developmental aspect such as fine or gross motor functions you can choose activities that help address those areas. A glossary defining certain terms and phrases can be found at the end of the manual as well as a section with additional resources and a section for writing notes.

Acknowledgment

Thank you to the parents who gave permission for us to use photographs of their children in this manual.
Quiet Play Activities
Drawing a Garage (shapes)

Use a writing utensil to draw lines and create a square, triangle, or rectangle. Place object (i.e. toy car) into the shape to make it a "garage".
**BENEFITS**

Works on fine motor skills

Teaches your child about different shapes and allowing them to draw successfully

Incorporates their interests (i.e. toys) with learning

**VARIATIONS**

Draw dots where the corners meet for each shape; ask your child to "build a garage for the car" by connecting the dots. Have your child place the toy in the shape.

Larger markers work best if grasping a smaller writing utensil is difficult

Grade the activity by showing your child first, make lines for them to trace, or even complete all but one side so they can finish the shape
Paper Animals

Rip pieces of paper and glue onto an outlined picture of an animal. Glue the ripped pieces onto the animal.
**BENEFITS**
Promotes fine motor coordination
Encourages school readiness skills
Can be a social activity
Strengthens hands
Promotes finger dexterity
Social activity

**VARIATIONS**
Draw an animal (or print from the internet): have your child rip paper pieces and glue them on the page to fill in the animal
Use thicker paper to give your child a greater challenge when ripping
Use stick glue if your child has difficulty using bottle glue
Sand Castles

Fill bucket with sand and tip over; repeat to create a base in any design. Add levels to sand castle by previous method.
SAND CASTLES

BENEFITS

Provides different textures for child to feel

Promotes hand strength and grip

Practice using both hands together

Social activity

Opportunity to express creativity

VARIATIONS

Use small and large hand shovels to vary the weight

Have your child use a pitcher to pour water

Hide/bury objects in the sand and have your child find

Decorate sand sculpture with small objects to promote fine motor skills (i.e. marbles, seashells)
Puzzles

Assemble a puzzle by sorting the pieces by ‘edge’, ‘corner’, and ‘middle’ pieces. Put together the outer edge and subsequently fill in with remaining puzzle pieces.
**Benefits**

- Works fine motor skills
- Challenges ability to visualize how to fit pieces together
- Encourages child to control objects in hands
- Challenges cognition & problem solving skills
- Practices sequencing steps
- Teaches shape recognition
- Strengthens intrinsic hand muscles

**Variations**

- Make a homemade puzzle by cutting shapes out of construction paper
- Vary the number of puzzle pieces depending on your child's skill level
- Teach your child to find the corners first; this will give them a starting point to work around

Use wooden puzzles; grabbing the piece by the peg will work on grasping with finger tips
Painting

Using a large white sheet of paper place finger tips into paint and transfer onto paper, using hand motions to spread the paint.
**Painting**

**BENEFITS**
- Provides tactile input from different textures
- Promotes Creativity
- Promotes fine motor control
- Can be a social activity
- Encourages learning colors
- Practices concentration
- Strengthens trunk control
- Teaches child to move objects in their hand
- Strengthens grasp

**VARIATIONS**
- Use an easel while sitting in a chair to promote trunk strength
- Use different brushes to increase hand grasp and fine motor skills
- Use stamps to paint if holding a brush is difficult
- Use fingers instead of brushes
Drawing

Provide your child with crayons to make scribbles on blank paper, focusing on making contact with the paper versus quality of the product.
## Drawing

### BENEFITS

- Promotes hand grasp
- Increase Fine-motor skills
- Promotes creativity
- Can be used for emotional regulation
- Works on moving and controlling small objects in the hands

### VARIATIONS

- Use a pencil gripper to teach your child an age-appropriate grasp for writing
- Use different writing materials such as crayons, colored pencils, chalks, and markers
- Use short or broken crayons to encourage a tripod grasp vs. full palm grip
- Print out dot-to-dot worksheets from the internet for your child to complete
Play-Doh™

Purchase Play-Doh™ to use at the table and begin by having your child squeeze the dough in their hands.
Benefits

Improves fine motor skills that can carry over into daily skills (i.e. tying shoes)

Strengthen hand and finger muscles

Increase finger dexterity

Promotes creativity

Facilitates handwriting-readiness

Variations

roll play doh into a coil and place buttons, coins, or beads into it and have child remove using their pincher fingers

Use a wire bristle brush to have your child "rake" the play-doh, which adds resistance
Use a variety of everyday utensils to promote different grasps and hand strengthening:

- cookie cutters
- meat tenderizer
- fork, knife, and spoon
- rolling pin
- safety scissors
- potato masher

Make your own dough having your child help with the process. You can add a scent that your child enjoys (i.e. vanilla, orange) and create unique colors.
Mazes

Use a writing utensil to navigate through different paths in order to find the end.
### Benefits

- Promotes hand dexterity and fine motor skills
- Challenges problem solving skills
- Strengthens ability to follow objects with the eyes
- Encourages concentration
- Keeping the pencil within the maze promotes precision with a writing utensil

### Variations

- Use mazes that are different shapes (i.e. circle vs. square) to promote movement in different directions
- Try different writing utensils such as crayons vs. pencils to add resistance
- Provide your child with hand over hand guidance if needed
- Use a pencil grip
Building & Stacking

Using large plastic blocks stack on top of one another.
BENEFITS

Promotes fine motor control by grasping blocks and pieces

Motor planning is challenged while stacking

Promotes abstract thinking when building with more complex patterns

Allows child to express creativity

Can be a social activity

VARIATIONS

Use blocks to spell out words

Use larger blocks if your child has difficulty grasping smaller blocks

Create a tower with blocks and challenge your child to mimic the design

Practice learning colors by having your child sort out specific colors and building by color

Use magnetic connecting toys to ease building, yet strengthen fingers when pulling them apart
Making Musical Instruments

Give your child the independence of choosing which instrument to make. Think of instruments that can be made with household items such as lids, jars, cans, bottles, etc.
Making Musical Instruments

Benefits

Encourages creativity and expression of self

Fine and gross motor development

Feeling of accomplishment

Sequencing to complete task

Variations (Instruments)

Fill plastic bottle with beads, beans, sand, etc.

Place noisy objects such as beads or rice in a sealable plastic container for a shaker

Stretch rubber bands over shoebox to make guitar
Paper Airplanes

Fold paper in half, length wise. Fold corners back along crease.
Fold these back twice more each to complete paper airplane.
Paper Airplanes

Benefits

Promotes fine motor control
Encourages creativity
Sequencing steps to create airplane
Improves hand dexterity
Practice using both hands at the same time

Variations

Use construction paper to add resistance to strengthen hands
Color/draw on paper before folding to work on fine motor skills
Start making the airplane and leave the last crease for your child to complete to ensure success
Games

Candy Land™

Benefits

- Encourages child to follow and understand instructions
- Helps child to learn how to take turns
- Encourages social participation
- Enhances concentration and thinking processes
- Works on fine motor functioning in order to flip over cards
- Provides opportunity to work on emotional regulation when game becomes challenging

Memory Games
Board Games

Benefits
- Increase hand strength by pressing on button to roll dice
- Increase fine motor function by moving pieces
- Encourages social interaction
- Improves counting skills
- Learn patience and taking turns

Games
- Improve fine motor through use of fingers and spinner.
- Pinch grasp to move piece
- Encourages social interaction
- Challenges cognition and understanding of rules

Trouble™

Chutes and Ladders™
Board Games

- Improves concentration
- Encourages social participation and taking turns
- Challenges problem solving and thought processing
- Develop fine motor coordination and pinch grasp
- Promote eye-hand coordination and finger dexterity
- Improve gross motor and whole body movements
- Encourages social participation
- Challenges problem solving/thought processing
- Develop fine motor coordination
Scissors

Start by having your child do simple snipping of paper. Encourage “free” cutting where your child does not follow any lines, just random cuts.
**Benefits**

- Improves hand and grip strength
- Enhances fine motor coordination
- Improves concentration while cutting along line
- Eye-hand coordination

**Variations**

- Have a conversation with your child by "talking" to each other with the scissors
- Have your child use the scissors to "eat" paper
- Cut different materials such as play-doh, straws, cardboard, etc.
- Cut items to be used as props for further use
- Draw a person on a sheet of paper with vertical lines at the top of the head. Have your child cut the lines to fray the paper so the person has flowing hair
Tea Party

Provide child with cups and plates; pretend to eat, pour, and drink.
Benefits

Promotes hand strength and grip

Encourages hand-eye coordination

Can be a social activity

Allows child to practice using eating utensils

Variations

Use different sizes of cups to practice different types of grasp

Have child pour water to increase hand strength and increase independence

Place weighted items such as play-doh in the cup for increased difficulty

At meal times provide your child with a play pitcher to pour their own beverage
Active Play Activities
Dress Up

Provide your child with items of clothing to put on.
Benefits
- Develops creativity and imagination
- Enhances fine and gross-motor coordination
- Creates self-confidence by allowing children to make choices and be independent
- Opportunity for socialization and impersonations

Variations
- Use variations in weight of clothes
- Use big enough buttons so your child can manipulate them
- Use clothes that require only zippers to fasten
Yard Work

Have your child assist with outdoor chores such as raking leaves, picking up sticks, and watering flowers.
**Benefits**

- Arms can be strengthened by carrying items
- Provides proprioceptive input through pushing and pulling activities
- Balance & Stability are supported through dynamic sitting or standing
- Strengthens grip
- Can increase self-esteem by helping
- Child practices how to use both arms and hands together

**Variations**

- Give your child an appropriate sized rake or shovel to use so they can have more control
- Build up yard equipment handles with foam if child is having difficulty maintaining grasp
- Have your child carry dirt or leaves in a bucket to make helping easier and work on grip strength
- Encourage push-pull activities such as pushing a wheelbarrow or pulling a wagon
Trampoline

Have child sit on trampoline and practice the up and down movement of bouncing.
Trampoline

Benefits

- Standing activities promote balance
- Provides proprioceptive input by jumping
- Increases leg strength
- Improves awareness of child’s body among other objects
- Can be a social activity
- Encourages coordination of body movements
- Promotes upright head position

Variations

- Use a small trampoline with a hand bar if child requires more stability
- Have your child sit on their bottom while you bounce the trampoline
- Roll a ball while sitting on the trampoline to practice dynamic sitting balance
- Jump on a trampoline (large or small) to music and stop when the music ‘freezes’; this supports a child’s ability to listen and follow directions, as well as control their body to ‘freeze’ without losing their balance
Wastebasket Basketball

Crumple paper up into a ball and have your child "shoot" the ball into a wastebasket either over-hand or under-hand.
WASTEBASKET BASKETBALL

BENEFITS

- Promotes using both arms and hands at the same time

- Strengthens hands and fingers

- Promotes hand & eye coordination

- Can be a social activity

VARIATIONS

- Use a clothes hamper for a basket; have your child toss a small ball into it

- Have your child back up a few steps after they make a basket to increase difficulty

- Use hand-over-hand to guide throwing motion

- Use a heavier "basketball" to increase arm strength
Kickball

Start out by having your child kick a ball while it's not moving. Increase difficulty by having your child kick a moving ball.
Kickball

Benefits
Promotes balance
Teaches gross motor coordination
Can be a social activity
Strengthens leg muscles
Following an object with eyes

Variations
If unable to kick the ball have your child sit in a chair and practice kicking while sitting
Use a bigger and lighter ball to ensure success
Start by kicking a ball short distances
Snowball Fight

Pack snow together to form a snowball and throw at each other. Your child should be far enough from the other person as to avoid injury.
Snowball Fight

Benefits
- Increases ability to move small objects in the hands
- Promotes hand and arm strength
- Promotes hand-eye coordination
- Opportunity for social interaction
- Aerobic activity increases heart and lung function

Variations
- Pack snow into a ball for a fun winter activity
- Use different sizes of socks folded into a ball for a warmer version!
- Have your child crumple paper with their hands to make the snowball
- Set up a clothes hamper to give your child a focus point when throwing
Bean Bag Toss

Toss bean bag with hand of choice and toss either over-hand or under-hand at the target.
Bean Bag Toss

Benefits

Promotes standing balance and coordination

Encourages eye-hand coordination

Encourages reaching of arms

Strengthen arms

Promotes ability to follow an object with eyes

Works on motor planning

Can be a social activity

Tactile input

Variations

Use different sized bean bags to provide varying weight

Use bean bags made with different types of fabric

Adjust the level of difficulty by varying the distance of the target

Play catch with a heavier bean bag for proprioceptive input

Use a clothes hamper to toss bags into
Building a Fort

Use bed sheets or other materials and pin them to surfaces using clothes pins. Sheets can be hung from ceilings as well to build the walls.
Building a Fort

Benefits
- Building a fort allows your child to use their imagination and creativity for a space that is all their own
- Promotes reaching of arms by hanging sheets overhead
- Enhances fine and gross motor skills by hanging and pinning sheets to objects
- Promotes eye-hand coordination and using both arms together

Variations
- Use cardboard boxes that your child may color and personalize
- Use clothespins to fasten sheets to furniture or other objects
- Have child assist putting poles together if assembling a manufactured tent
Jump Rope

Begin by laying the jump rope flat on the floor. Have your child practice stepping over the rope.
Benefits

- Provides proprioceptive input to the joints
- Provides a different movement experience for child
- Large joint compression may have a calming effect on your child
- Coordinating body movement
- Strengthens muscle by increasing tone
- Works on balance
- Taking turns promotes social skills

Variations

- Have an adult hold one end of the jump rope and move from side-to-side on the ground to use it as a squiggly snake and jump over!
- Have a person on each end with your child in the middle so that the speed can be controlled easily
- Tie the jump rope to stationary points (i.e. two sturdy chairs) and have your child jump over; increase height for more of a challenge
Riding a Bike

Begin by having your child sit on a tricycle and place feet on pedals.
Benefits

Uses Trunk control

Works on Balance

Strengthens legs

Promotes motor planning

Can be a social activity

Provides sense of independence

Variations

Begin with a tricycle to help your child learn the leg motions

If your child has difficulty pedaling use a jump rope to pull the bike from the front. This will make pedaling easier and prevent your child from feeling discouraged.
Riding a Bike

Additional Activities to support Skills necessary for riding:

Lay on your back with knees bent. Place a therapy ball between you and your child’s feet and press the ball, providing resistance to strengthen leg muscles used for riding a bike.

Wrap a theraband™ around your child’s chair legs; Your child can push/pull with their legs on the band to add resistance and strengthen leg muscles. This can be done anytime while engaging in quiet activities (i.e. coloring) or even at the dinner table.

Have your child sit on a swing as if they are riding a horse; you may need to provide support to their trunk, but with practice they will learn better balance and control of their body.
Catch

Toss a ball to your child making sure the size is appropriate for their hands.
Catch

Benefits

- Teaches hand-eye coordination
- Provides full body movement
- Increases strength and muscle tone
- Promotes core strength
- Encourages Concentration

Variations

- Use a weighted ball
- Different sizes may be used depending on child's ability to catch
- Roll the ball if child is unable to catch
- Use felt ball (i.e. tennis ball) and a Velcro mitt to assist in skill development
Sock Bowling

Set up items for your child to knock over with a bundled up pair of socks.
**BENEFITS**

Promotes eye-hand coordination

Works trunk control

Improves precision & accuracy

Strengthens hand grasp & release

Teaches cause and effect

Improves motor planning

Promotes balance

**VARIATIONS**

May use other items besides socks as a bowling ball (plastic ball, bean bag, rubber ball, basketball)

Paper towel rolls can serve as pins (or toilet paper rolls, block towers, plastic cups)

20 oz. pop bottles may be used as pins; for a greater challenge add weight to the bottles by adding beans or sand

Line the pins up in a horizontal line and have your child knock one pin down at a time to challenge focus and accuracy
Scooter Board

Have your child sit in the center of the scooter using arms and legs to propel.
**BENEFITS**

- Improve trunk control and stability
- Increases body awareness and positioning
- Strengthens upper and lower body
- Promotes motor planning and control
- Opportunity to engage socially

**VARIATIONS**

- Child can sit upright and use legs to propel or sit crossed-legged and use arms to propel
- Child can lay on stomach and use arms to propel
- Fasten end of rope to a stable foundation and have your child pull self along while seated or lying on scooter
- Play a game similar to soccer where your child has to try to hit ball into goal while on the scooter
Tag

Explain the rules of the game to your child:
One person is "it" and the object is to touch the other person so they are "out". Once they are "out" they have to wait until everyone is "out" to start a new game.
Tag

Benefits
- Aerobic activity helps heart and lung functioning
- Promotes gross-motor control and motor planning
- Improves coordination while running
- Social activity
- Can improve strategic thinking and problem solving.

Variations
- Mow a maze in the yard and the children have to stay in the mowed path. One child is the fox and tries to tag out the rabbits. This can also be used in the winter by shoveling out the maze.
- Freeze tag is when the person who gets tagged has to stay in that spot until someone else can come and tag them back in the game.
Playing Musical Instruments

Instruct your child to press, blow, or pluck instrument of choice. Focus on the enjoyment of making noise rather than the product.
Playing Musical Instruments

Benefits

Allows for expression of self and creativity
Incorporates fine and gross-motor movements
Intellectual stimulation
Promotes language
Can have calming effect on your child

Variations

Use instruments that promote oral motor control such as a whistle, recorder or kazoo
Use instruments that promote either fine or gross-motor movements such as a keyboard, triangle,
Use a variation of loud and quiet instruments to teach variation of sound ("this is soft, this is loud")
Having your child press piano keys promotes fine motor skills, motor planning, and strength
Swinging

Sit upright in swing. Swing legs out while pulling chains back with arms. Pull legs back and push chains out with arms at the peak of the upward swing.
Swinging

Benefits

- Provides a different movement experience for the child
- Promotes muscle and hand strength
- Promotes coordination of leg and arm movements
- Movement can have a self-soothing effect
- Increases trunk strength

Variations

- Set up targets such as blocks or boxes for your child to knock over
- Have a target available at different heights for your child to kick at
- While your child is in the swing, twist up the ropes/chains and then let go. This provides vestibular input for your child.
Winter Outdoor Activities

Making a Snowman
Roll first snowball along the ground to accumulate more snow;
This should be the largest in order to stack the next two on top of
the bigger one. Second and third snowball is created the same way.
Decorate the snowman by creating eyes, mouth, and nose.

Making a Snow Angel
Have your child lay on their back in a fresh plot of snow.
Move arms in a sweeping motion from waist to head.
Help your child to stand so they can see their snow angel.

Pulling a Sled
Using a rope attached to a sled have your child pull the sled in the snow.
Winter Activities

Making Snowmen

Benefits

- Rolling and pushing snowball around provides proprioceptive input

- Resistance of snow strengthens arm, upper body and leg muscles

Variations

- Use a spray bottle with colored water to color the snowman.

- Squeezing the bottle promotes hand strength
Winter Activities
Making Snow Angels

Benefits
- Moving arms and legs promotes muscle strength
- Improves coordination of both arms at the same time
- Provides proprioceptive input

Variations
- Create snow angels in varying depths of snow
Winter Activities
Pulling a Sled

Benefits
- Provides proprioceptive input
- Strengthens arms and legs
- Improves balance and walking coordination

Variations
- If hand strength is weak, tie rope around waist
- Help your child by both of you pulling the sled
- Pull sled on various depth of snow
- Pull sled with different amounts of weight
- Try pushing from behind if pulling is too difficult
Horseshoes

Grab horseshoe at rounded part of the shoe. Toss horseshoe under-hand at target and try to "wrap" the shoe around the stake.
Benefits

- Improves arm and hand strength with gripping and throwing
- Increases balance while stepping and throwing
- Encourages eyes to follow an object

Variations

- Use different size and weight of horseshoes
- For different challenges, set poles apart at different lengths
- Have your child throw the horseshoe at a larger target
Hoppity Ball™

Have your child sit on the ball with the handle between their legs, feet planted firmly on the ground. Push up with legs to bounce.
**Benefits**

- Promotes trunk & posture control
- Works on balance
- Provides proprioceptive input (can have calming effect)
- Encourages weight shifting
- Strengthens legs
- Promotes ability to follow objects with the eyes
- Improves motor Planning
- Strengthens hand grasp
- Promotes using hands together

**Variations**

- Place objects on the floor that your child must pick up by bending their trunk to the side, strengthening core muscles
- Have your child sit on the ball and play catch; Your child may feel more secure having the handle to hold onto
- Use a therapy ball if you do not have a bouncing ball with a handle and play catch with your child
- Have your child sit on the therapy ball while performing table activities to promote core strength
- Have your child lay on the therapy ball on their stomach while you hold your child's legs; pretend to "fly" as this will promote core and upper body strength
Hopscotch

Draw three squares in a line. Have your child jump onto each square using one or both feet.
**Benefits**

- Promotes balance and coordination
- Practice counting numbers
- Provides a different movement experience
- Encourages socialization
- Works fine motor (child makes squares with chalk)
- Strengthens leg muscles
- Promotes motor planning
- Challenges ability to follow numbers with the eyes so child knows what number square comes next

**Variations**

- Can make as many or as few squares depending on your child's skill level
- Variation of 1 block and 2 block square layouts
- Jump using both legs vs. one legged hop
- Use colors rather than numbers to identify squares
Glossary

**Fine-motor skills:**
Using hands and fingers to perform precise movements.

**Gross-motor skills:**
Skills necessary to perform large movements.

**Motor planning:**
Ability to perform specific movements in order to complete a task or activity.

**Proprioceptive input:**
The ability to sense stimuli occurring within one’s body.
References


Print Shop 2.0© was used to create the pages of the manual which included layout design, backgrounds, and clip art.

Other Resources


4. More quiet play activities:
   [http://www.activityvillage.co.uk/quiet_games_and_activities.htm](http://www.activityvillage.co.uk/quiet_games_and_activities.htm)

**Any questions regarding this manual please contact:**

Brittany Larson
bmlarson@medicine.nodak.edu

Seth Luoma
sluoma@medicine.nodak.edu

Gail Bass, Ph.D, OTR/L
gail.bass@med.und.edu
Chapter V
SUMMARY

The literature reviewed in Chapter II revealed that there is a need for structured home-based interventions for children with Down syndrome. Parents of children with Down syndrome expressed their concern regarding the lack of structured programs provided for their children (Menear, 2007). The purpose of this scholarly project was to develop a manual for parents of a child with Down syndrome that includes different types of play activities that can facilitate and support their child’s development. The manual was designed to provide parents with descriptions of play activities and rationale of how each activity helps to support development. The manual also includes ideas to modify each play activity. The initial step to each activity was broken down through activity analysis to increase user-friendliness. The manual fills the need for structured play activities at home which can help children with Down syndrome develop skills necessary for play and development.

A limitation of this product is the fact that the product has not been trialed by occupational therapists who are working with parents of children with Down syndrome. Because of this, feedback from parents and occupational therapists has not been obtained. Without feedback from either occupational therapists or parents, the effectiveness of the manual cannot be measured. A second limitation is that based on the literature reviewed for Chapter II, there appears to be a lack of research regarding the play of children with
Down syndrome. This potentially limits knowledge of different types of play activities for children with Down syndrome. Literature regarding a wider variety of play would allow for more activities to be adapted into the parent manual.

Use of the product can be implemented by contacting local pediatric healthcare settings who employ occupational therapists and providing them with the manual to be incorporated into their therapy program for children with Down syndrome and their parents. This product will not only serve as a reference for the therapist, but as an educational tool for parents to facilitate family involvement. The authors of the product will consult with the therapists to go through the manual with them to clarify any questions about the product. The manual may also be implemented by the authors through in-services for occupational therapists and parents of children with Down syndrome that describe how to use the manual to facilitate implementation of the manual, interventions and home program use.

Recommendations for the future include additional research on both quiet and active play specific to the development of children with Down syndrome. Additional research on Down syndrome and play activities would help to fill in the gaps of information regarding different areas of play and development. With the additional research, recommendations provided may be more client-centered. In order to measure the effectiveness of the parent manual, it is recommended that data be collected from parents and occupational therapists that have used the manual. Data should be collected through surveys and interviews.
It is hoped that the use of this product will help facilitate collaboration between OT’s and parents which will lead to quality home programs to enhance the developmental skills of children with Down syndrome.
Brittany Larson, Seth Luoma, and The University of North Dakota Occupational Therapy Department have my permission to use my child’s photograph as a part of Ms. Larson’s and Mr. Luoma’s Scholarly Project and in the presentation and distribution of the product that is developed as part of the scholarly project and in the presentation and distribution of the scholarly project in its entirety. These pictures were taken 11/13/10-11/14/10.

Bisa Bartsch  
Madyson Bartsch
Parent signature  (Child’s name)

Brittany Larson, MOTS
Student

Seth Luoma, MOTS
Student
Brittany Larson, Seth Luoma, and The University of North Dakota Occupational Therapy Department have my permission to use my child’s photograph as a part of Ms. Larson’s and Mr. Luoma’s Scholarly Project and in the presentation and distribution of the product that is developed as part of the scholarly project and in the presentation and distribution of the scholarly project in its entirety. These pictures were taken 11/13/10-11/14/10.

[Signature]
Parent signature

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(Child’s name)

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Student

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Student
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[Signature of Parent]  [Child’s name]

Student

[Signature of Student]  [M.S.]
Brittany Larson, Seth Luoma, and The University of North Dakota Occupational Therapy Department have my permission to use my child’s photograph as a part of Ms. Larson’s and Mr. Luoma’s Scholarly Project and in the presentation and distribution of the product that is developed as part of the scholarly project and in the presentation and distribution of the scholarly project in its entirety. These pictures were taken 11/13/10-11/14/10.

[Parent signature]

[Child’s name]

[Child’s name]

Student

Student
References


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