Development of Six Parenting Social Stories for Parents with Intellectual Disabilities

By

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A thesis submitted to the School of Community Services
in partial fulfillment of the requirements for
the degree of
Bachelor of Applied Arts in Behavioural Psychology

St. Lawrence College
Kingston, Ontario
Canada.

April, 2014

The procedures in this staff resource are meant to be used by agency staff, as part of the broader services they provide, or under supervision of agency staff.
Dedication

For Shirley Sickler, my grandmother,

    Thank you for being so proud of me in pursuing my education. I made a promise to you that I would finish this, and I did it, for you.
Abstract

When individuals with an intellectual disability enter into parenthood they will often have difficulty with the basic concepts of parenting, such as the health and safety of the child, child behaviour management, problem solving skills and stress management (Wade, Llewellyn & Matthews, 2008). In order to assist these individuals, resources must be developed and made readily available to them. The aim of this thesis was to create a resource for a community agency that works intensively in-home with parents in need of additional guidance and support. The objective of this resource was to effectively communicate the information that new parents with intellectual disabilities need in order to care for their children properly and independently. Six social stories were created, focussing on the newborn period of life from 0 to 3 months. The social stories present the most important information that was to be included in the training manual, in a condensed and simplified format. These individual social stories cover feeding, sleep schedules, diaper changing, comforting your baby, playing with your baby, and coping with stress. The information within these social stories was gathered from parenting books and websites and was written using simple sentences and step-by-step instructions paired with pictorial aids, which is recognized as the most effective format for individuals with intellectual disabilities. It is recommended for future research that a questionnaire be developed and completed by both agency staff and clients in order to assess the actual effectiveness and credibility of using social stories with individuals with intellectual disabilities.
Acknowledgments

I would like to thank Dr. Sheelagh Jamieson and Erin McCormick, for their continued guidance, support, and patience throughout working with me on the development of my thesis. In addition, I would like to thank my placement agency for providing me with a diverse learning experience. I would also like to thank my parents for believing in me throughout the entire process.
TABLE OF CONTENTS

DEDICATION.......................................................................................................................... i

ABSTRACT............................................................................................................................. ii

ACKNOWLEDGEMENTS....................................................................................................... iii

TABLE OF CONTENTS.......................................................................................................... iv

CHAPTER

I. INTRODUCTION................................................................................................................... 1

II. LITERATURE REVIEW........................................................................................................ 4

   - Introduction................................................................................................................... 4
   - Parents with Intellectual Disabilities............................................................................ 5
   - Parent Stress.................................................................................................................. 6
   - Children of Parents with Intellectual Disabilities........................................................ 7
   - Attachment and Child-Behavioural Management......................................................... 8
   - Parent Training.............................................................................................................. 9
   - Manual Intervention..................................................................................................... 10
   - Basic Child Care Procedures....................................................................................... 11
   - The Present Study – Training Manuals...................................................................... 12
   - The Present Study – Social Stories............................................................................. 13

III. METHODOLOGY................................................................................................................ 13

   - Setting........................................................................................................................... 13
   - Target Population......................................................................................................... 13
   - Development of Resource........................................................................................... 14
   - Design and Layout of Resource.................................................................................... 15

IV. RESULTS............................................................................................................................ 16

V. CONCLUSION/DISCUSSION............................................................................................... 17

   - Strengths and Limitations............................................................................................ 17
   - Multilevel Challenges................................................................................................... 17
   - Contributions to Behavioural Psychology Field......................................................... 18
   - Recommendations for Future Research...................................................................... 19

REFERENCES.......................................................................................................................... 20

APPENDICES.......................................................................................................................... 24

   Appendix A: Feedback Questionnaire............................................................................ 24
Chapter I - Introduction

The DSM-IV indicates that individuals labelled with an intellectual disability display deficits in their intellectual functioning. Further, the DSM-V indicates that individuals with this diagnosis have an IQ score of approximately 70 or below. The DSM-V describes three domains that encompass the areas of struggle for these individuals, and they are as follows: conceptual, social, and practical. Some of the common regions within these domains that these individuals struggle with are planning, reasoning, problem solving, and judgment (Reynolds, Zupanick, & Dombeck, 2013). Understanding the common areas of struggle for individuals with intellectual disabilities becomes useful when these individuals enter into parenthood as they will often find difficulty with basic concepts of parenting, such as the health and safety of the child, child behaviour management, problem solving skills and stress management for themselves, etc., (Wade, Llewellyn & Matthews, 2008). The lack of knowledge and skill development in the previously mentioned areas paired with the stress and uncertainty of parenting provides a clear sign that these parents are in need of additional supports. However, many parents with intellectual disabilities have been considered to be a hidden population as consistent record-keeping and proper screening procedures have failed to identify them in the past. Moreover, often the community agencies that offer this specialized assistance are unaware of many of these parents. Yet, more recently, community service workers of all types have increasingly reported having parents with intellectual disabilities being added to their caseloads, (International Association for the Scientific Study of Intellectual Disabilities (IASSID) Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008). This information provides a distinct indication that community agencies need to be providing more resources.
The majority of parents with intellectual disabilities have mild to borderline cognitive limitations (International Association for the Scientific Study of Intellectual Disabilities (IASSID) Special Interest Research Group on Parents and Parenting with Intellectual Disabilities, 2008). Thus, according to Wade et al. (2008) parents with intellectual disabilities are able to obtain essential parenting skills through the proper training. Wade et al. (2008) believe that parent training is actually demonstrated to be more effective when practiced within the home. It is for these reasons that more prominent resources need to be made available to parents within the hidden population. These individuals do not only struggle with a lack of comprehension for many of the basic parenting skills, but they also often lack the ability to independently acquire the resources that are available to assist them in this area. Without the appropriate assistance, these parents’ children are at risk of being removed from the home (Feldman, Ducharme & Case, 1999).

Based on this knowledge, it would benefit parents with intellectual disabilities to have an instructional resource, complete with information relating to the aforementioned areas; such as child care procedures, and methods for dealing with stress related to parenting, as well as additional guidance in other areas. It would be most advantageous for the parents to have some intensive in-home training sessions as well; using the instructional resource for reference and practice of the strategies and techniques with a professional present for guidance. These combined resources would allow for the parents to grow as individuals and as parents. If these strategies are practiced, and used consistently it would in turn produce healthy and functional children as well as improved parenting skills, and produce a stronger bond between the parent(s) and child(ren).
The purpose of this thesis is to create a resource for parents with intellectual disabilities that can be used continuously throughout their child’s newborn period of development. A resource with information on the essential elements of parenting broken down into practical applications, and step-by-step instructions will assist this population of parents with the everyday routines of being a new parent. Examples and pictorial aids will also be included in each of the individual social stories. This thesis describes the development of the social stories. The first social story presents information on “feeding your newborn.” The second one provides information on “creating a sleep schedule for your newborn.” The third social story provides “information and step-by-step instructions for diaper changing” and the fourth presents information on “how to comfort your new baby.” The fifth social story offers techniques for “how to play and engage with your baby” and the final one offers strategies for “coping with the stress of parenting.” These topics will contain concrete instructions that are easy to understand and translate to their home environment with their child(ren). Further, it is important to note that social stories should initially be used in conjunction with intensive in-home training, nevertheless, they will be given to families in need free of charge. As previously mentioned, these social stories will allow for parents with intellectual disabilities to build on their strengths as well as develop new skills and this will in turn provide a healthy, loving, and stable home for the child(ren).
Chapter II – Literature Review

Young and Hawkins (2006) present the argument that parents with intellectual disabilities should be provided with the same opportunities as all other parents. The Children Act, which came into effect in the United Kingdom in 1989, persuaded many individuals world-wide with intellectual disabilities to make the choice to become parents. The reasoning for this being that this act placed more emphasis on the parental role of caring and protecting the child rather than just simply on child care procedures. In 1990, The Children and Family Services Act came into effect in Canada, representing the same values presented within The Children Act (Office of Legislative Counsel, 2009). Essentially this act advocates for the keeping the child(ren)’s best interests in mind and promotes keeping the child(ren) with the family. The agency of the child and family services act will even provide reasonable means in order to ensure that child(ren) are kept with their families, i.e., improving the families’ financial situation, housing situation and even providing specialized assistance for improving parenting skills (Office of Legislative Counsel, 2009). The increasing societal recognition of independence and security of individuals with intellectual disabilities wishing to be parents convinced many of them to begin their own families.

Within the last 20 years, the number of individuals with intellectual disabilities having children has increased (Young & Hawkins, 2006). According to Wade et al. (2008) in response to this increase there has been a significant rise in the amount of research that has gone into the lives of parents with intellectual disabilities. It is critical that society is aware that intellectual disability does not equal inadequate parenting (Mildon, Wade & Matthews, 2008). Young and Hawkins (2006) explain that many of these parents have the ability to be suitable parents to their children; they just need more support to do so. It has been demonstrated that the parenting skills
of parents with intellectual disabilities actually improve with the appropriate training that is tailored to their learning abilities and needs (Young & Hawkins, 2006). The International Association for the Scientific Study of Intellectual Disabilities (IASSID) Special Interest Research Group on Parents and Parenting with Intellectual Disabilities (2008), states that parents with intellectual disabilities can in fact apply their knowledge to situations and maintain and generalize the skills they learn as well. It is also critical that the information being presented and the skills being taught are something that the parent(s) have identified as an area that is of interest to them and/or that they would like to work on, as this will motivate the parent(s) to engage in the training process.

Parents with Intellectual Disabilities

The IASSID (2008), suggests that there are three different categories of parents with intellectual disability that must also be considered before an appropriate intervention can be determined. The first describes a population who have a past of institutionalization and have now successfully transitioned into the community. The second describes a population that has never been institutionalized but has instead received community services throughout their lifetime. Finally, the third population is informally described as the hidden population as they have essentially lived their lives with little to no supports and have managed to stay out of the system. However, when individuals within this particular population become parents the community seems to immediately become more involved. The parent’s cognitive abilities are questioned as they are now responsible for the well-being of a child (IASSID, 2008).

Parenting Stress

Parenting is challenging for those without any sort of disability and therefore may be even more overwhelming for parents with intellectual disabilities (Murphy & Feldman, 2002).
Parenting stress is one of the highlighted areas of concern when working with parents with intellectual disabilities. Esbensen and Benson (2006) explain that stress is an important area to focus on with individuals with intellectual disabilities as it can be a trigger for depression and other problem behaviours. Stress is inevitable for all parents, yet the way in which the stress is dealt with greatly effects the child(ren). Young and Hawkins (2006) explain a Canadian study conducted by Maurice Feldman in 1997, in which a Parenting Stress Index was used to assess levels of stress in mothers with intellectual disabilities. The results of the study showed that these mothers experienced a significantly higher amount of stress overall in comparison to a typically developed group of mothers. In a study conducted by Bohr, Halpert, Chan, Lishak and Brightling (2007) parenting stress is described as being derived from the parent’s perception of the accessibility of the resources that can assist them in coping with the stress. Bohr et al. (2007) continue to say that based on this knowledge, working on an intervention with parents that includes an educational component as well as a promotion of confidence and general self-efficacy will potentially relieve parent stress. With the parents feeling more confident in their abilities and their stress being alleviated, the parent-child relationship can develop further. An intervention was conducted with typically functioning parents that was delivered in a group setting within a mental health center. The attachment based intervention was conducted in order to establish the effectiveness of group parenting programs. Overall, post-intervention results showed improvements in parent confidence and a decrease in parenting stress (Bohr et al. 2007). The goal of the parent training manual is to relieve these parents of some of their unnecessary stress that stems from them simply being unsure of how or where to access the support they need. The parent training manual would be an asset in these parents’ homes as they would have
unlimited access to information presented in such a way that is tailored to their learning abilities and needs.

**Children of Parents with Intellectual Disabilities**

The children of parents with intellectual disabilities are unfortunately at-risk for obtaining a number of different intellectual disabilities themselves, including a developmental delay and behavioural disorders stemming from their intellectual disabilities (Feldman & Case, 1999). These children are also regrettably at-risk for inadvertent maltreatment as the parents may not always be aware of the child’s needs, nor how those needs should be addressed. This can lead to extended malnourishment, improper cleaning and sterilizing routines and even child apprehension if the parent(s) are not provided with the knowledge and tools to practice the techniques (Feldman & Case, 1999). In fact, the IASSID (2008), states that children of parents with intellectual disabilities are more likely to be permanently removed from their homes than children of parents with addictions or mental illness. On the opposite end of the spectrum, children of parents with intellectual disabilities that are not delayed in any form are still at-risk for mentally outgrowing their parents and thus taking on a caregiver role at a young age (Young & Hawkins, 2006). The child(ren)’s development and well-being must be considered when the availability of resources for these parents is lacking (Young & Hawkins, 2006).

**Attachment and Child Problem Behaviours**

Other identified areas of concern when working with parents with intellectual disabilities is ensuring that a healthy attachment is established between the parent(s) and the child(ren). Individuals with intellectual disabilities can also struggle with social situations and interactions. This could in turn have a negative effect on their relationship with their child(ren) as they are
unsure of how to properly interact with them (Murphy & Feldman, 2002). Kindsvatter and Desmond (2013), explain that parents who exhibit attachment insecurity in forms such as clinging or distancing themselves from their children could, as a result, continuously experience parent-child conflict. When the parent(s) and child(ren)’s efforts to have their needs met are consistently ineffective, a pattern of behavioural responses is formed and unfortunately has significant potential to carry on throughout future generations and greatly affect parent-child relationships. Behavioural issues may also stem from attachment needs not being properly addressed as the child(ren) will often display inappropriate and problematic behaviours in order to provoke the response from their parent(s) that they are seeking. Interventions created to improve parent-child attachment involve a great deal of parental commitment to responding to their child calmly and consistently. The parents must also be attentive and highly aware of their child(ren)’s expression of emotions. However, these concepts often do not come naturally to parents with intellectual disabilities and that is why frequently a third party is needed to guide the parent(s) in learning how to respond appropriately to their child(ren)’s needs. Murphy and Feldman (2002) state that parents with intellectual disabilities prefer interactive forms of learning which are practical and applicable to their everyday lives. Yet, parents also displayed a preference to having pictorial aids to assist in their learning. Therefore, if professional in-home training is not an option at that time; having a training manual with brief informal instructions and pictorial aids would be an asset to parents with intellectual disabilities.

**Parent Training**

With the understanding that parents with intellectual disabilities require more support than typically developed parents, it is clear that parent training programs and/or resources need to be made more accessible to this population of individuals. Moreover, it is imperative to ensure
that the parent training takes place in the environment that it is most needed in; which is typically the home (Mildon et al. 2008). Wade et al. (2008) explain that contextual factors must also be critically considered when working with parents with intellectual disabilities as these factors highly influence the intervention outcomes. Wade et al. (2008) discuss the four domains of contextual factors that should be addressed when working with parents on developing the most effective intervention for them. The domains are as follows: environmental factors which includes their socioeconomic status and neighbourhood, familial factors which includes the parent’s support system, parent factors which includes any prevalent mental health issues and finally child factors which typically consists of behavioural issues. Within a study that encompassed the concept of contextual factors, significant post-intervention changes in parenting skills were apparent with the intervention group in comparison to the non-intervention group (Wade et al. 2008). When developing an intervention or training plan with the parents, it is important that the professional assigned to their case take the contextual factors into consideration and encourage the parent(s) for every step they take.

In another study conducted by Llewellyn, McConnell, Russo, Mayes and Honey (2002), in home parent education sessions were held weekly with parents with intellectual disabilities. The sessions would consist of discussion and participation, reviewing topics previously covered as well as the presentation of a new topic to focus on for the week. The educator would then work one-on-one with the parents on completing a section of the illustrated booklet provided with the in-home sessions. A parent evaluation was given to the families involved in the study following its completion. The results showed that the majority of parents were able to retain more information having pictorial aids supplemented throughout their education program in addition to them also simply preferring pictures to words. Parents also displayed a preference to
the interactive format of learning that they engaged in with the educator. Actively participating with the parents promotes practice and eventually establishes healthy habits. It was acknowledged that this population of parents must have attainable goals in order to keep them motivated. In addition, information should not all be presented at once; which is why introducing one new topic each week is most effective (Llewellyn et al., 2002). Each of these important factors must be carefully considered when developing a parent training program and/or resource for parents with intellectual disabilities in order to obtain maximum results.

**Manual Intervention**

Feldman and Case (1999) explain that intensive intervention using behavioural techniques is a highly effective method of teaching parents with intellectual disabilities. These intensive intervention programs have demonstrated improvements in child-health and development and in turn decrease the rate of child apprehension (Feldman & Case, 1999). This knowledge influences the necessity for direct and detailed forms of parent training intervention.

In another study conducted by Meldon et al. (2008) in home evidence-based parent education for parents with intellectual disabilities was implemented with each family within the study. Multiple dependent variables differed across the families involved in the study and some of these included the parent’s stress associated with parenting, the parent-reported child problem behaviours and the overall quality of the home environment. Generally, the results of this study were that the parents found the training as well as the training method to be helpful. Further, the parents mentioned that the program was consistent with their goals, beliefs and lifestyles. According to Meldon et al. (2008) parenting strategies are taught using concrete and practical methods that match the parent’s level of competency. Practicing techniques, modeling and
general discussion are some strategies that have been successful when working with parents with intellectual disabilities. This particular study focused on teaching parents skills in four designated areas of parenting. The areas of focus included child behaviour management, parent-child interactions, decision making and basic child-care procedures.

Wade et al. (2008) take a different approach and states that self-instructional manuals are a cost-effective and useful method of teaching new skills to parents with intellectual disabilities. Incorporating simple and concrete instructions with pictorial aids has been a success in the past when combined with the proper in-home training. However, the success rate of the use of self-instructional manuals is highly based on the parents overall acceptance of the material from the beginning of the program which is why it is critical that the resources are tailored to the parent’s specific abilities and needs. In addition, using only self-instructional training manuals with parents with intellectual disabilities is less effective in comparison to using the manuals paired with an instructional audiotape for example. This information would advocate that parents with intellectual disabilities may need multiple approaches to intervention, such as a training manual paired with in-home training sessions. Further, Wade et al. (2008) state that the intervention intensity for these families should be frequent with either once or twice weekly sessions in order to promote consistency and solidify new concepts. According to Feldman and Case (1999) these types of intensive educational programs for parents with intellectual disabilities are still very rare. This is believed to be because many agencies do not have the staff, nor the funding to provide this type of service to the community (Feldman & Case, 1999). Based on this unfortunate truth, Feldman and Case (1999) along with Wade et al.(2008) present the concept of creating a cost-effective solution which focuses more on self-learning and needs little to no professional assistance in administration.
The concept of self-learning has been introduced as an alternative to the therapist run training sessions (Feldman & Case, 1999). In a study conducted by Feldman, Ducharme and Case (1999) the skills chosen to teach to mothers with intellectual disabilities were chosen based on whether the mother needed training in that area and also if there was a manual available to aid in the training. Miltenberger (2008) describes the concept of self-learning as self-management; engaging in a controlling behaviour in order to increase the future occurrence of the controlled behaviour. Using this concept with the parent training manuals would mean that the case worker would be working with the parent(s) to create the habit of referring to the training manual (controlling behaviour) each time the parent was unsure of how to respond to his or her child’s needs and instead may have perhaps ignored their child or overreacted in an unhealthy manner (controlled behaviour). Similarly, self-instructions to tell themselves what or how to do something at the appropriate time can be an effective tool to serve as a reminder (Miltenberger, 2008). These concepts promote independence and self-monitoring which are both necessary components to parenting and can be taught in a concrete manner to parents with intellectual disabilities. Feldman and Case (1999) go on to say that there are resources geared towards the parent population of individuals with intellectual disabilities and these resources include pictorial manuals which have been used in multicomponent parent training programs. Feldman et al. (1999) describe the manuals used in the study as being made simple with the instructions at no more than a third grade reading level. Line drawings were used for the pictures as previous interventions performed with parents with intellectual disabilities showed that they preferred them. A brief one-sentence instruction was placed beside the picture in the manual and there were only ever two pictures per page. In contrast to Wade et al. (2008), Feldman et al. (1999) state that self-learning techniques can even be as effective as therapist-directed interventions.
The many risks that the children of parents with intellectual disabilities are faced with increases the need for providing parents with intellectual disabilities with the appropriate self-learning resources. Additional training, support and guidance will ensure that they are well equipped to parent their child(ren) independently and provide a positive and nurturing environment.

**Basic Child Care Procedures**

If professional in-home training is available, making sure that the training is conducted within the parent’s home is necessary in maintaining consistency and generalization of the skills being taught (Murphy & Feldman, 2002). In-home sessions will warrant better opportunities to practice child care procedures such as bathing, changing, feeding and monitoring the child. In-home sessions also allows for case workers to educate parents on potential dangers, precautions they should take, and how to respond to an accident (Murphy & Feldman, 2002). Ideally, the training manual is designed to be paired with weekly in-home training sessions with a professional in order to elicit the most effective outcomes with the parents as well as ensure that they are able to properly practice their skills within the comfort of their home. Nevertheless, this is where the concept of self-learning becomes imperative (Wade et al. 2008).
The Present Study – Training Manuals

Training manuals are still a highly effective method of training parents with intellectual disabilities. In a study conducted by Feldman et al., (1999) 10 mothers with intellectual disabilities displayed significant improvements in child-care skills from baseline to intervention just by referring to training manuals unprompted. If parents have a resource that they can regularly refer to when they feel that they need it; their consistency, confidence, and self-sufficiency will improve. Their relationship with their child(ren) will also evolve as a result. If all parents with intellectual disabilities were provided with a free training manual there would be significant progress in the areas that they typically struggle with, as they would have immediate, and unlimited access to the answers to their questions. If these parents are provided with the support and assistance that they require within their child(ren)’s early years of life, they will undoubtedly be loving, and well-equipped suitable parents. Therefore, the purpose of this thesis is to describe the development of a parent training manual for parents with intellectual disabilities. The aim of this parent training manual is to provide a cost-effective, non-intrusive permanent resource for parents with intellectual disabilities that may not have access to other resources, or simply have not yet been directed to them. If parents refer to the manual on a regular basis their parenting skills may improve. In addition to that, they may have a stronger relationship with their child(ren), and present as more confident, and independent individuals.
The Present Study - Social Stories

Social stories were created for, and typically used by children with a diagnosis of Autism Spectrum Disorder (ASD); however, they can be created for, and used with any population that struggles with reading, language, and understanding challenging concepts. Social stories were originally created by Carol Gray in 1991, and they provide the means for individuals to better comprehend a difficult idea and perhaps participate in trying something new. According to Samuels, R., and Stansfield, J., (2012), social stories are to be tailored to those who will be reading them. They should include a description of who is involved and how the sequence of events should be carried out (Samuels, R., & Stansfield, J., 2012). Examples and suggestions for the appropriate response during the situation should be provided, in addition to a brief explanation of the importance of responding in the manner described (Samuels. R., & Stansfield, J., 2012).

Samuels, R., and Stansfield J., (2012) conducted a study using social stories to increase pro-social behaviours involving four adults with learning disabilities and characteristics of ASD. The results of this study demonstrated that social stories can be an effective form of intervention for improving appropriate communication and behaviour, however it is suggested that further studies be conducted over a longer period of time in order to determine the effectiveness of prolonged use (Samuels R., & Stansfield, 2012).
Chapter III – Method

Setting

This child’s mental health agency offers intensive in-home training for parents who wish to attain skills in order to prevent more severe issues from arising with their children later. Referrals are made independently or by another agency that the family is involved with. There is a vast majority of families with differing abilities involved with the intensive services that the agency offers. Agency staff felt that the creation of a variety of social stories for parents with intellectual disabilities would be a beneficial resource to have available to the intensive in-home staff as they currently do not have access to this type of resource. Parents with intellectual disabilities were identified as being one of the more difficult populations to work with intensively as they often require more time to process concepts presented, as well as additional practice of techniques. A feedback questionnaire regarding the effectiveness, and usefulness of the social stories when used with parents with intellectual disabilities was given to agency staff in order to obtain results for this study. This resource is intended to be supplementary to intensive in-home training with a professional; however, it is a resource that should be left with the family in order for them to establish the habit of referring to in between appointments.

Target Population

The recipients of these free social stories will be parents with a known formal diagnosis of an intellectual disability, or parents that the agency may believe to be struggling with the foundational concepts of parenting. The children of these parents must be within 0 to 3 months old as the social stories specifically address the fundamental concepts of parenting within the newborn stage of a child’s development. These social stories are designed to be used in
conjunction with intensive in-home training sessions with a professional, ideally twice weekly for two hours. Providing a professional for guidance and demonstration of the concepts presented within the social stories is effective when working with parents with intellectual disabilities as it is interactive in format. However, the social stories are also designed to promote self-learning and independence. Furthermore, without a professional present it is essential that the social stories be highly descriptive and complete with several examples and pictorial aids for additional guidance.

**Development of Resource**

The social stories were constructed using information from online articles, editorials, websites, and books. Each social story covers a critical topic for first time parents caring for a newborn. The social stories created include: feeding, sleep schedules, diaper changing, playing, comforting the baby, and coping with stress. Each social story includes information on the topic and strategies that parents can use within these highlighted areas. Parents must be able to quickly and easily find the answer to their questions, which is why the social stories are written using basic language at no more than a third grade reading level. Particularly difficult concepts are broken down into step-by-step instructions accompanied by pictorial aids. The social stories include line-drawings, actual photos, and brief instructions in order for the parents to better understand the appropriate way to respond to their child’s needs. The pictorial aids are there not only to assist in the explanation of a concept to parents; but also to ensure that they feel secure in carrying out an action with their child(ren) autonomously. The aim of these social stories is to assist in building on the strengths that the parents already possess, while also increasing their confidence to parent their child(ren) independently. Parents will be able to quickly and
accurately access answers to their questions about parenting a newborn in six of the highly identified areas of struggle.

**Design and Layout of Resource**

*Feeding*

The first social story covers the topic of feeding the newborn. Bottle feeding alone is discussed within this social story as nursing is a personal choice and is typically taught by the nurses in the hospital immediately after giving birth. Concepts such as measuring the proper amount of formula, the amount the baby should be eating, instructions for hold the baby while feeding, as well as instructions for how to burp the baby after feeding is described in this social story.

*Sleep Schedule*

This next social story involves establishing a sleep schedule for the newborn. Reasons for the importance of a sleep schedule are discussed, as well as where the baby should be sleeping, and how often the baby should be sleeping. This information is crucial to the baby’s health and will aid in their development.

*Diaper Changing*

In this third social story, learning the baby’s cues for recognizing when they need their diapers need to be changed is explained. Step-by-step instructions are used within this social story in order to clearly describe how to efficiently complete this repetitive task.
Playing with the Baby

The importance of interacting and playing with the baby is explained within this fourth social story. The newborn period of the baby’s life is should be filled with one-on-one bonding time. Developing a healthy and loving relationship with the baby is extremely important, and involves a significant amount of social interaction; this can sometimes be an area of difficulty for parents with intellectual disabilities. Examples for how parents can play with their newborn baby are provided throughout this social story. Some of these include getting down to the child’s level, making eye contact, talking and playing with them, and cuddling with them are all elements emphasized throughout.

Comforting the Baby

In this fifth social story examples for why, or when the baby would need to be comforted are provided. In addition to this, several methods in which parent(s) can comfort the baby are clearly presented throughout. Making sure the baby feels comforted when they are upset ensures that the baby knows that they are safe, cared for, and loved. Each of these components are essential for the development of the baby as well as a healthy relationship, and attachment between the parent(s) and the baby.

Coping with Stress

The final social story covers stress related to parenting. It has been demonstrated that parents with intellectual disabilities actually experience significantly more stress than typically functioning parents, and therefore are in need of more resources to effectively manage their stress. This social story briefly discusses stress related to being a new parent, including when and where it can occur as well as typical reasons for why it occurs. It is important that parents
understand that stress is normal and this is emphasized throughout this social story. Discovering and recognizing stress triggers are also briefly touched upon. Once parents are able to identify when they are feeling stressed, and realize what has triggered it, they will be able to choose an effective coping strategy to minimize the stress that they are feeling. Parents are provided with healthy, therapeutic strategies for dealing with their stress such as breathing exercises, talking with a friend, going for a walk, writing in a journal, exercising, etc. It is critical that parents establish stability within themselves in practicing these coping strategies as they will in turn create stability for their child(ren).

For parents with intellectual disabilities, having access to a resource such as these social stories will enable them to find the solution to their problem immediately. These social stories promote independence and responsibility as well as a form of immediate reinforcement if the correct strategies are used in accordance to the situation.
Chapter IV-Results

Feedback from an agency staff member who has clients within the targeted population, completed a questionnaire (Appendix A), regarding the usefulness and practicality of the social stories as a resource, as well as the estimated effectiveness of the social stories when working with parents with intellectual disabilities. The feedback provided was positive, and supportive of the use of social stories when working with parents with intellectual disabilities who have newborn babies. The agency staff member explained that the formatting and information provided in the social stories was both beneficial to her cliental, and clearly presented. The agency staff member stated that she planned to use some of the social stories with her clients immediately. However, feedback from clients, parents with intellectual disabilities, about how useful they felt the social stories were in their day-to-day activities could not be attained because ethics board approval had not been sought for working with human subjects. The social stories were given to the agency to use at their disposal with parents that they feel may benefit. The goal in creating these social stories was to provide a resource for parents in need, as well as constructing an additional tool for staff in need of assistance when working with parents with intellectual disabilities. The agency can copy any of the social stories in order to give copies to families and other staff members to use as a resource when working with parents with intellectual disabilities.
Chapter V – Conclusion and Discussion

Strengths and Limitations

The original plan for this thesis was to complete a parent training manual for parents with intellectual disabilities. The manual was to address common areas of difficulty for those parenting children in the early years from ages 0 to 6 years old, as well as strategies for improving these areas. It was a promising idea that was strongly supported with empirical evidence as well as being a resource that the agency felt they could use with their clients; however, time constraints became a factor in the creation of this large manual and it was no longer a viable option. Language and the grade level at which this manual was to be written in was also recognized as a struggle for this writer as it needed to be at no higher than a third grade reading level in order to align with the empirical research. Each of these contributing factors led to the idea of creating social stories as they are straightforward and written as single-sentence statements and instructions which also closely aligns with the empirical research. Six individual social stories concentrating directly on the newborn stage of development from 0 to 3 months old became the new focus. Having a newborn to care for is a particularly overwhelming task for typically functioning parents and therefore, an even more difficult for those with intellectual disabilities. Moreover, if time allowed for the opportunity to use these social stories while still on placement with the respective agency, and working with the clients that could have benefited from them; it would have been interesting to observe the clients’ reaction to the idea of social stories. Also, conducting a discussion with the clients, based on how useful they felt social stories were in assisting them in caring for their newborn(s) would have been helpful feedback.
Multilevel Challenges

*Client Level*

Although there are several community agencies striving to support parents with intellectual disabilities, many parents are still overlooked. Feldman and Case (1999), describe the children of these parents as being at risk of neglect and maltreatment, if parents are not provided with the necessary information for how to properly care for their children. Due to the fact that many parents with intellectual disabilities do not have any affiliation with community agencies, it is important that they are equipped with an informative parenting resource(s), like social stories, that are tailored to their learning abilities.

*Program Level*

It is difficult to determine how valuable social stories would be to staff members within the community agency as the social stories have not yet been used or evaluated by staff. The effectiveness of the social stories is also difficult to determine as there is minimal research regarding the use of social stories with adults with intellectual disabilities. However, because parents with intellectual disabilities were identified by agency staff as being a more challenging population to work with, it is important that they have a supplementary resource to use during sessions with clients, in addition to leaving the social stories with the clients in order for them to practice their skills.

*Organizational Level*

Parents with intellectual disabilities need additional time and a substantial amount of repetition in learning and practicing their parenting skills. Although social stories are tailored to
these individuals’ learning abilities, there is minimal research supporting how effective social stories are, used in conjunction with in-home training sessions or simply used as an independent resource for parents. Moreover, while parents with intellectual disabilities were identified by agency staff as being a challenging population to work with, this particular agency specializes in short-term, in-home work with families, and does not often receive these types of referrals. Thus, there is a question as to how much the social stories would actually be used within the agency. Conversely, having a resource such as social stories, available to agency staff when they do receive these referrals will be beneficial to both the staff and the clients.

*Societal Level*

There is a stigma attached to the idea of asking for help within our society, and it is especially important that individuals with intellectual disabilities know that it is OK to ask for assistance. They need to be aware of their skills as well as areas that they can improve upon, in order to ensure that their children are provided with the appropriate care.
Contributions to the Behavioural Psychology Field

This thesis has contributed to the behavioural psychology field through creating an alternative method of assisting new parents with intellectual disabilities. The newborn stage of life is often considered one of the most challenging times for parents and therefore, being equipped with basic knowledge, and instructional resources, such as the social stories, is an advantageous new method of independent learning for parents with intellectual disabilities as these parents may not always have access to community outreach services. Social stories promote autonomous skill development and the goal is for the parents using these to become confident in their abilities to care for their child(ren). Social stories are similar to parent training manuals in that they provide the necessary information and are always available to use; yet dividing the information from the manual into multiple short stories is far less intimidating than simply handing the parents a training manual and expecting them to find the answers to their questions.
Recommendations for Future Research

If further research is conducted on this topic it is strongly recommended that the creation of the social stories be completed while still working with the agency in order to test their usefulness with clients, and to determine their overall value while working with adults with intellectual disabilities. Following that, it is also recommended that a questionnaire be developed and completed by clients in order to obtain supporting evidence of the effectiveness of social stories used in this type of setting.
References


References for Social Stories

Friedman, J., MB., ChB, FRCP(C), FAAP (2009). Canada’s Toddler Care Book. The Hospital for Sick Children. Robert Rose Inc. Toronto, ON.


http://www.babycenter.com/
APPENDIX A

Feedback Questionnaire

1. Do you feel that these social stories would be useful when working with parents with intellectual disabilities who have a newborn baby?

Yes! They were clear and well illustrated.

2. Would you use these social stories when working with parents with intellectual disabilities on learning basic parenting skills?

Yes. I printed the “dealing with stress” story right away, for use with a particular parent I am working with. Pictures and step by step instruction work best for this Mother.

3. Do you feel that the information provided in these social stories is written at the appropriate level for individuals with intellectual disabilities?

Yes. The Mother that I am working with cannot read, however, I am certain that if we read them together a few times, she will preserve the information.

4. Do you feel the information provided in these social stories covers many of the most important concepts within the basics of parenting a newborn baby?

Yes. Attachment, eating, sleep, diapers, play, parental stress management….well done. Could add, “Is my baby sick”? and “Does my baby have colic”?

5. Would you feel comfortable leaving these social stories with new parents with intellectual disabilities in order to promote independent learning of these basic concepts? (Please note: these social stories were designed to be used initially in conjunction with consistent in-home training with a professional, and then left with the parents to use autonomously when they have questions, or are unsure of something).

Yes. Some of my parents would clearly benefit from having info presented in this way.

6. Is there anything you would add to, or change about these social stories in order to improve them for the targeted population of parents with intellectual disabilities?

I might add some pages about getting help by calling their Physician and Public Health, with phone numbers, if they have questions/concerns. Also to call friends and family for moral support, with a space for phone numbers as well.
Feeding my Baby
Sometimes my newborn baby will cry when they are hungry.
When I feed my baby I need to first measure out how much formula they need, then mix it with water, and heat it up.
At my baby’s doctors appointments, the doctor will tell me about my baby’s growth, and how much they should be eating.
It is important that I do not give my baby more than 32 ounces of formula a day.

It is important that I hold my baby properly when they are eating so that they do not choke.
I can do this by holding my baby close to my body and making sure their head is supported.
When my baby is finished eating I need to burp them.
To burp my baby I should place my baby’s head over my shoulder and gently pat their back.
Every baby is different, but most babies need to eat every 2-3 hours.
Babies are like us; sometimes they will be hungrier than they usually are, and sometimes they might not be hungry at all.
I can keep track of when and how much they are eating by writing it down in my baby journal.

I will write down what time they eat and how many ounces they eat.
Keeping track of my baby’s eating will make sure they are healthy and happy.


BabyCenter.com
Sleep and Sleep Schedules
My newborn baby needs a lot of sleep because it is important for their health and growth.
In this stage they will need 16-17 hours of sleep a day.
The longest my baby will sleep in between feedings is about 4 hours.
Even though this will be tiring for me, it is very important that I respond to my baby when they wake up.
I should help my baby learn when it is daytime, and when it is nighttime.
During the daytime I should try to keep them awake duringfeedings.
During the nighttime I should try to be quieter and keep the lights low.
I can also start a bedtime routine for my baby by feeding them, changing them, cuddling with them and putting them to bed.
Learning my baby’s cues will help me get to know when they are tired.
Sometimes baby’s will rub their eyes or become more fussy than usual.
I can keep track of when my baby sleeps and for how long they sleep
for using my baby journal.

I will write down what time they fell asleep, and how long they slept.
Keeping track of my baby’s sleep will make sure they are happy and healthy.


BabyCenter.com
Diaper Changing
It is important to change my newborn baby’s diapers as soon as I notice they are dirty.
Every baby is different but most newborn babies will go through 8-10 diapers a day.
The kind of diapers that I use is a personal choice. I can choose from disposable diapers which I use only once, cloth diapers which I use, wash, and use again, or a mix of the two which has both disposable and reusable parts.
The instructions for how to change my baby are as follows:

First, I need to wash my hands.
I need to make sure the area where I am going to change my baby is clean.
I need to make sure I have everything I need to change your baby’s diaper close by. The items I will probably need include: baby wipes, diaper cream, clean diapers.
I need to make sure that my baby is not able to roll away from wherever I am changing them.

While I am changing my baby, I should talk to them or mimic their sounds. This is a perfect chance to bond with my baby one-on-one.
Next, I undo the tabs of my baby’s dirty diaper and gently lift my baby’s bottom up by holding their ankles.
Then take off the dirty diaper and use baby wipes to wipe my baby’s bottom. If I have a baby girl, I need to make sure to wipe from front to back.
Then I place a clean diaper underneath my baby’s bottom and make sure the tabs of the diaper are on the backside.
Pull each tab from the back of the diaper and Velcro it to the front.
After, I should check to make sure that the diaper is snug but not too tight.
Also, check that my baby’s diaper is pulled up to their bellybutton, only after their umbilical cord stump has fallen off.
Finally, I dress my baby again and wash my hands well.
Comforting my Baby
Sometimes my newborn baby cries when they want to be held.
I should go to my baby right away when they cry.
I should pick my baby up with a smile on my face.
I should talk to them to make them feel better because the sound of my voice is comforting to my baby.
If I do the same thing each time I go to my baby they will learn to trust me.
I can comfort my baby by picking them up and walking around with them in my arms.
I can sing or hum to my baby.
I can offer them a pacifier.
Once my baby stops crying, I can put them down in their crib and continue with what I was doing.
Sometimes my baby will continue to cry even after I have done everything I can do to comfort them.

When this happens, it is okay; sometimes babies just need to cry.
Comforting my baby is important because it is a special time for me and my baby to bond.
Playing With my Baby
Playing with my new baby is very important.
Playing with my baby will help them learn new things and make sure that we are bonding.
Babies are never too young to play.
I can play with my baby in many different ways.

I can sing to my baby.
I can use “happy-talk,” which is when I mimic my baby’s sounds and talk with them; this helps them learn to communicate.
I can gently lay my baby on their back and play “peek-a-boo” with them.
I can listen to read-aloud books with my baby.
I can use sensations with my baby by placing soft objects around them with different textures for them to touch and feel.
I can pick my baby up and hold them or sit with them in a rocking chair.
Also, holding my baby close makes them feel happy and safe and I should make sure I am doing this often.

These are all ways that I can bond with my baby and this is important for our relationship.

Friedman, J., MB., ChB, FRCP(C), FAAP (2009). Canada’s Toddler Care Book. The Hospital for Sick Children. Robert Rose Inc. Toronto, ON.

BabyCenter.com
Coping with Stress
Being a parent is stressful.

Newborn babies especially need a lot of care, time, and attention.
It is important that I remember that it is okay to ask for help if and when I need it.
There are also things that I can do myself to help me deal with the stress I am feeling.
When I wake up, I can make a list of 2 or 3 things that I want to focus on during that day.

Daily List - Wednesday

1. Clean the bathroom
2. Walk the dog
3. Do the dishes
Doing this may help me feel more organized.

Also, when I do what I had planned to do for that day, it can help me deal with worries that I might have or stress that I may be feeling.
Another way that I can deal with my stress is by exercising.
I can go for long walks.

I can go for a light jog.
I can go to my local gym and workout.
Another way that I can make myself feel less stressed is to make sure I get enough sleep.
This means trying to get most of my sleep during the night.
Then, taking a nap or two during the day while my baby is also napping.
Eating healthy is very important for dealing with stress.
I should make sure that I am eating at least 3 meals a day.
I should avoid eating a lot of junk food and save my favourite unhealthy snacks as treats to have once in a while.
I will be a better parent to my baby if I am healthy.