

Working With Children Having Multiple Disabilities: A Practical Guide

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This is to certify that the thesis prepared

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Abstract

The aim of this investigation is twofold: (1) to explore best practices with regards to teaching students with multiple disabilities in a formal and informal learning environments (2) to create a practical guide for individuals who work with this target population. As a production and evaluation thesis equivalent, the methodology utilized for the data collection and evaluation is based on an action research model in which I collaborated with experts and practitioners in the field to acquire better knowledge and understanding of what techniques and strategies work best in teaching children who have a multiple disabilities. Employing an interactive/iterative approach, I used a combination of the initial questionnaire, interviews and literature searches to provide the content for the creation of a practical manual for field workers. This manual is comprised of a compilation of teaching techniques and strategies obtained from the data collected as well as examples of best practices as identified by those professionals who provided feedback. In the first phase of developing the manual, data were gathered and analyzed and a first draft was completed. An evaluation was then undertaken with experts in the field as well as others working with this population to review it and point out any inconsistent/missing information, lack of coherence, or problems with regards to how information was presented. These comments were then incorporated into a revised text that was submitted, once again, to experts in the field for a final summative evaluation in English and its multiple translations (French, Spanish, Quechua). The final edited manual will be published in the form of a practical guide that will be made available to professionals, volunteers and parents

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CHAPTER 1

INTRODUCTION AND BACKGROUND

Having had the opportunity to travel and volunteer my summers working with individuals with disabilities in Cusco, Peru, as well as being personally engrossed in the technologies of our day, it seemed only fitting to develop a related project that was technology centered. The goal was simple enough, or so I thought, connecting people through technological means in both Canada and Peru in an educational and interactive capacity. Although technology would end up being a small part of the second stage of my Master's project, it became evident that a reliance on technology and infrastructure (internet) was not only unfeasible but was seen as culturally unimportant (except for Facebook). It took the rest of the eight weeks of my initial stay in Peru to ponder and work with the people there in an effort to devise a project that might contribute to the greater wellbeing of others.

After initial inquiries and discussions with the local population as well as people back in Canada, the idea of creating a manual for individuals working with the multi-disabled population became even more of a reality. The goal of this manual, which remains true to this day, was to provide valuable hands-on information for individuals working with this population in a productive and time efficient way. Although academic research has played a role in the creation of this manual, the majority of the information gathered has come directly from people (lay persons and professionals) working or having contact with children having multiple disabilities by means of a questionnaire and interviews. As reflected in the caregiver approach promoted by the manual, the aim was to provide these students with the added individual and group attention that they need in order to achieve their potential and develop effective ways of communicating and functioning in their various educational and social settings.

This introduction begins by defining the target population for this project, and then identifies three of several key issues that needed to be addressed for the creation of the Manual: learning environments, communication, and support to teachers and caregivers.

Defining the Target Population

Before addressing the above three cited issues, one needs to define one's target population. Creating a manual for practitioners thus began by identifying the key stakeholders. This starts with defining who the students are with whom they work. Essentially, they are children and young adults who are 'diagnosed' with one or more impairments ranging from minor learning impairments to more pronounced impairments such as autism or visual impairments.

Parentcenterhub.org (2018) defines a person who is multi-disabled as having two or more disabilities and who require extensive and ongoing treatment. Usually the disability encompasses voluntary or involuntary motor function, cognitive functioning and any other sensory problem such as hearing or vision.

Although teachers, staff and caregivers are not the ones making a formal diagnosis of an individual's disabilities, they nevertheless play an important role on a practical level as they communicate and work with these children and young adults on a daily basis. The Diagnostic and Statistical Manual of Mental Disorders (DSM) is the most commonly used tool for diagnosis, and ought to be administered by a psychiatrist or professional who is trained in its use. However, individuals working with this population usually relay critical information (behavioral, cognitive functioning) about the child in order for a diagnosis to be made. For example, the criteria used to assess autism still depends more on the use of behavioral cues than strictly scientific criteria that emphasize cognitive deficits, neurological disorder, and even genetic factors (Baron-Cohen, Leslie, & Frith, 1985). In other words, those diagnosing multi-impaired and visually impaired children use behavioral cues (e.g. sleep disorders, aggression, agitation, self injury) as these children display more developmental disorders than those having single impairments

(Ageranioti-Bélangier et al, 2012; Alimovic, 2013; Good, Jan, Burden, Skoczenski, & Candy, 2001). Given these circumstances, teachers and other workers dealing with this population play an important role in both the assessment and treatment process. Furthermore, for a diagnosis to be valid, it is paramount that teachers and workers involved in the process work with other key stakeholders such as parents, other professionals and administrators with whom they can share diagnostic information or knowledge of particular issues that involve a student with impairments. This will, in turn, not only help them to convey more accurate information regarding these children but also to help educate themselves and other individuals working with this population.

An objective of the Manual is to provide caregivers with a deeper knowledge of the type of information that can be useful for anyone dealing with autism and other impairments, either at the diagnostic stage, and/or in the design and implementation of effective interventions. Firstly, they can use this information to acquire a better understanding of the disorder and the persons involved. Secondly, when working with other workers such as psychologists, mobility instructors, speech pathologists etc., a teacher or worker will be able to analyze and explain certain behaviours more accurately, especially if they know the terminology and context in which it is applied. For example, the term visual impairments or low vision is referred by the American Association for the Blind as any individual who is not able to function or has a reduction in daily activities due to a decrease in vision. Other types of visual impairment include being legally blind (vision loss equal or less than 20/200) and total blindness. Furthermore, the American Foundation for the Blind (2017) categorizes and defines visual impairment in a more detailed and extensive manner that includes many other criteria. Understanding these criteria enhances better communication and action in the field.

Learning environment

The environment in which teaching occurs was originally considered by this author as being an important factor in the learning process involving students with disabilities. Although

accentuated in the original proposal, subsequent research and feedback from project participants indicated that this was not as significant a factor as initially anticipated. Nevertheless, the context in which learning takes place can influence outcomes, and, as such, has been duly acknowledged in the literature. More importantly, Hofstein and Rosenfeld (1996) have suggested that learning contexts should be ‘mixed’ in order to enhance the learning experience. Essentially the “formal” setting is one in which a teacher is in charge of a classroom and where there is a formal curriculum, and the “informal setting is where the content is not fixed and possibly un-sequenced and where attendance is usually voluntary. The problem of clearly defining such settings is often left to interpretation given that it can be difficult to distinguish between the two as both formal and informal learning can take place in both environments and are often complimentary (Eraut, 2004; Boekaerts & Minnaert, 1999).

With regards to this project, I gathered data from professionals and laypersons in both formal and informal learning environments. The greater number of responses came from formal learning environments partly due to the fact that the majority of participants solicited were from a formal setting. Although much of the information in this manual has been gathered from a formal teaching environment, any individuals working with children in an informal setting can also use these techniques.

Communication

According to Frymier and Houser (2000), communication between a teacher and a student is vital to the acquisition of knowledge as well as to the proper functioning of the classroom. One of the main issues in working with students having multiple disabilities is the fact that communication between the teacher and student is often hindered by a lack of ability by the latter to communicate in conventional ways i.e. speech, vision, and physical and mental delays (Blockberger & Johnston, 2003; Blockberger & Sutton, 2003).

As this is not a simple process and requires innovative techniques in overcoming the obstacles that present themselves, an analysis was made of best practices and evidence based approaches that have been successfully implemented by the participants solicited. The use of augmentative and alternative communication and the role of technology were also explored with regards to facilitating and enhancing the exchange of information between teacher and student. As more amply described in subsequent sections of this paper, communication was found to be a major topic that the participants in our study considered important when working with children having impairments.

Support to Teachers and Care-Givers

Another important issue in working with the multi-disabled relates to the pressures placed on professionals and support personnel that affect their ability to do their job. In a guide produced by Bettini, Cheyney, Wang, and Leko (2015), particular attention is given to special educators and how they can and should be supported by the administration of a school. Attention is also placed on how to retain the services of these special educators who play a vital role in the process. Valli and Buese (2007) go further and develop a theory that in certain parts of North America, legislative changes in the law have impacted teachers and students negatively. They state that, overall, there has been an increase in the degree of responsibility as well as the intensity in four areas of the profession: instructional, institutional, collaborative, and learning. What this means is that anything from the curriculum content covered in class to the expectations placed on teachers to work cooperatively can be challenging because of a lack of adequate support structures. I will close this chapter with the overall rationale for the manual.

Rationale for the Framework of the Manual: Why Have a Practical Guide?

In recent years, the proliferation of a large number of online resources has further increased the ability of individuals working with this population to have access to a wide array of information regarding special education. A great example of this can be seen on the Ontario

Teachers Federation webpage (<http://www.teachspeced.ca/teaching-strategies-students-special-needs>). This resource breaks down the large amount of information into three categories.

Students Needs, Exceptionalities Determined by the IPRC and Diagnosed Medical/Psychological Conditions. Although this project's manual does not have the kind of detail that can be found in online resources such as the one cited above, it does add a practical dimension to certain key ideas and strategies that are useful in working with children having visual impairments, autism, and multiple disabilities. Furthermore, as an online resource, this important information will not only reach the local community but an international one as well. This allows for community and country-specific strategies to be shared across borders. An example of this can be seen in the work undertaken by Bondy and Frost (1993) where the 'Picture-Exchange Communication System', commonly used in the United States, is brought into a Peruvian context. This system uses the child's ability to track and imitate which can be difficult to use when working with autistic individuals. If such information was not freely distributed via the internet, most practitioners would be guided in their work only by the potentially limited resources offered by their immediate environment. On the same note, it seems important that disorders such as autism should be examined and observed in terms of what respective cultures have to offer one another with regards to systems of communication and strategies in working with special needs individuals (Dyches, Wilder, Sudweeks, Obiakor & Algozzine, 2004)

In the next chapter I discuss why a practical manual would be useful for those working with children having multiple disabilities, including practical applications for select circumstances. The research strategy and method, data collection and analysis, and the formative and summative evaluations will also be highlighted.

CHAPTER 2

RESEARCH METHOD, DATA ANALYSIS AND EVALUATION PROCESS

Practical Application of the Manual

As mentioned above, there are numerous research studies that have been done with regards to working with this particular population. The majority of them, however, are either purely academic in nature or end up in textbooks that present a prodigious amount of information with little reference to practical application. When teachers are hired to work with this population, they do not necessarily have hands-on experience in working with children having multiple disabilities (Mader, 2017). Providing them with best practices that have been obtained from experienced individuals working in the field is an added bonus that this manual offers as compared to what appears to be available on this subject.

The availability of a ‘small manual’ that a teacher can easily read and comprehend can greatly facilitate how effectively they are able to utilize best practices and implement well researched techniques and strategies. Additionally, the manual will make available downloadable charts and checklists that will provide teachers with the extra ability to adapt the manual content to each of their unique cases. These checklists are discussed and outlined below and can be found on ilovetolearn.ca.

Research Strategy and Method

Creating a best practice guide for teachers and professionals working with a multi-handicapped population posed challenges given the fact that there are few such practical guides available and that there is not a great deal of information on the important elements that need to be addressed. As such, it was felt that an exploratory research method soliciting the input of experts in the field would best serve the purpose for this project in providing much needed insight on the topic.

There were three main methods that were used to gather data for this English version of the manual: reviewing available literature, having professionals in the field answer a questionnaire and conducting in-depth interviews with these same individuals. The bulk of the literature review was done prior to the start of this project in order to ascertain whether or not the manual would add to the existing body of knowledge and its usefulness in the field of special needs. The second part of the research consisted of obtaining information and feedback from professionals who were working or had worked with a special needs population. The initial literature review informed the design of the questionnaire and interview protocols for this second stage. Subsequently, formative and summative evaluations were undertaken on drafts of the Manual to validate the findings. The data collected using this flexible approach ensured that the guide would be both scholarly and practical. As well, it should be noted that given the employment of a form of action research (Creswell, 2015), the author made use of both input from key stakeholders, as well as his own knowledge and experience in the formulation of the questionnaire and the subsequent analysis of the data obtained.

Population and Sample

The population that was utilized in this study was not randomly selected for logistic reasons and feasibility. In keeping with exploratory research methods, a convenience sample of 26 participants comprised of professionals, volunteers and parents was selected based on their involvement with individuals having multiple impairments. In certain cases, individuals (e.g., nurse, gym teacher) who could give their professional advice on certain aspects of the manual were also asked to participate. The following is a breakdown of participants:

Formal Teaching Setting (21 Participants)

1. Classroom Teacher (4)
2. Special Needs Teacher (6)
3. Itinerant Teacher (2)

4. Gym/Swim Teacher (1)
5. New Teacher (1)
6. Child Care Worker (1)
7. Préposé aux Bénéficiaires (1)
8. Volunteers (2)
9. Nurse (1)
10. Computer Technician for Visually Impaired Student (1)
11. Music Specialist (1)

Informal Teaching Setting (5 Participants)

1. Red Cross Life Guard/ Swim instructor (1)
2. Parents/Family Members (2)
3. Volunteer (1)
4. Special Needs Coordinator (1)

Sampling Rationale. Many of these participants were contacts that I had made over the years working in the field. On my many trips to Peru, I was also able to solicit the help from the Director of the “CATÓLICA DE CUSCO” association as well as a few individuals working in various centers that work closely with children having autism and other impairments.

Subject matter experts were also recruited from both formal and informal learning settings as this manual was meant not only to be used by professionals and paraprofessionals, but by other individuals such as parents and volunteers who work in various ways with these individuals.

Sampling Procedure

The first step taken was to contact various individuals to see if they wanted to be part of this project (Appendix 1). This included teachers, CCW’s, and other professionals who were working with this population at the local and international level. Parents and volunteers from various organizations and support groups were also recruited as participants.

Constructing a Questionnaire

The questionnaire (Appendix 2) comprised of four sections dealing with the physical, emotional, behavioral and developmental areas affecting learning was informed by some studies that describe the importance of certain key variables (e.g., physical space) and how they relate to the personal, social and overall development of a child having disabilities (Missiuna & Pollock, 1991). Ultimately, the formulation of these questions was based on previous literature and on my professional experience in the field, including numerous discussions and exchanges that I have had over the years with teachers and other individuals working with this population.

Data Collection, Methods and Protocols

Each of the 26 participants were given a questionnaire followed by an interview in order to expand on their written answers. With respect to submitting and receiving the data from the participants, the use of email, person-to-person contact and/or Skype were predominantly used as means of communication. Once the data were collected from the administered questionnaires the content was recorded in Dedoose.

Process

The following is an overview of the process of contacting the participants and the process of obtaining the data:

1. In mid 2015, participants were contacted by email, telephone and in person in order to discuss the research being conducted (Appendix 1). The participants included teachers, CCW's, volunteers, caregivers and other professionals in both Canada and Peru. These individuals were known to me personally or were referred to me through various contacts.
 - These individuals were asked to participate in an exploratory study to obtain their best practices and opinions with regards to their work with children having multiple disabilities.

2. Once they agreed to participate they were sent (via email, person to person or courier) the Questionnaire and a consent form (Appendix 2).
3. By the end of 2015 most of the questionnaires had been completed and were returned to me in person, by courier, or email and were numbered to ensure confidentiality. The data were entered into an online research tool called Dedoose.
4. It was later decided that it would be simpler to organize the data into an excel spreadsheet format instead of continuing to use Dedoose (Appendix 8).
5. By August 2016, as the data were being organized (see below) and the framework of the manual constructed (Chapter 3), interviews were scheduled with the four participants that agreed to take part in this process (Appendix 3).
6. The process of writing the manual began in September of 2016 by using a free template taken from thebookpatch.com (Appendix 6 & 7).
7. By the end of 2016 the first draft of the manual was complete. I took the next month to review and edit it. By January 2017, participants were asked to complete a formative evaluation of the manual itself (Appendix 4). They were given a hard copy of the manual on which they could make corrections, suggestions and leave comments. The formative evaluation comments were then integrated into the manual.
8. Around February of 2017, the English manual was given to the Spanish and French translators to start the process of translating it into Spanish.
9. By June 2017, the modifications were finalized, a PDF version of the English manual was handed back to the participants. A link (<https://www.surveymonkey.com/r/5DHQXBR>) to a survey Monkey Summative evaluation form was also sent to them with the grading rubric (Appendix 5).
10. At this point, any final revisions made to the English Manual were given to the Spanish and French translator.

11. Once the Spanish translation was complete it was given to a native Peruvian living in the United States to translate the Spanish version into Quechua.
12. In July and August of 2017, I was in Peru and had the chance to have an administrator, psychologist and a professor of Quechua studies review the Spanish and Quechua version of the manual. This was done in the same way as the other summative evaluations.
 - During the same trip to Peru, I was brought to the Ministry of Peruvian Education in Peru to submit the Spanish and Quechua versions of the manual so that the ministry would get it approved for use in Peru (Appendix 12).
 - In April 2018, the manuals was officially accepted by the Peruvian Ministry of Education in Cusco (Appendix 13).

Materials and Protocols Utilized

The materials utilized in this research consisted primarily of the following:

1. Consent Form: The consent form was given to the participants prior to their completing the questionnaire.
2. Questionnaire: The questionnaire, consisting of 4 main topics, was given to the participants in either hardcopy or email.
3. Dedoose: Dedoose is an online data research platform that was used for the preliminary data entry. It was later decided that the data would be entered into an excel spreadsheet in order to simplify the process.
4. Microsoft Office: Microsoft Word was use for writing the manual and an Microsoft excel was used for organizing the data into an excel spread sheet.
5. Interview Forms with Questions: The interview forms and questions were given to the participants either in person or by email.

The following is an overview of the protocols utilized with regards to the contacting and interviewing of participants and the evaluation of the English and translated versions of the manual:

1. The consent to participate form was used to discuss the project as well as to give the participant the consent forms needed to participate in this project (Appendix 1).
2. The main questionnaire and consent form was given to each participant in either hard copy or electronically (Appendix 2).
3. The formative evaluation instructions and rubric were given to participants along with a copy of the first draft of the manual. This was done either by hard copy or electronically (Appendix 4).
4. The summative evaluation instructions and rubric were given to participants after changes resulting from the formative evaluations were integrated into the first draft of the English and translated versions of the manual. Participants were asked to review the manuals once again and give a final 'mark' based on the same rubric that was used for the formative evaluation (Appendix 5).
5. The Summary Protocol Form (SPF) was required by Concordia University to be completed and submitted prior to the start of this research project in order to assure that all ethical considerations were respected (Appendix 11).

Responses and Results

All of the participants to whom questionnaires were sent, responded by providing detailed feedback on each of the 4 themes presented. The information retrieved from the responses to the questionnaire was recorded in a content analysis using Dedoose. The initial coding, as depicted in the Analysis of Data section below, required me to look at these responses and find key ideas and phrases (e.g scheduling physical activities for students and create a safe and confidential place in the classroom so students feel safe and express themselves) that could later be used to

organize these themes within the manual sections. Ultimately, this process resulted in 100 codes being extrapolated from the responses received. It should be noted that some ideas came up frequently such as the importance of communication as well as the emotional state of the child which facilitated the further shrinking of the codes to 27 and 8, a number that seemed far more reasonable and manageable.

Although most of the information was obtained from the questionnaire, literature and personal experience, I wanted to see if there was any other information that would prove useful for the manual. Using the interview protocol (Appendix 3), I conducted 4 interviews with professionals that had been working in the field for a combined 70+ years of service. The results are presented in the Follow up Interviews below.

Analysis of Data

The following provides a step-by-step process in how the data were analyzed:

1. The data were entered by me, the researcher, within Dedoose and the categories were chosen based on what I had found to be the most prevalent and reoccurring topics that the participants had mentioned in their responses. The data contained in Dedoose were coded by me using over 100 different themes such as 'flexibility, vigilant, posture'. I further reduced these categories in an attempt to pull together the practical applications for which the data could be used for. This resulted in 27 new categories/themes: curriculum and evaluation; emotional wellbeing; physical and mental wellbeing; team work; music; routine; explore; stimulation; nutrition; teaching personnel and responsibilities and tips; classroom; social; activities and games; genuine; meaningful learning; goal setting; student centred; questions; giving your students a voice; respect; lead by example; safe and comfortable environment; communication; behaviour; miscellaneous; students having visual impairments; devices and equipment.

Due to time constraints and scheduling, it was hard to find someone who was available to be a second 'coder' and who was willing to go through all the information and code it. Given this situation, I did find one individual who was experienced in working with children having disabilities and who was willing to 'review' my coding and suggest alternative ways of organizing the data. She commented on the fact that many of ideas and comments submitted by the participants did overlap and could be placed in other categories. An example of this can be seen in one of the comments made by a participant - 'Teach the students how to communicate and interact socially'. Appropriate ways to communicate.' Her comment was that this could also be placed in the Long-Term care chapter of the manual.

2. At this stage, I was faced with the dilemma of how to frame the manual. This resulted in my creating 8 themes or categories (physical and learning environment; pedagogical orientation to enhance learning; teaching strategies and techniques; adaptive measures and tools for learning; Curriculum development and evaluation; physical, emotional and psychological condition of students; conditions that enhance the physical, emotional and psychological well being of students). My rationale for reducing these themes from 100 to 27 to eight and then finally to 6 was to simplify and make sure that all the data obtained in the questionnaire was represented and reflected in the manual in a comprehensive yet simple way as to not overwhelm the reader. It is important to note that although the same reviewer did briefly review the code refinement process, it was only until the last six themes were coded that she had more time to go through all the comments and data as well as to make sure that the categories themselves were an accurate reflection of the reality of working with individuals having multiple impairments.

3. At this point I was still at an impasse. Although the themes from the data were contained in these eight categories, I felt that the ‘manual’ categories needed to be organized in a way whereby each category would lead into the next one, creating a document that would flow more coherently. Fortunately, I came across an online blog by Steven Handel (2009) that discussed ‘six aspects of a balanced person’. This article resonated with me because of how simple and straightforward the categories sounded (Physical, Mental, Emotional, Social, Work/Financial, Spiritual), as well as how it seemed to touch upon all the main aspects of an individual’s life. These categories also seemed to validate what I found to be important in working with children having multiple impairments.
4. It was because of this holistic framework that I decided to re-organize and combine these blog categories and the eight themes cited above. Social was turned into communication given that communication is the underlying way that social interactions are manifested. Spiritual - personal growth and actualization were both seen as intrinsic motivators for leading a fulfilled life. Finally, financial and long-term care were combined due to the fact that when individuals having multiple disabilities progress through life, concepts of ‘finance’ and daily living are extremely important concerns.
5. This exercise resulted in a final six adapted categories (communication, emotional needs, physical space, mental health and wellbeing, personal growth and actualization, long-term care) which were eventually utilized in the guide as the primary areas of intervention by professionals. The same person as mentioned above was asked to review the data table (Appendix 8) with these final categories. Her comments stated that much of the information could be placed in other sections of the manual. For example, the comment “family’s involvement and support, learning ASL.’ was placed in the ‘communication’ section of the manual although the reviewer said that they could also go

into the 'long term care' section. I would even add that this comment could go in any section of the manual.

6. At this point it was important to me to run these categories by another person to see if they flowed well and touched upon the main important topics outlined in the manual. An interview with a colleague that had worked with this population for more than 40 years mentioned that these six categories did in fact encapsulate all the information and allowed for an easy simplified read and holistic way of working with this population. This person was chosen because of the many years spent in the field and their experience in dealing with similar issues affecting this population.

Follow up Interviews

Follow-up interviews were conducted with four participants in an attempt to gain added or extra information once the initial data from the questionnaires was received (Appendix 8). It should be noted that the persons interviewed were selected for their expertise and experience in the field with regards to providing insight as to the holistic nature and usefulness of the manual categories. This input was very useful as it provided in-depth information about the categories retrieved from the formative evaluations. All four interviewees were given the interview protocol in written, electronic or oral format (Appendix 3) and their input is as follows:

Interview #1. One of the first interviews conducted in March of 2016 was with a teacher having more than 40 years of experience working with this population. The main purpose for this interview was to have an expert in the field review the manual categories and comment on why these categories were important. She found communication to be noteworthy because of its most underlying importance in everyday interactions. Emotional needs, was found to be important because these children, like all humans, need to feel like they are being heard and understood. Physical space was deemed important because everyone needs to be ware of their environment, even if minimally. Mental health and wellbeing were found to be important because of their

importance in learning. Furthermore, it would be hard for an individual to focus on learning if they were found to have mental health problems. Personal growth and actualization were considered important in allowing these individuals to feel a part of their society and they can take a part and have a role in their environment. The last category was long-term care which is often ignored until it is too late. Although the original questionnaire did I not have any specific questions regarding long-term care, it is an important topic for all individuals working with individuals with multiple impairments to work towards and consider.

Overall this participant found these categories to be important in creating a holistic framework for working with individuals having disabilities.

Interview #2. Conducted in October 2016, the main objective of this interview was to provide further validation to the manual's categories. Communication was thought to be important because it helped create an atmosphere centered on their learning as well as creating ways to interact with the individuals focused on their language capabilities. Emotional cues were found to be important to find appropriate tools and measures of intervention for the child's emotional wellbeing. Understanding the physical space and boundaries that the individual will accept is important in order to allow proper functioning within any given environment. Mental health and wellbeing are important because individuals with multi impairments can be extra sensitive to their surroundings and are therefore susceptible to mood fluctuations. Personal growth and actualization requires extra patience because, although a slow process with individuals having multiple impairments, all individuals feel like they have grown and achieved their goals. Long-term care is a big stress for caregivers and others working with individuals having multiple impairments. Tackling this early on can reduce stress and better prepare the individual to move on to other programs. As in the first interview, a holistic way of working with this population was seen to be important.

Interview #3. Also conducted in October 2016, this interview was conducted in order to see if the sections of the manual were valid. Communication was seen to be important because aside from promoting all other sections of this manual, it gives the client and workers a way of exchanging messages and communicating. Focusing on emotional needs allows the individual to develop positive emotions instead of self-destructive ones. Sometimes, physical environments can be taken for granted as not being important. It is important to know that individuals perceive their environment differently; we can facilitate a proper working environment (i.e. temperature, lighting, etc.) knowing that mental health and wellbeing affects how the individual views themselves. Unsupported mental health can lead to negative and destructive outcomes. Personal growth and actualization allows individuals working with this population to try and access an individual's strengths to improve their environment and circumstances. Long-term care is important because of how it is fundamental in a holistic framework. A social worker should be involved with individuals having multiple impairments in order to make sure that proper services are given to them.

Interview #4. Conducted in October 2016, this interview focused on the question: "what competencies do you find our children need to develop safely in their environment?". She stated that establishing communication with the student is important in order to interact safely with their environment. Life skills such as going to the grocery store can also be very important for individuals that may have difficulty with daily life skills.

Focus Groups

Due to a lack of participants being able to participate, it was decided not to utilize focus groups as originally planned.

Formative and Summative Evaluations

According to Garrison and Ehringhaus (2007), formative evaluations differ from summative evaluations in that the formative evaluation is supposed to be conducted in order for the learners

to obtain feedback on their learning process. Summative evaluations are meant to evaluate intermittent points or ‘benchmarks’ within this learning process. In the early development of a program, formative evaluations are very useful in providing information that can assess whether a program or intervention addresses a significant need (Stetler et al., 2006). When a program or project is terminated, a summative evaluation (or ex post) is important in determining whether the initial goals and objectives have been achieved (Evaluation Toolbox, 2010).

With regard to this manual, a formative evaluation was given to participants in order to obtain their feedback in the form of comments, suggestions and to propose possible changes that they thought would refine the manual for me the ‘learner’. The summative evaluation was conducted after all the revisions from the formative evaluation were considered and/or implemented within the manual and was to confirm that these changes were accurate. The rubric (see Appendix 4 & 5) was used for both the formative and summative evaluations respectively and was created by me and based on my professional experience as a teacher as well as by comparing examples of other online rubrics. There are seven main areas of the rubric on which participants based their final grades:

1. Organization: The organization of the manual focused on making sure that the breakdown of the manual was organized in a way that allowed the manual to flow from section to section as well as to make sure that all sections were relevant to this practical guide.
2. Quality and focus of information: This section was meant to see if all the relevant topics had been addressed as well as all questions answered.
3. Amount of Information: This manual was meant to be small and compact as well as practical and informative to the reader. The amount of information included or excluded was important to get feedback on.

4. Sources: It was important for me to have the evaluators comment on the amount of information received from the literature and if it was adequately sourced for this manual.
5. Mechanics: The mechanics of the manual had to do with the syntax of the manual and how it was written. This section is important in any newly written document.
6. Diagrams and illustrations: Considering that this manual was meant to be compact yet informative to the reader, the amount of space allocated to pictures and tables was an important consideration.
7. Usefulness: The overall usefulness that the evaluators thought this manual would be in a working or home environment was paramount in the entire creation of this manual.

Results of Formative and Summative Evaluations

Fourteen participants returned evaluation rubrics submitted to them as part of the formative evaluation process. Although the original 26 participants were asked to participate, due to time constraints, there were a few individuals that were not able to respond. It was for this reason that I asked a few other professionals in the field to evaluate the manual. As mentioned above, the main goal in having the participants submit a formative evaluation of the manual was to get feedback on its content, structure and organization. Each participant was given the same rubric and instructions (Appendices 4 and 5) requesting them to review the manuals and to note any inconsistencies as well as to suggest improvements to the actual text. Participants were also instructed to add any comments, corrections, and suggestions in the manual as well as to mark the rubric. The process of the summative evaluations started with my transcribing the written instructions into an email and the rubric into an online survey platform (survey monkey: <https://www.surveymonkey.com/r/5DHQXBR>). This was done in order to streamline the process of administering the summative evaluation. Considering that the evaluators did not need to write

their comments on the manual and the main goal of the summative evaluation was to mainly get a ‘final grade’, it was also more practical and efficient to send a link. The same rubric was used for both the formative and summative evaluations. The link was sent to participants and a total of 11 responses were later collected and reviewed.

An analysis of the data collected and the changes made to the manual are also provided (Appendix 9). The following is a summary of the results obtained from each category:

Organization. Within the context of this project, the organization section of the rubric refers to ‘The manual is organized and well constructed. (From cover to cover, how does the manual flow, i.e. chapter breakdown, general structure of the manual?)’

The formative evaluation showed that the majority of respondents were satisfied that the manual was organized and constructed well and reflective of the above definition of organization. Participants commented on such things as the manual being clear, easy to read and well organized. In response to a comment about the conclusion needing to be more definite, the conclusion was adjusted in order to make the conclusion as concise, informative and final as possible.

The final summative evaluation, consisting of 11 respondents, stated that they ‘strongly agreed’ that the organization of the manual was well organized and constructed. There was one participant that did not mark this section.

Quality and focus of Information. Quality and focus of information referred to whether or not ‘All topics are addressed and all questions answered (Are all important topics and questions present and thoroughly answered to the best of your knowledge)’. Of the 14 formative responses obtained with regards to the quality and focus of information section, one response suggested that the definition section should contain more detailed definitions. This resulted in my combining both the definition and resource section of the manual into a table format which will provide the reader with the definitions as well as the professionals that may be involved and the

corresponding resources (Appendix 15). The following is the table that appears within the English manual.

	Definition	Professional/Layperson Involvement	Resources
Attention deficit hyperactive disorder	Attention-deficit/hyperactivity disorder is characterized by individuals (childhood through adulthood) struggling with chronic hyperactivity, impulsiveness, and lack of concentration.	Parents or Caregiver, Counsellor, Educational Psychologist, Occupational Therapist, Doctor, Psychiatrist Volunteers, etc.	General Resources http://goo.gl/138z9h.org Book List and Resources http://goo.gl/R19Y5A
Autism spectrum disorder	Autism spectrum disorder is an umbrella term that encompasses many variations and degrees of autism.	Parents or Caregiver, Counsellor, Educational Psychologist, Occupational Therapist, Doctor, Psychiatrist, Dietician, Speech and Language Therapist, Volunteers, etc.	Support and Resources http://goo.gl/P5BFS3 http://goo.gl/FvRI

Figure 1. Definition and Resource table from ‘Working with Children who have Multiple Disabilities: A practical Guide’

The final summative evaluation later confirmed that the manual had good quality and focus of information. Nine responses stated that they ‘strongly agreed’ and two stated that they ‘agreed’.

Amount of Information. The amount of information section of the rubric refers to ‘The amount of information found in this manual thoroughly answers the questions. (In each of the sections, was there an appropriate amount of information -/+ given in order to answer the question appropriately?)’.

There were a few comments with regards to examples needing to be clarified or rendered more specific. However, for the most part most evaluators said that the amount of information was adequate. This was taken into consideration when reviewing and editing the manual. Extra detail was added in various places such as in the final summary charts as well as throughout the

text. It is important to note that in keeping with the idea of making this manual ‘small and practical’, detail was also limited to the practical applications and uses of the this manual. A comment about adding a section for social skills was also considered but, since there was already a great deal of information on social skills throughout the manual, it was decided not to have a specific section on the subject.

The final summative evaluation later confirmed that the amount of information was adequate as ten respondents stated that they ‘strongly agreed’ while only one mentioned that they only ‘agreed’ that the definition above accurately reflects the information in the manual.

Sources. The sources referred to the ‘All sources of information are accurately documented. (Were any of the sources provided inaccurate or inappropriate for the subject matter?)’

On the whole, the majority of respondents felt that the sources were relevant and accurate although a few stated that they had difficulty in confirming the sources provided in the text. Considering that these individuals did not necessarily have access to the articles, no substantive changes were made.

The summative evaluation later confirmed that nine participants ‘strongly agreed’ and two only ‘agreed’ that the sources were accurately reflected its stated definition.

Mechanics. The mechanics of the manual ‘The manual is well written, i.e., spelling mistakes, sentence structure, paragraph structure etc., was, by far, the section that required the most work as most respondents pointed out that spelling, grammar and some sentence structures needed to be addressed. In order to address these concerns, the manual, went through numerous edits and revisions.

In the summative evaluation of this section, six respondents stated that they ‘strongly agreed’ while five ‘agreed’ that the manual’s mechanics (grammatical and sentence structure) were satisfactory and required only minor grammatical changes. Although the participants were not required to write extensive comments within the summative evaluation, the fact that there was

mention of grammatical typos needing to be addressed and the fact that virtually half of the respondents said that they “agreed”, required me to go through the manual in order to fix any errors.

Diagrams and illustrations. The diagrams and illustrations part of the rubric states that ‘Diagrams and illustrations are accurate and add to the reader’s understanding of the topic. (Are there too many, not enough or inappropriate pictures present in the manual?)’.

While a majority of respondents mentioned that the illustrations and diagrams were more than adequate, a few stated that it would be good to have more detail within the examples and text. This was taken into account during the revision process and although chapter summaries were added through out the manual as well as functional checklists at the end of the manual, it was also decided to add these charts and checklists to ilovetolearn.ca (<https://goo.gl/sZWx2r>) in order to facilitate their use and to allow the person using the manual to edit the diagrams to best fit their own students.

The summative evaluation later confirmed that the diagrams and illustrations were sufficient in adding to the reader’s understanding of the topic. Nine participants said that they ‘strongly agreed’ and 2 said that they ‘agreed’ that the manuals had sufficient diagrams and illustrations.

Usefulness. The usefulness of this manual referred to ‘This manual will be very useful in my work with this target population. (Would you find this manual useful for individuals working with this population? Please elaborate)’.

Based on the 14 respondents this manual was seen to be useful in its practical application for new teachers as well as within rural communities. One respondent stated that the examples should be more specific, although this was considered during the editing process. Due to the general nature of this manual it was also decided to use one example per chapter and use that example to explain the parts of the chapter. The decision to leave the examples as is was also based on the fact that only one respondent out of 14 mentioned the suggested change.

In the summative evaluation nine participants said that they ‘strongly agreed’ and 2 said that they ‘agreed’ that this manual would be useful in a practical setting.

Summative Evaluations for the Translated Versions of the Manual (French, Spanish, and Quechua)

The translated versions of the manual into French, Spanish and Quechua underwent modified processes of evaluation. This was in part due to time constraints and the number of participants available to evaluate the translated manuals. The following describes the process that each of the translated versions went through in order to ensure that they were an accurate reflection of the original English manual.

***French manual.** The French version of the manual was translated and edited by an individual who had previous experience in translating similar documents. The translator was given the English manual and asked to translate it into French.*

Once the translation was completed it was given to another professional within the field who agreed to compare both the English manual and the French translation in order to ascertain the French translations level of accuracy. It was determined that the translation was accurate and other than needing to be edited for grammatical mistakes and some sentence structure issues, the translation was faithful to the original English manual.

The summative evaluation was conducted in the same way that the English manual was. The rubric was translated by the translator in order for it to be evaluated. Due to a lack of participants, there were only two summative evaluations submitted. The only problem noted was in the mechanics of the manual, that is, minor typographical errors and sentence structure that needed to be changed or added. The manual was then revised a second time by the same person who revised it the first time. The rest of the sections were graded either as ‘strongly agree’ or ‘agree’ and no further changes were made.

Spanish manual. *The Spanish version of the manual was translated from the original English manual by a professional living in Peru and who was familiar with the culture of the area as well as the Spanish language.*

Once the manual was translated, the translator found two individuals to edit the manual in order to make sure that it accurately reflected the original English manual. In much the same way as the French translation, the Spanish translation was seen to require minor editing and was considered to be accurate with regards to the English manual. The changes were then incorporated within the Spanish manual.

For this version of the manual there were three participants who submitted a summative review based on the original English rubric that was translated into Spanish. All of them stated that the manual was useful with some reservations expressed with regards to the mechanics, diagrams and illustrations. It is important to note that all the participants mentioned that there were not enough diagrams and illustrations. Upon speaking with them it was later determined that they had not considered all the ‘charts’ within the manual when answering that question.

Although the feedback from these participants did prove useful, an opportunity, organized by these three individuals, arose to submit the manual to the Peruvian Ministry of Education (Cusco) for a final review. The changes that were recommended by the Ministry of Education in Cusco, Peru are shown in Appendix 12. These changes were then integrated within the Spanish manual by an individual working with this population in Peru. Once the changes were made, the manual was resubmitted to the ministry. On April 9th, a letter was sent to this researcher by the Ministry stating that the manual had been accepted as an official reference text.

Quechua Manual. The Quechua version of the manual was translated by a former teacher who taught in the Quechua language in Peru. Unlike the other translations, the translation into Quechua was done by using the Spanish version of the manual. This was done because the

Quechua teacher didn't know English and it was far simpler translating from Spanish to Quechua as opposed to translating from English to Quechua.

The editing process that this translation went through was different than the others in that the translator translated at the same time she gave it to her colleagues for review in order to make sure ideas and concepts were translated accurately. This was very important in that some concepts were hard to translate into Quechua. An example of this was that the concept of "multiple impairments" did not exist within the Quechua language. It was explained to me that "everyone is capable". The solution for this was for the translator to use that latter term in Quechua but then go on to explain the differences.

Once the translation was completed, the manual was reviewed by one of the three individuals that reviewed the Spanish manual. This individual is currently a Professor of Quechua studies at the University of Cusco. He mentioned that the Quechua translation was accurate and that it accurately reflected the Spanish manual. He also mentioned that the changes suggested by the Ministry would not affect the Quechua manual and its accuracy.

This version of the manual was also submitted to the Peruvian Ministry of Education in Cusco. As with the Spanish manual, the preliminary review was very favorable. As is, this translation was deemed to be very useful within the rural communities in Peru in that there is not a lot of material that is translated into Quechua on the topic of multiple impairments.

CHAPTER 3

PRODUCTION TIMELINE AND PROCESS

Drafting the Manual

This chapter provides additional information about the actual production part of the thesis-equivalent, i.e., designing, producing and implementing the Manual itself. Developing a user-friendly guide for teachers and those working with learners having multiple disabilities is a complex process, in part because there is little precedent for such a tool. It is critical to understand that the data collection described above was really ‘an iterative, collaborative cycle, aligned with an action research model, but also reflective of standard ADDIE models’ (Gustafson & Branch, 2002). The content and organization of the final manual resulted from several years of conceptualization, discussion, review, revision, as well as more formal formative and summative evaluations once the product describe below took on a solid draft form.

As such, once all the data were collected from the questionnaires and analyzed, an initial framework for the manual was created. This task involved putting together and completing each section based on the data, research, as well as my experience. As described before, the themes that emerged from the qualitative data, along with the organizational approach suggested by Handel (2009), formed the basic foundation of the manual.

Process in the Drafting of Manual

The following timeline describes the process by which this manual was conceived and constructed.



Figure 2. Original art by Michael D'Abate used on the front and back cover of 'Working with Children who have Multiple Disabilities: A practical Guide.'

July-December 2014 - preliminary investigation. As noted briefly at the start of this thesis, during my first trip to Peru I had two main ideas for a project. My first idea was to develop a program that would use chrome books and the internet as the main means of communicating between Peru and Canada. Originally I was told that this would not be a major issue by some contacts that I had in Peru. However, once I had a chance to explore the infrastructure and interest level, the project quickly lost steam. The internet, although possible, was either too slow or too expensive to install. The second idea I had was to incorporate my passion for yoga and mindfulness within an increasing technologically centered world. This was more of a curiosity and would later add the element of mindfulness to my final project. Subsequently, it was decided to incorporate a mindful and holistic approach to working with children having disabilities. The idea was to create a manual that was small and practical in a form that could be used as a quick reference for individuals working with this population.

January 2015 - planning stages for the manual. There were two main sections of the thesis proposal that were needed before the study could get under way. Firstly, the SPF (Summary Protocol Form) was completed in order to fulfill the ethical standards set by Concordia

University. Secondly, The questionnaire, consent forms as well as the different protocols required by Concordia University were completed and the whole proposal along with a timeline and rationale for conducting the survey was handed in and later approved..

I explored the different ways that I could have developed this manual and decided that I would use an online publishing house. “The Book Patch” was chosen due to the fact that they had ready-made templates for me to use as well as allowing the person ordering the manual to order a printed copy straight from the printing house. Although the manuals are currently on thebookpatch.com the primary means of distributing this manual will be on ilovetolearn.ca. Described in more detail in the following chapter, ilovetolerant.ca is a website that I created as a platform for discussion and consultation as well as to disseminate the manual.

During 2016 - Administered questionnaire, collected and analyzed data. I collected the official consent forms and questionnaires from the participants. This was an ongoing process that took most of 2016. Individuals working with this population from Canada, United States, and Peru were solicited. Subsequently, the data were collected and analyzed as described in the previous chapter. A rough draft of the manual was written in chapters and then put together using the template from thebookpatch.com

2016 – 2017 formative and summative evaluations. The formative evaluation consent form, rubric and a copy of the manual were provided to each of the participant taking part in evaluating the English manual. As mentioned above, the French, Spanish and Quechua translations went through a revision process instead of the formative evaluation. This revision process was to primarily see if the translations were accurate when compared to the English copy of the manual. After the changes were incorporated within the English manual as well as the translated versions, a summative evaluation was then given to the participants for final grading. All versions of the manual went through the summative evaluation using translated versions of the same rubric and instructions for French, Spanish and Quechua translations.

Early 2018 – Publication of the manual including website. A final version of the manuals will be posted on bookpatch.com for those who want an official hard copy to be sent to them. The idea behind creating the website was primarily to make it a forum for sharing resources as well as a consulting component. Making it available online also makes it easier for individuals to download it and print it in Peru.

Materials and Forms Utilized.

The following are a list of materials and forms that were used in the construction and publication of the manual:

- Manual templates (website <http://www.thebookpatch.com>):
- Cover page and Main body (Appendix 6 and 7)
- Original art for the front page by the author
- Data Collection Table (Appendix 8)
- Suggested Changes by the Ministry of Education in Cusco Peru, (Appendix 12)
- Spanish Manual approval (Peruvian Ministry of Education) (Appendix 13)
- French, Spanish and Quechua Translations (Appendix 14)
- Manual (final English version) (Appendix 15)

Layout of Manual

The template used for this manual was taken from a free template provided by www.thebookpatch.com. The dimensions of the manual is 4”25 x 6”87 as well as being spiral bound. The reason for this was to make the manual as portable and easy to read on the go as possible.

The front cover page (Appendix 6) consists of a title and Author and the back cover (Appendix 6) consists of details of the publication. Both front and back covers depict an image of adults and children that was painted in Peru (*Figure 2*).

A graphic artist took part of reviewing this manual as well as constructing the front and back cover using the original art as shown above.

The body of the manual (Appendix 7), included in the template, consists of 40-60 double sided pages depending on the translated version.

Content

The content of this manual was primarily taken from the data obtained from the administration of the questionnaire (Appendix 8), interviews as well as my own experience working in the field. That process was described in detail in Chapter 2. The data were then organized into six categories (communication, emotional needs, physical space, mental health and wellbeing, Personal Growth and Actualization, long term care) modified from an article by Steven Handel (2009).

Original Art

This manual also contains original art that was taken from my work in both Canada and

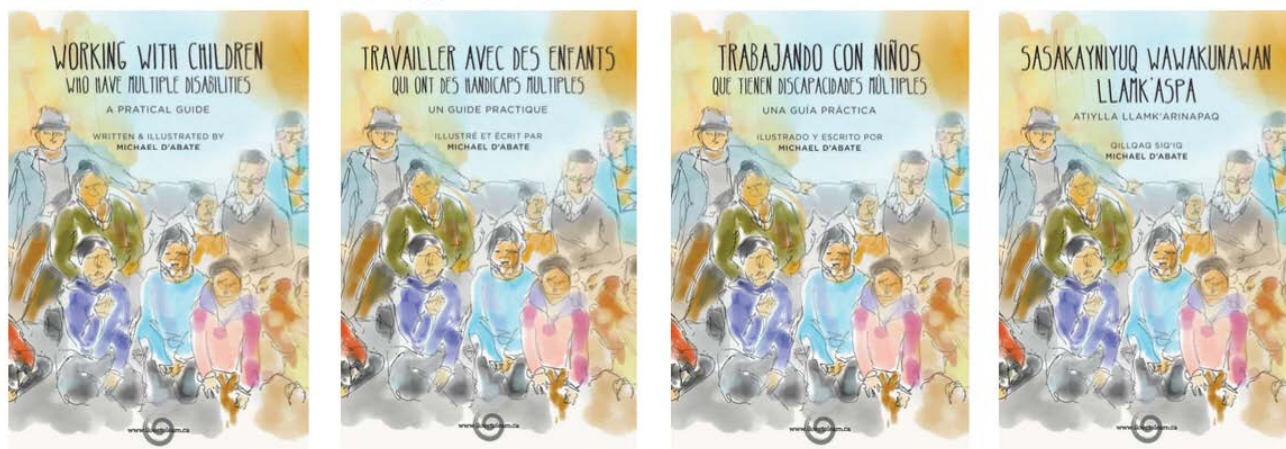


Figure 3. Original art by Michael D'Abate used on the front and back cover of the four versions of 'Working with Children who have Multiple Disabilities: A practical Guide.'

Peru. The cover page was painted on a digital canvas and then made into the front and back cover. The subject matter was of the first group of children and workers that I worked with in

Peru. The images within the manual were painted from various pictures of students in Canada and Peru.

Marketing of the Manual

Originally, the one way to obtain a copy or bulk orders of this manual was to purchase it online directly from www.thebookpatch.com. Recently, an independent website www.ilovetolearn.ca and Facebook page was created in order to make the manual more accessible digitally as well as in print format. Along with other resources, the website will have all four manuals available to download. A donation of 10\$ is requested for each purchase with the proceeds from the digital downloads going to fund the projects as well as provide some funding for the upkeep of the website.

CHAPTER 4

CONCLUSION

Discussion and Reflections

The aim of this study is to explore best practices with regards to teaching students having multiple disabilities in formal and informal learning environments and to create a practical guide for individuals who work with this target population. The practical application of this manual is three fold: firstly, to facilitate and enhance the ability of teachers/caregivers to work with students having multiple disabilities in an educational setting; secondly, to add to a teacher's repertoire of knowledge without being overwhelming and adding to their already increasing workload; thirdly, by fulfilling the first two objectives, empowering the students themselves to be better able to interact within their immediate surrounding and more effectively communicate with their teachers. The manual, incorporating much of what emerged from the exploratory research conducted with professionals in the field, appears to have achieved these goals according to the positive feedback from those consulted in the formative and summative evaluation processes.

The approach to explore what professionals in the field consider as important interventions with regards to working with children having multiple disabilities as fruitful and has resulted in the creation of a guide for practice in four languages. However, as is the case with much research of this nature, what you start off with is not necessarily what you end up with. I began by assuming that by utilizing a content analysis program such as Dedoose on data collected from a large number of professionals, the output would produce a list of categories that could be automatically be converted into a short list of useful interventions. As useful as this input was, the resulting list was less than satisfactory and manageable, and compelled me to re-examine the literature for other ideas and direction. Converting the knowledge and wisdom of 26 participants into a cohesive, accessible product proved challenging.

As I have always felt strongly about a holistic approach that emphasizes natural life experiences, I was particularly impressed with an article by Steven Handel (2009) that seemed to resonate well with me. Encouraged, I proceeded to see if it correlated with the data and found, to my delight, that it was a good fit, using his framework of six aspects of a balanced person. Data from the formative and summative evaluations proved to be helpful in not only validating the results but providing constructive feedback that led to changes being made to the final English version of the manual. This once again illustrates the critical interplay between “theory” and practice, key elements in the participatory action research model I chose to emulate, where applicable.

Challenges and Future Considerations

As inspiring and reflective as the process was, limitations need to be acknowledged. Due to scheduling and a difficulty in receiving information from the participants in Peru, there were only a handful of individuals who participated from that country. This was somewhat of a disappointment although the information received proved very useful in bringing to the table the cultural differences between Peru and Canada. To date, the manual (both Spanish and Quechua) has been well received by the ministry of education (district of Cusco) and revisions have been suggested to render it more culturally relevant. While deemed a “limitation”, these circumstances reminded me of the importance of recognizing environmental and cultural contexts that inform the potential impact of such a production on its intended target population. As noted before, it became obvious to me in my early trip to Peru that this manual would only be as useful as the number of people who have access to it and who could read it in their own language. What was initially envisaged as a digital solution transformed into the creation of an accessible, community-centered response to teachers facing multiple needs with multiple constraints. The common theme however was the kids, and their needs, and our responsibility to empower them. Language can be a barrier, so this thesis’s production addressed this issue. Finally, a further aim

was and is to distribute the manual, free of charge, to individuals who would not otherwise have access to it.

As already stated, the exploratory nature of this study does not give me much latitude in extending the conclusions beyond the fact that these intervention strategies were inspired from the practices of a relatively small sample of professionals I had access to and who were working in the field. Nevertheless, as already mentioned above, the suggestions and best practices that were obtained from these experienced individuals is an added 'hands on' bonus that this manual offers as compared to what appears to be available on the topic. Furthermore, I feel that the content of this manual can be an invaluable and a useful tool to those working with children having multiple disabilities within emergent cultural communities such as those in Peru. As one evaluator remarked, this particular translated text was very useful within the rural community in Peru as there is not a lot of material that is translated into Quechua on the topic of multiple impairments. As a further acknowledgement of the relevance and potential usefulness of this exercise, the Spanish version of the manual has already been accepted as an official reference text by the Peruvian Ministry of Education. Future research, however, is recommended and ought to focus on evaluating the effectiveness of these strategies with regards to improving learning and the well being of the children and the extent to which this guide is helpful and a support to professionals and other individuals working with these children. Finally, it would be most interesting to determine in what ways and the extent to which cultural context plays a role in the creation and application of this guide. This line of research might also examine the extent to which practices and customs in specific cultural settings impact on how teachers (and the support system) are expected to interact with this population of learners. For example, in contexts where an active, extended family is common, opportunities may present themselves differently from other societal contexts. Practitioners must always follow not just guidelines, but innovate in positive ways on behalf of the children with the community they live in.

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APPENDICES

APPENDIX – 1 CONSENT TO PARTICIPATE

I understand that I have been asked to participate in a research project being conducted by Michael D’Abate of the Educational Technology Masters program under the supervision of Professor Richard Schmid of The Education Department of Concordia University in Montreal, Quebec.

Contact information	Email	Phone
Michael D’Abate	m_dabate@education.concordia.ca	514-804-2419

A. PURPOSE

I have been informed that the purpose of this manual is as follows:

1. The primary aim in creating this manual is to facilitate and enhance the ability of individuals to work with visually impaired, autistic and multi-disabled students in a formal educational setting.
2. Secondly, this manual is meant to add to a individuals repertoire of knowledge without being overwhelming.
3. Thirdly, by realizing the first two objectives, the students themselves will be better able to interact within their immediate surrounding and more effectively communicate with their teachers.

B. PROCEDURES

I understand that I will participate in an interview/questionnaire conducted by Michael D’Abate outside of official school hours. The goal of the interview is to gather information that will be cross-referenced and collated with an extensive review of the literature.

C. RISKS AND BENEFITS

I understand that this research will benefit the participants by informing them of best practices and pedagogical strategies in a concise and cost effective manner.

D. CONDITIONS OF PARTICIPATION

Consent Form

- I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences.
- I understand that my participation in this study is CONFIDENTIAL (i.e., the researcher will know, but will not disclose my identity).
- I understand that the data from this study may be published.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT.
I FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY.

NAME (please print) _____

SIGNATURE _____

If at any time you have questions about the proposed research, please contact the student investigators or their supervisor, Dr. Richard Schmid of Concordia University (514-848-2424 ext. 2001, schmid@education.concordia.ca).

If at any time you have questions about your rights as a research participant, please contact the Research Ethics and Compliance Advisor, Concordia University (514.848.2424 ext. 7481 ethics@alcor.concordia.ca).

APPENDIX – 2 QUESTIONNAIRE CONSENT

Check the box below to indicate that you have read and agree with the following:

I am a willing participant in “Working with Blind, Autistic and Multi-Disabled Children:
A practical Guide”

I understand that I am free to withdraw my consent and discontinue my participation at
anytime without negative consequences.

I understand that my participation in this study is CONFIDENTIAL (i.e., the researcher will
know, but will not disclose my identity).

I understand that the Participant will have the opportunity to revisit the information in this
survey with the researcher at a later date and at his/her convenience.

I understand that the data I choose to share from this study will be viewed as research and
potentially be published in the final manual.

I Agree

Please answer these questions to the best of your ability. The answers should reflect your
personal and/or professional opinions regarding your interactions with visually impaired, autistic
and/or multi-disabled children.

Q1 - What are some strategies you find helpful in ensuring the physical health and wellbeing of the students you work with or that are in your care? Please feel free to use the whole page and draw diagrams if needed.

(e.g. arranging for wheelchair bound children to get off their wheelchairs and go down on mats)

Q2- What are some strategies you find helpful in ensuring the emotional health and well being of the students you work with or that are in your care?

(e.g. activities, gestures, class room games or anything that will have an impact on their emotions.)

Q3- What are some strategies you find helpful when dealing and working with a child's behavior? This can be anything from a child's negative behavior to stimulating a child's creativity.

Q4- What are some strategies you find helpful for ensuring the development and mental health of the students you work with or that are in your care?

(e.g. activities, gestures, class room games or anything that will have an effect on their emotions)

APPENDIX – 3 INTERVIEW PROTOCOL

I. Information about the Interview:

Interviewee: _____ Interviewer: _____

Date: _____ Time: _____ Place: _____

II. Consent and Introduction

- Thank you for completing the questionnaire
- Do you consent to this follow up discussion

Yes _____ No _____

We will be going over each question that was answered in order to clarify and elaborate on the details.

IV. Interview Questions: General Comments

Q1 - What are some strategies you find helpful for ensuring the physical health and wellbeing of the students you work with or that are in your care? Please feel free to use the whole page and draw diagrams if needed.

Q2- What are some strategies you find helpful for ensuring the emotional health and wellbeing of the students you work with or that are in your care?

Q3- What are some strategies you find helpful when dealing and working with a child's behavior? This can be anywhere from a child's negative behavior to stimulating a child's creativity.

Q4- What are some strategies you find helpful for ensuring the development and mental health of the students you work with or that are in your care?

6. What else would you like to add?

V. Wrap Up and Thank Participant for Time

- Thank you very much for your time today. I appreciated hearing your insights.

APPENDIX – 4 FORMATIVE EVALUATION INSTRUCTIONS

After reviewing the manual please write any comments and/or questions pertaining to the following criteria directly onto the copy of the manual you received with these instructions.

The following are guidelines that you can use to help guide your comments and/or questions:

Organization	<u>The Manual is organized and well constructed.</u> (From cover to cover, how does the manual flow. i.e. chapter breakdown, general structure of the manual.)
Quality and focus of Information	<u>All topics are addressed and all questions answered.</u> (Are all important topics and questions present and thoroughly answered to the best of your knowledge.)
Amount of Information	<u>The amount of information found in this manual thoroughly answers the questions.</u> (In each of the sections, was there an appropriate amount of information -/+ given in order to answer the question appropriately.)
Sources	<u>All sources of information are accurately documented.</u> (Was any of the sources provided inaccurate or inappropriate for the subject matter.)
Mechanics	<u>The manual is well written.</u> (i.e. spelling mistakes, sentence structure, paragraph structure etc.)
Diagrams and Illustrations	<u>Diagrams and illustrations are accurate and add to the reader's understanding of the topic.</u> (Are there too many, not enough or inappropriate pictures present in the manual.)
Usefulness	<u>This manual will be very useful in my work with this target population.</u> (Would you find this manual useful for individuals working with this population? Please elaborate.)

APPENDIX – 5 SUMMATIVE GRADING RUBRIC

Name: _____

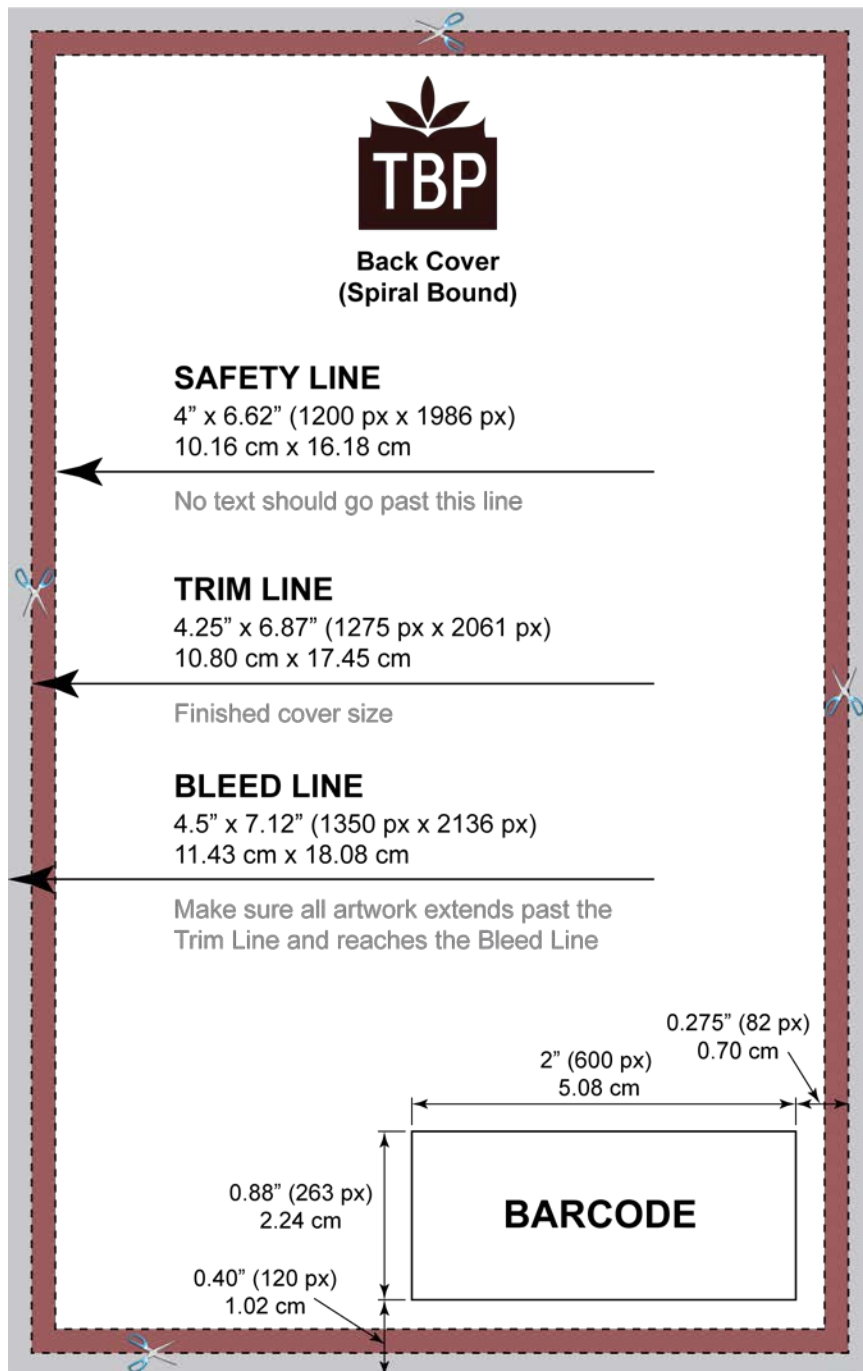
Profession: _____

Please choose the comments that best fit each category.

		Strongly Agree	Agree	Disagree	Strongly Disagree
Organization	The Manual is <u>organized and well constructed</u> . (From cover to cover, how does the manual flow. i.e. chapter breakdown, general structure of the manual.)				
Quality and focus of Information	All topics are addressed and all questions answered. (Are all <u>important topics and questions present and thoroughly answered</u> to the best of your knowledge.)				
Amount of Information	The amount of information found in this manual <u>thoroughly answers the questions</u> . (In each of the sections, was there an appropriate amount of information +/- given in order to answer the question appropriately.)				
Sources	All sources of information are <u>accurately documented</u> . (Was any of the sources provided inaccurate or inappropriate for the subject matter.)				
Mechanics	The manual is well written. (i.e. spelling mistakes, sentence structure, paragraph structure etc.)				
Diagrams and Illustrations	<u>Diagrams and illustrations are accurate and add to the reader's understanding of the topic</u> . (Are there too many, not enough or inappropriate pictures present in the manual.)				
Usefulness	This manual will be very useful in my work with this <u>target population</u> . (Would you find this manual useful for individuals working with this population? Please elaborate.)				

Comments: _____

APPENDIX – 6 COVER PAGE



APPENDIX – 7 MAIN BODY

[Book Title]
[Optional Book Sub Title]

by
[Author Name]

APPENDIX – 8 DATA COLLECTION TABLE

Data review to define and organize the sections of the manual

*26 participants total. One participant coded as 15b = On the following chart this is why there are only participants numbering from 1-25.

QUESTIONNAIRE QUESTIONS	CONCEPTS TAKEN FROM Q1 PARTICIPANTS	CONCEPTS TAKEN FROM Q2 PARTICIPANTS	CONCEPTS TAKEN FROM Q3 PARTICIPANTS	CONCEPTS TAKEN FROM Q4 PARTICIPANTS
MANUAL CHAPTERS	<i>What are the strategies you find helpful in ensuring the physical health and wellbeing of the students you work with or that are in your care?</i>	<i>What are some strategies you find helpful in ensuring the emotional health and well being of the students you work with or that are in your care?</i>	<i>What are some of the strategies you find helpful when dealing and working with a child's behaviour? This can be anything from a child's negative behaviour to stimulating a child's creativity.</i>	<i>What are some strategies you find helpful for ensuring the development and mental health of the students you work with or that are in your care?</i>
COMMUNICATION	<ol style="list-style-type: none"> 1. Students Communication ability. 2. Proper distribution of medication. 3. 4. Staff communication 5. Subtle observations and communications with student. 6. Communicate needs to students to administration. 7. 8. Communication with other professionals (i.e. OT) 9. Communication with staff and co workers. 10. 11. Communication in sign requires a clear line of sight between you and the students. 12. Communication between staff for help in classroom. 13. 14. Enquirer with previous professionals working with the child. 15. Communicate to other 	<ol style="list-style-type: none"> 1. Communicate with child, parents, teachers and therapists. Get to know you student. 2. 3. 4. Use music to communicate. 5. Use simply and clear language. Use cue cards. Speak to parents often. Alternative programs can be used. 6. Use games to build trust with your students. 7. Let the child lead in the daily routine 8. 9. 10. Allow the students the opportunity to voice there opinion and concerns and problems. 11. Working with ASL and other forms of communication will facilitate communication with your students. 12. Relate to students and creat trust. 	<ol style="list-style-type: none"> 1. Follow up any timeout with communication with the child and reinforce positive behaviours. 2. 3. 4. Explain expected behaviours at the beginning of the year. 5. Communicate with parents and use strategies already used at home for consistency. 6. 7. Stop the activity and refocus attention of the group when needed. 8. Giving them the tools to communicate if the cannot communicate in conventional ways. 9. 10. Communicate and listen to your student. 11. 12. 13. Communicating through daily calendar. 14. Record this bad behaviour in a chart. 	<ol style="list-style-type: none"> 1. 2. 3. 4. Discuss and communicate feelings. Communicate with professionals if the need be. 5. 6. Teach the students how to communicate and interact socially. Appropriate ways to communicate. 7. 8. 9. 10. 11. 12. Communicate with child. 13. Family' s involvement and support. Learning ASL. 14. 15. Know and understand your students. 15b. Make a connection with each student. Share stories 16.

	<p>personnel how adapted equipment works. Contact parents for questions if need be.</p> <p>15b. 1-1 time to talk for a few minutes with each student.</p> <p>16. Talk to students even if they cannot communicate. Communicate between personnel.</p> <p>17.</p> <p>18. Communicate with other professionals.</p> <p>19.</p> <p>20.</p> <p>21.</p> <p>22.</p> <p>23. Communicate with personal such as nurse and OT.</p> <p>24.</p> <p>25. Get to know your students. Communicate with parents as much as possible.</p>	<p>13.</p> <p>14.</p> <p>15. Involve your students in the decision making.</p> <p>15b.</p> <p>16. Upset children usually are upset because they are having problems communicating.</p> <p>17. Get down to their level and explain what is next to come. I.e. story time.</p> <p>18. Communicate with student regarding school work and try to find adaptations to issues that may arise. Communication within administration.</p> <p>19. Have friendly conversations with students. Communicate with students and their teachers to allow for follow through.</p> <p>20.</p> <p>21. Inform other teachers what work has been done to allow for followthrough</p> <p>22. Communication and letting your students what is happening next and why.</p> <p>23. Communicate with personnel and specialist.</p> <p>24. Greet and speak to your students.</p> <p>25. Communicate and make sure students know what is expected.</p>	<p>15. Clearly communicate rules and what is expected of them.</p> <p>15b. Establish rules and framework from the first day.</p> <p>16. Try to get the child to communicate in whatever way they can. I.e. pictures, gestures.)</p> <p>17. Show the child that you respect how they feel.</p> <p>18. Communicate with specialists that may help resolve issues.</p> <p>19. Talk to the student to try and find out what these behaviours are a product of.</p> <p>20. Convey a clear idea of choice making.</p> <p>21. Communicate your intentions with your students.</p> <p>22.</p> <p>23. Communicate routine clearly.</p> <p>24. Ask them what the problem is.</p> <p>25. Explain daily messages and daily schedule.</p> <p>26.</p> <p>27.</p>	<p>17.</p> <p>18.</p> <p>19.</p> <p>20.</p> <p>21. Reflecting there sounds or movements can give you access to their world</p> <p>22.</p> <p>23. Use daily communication reports with parents and other professionals.</p> <p>24.</p> <p>25.</p> <p>26.</p> <p>27.</p>
EMOTIONAL NEEDS	<p>1. Create fun games</p> <p>2.</p> <p>3. Consider students emotional needs when implementing an activity.</p> <p>4.</p> <p>5. Relieving tension for swimming lesson</p> <p>6.</p> <p>7.</p> <p>8.explain what you will be doing so the child knows before it is done.</p> <p>9. Speak in a soft, clear and melodic voice.</p> <p>10.</p> <p>11.</p> <p>12.</p> <p>13. Teach relaxing techniques</p>	<p>1. Teach them how to express themselves reducing emotional uneasiness.</p> <p>2. Show lots of affection to students as they might not be getting any at home.</p> <p>3. If a wheelchair bound child starts to cry have them placed on a mat.</p> <p>4. Create a safe environment for you students to explore without feeling judged.</p> <p>5. Be positive towards your students.</p> <p>6. Elevate anxiety from real or imagined fears.</p> <p>7. Let the child lead in routine activities to minimize emotional</p>	<p>1.</p> <p>2. Reinforce positive behaviour with a smile or hug.</p> <p>3.</p> <p>4.</p> <p>5.</p> <p>6.</p> <p>7. Playing a song can elevated tensions when dealing with behaviour issues.</p> <p>8.</p> <p>9.</p> <p>10. Largely related to emotional health and has a lot to do with the child feeling listened to and acknowledged.</p> <p>11.</p>	<p>1.</p> <p>2.</p> <p>3.</p> <p>4. Discuss feelings periodically.</p> <p>5.</p> <p>6.</p> <p>7.</p> <p>8.</p> <p>9.</p> <p>10.</p> <p>11.</p> <p>12.</p> <p>13.</p> <p>14.</p> <p>15. Make each student feel special and important.</p> <p>15b.</p> <p>16.</p> <p>17.</p>

	<p>14. Communication with school personnel for any health issues. I.e. nurse.</p> <p>15.</p> <p>15b.</p> <p>16.</p> <p>17.</p> <p>18.</p> <p>19.</p> <p>20. If the student is crying and uncomfortable it is important that you deal with this before you go any further.</p> <p>21. Attendants should communicate with teachers for details of student they are working with.</p> <p>22. Reduce stressors. Consider the emotional undertones of you voice that might be behaviour triggers.</p> <p>23. Legally the PAB's are the ones that can transfer students to and from their wheelchair.</p> <p>24.</p> <p>25.</p>	<p>outbursts. Allow them to hold something that makes them focus.</p> <p>8.</p> <p>9. Sing songs and creat a positive and enthusiastic mood for the classroom.</p> <p>10. Showing that you are interested in them allows them to be more at ease in class.</p> <p>11. Allow the child to be confident in their intuition will help to keep them calm as well as facilitate learning.</p> <p>12. More complex because each student responds differently to situations.</p> <p>13. Sensory integration techniques such as sensory stimulation will help emotional regulation.</p> <p>14. Singing and music helps students emotional wellbeing.</p> <p>15. Interact with the person and make sure they feel important and valued.</p> <p>15b. Creating a sense of welling is critical for emotional wellbeing.</p> <p>16. Try to get into there head and figure out what are the issues.</p> <p>17. Discomfort because they cannot express what's wrong.</p> <p>18. Explain to student that they can have extra time to reduce anxiety of finishing assignment on time.</p> <p>19. Let the students take charge in their own learning will make them happier students.</p> <p>20. away attention to what the child likes will make them happy. Avoid anything that will creat negative responses.</p> <p>21. Giving the student something that is personalized usually makes them happy.</p> <p>22. Consistent structured routine. Advanced warning and explanation.</p>	<p>12.</p> <p>13.</p> <p>14.</p> <p>15.</p> <p>15b.</p> <p>16. Let them express their emotions. I.e. scream out.</p> <p>17. Letting the child know that the way they feel fine and respected by you. Listen to their needs so they don't feel left out.</p> <p>18.</p> <p>19. Resolve their frustrations with their devices usually solves the issues with behaviour.</p> <p>20.</p> <p>21. Sometimes there is jealousy by students. Explain to them them you have to help another person too.</p> <p>22. Deep pressure can sooth children.</p> <p>23.</p> <p>24.</p> <p>25.</p> <p>26.</p> <p>27.</p>	<p>18.</p> <p>19.</p> <p>20.</p> <p>21.</p> <p>22.</p> <p>23.</p> <p>24.</p> <p>25.</p> <p>26.</p> <p>27.</p>
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		<p>Promotion of communication.</p> <p>23. Use soothing and calm voice. Use play to obtain emotional health.</p> <p>24. Ask them if they are excited today. Get them excited. Positive reinforcement.</p> <p>25. You will get better responses if the students know what to expect.</p>		
PHYSICAL SPACE	<ol style="list-style-type: none"> 1. Move around independently. 2. Understand medical baselines 3. opportunity to move around. 4. Orienting visually impaired students to their surroundings. 5. Adapt physical space to encourage improving skills. 6. Adapt the class as per students needs. 7. Adapt physical pace for the needs of the children. 8. 9. Make sure that child is safe. 10. Find excuses for the students to get up and move. 11. Allow the students to mill around if they want to. 12. Close and constant supervision to avoid safety concerns. 13. Scheduling physical activities for students. 14. Allow students to explore their environment. Swimming is important. 15. Scan area and anticipate for potential dangers. 15b. Activities such as brain gym or balance boards for students in wheelchairs. 16. Physical activity in safe environment. Making sure the physical space is safe and clean. Make sure they are comfortable. 17. Make proper adaptations i.e. spraying stairs with bright coloured 	<ol style="list-style-type: none"> 1. 2. 3. If a wheelchair bound child starts to cry have them placed on a mat. 4. 5. 6. 7. Allow them to be physically comfortable i.e. removing socks. 8. Playing outside and physical tactile stimulation (i.e. massage) 9. Create a comfortable and stress free environment for them. 10. 11. 12. Physical space affects emotional state of the student. I.e. lightning, temperature of room. 13. 14. 15. 15b. 16. 17. 18. Suggest that student goes to lunch room with a friend. 19. 20. 21. 22. 23. 24. 25. Physical activities such as yoga, circle time, and sharing physical space in group activities. 	<ol style="list-style-type: none"> 1. 2. First rule out any biological reason for the behaviour. 3. For behaviour, physical touch is key i.e. holding there hand. 4. Have a physical reward system. 5. 6. 7. Use tactile objects to distract. 8. 9. 10. 11. 12. 13. A gradual introduction of activities and routines. 14. 15. When a child is out of control bring them to a quiet space to calm down. 15b. Make them understand that violence in any way is unexceptable. 16. 17. Putting wheel-bound students down on the mat often helps relieve discomfort. 18. 19. 20. Redirect negative or unsafe behaviours i.e. hitting. 21. 22. Aggressive behaviour can be felt with by balancing physical and sitting activities. 23. Routines. Different interesting sections of the classroom. Timeout. 	<ol style="list-style-type: none"> 1. 2. 3. 4. Drama activities to help express themselves. 5. 6. 7. 8. 9. 10. 11. 12. Temperature and atmosphere variables may affect mental health and wellbeing. 13. 14. 15. 15b. 16. 17. 18. 19. 20. 21. 22. 23. 24. 25. Create a safe and confidential place in the classroom so students feel safe and express themselves. 26. 27.

	<p>pain.</p> <p>18. Arrange for orientation and mobility if needed.</p> <p>19. Make sure that children are responsible to making sure that there space is safe and that they wont get hurt.</p> <p>20. Make sure that the temperature and other variable that make the student uncomfortable.</p> <p>21. Adapt area so that instruments can be used without the risk of injury.</p> <p>22. Establish movement routines to promote good physical fitness.</p> <p>23. Swimming activities and making sure that wheelchair bound students get out of there chair periodically.</p> <p>24. Creat safe space to play and move around. I.e. remove toys that can be tripped over.</p> <p>25.</p>		<p>24. Use toys and redirect appropriate behaviour and promote creativity.</p> <p>25. Turn off lights, low music, closing door. Creat a soothing atmosphere</p> <p>26.</p> <p>27.</p>	
MENTAL HEALTH AND WELLBEING	<p>1. Consider cognitive ability.</p> <p>2.</p> <p>3. Do not over stress student for activities.</p> <p>4. Reduce injuries and mental strain.</p> <p>5. Foster independence.</p> <p>6. Facilitate their learning adds to their wellbeing.</p> <p>7. Adapting according to strengths and weaknesses for maximum participation.</p> <p>8.</p> <p>9.</p> <p>10.</p> <p>11.</p> <p>12.</p> <p>13.</p> <p>14.</p> <p>15.</p> <p>15b. Make sure students are not hungry so that they scan focus on their school work.</p> <p>16.</p> <p>17.</p> <p>18.</p> <p>19.</p> <p>20. Reduce stressors that</p>	<p>1. Recognize their accomplishments big or small.</p> <p>2.</p> <p>3.</p> <p>4.</p> <p>5.</p> <p>6. Activities that give equal chance to all students (I.e. timid students still get the opportunity to voice their opinion.</p> <p>7. Provide praise at every opportunity.</p> <p>8.</p> <p>9.</p> <p>10. Never let work take over what is important.</p> <p>11.</p> <p>12.</p> <p>13.</p> <p>14.</p> <p>15. Respect the child and their rhythm.</p> <p>15b.</p> <p>16.</p> <p>17.</p> <p>18.</p> <p>19.</p> <p>20.</p>	<p>1.</p> <p>2.</p> <p>3.</p> <p>4.</p> <p>5.</p> <p>6.</p> <p>7.</p> <p>8.</p> <p>9.</p> <p>10.</p> <p>11.</p> <p>12.</p> <p>13.</p> <p>14.</p> <p>15.</p> <p>15b.</p> <p>16.</p> <p>17.</p> <p>18.</p> <p>19.</p> <p>20.</p> <p>21.</p> <p>22.</p> <p>23.</p> <p>24.</p> <p>25.</p> <p>26.</p> <p>27.</p>	<p>1. I firmly believe that developmental and mental health is directly linked to all of the areas in the earlier questions: physical health from question 1, emotional health from question 2 and even behavior (displaying appropriate behaviors to become a positive contributing member of society). So my answer to question 4 would repeat all the areas I brought up in questions 1-3.</p> <p>2. Intervene in a developmentally appropriate manner. Promoting autonomy do you want your medication in class or in the nurses office.</p> <p>3. Paying attention to the needs of the child is my number one priority, everything related to education must be flexible.</p>

	<p>can trigger certain behaviours.</p> <p>21.</p> <p>22.</p> <p>23.</p> <p>24.</p> <p>25. Play on the strengths and weakness of the student.</p>	<p>21.</p> <p>22.</p> <p>23.</p> <p>24.</p> <p>25. Having a nurse in this setting allowed students to have peace of mind concerning their health</p>		<p>4. Allow students to share feelings</p> <p>5 The answers are mostly comprised in the previous questions. Express expectations.</p> <p>6. The importance of social education.</p> <p>7. Instill self worth, creative and confidence. Teaching your students to be reliable and dependable. Praise children's efforts.</p> <p>8. Catching the ball, passing it to eachother. Watching movies in the tablet. Feeling different textures.</p> <p>9. Reduce immediate pressure of completing activities. Choice making. Motivate and encourage your student in a fun way or game.</p> <p>10. Listening to them, asking them questions, sitting with them on breaks, smiling and treating children.</p> <p>11. Encourage them to trust there intuition.</p> <p>12. See if they are well nourished, rested, physical activity. Self esteem and goal setting. Allow them to accomplish manageable but challenging tasks.</p> <p>13. Creat meaningful activities that will help them translate to daily activities. Sorting out cutlery instead of pegs on a peg board.</p> <p>14.</p> <p>15. Encourage to try new things, praise often, use their preference to adapt activities. . Make each student feel special and important</p> <p>15b. Understanding the differences in upbringing as to better understand your students.</p> <p>16. Never do things for them if they can do it themselves.</p> <p>17.</p>
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				<p>18.</p> <p>19. Allow them to make choices. Give them time to process information. Giving them meaningful praise.</p> <p>20.</p> <p>21. Give the child space to be himself. Reflecting there sounds or movements can give you access to their world. Encouraging them to reach their goals.</p> <p>22. Stories with concrete objects can reinforce concepts. Use music and play through songs.</p> <p>23. Positive reinforcement. Make sure that any report of abuse is taken care of.</p> <p>24.</p> <p>25. Create a safe and confidential place in the classroom so students feel safe and express themselves.</p> <p>26.</p> <p>27.</p>
<p>PERSONAL GROWTH AND ACTUALIZATION</p>	<p>1. Being part of Defi Sportif.</p> <p>2.</p> <p>3. Being part of the bicycle program.</p> <p>4.</p> <p>5. Improve swimming</p> <p>6.</p> <p>7.</p> <p>8.</p> <p>9.</p> <p>10.</p> <p>11.</p> <p>12. Help child succeed by being one step in front of them.</p> <p>13.</p> <p>14.</p> <p>15. encourage students to try and explore their own environment. Give them a voice.</p> <p>15b</p> <p>16</p> <p>17.</p> <p>18.</p> <p>19. Allowing the students to assume more responsibility so they can be independent.</p> <p>20.</p> <p>21.</p>	<p>1. Encourage= parents to watch their students at events such as Defi Sportif. This will encourage the student.</p> <p>2.</p> <p>3.</p> <p>4. Teach the children about their disabilities and the disabilities of their classmates.</p> <p>5. Modify the program to make sure they succeed especially if they repeatedly fail at something.</p> <p>6.</p> <p>7. Use expressions such as growth and positive repossess so that the child can grow.</p> <p>8.</p> <p>9.</p> <p>10.</p> <p>11. Making sure that everybody contributes something to the class will allow them to personally grow.</p> <p>12. Incorporate interests in activities.</p>	<p>1.</p> <p>2.</p> <p>3.</p> <p>4.</p> <p>5.</p> <p>6. "Do the right thing" give the students the ability to make choices. (Empowering them)</p> <p>7. Train the group in an activity so that they can feel empowered to run their own playtime.</p> <p>8.</p> <p>9.</p> <p>10.</p> <p>11.</p> <p>12.</p> <p>13. Providing opportunities for choice making.</p> <p>14.</p> <p>15. Encourage the children to try new things.</p> <p>15b</p> <p>16. Ensure that you DO NOT facilitate learned helplessness. I.e. saying poor dear.</p> <p>17.</p> <p>18.</p> <p>19.</p>	<p>1. Promoting autonomy.</p> <p>2.</p> <p>3.</p> <p>4.</p> <p>5. Express expectations</p> <p>6.</p> <p>7.</p> <p>8.</p> <p>9.</p> <p>10.</p> <p>11.</p> <p>12.</p> <p>13.</p> <p>14.</p> <p>15.</p> <p>15b</p> <p>16.</p> <p>17.</p> <p>18.</p> <p>19.</p> <p>20.</p> <p>21.</p> <p>22.</p> <p>23.</p> <p>24.</p> <p>25.</p> <p>26.</p> <p>27.</p>

	<p>22. 23. 24. 25. Focus on routines so that the student can become independent.</p>	<p>13. 14. 15. Involve the person in decision making will allow them to gain confidence. Offer support and challenge students when needed 15b. Create a sense of belonging. 16. 17. 18. 19. 20. 21. 22. 23. 24. 25. 26. 27.</p>	<p>20. Encourage and teach them to make choices. 21. 22. 23. 24. 25. 26. 27.</p>	
<p>LONG-TERM CARE</p>	<p>1. Encourage community interaction. 2. 3. Teaching qualities for independent living. 4. 5. Challenging activities to foster independence 6. 7. 8. 9. 10. 11. 12. 13. Teach the children the strategies needed to function i.e. traveling. 14. 15. 15b. 16. Make them understand why decisions are being made so that they understand for future when they might need to make decision on their own. 17. 18. 19. teaching children to eventually take care of their own needs as much as possible. 20. 21.</p>	<p>1. 2. 3. 4. 5. 6. 7. 8. 9. 10. 11. 12. 13. 14. 15. 15b. Allowing them to set goals for the year can provide them with structure in the future and independence. 16. 17. 18. 19. 20. 21. 22. 23. 24. 25. 26. 27.</p>	<p>1. 2. 3. 4. 5. 6. 7. 8. 9. 10. 11. 12. Even in a class where there are no verbal students showing them and teaching them how to behave in different settings is important. 13. 14. 15b. 16. 17. 18. 19. 20. 21. 22. 23. 24. 25. 26. 27.</p>	<p>1. 2. 3. 4. 5. 6. 7. 8. 9. 10. 11. 12. 13. 14. 15b. 16. 17. 18. 19. 20. 21. 22. 23. 24. 25. Cooking with direct instruction and understanding that this area would be a life-long necessity for my students. 26. 27.</p>

	22.			
	23.			
	24.			
	25.			

APPENDIX – 9 FORMATIVE EVALUATION TABLE

*It is important to note that, most of the comments in the formative evaluations were written directly on the copy of the manual. The below comments represent ideas that were taken from the manual i.e. grammar as being the main problem as well as direct comments made by the participants. The numbers indicate the participants in order i.e. participants 1-14 however, do not directly relate to their original participant code.

<u>RUBRIC SECTIONS</u>	<u>FORMATIVE EVALUATION COMMENTS</u>
<u>ORGANIZATION</u>	<ol style="list-style-type: none"> 1. SECTIONS ARE CLEAR 2. FLOWS AND EASY TO READ. TOPICS ARE ADDRESSED 3. WELL ORGANIZED AND EASY TO READ 4. READER FRIENDLY STRUCTURE 5. GUIDE IS WELL ORGANIZED 6. VERY WELL ORGANIZED AND STRUCTURED. FLOWS WELL AND READER FRIENDLY. 7. WELL ORGANIZED AND GREAT FLOW 8. GOOD BUT COULD USE MORE DEFINITE CONCLUSION 9. VERY WELL ORGANIZED AND STRUCTURES. THE LAYOUT FLOWS WELL AND IS READER FRIENDLY. SOME RIGHT/LEFT JUSTIFICATIONS NEED TO BE FIXED. 10. SIMPLE AND EASY TO FOLLOW 11. VERY WELL ORGANIZED AND GOOD FLOW. SUGGEST THAT DEFINITION SECTIONS WOULD GO AT THE BEGINNING. 12. FLOWS WELL 13. TABLE OF CONTENTS IS CLEAR AND EASY TO ACCESS SECTIONS 14. THE IDEAS PRESENTED ARE EXCELLENT AND VERY USEFUL
<u>QUALITY AND FOCUS OF INFORMATION</u>	<ol style="list-style-type: none"> 1. TOPICS ARE ADDRESSED 2. ALL TOPICS ARE ADDRESSED AND EXPLAINED. MORE EXAMPLES WOULD BE USEFUL. 3. THE FOCUS WAS GOOD AND ON THE CHILDREN. 4. GOOD GUIDE FOR FRONTLINE WORKERS. 5. TOPIC IS RELEVANT FOR NEW WORKERS. 6. . 7. SO, SO, COMPREHENSION PLUS HOLISTIC 8. GOOD 9. IF THERE ARE SPECIFIC QUESTIONS PROVIDED THEM AT THE BEGINNING OF THE MANUAL. 10. YES 11. IMPORTANT TOPICS ARE ALL COVERED 12. COVERS IMPORTANT TOPICS 13. DEFINITIONS ARE DEFINITELY NECESSARY FOR CLARIFICATION. 14. .

<p><u>AMOUNT OF INFORMATION</u></p>	<ol style="list-style-type: none"> 1. INFORMATION IS GOOD HOWEVER MORE CONCRETE EXAMPLES ARE NEEDED. 2. SOME SECTIONS WOULD BE BETTER WITH MORE DETAIL. 3. . 4. Perhaps a section on social skills might be useful. 5. THE MANUAL COVERS ALL THE RELEVANT TOPICS REGARDING PROGRAM PLANNING. 6. . 7. GOOD AMOUNT OF INFO. VERY RELATIVE 8. GOOD 9. EACH SECTION APPEARS TO HAVE SUFFICIENT AMOUNT OF INFORMATION 10. YES I LIKE THE SCENARIOS BEFORE THE INFORMATION IS PRESENTED. 11. VERY THOROUGH INTERPRETATION PROVIDED. 12. EASY TO READ 13. SOMETIMES THERE WERE EXAMPLES OF YOUNG STUDENTS AND OTHER TIMES OLDER STUDENTS. CLARIFICATION NEEDED. 14. .
<p><u>SOURCES</u></p>	<ol style="list-style-type: none"> 1. INFORMATION IS NOT SOURCED MUCH 2. NO PROBLEMS THAT THEY SEE 3. ALL SOURCES WERE ACCURATE 4. Well researched and accurate 5. CANT ADDRESS THIS 6. YES 7. NOT AS RELEVANT GIVEN THAT THIS IS GUIDE 8. . 9. THE SOURCES APPEAR TO BE RELEVANT AND APPLICABLE TO YOUR TOPIC. 10. YES 11. APPEARS TO BE CORRECT AND VERY RELEVANT 12. . 13. REFERENCES ARE VARIED WHICH ALLOWS FOR COMPARATIVE INFORMATION 14. .
<p><u>MECHANICS</u></p>	<ol style="list-style-type: none"> 1. NEEDS MAJOR EDITING 2. THERE ARE SOME EASILY FIXABLE GRAMMATICAL ERRORS. 3. A FEW PLACES I NOTICED COULD BE CHANGED. 4. FEW GRAMMATICAL MISTAKES 5. FAIR. NEEDS REVISION 6. YES 7. TYPOS 8. MOSTLY GOOD, SEE PAGE NOTES 9. VERY WELL WRITTEN. NEED PROOF READING. 10. A FEW. LOOK THROUGH 11. OVERALL WELL WRITTEN BUT NEEDS A FEW MORE READ THOUGHT FOR

	<p>SPELLING MISTAKES/SYNTAX</p> <ol style="list-style-type: none"> 12. SEE NNOTES INSIDE (GRAMMER CORRECTIONS) 13. A COUPLE OF PARAGRAPHS CAN BE ORGANIZED WIHOUT LOOSING YOUR POINT. 14. CORRECTIONS IN MANUAL
<p><u>DIAGRAMS AND ILLUSTRATIONS</u></p>	<ol style="list-style-type: none"> 1. MORE ILLUSTRATIONS WOULD BE NICE 2. COMPLETE. 3. . 4. . 5. NICE PICS 6. . 7. . 8. SCARCE BUT EXCELLENT COVER ART. 9. ILLUSTRATIONS AND DIAGRAMS ARE GREAT. VISUALLY APPEALING 10. ADD MORE 11. EXAMPLES AND TIOPS AND STRATEGIES ARE GREART VISUALS. 12. BEAUTIFUL 13. . 14. .
<p><u>USEFULNESS</u></p>	<ol style="list-style-type: none"> 1. NEED MORE SPECIFIC EXAMPLES 2. THIS WOULD BE A GREAT MANUAL AS THE INFORMATION IS EXTREMELY RELEVANT. 3. YES I THINK IT WOULD BE GOOD FOR NEW WORKERS AND OLD WORKERS. 4. GOOD MANUAL FOR FRONT LINERS AND GOOD REMINDERS FOR EXPERIENCED WORKERS. 5. . 6. GOOD INTRODUCTION TO THE TOPICS OF WORKING WITH MULTI-DISABLED CHILDREN. 7. GREAT FOR ISOLATED AND RURAL AREAS. 8. YES GOOD DETAILED ANALYSIS 9. YES I WOULD LOVE A COPY SO I CAN USE IT IN MY OWN WORK WITH THIS POPULATION. ALSO WOULD RECOMMEND IT TO OTHERS. 10. YES 11. AS A NEW TEACHER I CANNOT WAIT TO HAVE A COPY. 12. USEFUL FOR NEW PROFESSIONAL WORKERS. 13. USEFUL FOR NEW WORKERS OF SPECIAL NEEDS STUDENTS. 14. .

APPENDIX – 10 SUMMATIVE EVALUATION TABLE

SUMMATIVE EVALUATION RESULTS					
<u>ENGLISH</u> <u>MANUAL</u>	11 TOTAL PARTICIPANTS	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
	ORGANIZATION	11			
	QUALITY ANF FOCUS OF INFORMATION	9	2		
	AMOUNT OF INFORMATION	10	1		
	SOURCES	9	2		
	MECHANICS	6	5		
	DIAGRAMS AND ILLUSTRATIONS	9	2		
	USEFULNESS	9	2	10	
<u>FRENCH</u> <u>MANUAL</u>	2 TOTAL PARTICIPANTS	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
	ORGANIZATION	1	1		
	QUALITY ANF FOCUS OF INFORMATION	2			
	AMOUNT OF INFORMATION	1	1		
	SOURCES				
	MECHANICS	1		1	
	DIAGRAMS AND ILLUSTRATIONS	2			
	USEFULNESS	1	1		
<u>SPANISH</u> <u>MANUAL</u>	3 TOTAL PARTICIPANTS	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
	ORGANIZATION	1	2		
	QUALITY ANF FOCUS OF INFORMATION	1	2		
	AMOUNT OF INFORMATION	1	2		
	SOURCES		2		
	MECHANICS	1		2	
	DIAGRAMS AND ILLUSTRATIONS			2	
	USEFULNESS	3			

<u>QUECHUA</u> <u>MANUAL</u>	1 TOTAL PARTICIPANTS	STRONGLY AGREE	AGREE	DISAGREE	STRONGLY DISAGREE
			1		
	ORGANIZATION		1		
	QUALITY ANF FOCUS OF INFORMATION		1		
	AMOUNT OF INFORMATION		1		
	SOURCES		1		
	MECHANICS		1		
	DIAGRAMS AND ILLUSTRATIONS		1		
	USEFULNESS		1		

APPENDIX – 11 SUMMARY PROTOCOL FORM SPF



SUMMARY PROTOCOL FORM (SPF)

Office of Research – Research Ethics Unit – GM 900 – 514-848-2424 ext. 7481 –
<mailto:oor.ethics@concordia.ca> – www.concordia.ca/offices/oor.html

IMPORTANT INFORMATION FOR ALL RESEARCHERS

Please take note of the following before completing this form:

- You must not conduct research involving human participants until you have received your Certification of Ethical Acceptability for Research Involving Human Subjects (Certificate).
- In order to obtain your Certificate, your study must receive approval from the appropriate committee:
 - Faculty research, and student research involving greater than minimal risk is reviewed by the University Human Research Ethics Committee (UHREC).
 - Minimal risk student research is reviewed by the College of Ethics Reviewers (CER; formerly the “Disciplinary College”), except as stated below.
 - Minimal risk student research conducted exclusively for pedagogical purposes is reviewed at the departmental level. **Do not use this form for such research.** Please use the Abbreviated Summary Protocol Form, available on the Office of Research (OOR) website referenced above, and consult with your academic department for review procedures.

- Research funding will not be released until your Certificate has been issued, and any other required certification (e.g. biohazard, radiation safety) has been obtained. For information about your research funding, please consult:
 - Faculty and staff: OOR
 - Graduate students: School of Graduate Studies
 - Undergraduate students: Financial Aid and Awards Office or the Faculty or Department
- Faculty members are encouraged to submit studies for ethics by uploading this form, as well as all supporting documentation, to ConRAD, which can be found in the MyConcordia portal.
- If necessary, faculty members may complete this form and submit it by e-mail to oor.ethics@concordia.ca along with all supporting documentation. Student researchers are asked to submit this form and all supporting documentation by e-mail, except for departmental review. Please note:
 - Handwritten forms will not be accepted.
 - Incomplete or omitted responses may result in delays.
 - This form expands to accommodate your responses.
- Please allow the appropriate amount of time for your study to be reviewed:
 - UHREC reviews greater than minimal risk research when it meets on the second Thursday of each month. You must submit your study 10 days before the meeting where it is to be reviewed. You will normally receive a response within one week of the meeting. Please confirm the deadline and date of the meeting with the staff of the Research Ethics Unit.
 - CER reviews, and delegated reviews conducted by UHREC generally require 2 to 4 weeks.
- Research must comply with all applicable laws, regulations, and guidelines, including:
 - The [*Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*](#)
 - The policies and guidelines of the funding/award agency
 - The [*Official Policies of Concordia University*](#), including the *Policy for the Ethical Review of Research Involving Human Participants, VPRGS-3*.

- The Certificate is valid for one year. In order to maintain your approval and renew your Certificate, please submit an Annual Report Form one month before the expiry date that appears on the Certificate. You must not conduct research under an expired Certificate.
- Please contact the Manager, Research Ethics at 514-848-2424 ext. 7481 if you need more information on the ethics review process or the ethical requirements that apply to your study.

ADDITIONAL INFORMATION FOR STUDENT RESEARCHERS

- If your research is part of your faculty supervisor's research, as approved, please have him or her inform the Research Ethics Unit via e-mail that you will be working on the study.
- If your research is an addition to your faculty supervisor's study, please have him or her submit an amendment request, and any revised documents via e-mail. You must not begin your research until the amendment has been approved.

INSTRUCTIONS FOR COMPLETING THIS FORM

- Please make sure that you are using the most recent version of the SPF by checking the OOR website.
- Please answer each question on the form; if you believe the question is not applicable, enter not applicable.
- Do not alter the questions on this form or delete any material. Where questions are followed by a checklist, please answer by checking the applicable boxes.
- The form can be signed and submitted as follows:
 - Faculty research submitted on ConRAD will be considered as signed as per section 16.
 - SPFs for faculty research submitted via the faculty member's official Concordia e-mail address will also be considered as signed as per section 16.
 - Both faculty and student researchers may submit a scanned pdf of the signature page by e-mail. In this case, the full SPF should also be submitted by e-mail in Word or pdf format (not scanned).
 - If you do not have access to a scanner, the signature page may be submitted on paper to the OOR.

ADDITIONAL DOCUMENTS

Please submit any additional documents as separate files in Word or PDF format. **1. BASIC INFORMATION**

Study Title:

Principal Investigator:

Principal Investigator's Status:

- Concordia faculty or staff
- Visiting scholar
- Affiliate researcher
- Postdoctoral fellow
- PhD Student
- Master's student
- Undergraduate student
- Other (please specify):

Type of submission:

- New study
- Modification or an update of an approved study.
- Approved study number (e.g. 30001234):

Where will the research be conducted?

- Canada
- Another jurisdiction:

2. STUDY TEAM AND CONTACT INFORMATION*

Role	Name	Institution[†]	Phone	e-mail address
		/	#	

		Department / Address‡		
Principal Investigator	Michael D'Abate	Department of Education Concordia University	514-804-2419	m_dabate@education.concordia.ca
Faculty supervisor§	Richard Schmid	Department of Education Concordia University	(514) 848-2424, x2001	schmid@education.concordia.ca
Committee member¶				
Committee member¶				

Additional Team Members°				

Notes:

* If additional space is required, please submit a list of team members as a separate document.

†For team members who are external to Concordia only.

‡For individuals based at Concordia, please provide only the building and room number, e.g. GM-910.03.

§For student research only.

¶For research conducted by PhD and Master's students only.

°Please include all co-investigators and research assistants.

3. PROJECT AND FUNDING SOURCES

Please list all sources of funds that will be used for the research. Please note that fellowships or scholarships are not considered research funding for the purposes of this section.

Funding Source	Project Title*	Grant Number†	Award Period	
			Start	End

Notes:

* Please provide the project title as it appears on the Notice of Award or equivalent documentation.

† If you have applied for funding, and the decision is still pending, please enter “applied”.

4. OTHER CERTIFICATION REQUIREMENTS

Does the research involve any of the following (check all that apply):

- Controlled goods or technology
- Hazardous materials or explosives
- Biohazardous materials
- Human biological specimens
- Radioisotopes, lasers, x-ray equipment or magnetic fields
- Protected acts (requiring professional certification)
- A medical intervention, healthcare intervention or invasive procedures

Please submit any certification or authorization documents that may be relevant to ethics review for research involving human participants.

5. LAY SUMMARY

Please provide a brief description of the research in everyday language. The summary should make sense to a person with no discipline-specific training, and it should not use overly technical terms. Please do not submit your thesis proposal or grant application.

The aim of this investigation is twofold: (1) to explore best practices with regards to teaching autistic and blind students in a formal school setting (2) to create a practical guide for individuals who work with this target population. Using an action based research model, that is, a combination of interviews, literature search, and focus groups, will allow for a better knowledge and understanding of what techniques and strategies work best in teaching children that are both autistic and blind. The intended manual will comprise of a compilation of these teaching techniques and strategies as well as examples of best practices as identified in the research. Once the data is gathered and the first draft of the manual is completed, the subject matter experts as well as others working in the field will review it and point out any inconsistent information, lack of coherence, or problems with regards to how information is presented. Once the comments are received the revisions will be made and submitted for final review

6. RISK LEVEL AND SCHOLARLY REVIEW

As part of the research, will participants be exposed to risk that is greater than minimal?

Minimal risk means that the probability and magnitude of the risks are greater than those to which participants would be exposed in those aspects of their daily lives that are pertinent to the research.

Yes

No

Has this research received favorable review for scholarly merit?

Scholarly review is not required for minimal risk research.

For faculty research, funding from a granting agency such as CIHR, FQRSC, or CINCQ is considered evidence of such review. Please provide the name of the agency.

For student research, a successful defense of a thesis or dissertation proposal is considered evidence of such review. Please provide the date of your proposal defense.

- Yes Funding agency or
 date of defense:
- No
- Not required

If you answered no, please submit a Scholarly Review Form, available on the OOR website. For studies to be conducted at the PERFORM Centre, please submit the Scientific Review Evaluator Worksheet.

7. RESEARCH PARTICIPANTS

Will any of the participants be part of the following categories?

- Minors (individuals under 18 years old)
- Individuals with diminished mental capacity
- Individuals with diminished physical capacity
- Members of Canada’s First Nations, Inuit, or Métis peoples
- Vulnerable individuals or groups (vulnerability may be caused by limited capacity, or limited access to social goods, such as rights, opportunities and power, and includes individuals or groups whose situation or circumstances make them vulnerable in the context of the research project, or those who live with relatively high levels of risk on a daily basis)

None of these categories are included in this project.

Please describe potential participants, including any inclusion or exclusion criteria. The participants of this study will be separated according to formal/informal teaching settings and be limited to individuals that have been or are still working with a special needs population. It is important to note the different categories of participants because of their different functions within a formal/informal learning environment. By differentiating

between these different individuals it will be easier to construct this manual tailored to their own unique needs. The following is a rough breakdown of possible groups of individuals that will be asked to participate:

Formal Teaching Setting (i.e. schools and other organizations)

1. Teachers (5+ years experience)
2. New Teachers (0-5 years experience)
3. Substitute teachers
4. Child Care Workers (CCW)
5. Volunteers

Participants within the formal teaching setting will be recruited from a number of professional contacts made over the years working in the field. Schools such as Philip E. Layton (school for the visually impaired) and organizations such as the YM-YWHA (Wesbury Y special needs programs) will be predominantly used. In Peru, The organization that will be approached will be KIYA Survivors, who works closely with a school for children having Autism and other impairments.

Informal Teaching Setting (i.e. home life, social events)

1. Parents/Family Members
2. Friends
3. Volunteers

These participants will be recruited by word of mouth and through contacts that have been established over the years and through the organizations mentioned above.

It will be important to get subject matter experts from both formal and informal learning settings because this Manual is meant to, not only, be used by professionals and para-professionals but by other individuals such as parents and volunteers who work in various ways with these individuals.

a) Please describe in detail how potential participants will be identified, and invited to participate. Please submit any recruitment materials to be used, for example, advertisements or letters to participants.

Participants for this research will include both those that I have worked with as well as any other individuals that they might recommend from outside of their present work place. This group will include people here in Montreal as well as in B.C. and Peru. The one qualifying variable will be that these professionals/para-professionals have cared or worked with children having a Visual Impairment, Autism, and/or Multi-Disabled.

b) Please describe in detail what participants will be asked to do as part of the research, and any procedures they will be asked to undergo. Please submit any instruments to be used to gather data, for example questionnaires or interview guides.

Each of these participants will be given a questionnaire followed by an interview in order to expand on their written answers. The number of participants will vary between 10 and 15 and include individuals who are involved locally as well as internationally (Peru). The main modality by which participants will be selected in Peru will be through existing NGO's and/or centers that already work within the system. Bondy (1993) uses this strategy in implementing the "Picture-Exchange Communication System or (PECS), which was developed in the United States. Through the help and involvement of organizations in Peru, this research group was able to attain its goals. With respect to submitting and receiving the data from the participants, the use of email and Skype will be a predominant means of communication. In addition to this, I will be spending the month of July and August in Peru and will be working directly on data collection.

c) Do any of the research procedures require special training, such as medical procedures or conducting interviews on sensitive topics or with vulnerable populations? If so, please indicate who will conduct the procedures and what their qualifications are.

There is no special training required to conduct this research.

8. INFORMED CONSENT

a) Please explain how you will solicit informed consent from potential participants. Please submit your written consent form. In certain circumstances, oral consent may be appropriate. If you intend to use an oral consent procedure, please submit a consent script

containing the same elements as the template, and describe how consent will be documented.

Following a briefing of the research project, we will ask participants to sign the consent form (appendix 1) giving permission to the researcher to use the data obtained.

b) Does your research involve individuals belonging to cultural traditions in which individualized consent may not be appropriate, or in which additional consent, such as group consent or consent from community leaders, may be required? If so, please describe the appropriate format of consent, and how you will solicit it.

No it does not.

9. DECEPTION

Does your research involve any form of deception of participants? If so, please describe the deception, explain why the deception is necessary, and explain how participants will be de-briefed at the end of their participation. If applicable, please submit a debriefing script.

There will be no deception involved in our project.

10. PARTICIPANT WITHDRAWAL

a) Please explain how participants will be informed that they are free to discontinue at any time, and describe any limitations on this freedom that may result from the nature of the research.

Participants will be informed in writing (appendix 1) that they may discontinue at any time without any negative consequences.

b) Please explain what will happen to the information obtained from a participant if he or she withdraws. For example, will their information be destroyed or excluded from analysis if the participant requests it? Please describe any limits on withdrawing a participant's data, such as a deadline related to publishing data.

Any information that could be directly linked to any individual will NOT be used in this study however, information that can be backed up by research and other sources could

potentially be used even if the participant had withdrawn from the study. In either case, the participants identity or connection to the to the data will not be included in the manual, the thesis report, or any potential publication.

11. RISKS AND BENEFITS

a) Please identify any foreseeable benefits to participants.

This research will benefit the participants by informing them of the important strategies in working with children having visual impairments, autism, and/ or who are multi-disabled. These strategies will be compiled into a manual that they can easily utilize in formal and informal teaching settings.

b) Please identify any foreseeable risks to participants, including any physical or psychological discomfort, and risks to their relationships with others, or to their financial well-being.

Due to the nature of the study, there are no foreseeable risks or potential harm to the participants.

Please indicate how the risks identified above will be minimized. Also, if a potential risk or harm should be realized, what action will be taken? Please attach any available list of referral resources, if applicable.

Not applicable

c) Please describe how the risks identified above will be minimized. For example, if individuals who are particularly susceptible to these risks will be excluded from participating, please describe how they will be identified. Furthermore, if there is a chance that researchers will discontinue participants' involvement for their own well-being, please state the criteria that will be used.

Not applicable

d) Please describe how you will manage the situation if the risks described above are realized. For example, if referrals to appropriate resources are available, please provide a list. If there is a chance that participants will need first aid or medical attention, please describe what arrangements have been made.

Not applicable

12. REPORTABLE SITUATIONS AND INCIDENTAL FINDINGS

a) Is there a chance that the research might reveal a situation that would have to be reported to appropriate authorities, such as child abuse or an imminent threat of serious harm to specific individuals? If so, please describe the situation, and how it would be handled.

Due to the nature of this project, it is highly unlikely that such information would emerge. However, should this occur, the proper authorities would be notified.

b) Is there a chance that the research might reveal a material incidental finding? If so, please describe how it would be handled.

Again, due to the nature of this project, it is highly unlikely that such a finding would emerge. However, should this occur, the proper authorities would be notified.

13. CONFIDENTIALITY, ACCESS, AND STORAGE

a) Please describe the path of your data from collection to storage to its eventual archiving or disposal, including details on short and long-term storage (format, duration, and location), measures taken to prevent unauthorized access, who will have access, and final destination (including archiving, or destruction).

- Data will be collected and recorded on paper.
- This information will then be transcribed to a spreadsheet and coded by topic and category.
- The data on paper will be filed away and eventually disposed of if required. all subsequent steps needed to create the manual will be taken from the spreadsheet where there is not connection to the participant.
- The data will be reviewed and will eventually be used to create the manual.

b) Please identify the access that the research team will have to participants' identity:

<input type="checkbox"/>	Anonymous	The information provided never had identifiers associated with it, and the risk of identification of individuals is low, or very low.
<input type="checkbox"/>	Anonymous results, but identify who participated	The information provided never had identifiers associated with it. The research team knows participants' identity, but it would be impossible to link the information provided to link the participant's identity.
<input type="checkbox"/>	Pseudonym	Information provided will be linked to an individual, but that individual will only provide a fictitious name. The research team will not know the real identity of the participant.
<input type="checkbox"/>	Coded	Direct identifiers will be removed and replaced with a code on the information provided. Only specific individuals have access to the code, meaning that they can re-identify the participant if necessary.
<input type="checkbox"/>	Indirectly identified	The information provided is not associated with direct identifiers (such as the participant's name), but it is associated with information that can reasonably be expected to identify an individual through a combination of indirect identifiers (such as place of residence, or unique personal characteristics).
<input checked="" type="checkbox"/>	Confidential	The research team will know the participants' real identity, but it will not be disclosed.
<input type="checkbox"/>	Disclosed	The research team will know the participants' real identity, and it will be revealed in accordance with their consent.

<input type="checkbox"/>	Participant Choice	Participants will be able to choose which level of disclosure they wish for their real identity.
<input type="checkbox"/>	Other (please describe)	

c) Please describe what access research participants will have to study results, and any debriefing information that will be provided to participants post-participation.

Each participant will be able to give a formative evaluation after the first draft of the manual has been put together. Once the corrections have been made and the final draft produced each participant will receive a copy of the manual for their personal use.

d) Would the revelation of participants' identity be particularly sensitive, for example, because they belong to a stigmatized group? If so, please describe any special measures that you will take to respect the wishes of your participants regarding the disclosure of their identity.

None of the participants will be identified.

e) In some research traditions, such as action research, and research of a socio-political nature, there can be concerns about giving participant groups a "voice". This is especially the case with groups that have been oppressed or whose views have been suppressed in their cultural location. If these concerns are relevant for your participant group, please describe how you will address them in your project.

This issue does not apply to participants in this project.

14. MULTI-JURISDICTIONAL RESEARCH

Does your research involve researchers affiliated with an institution other than Concordia? If so, please complete the following table, including the Concordia researcher's role and activities to be conducted at Concordia. If researchers have multiple institutional affiliations, please include a line for each institution.

Researcher's Name	Institutional Affiliation	Role in the research (e.g. principal investigator, co-investigator, collaborator)	What research activities will be conducted at each institution?

15. ADDITIONAL ISSUES

Bearing in mind the ethical guidelines of your academic or professional association, please comment on any other ethical concerns which may arise in the conduct of this research. For example, are there responsibilities to participants beyond the purposes of this study?

16. DECLARATION AND SIGNATURE

Study Title:

I hereby declare that this Summary Protocol Form accurately describes the research project or scholarly activity that I plan to conduct. I will submit a detailed modification request if I wish to make modifications to this research.

I agree to conduct all activities conducted in relation to the research described in this form in compliance with all applicable laws, regulations, and guidelines, including:

- The [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans](#)
- The policies and guidelines of the funding/award agency
- The [Official Policies of Concordia University](#), including the *Policy for the Ethical Review of Research Involving Human Participants, VPRGS-3*.

Principal Investigator Signature: _____

Date: _____

FACULTY SUPERVISOR STATEMENT (REQUIRED FOR STUDENT PRINCIPAL INVESTIGATORS):

I have read and approved this project. I affirm that it has received the appropriate academic approval, and that the student investigator is aware of the applicable policies and procedures governing the ethical conduct of human participant research at Concordia University. I agree to provide all necessary supervision to the student. I allow release of my nominative information as required by these policies and procedures in relation to this project.

Faculty Supervisor Signature: _____

Date: _____

APPENDIX – 12 SUGGESTED CHANGES BY THE MINISTRY OF EDUCATION IN CUSCO PERU

REVISION DEL LIBRO TRABAJANDO CON NIÑOS QUE TIENEN DISCAPACIDADES MULTIPLES

AUTOR: Michael D' abate

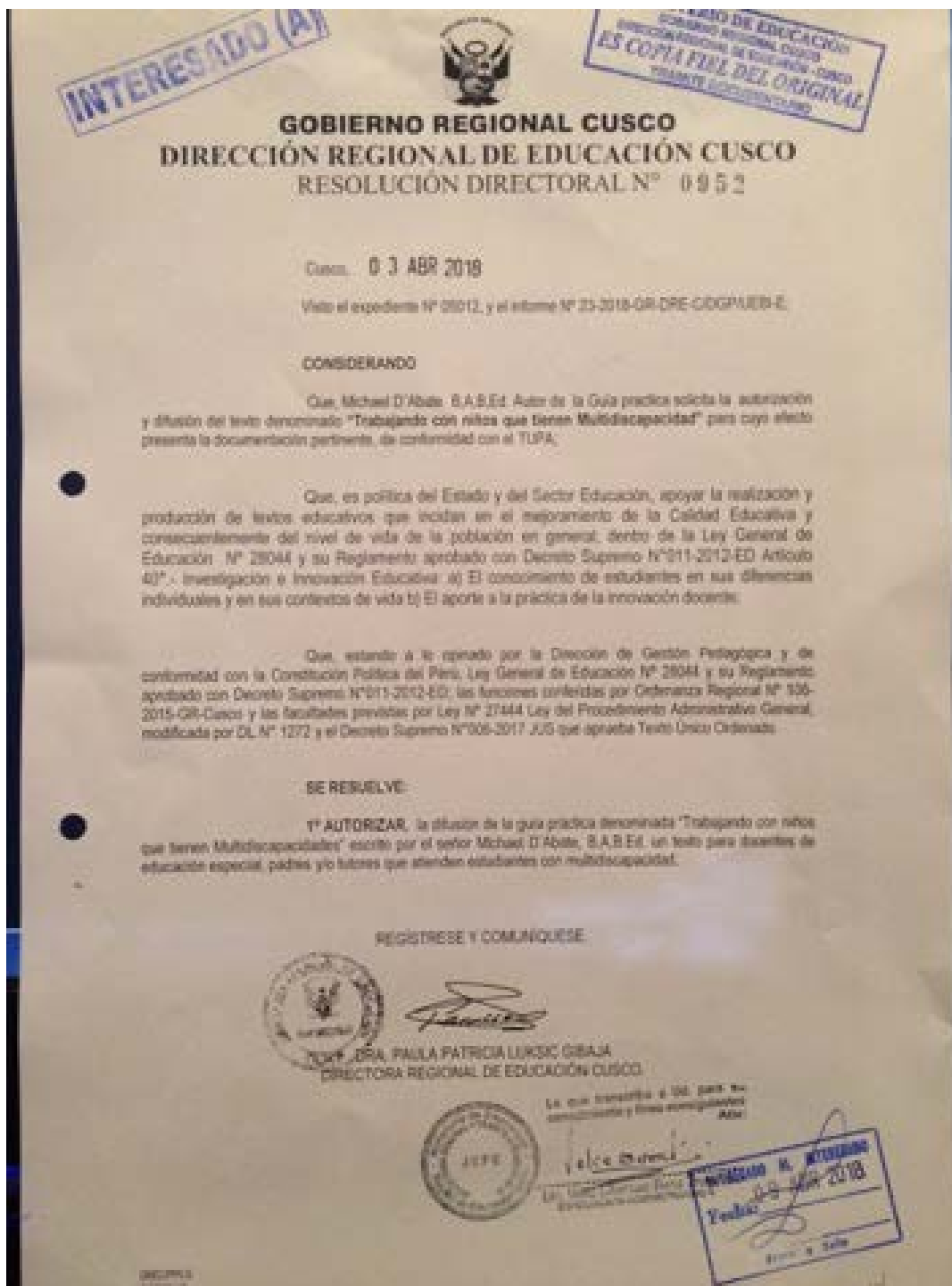
REVISION: Gabriela Valenza León

ADAPTACION DE TERMINOS:

- En el Marco Educativo la atención de los estudiantes con discapacidad se denomina estudiantes con Necesidades Educativas Especiales. (NEE). Esta atención se da dentro del modelo social.
- Discapacidades múltiples: Multidiscapacidad
- Autismo: Trastorno del Espectro Autista.
- La Educación Peruana está organizada en diferentes Áreas de desarrollo, las cuales dentro del marco inclusivo deben ser adaptadas para dar respuesta a las Necesidades Educativas Especiales de los estudiantes con multidiscapacidad las áreas son las siguientes:
 - **Comunicación:** (Desarrollo de la comunicación, intención comunicativa, etc.)
 - Personal Social (Identidad, autonomía, auto valimiento, familia, seguridad, desarrollo emocional)
 - **Matemática** (Desarrollo de conceptos cognitivos básicos, atención, percepción, memoria, etc.)
 - **Ciencia y ambiente:** (Conocimiento del cuerpo, sensaciones, integración sensorial,)
 - **Psicomotricidad:** (Coordinación dinámica general, esquema corporal, conductas perceptivo motrices, etc.)
- Expediente: Evaluaciones previas, en el marco escolar se habla de Carpetas Individuales de los estudiantes.
- Tutorías privadas: Terapias particulares.
- Planes de Educación Individual: Planes de Orientación Individual (POI)
- Informe Psicopedagógico: Evaluación integral del estudiante, institución educativa, familia, contexto para recoger información y determinar las Necesidades Educativas Especiales.

- Los estudiantes con ceguera en cambio requieren el uso de estrategias también específicas en comunicación como el aprendizaje de Braille si es ciego total o en tinta con macrotipos si presenta baja visión, el personal complementario que debe intervenir en el equipo es el Profesor de O y M (Orientación y Movilidad), el profesor de AVD (Actividades de la Vida Diaria), las adaptaciones se realizaran a los materiales, etc.
- Respecto a la atención de los estudiantes que presentan TEA (Trastorno del Espectro del Autismo) requieren en cambio otro tipo de atención, pues sus necesidades son muy diferentes, ya que presentan alteración en la comunicación y en la interacción social.
- Por todo lo mencionado mi sugerencia es que el libro se centre en una sola discapacidad, puede ser multidiscapacidad, discapacidad visual (Ceguera – baja visión) o Trastorno del Espectro Autista, pues la respuesta a las necesidades educativas especiales son específicas para cada tipo de discapacidad.
- Respecto a la organización del libro mi sugerencia es que se presente de la siguiente manera:
 - Delimitación del concepto de la Discapacidad que se va a tratar.
 - Aspectos relacionados con la Determinación de las Necesidades Educativas Especiales.
 - Equipo de trabajo
 - Orientación a la Familia.
 - Propuesta de Actividades por áreas de atención (Comunicación, autonomía, etc.)
- Otra de las dificultades que encuentro en el libro es la falta de estructura para el desarrollo de algunas áreas, por ejemplo Comunicación, pues se debe considerar el desarrollo de esta, evaluar el nivel de comunicación, así como el uso de SAACs, (Sistemas Aumentativos y Alternativos de Comunicación), el proceso de implementación de los SAACs si es necesario, etc.
- Finalmente quiero mencionar que por problemas de traducción hay párrafos del libro que no se entiende, por lo que deben ser nuevamente estructurados o escritos.

APPENDIX – 13 SPANISH MANUAL APPROVAL (PERUVIAN MINISTRY OF EDUCATION)



APPENDIX – 14 FRENCH, SPANISH AND QUECHUA VERSIONS OF THE MANUAL

ENGLISH

<https://goo.gl/VLGNAK>

FRENCH

<https://goo.gl/JSLnst>

SPANISH

<https://goo.gl/orULq1>

QUECHUA

<https://goo.gl/vaYJei>