School Success for Haitian Children with Autism

A Parent Training Manual to Overcome Cultural, Language and Other Barriers

outreach training education advocacy

Autism Special Education Legal Support Center
Massachusetts Advocates for Children

School Success for Haitian Children with Autism

A Parent Training Manual to Overcome Cultural, Language and Other Barriers

Principal Author: Leslie Hughes

Contributing Author: Kerlyne Pacombe, MSW, LICSW

MAC MASSACHUSETTS ADVOCATES *for* CHILDREN

Massachusetts Advocates for Children
Autism Special Education Legal Support Center
25 Kingston Street
Boston, MA 02111

United Way
United Way of Massachusetts Bay and Merrimack Valley

Massachusetts Legal Assistance Corporation

The **Autism Special Education Legal Support Center** is a project of Massachusetts Advocates for Children providing training, technical assistance and advocacy services to ensure that children with autism overcome lowered expectations and receive equal educational opportunities. The Center also provides intensive training and legal advocacy for parents who face cultural and language barriers in selected Haitian and Latino, and other immigrant communities.

Autism Center Team Members

- **Julia Landau, Esq.**
  Autism Center Director
- **Tina Fitanides, Esq.**
  Policy Analyst
- **Leslie Hughes**
  Autism Public Education Specialist
- **Leslie Lockhart**
  Helpline Coordinator
- **Catherine Mayes**
  Autism Project Advocate
- **Tom Mela, Esq.**
  Managing Attorney
- **Dan Perlman, Esq.**
  Staff Attorney
- **Johanne Pino**
  Project Coordinator

Massachusetts Advocates for Children

MAC's mission is to be an independent and effective voice for children who face significant barriers to equal educational and life opportunities. MAC works to overcome these barriers by changing conditions for many children, while also helping one child at a time. For over 40 years, MAC has responded to the needs of children who are vulnerable because of poverty, race, limited English or disability.

- **Jerry Mogul**
  Executive Director
- **Matthew Iverson, Esq.**
  Board Chair

25 Kingston Street
Boston, MA 02111
617-357-8431
www.massadvocates.org

The Haitian American Public Health Initiative (HAPHI) is a minority run, non-profit agency dedicated to providing members of the Haitian-American community in Metro Boston with culturally and linguistically accessible information and services to improve their health and wellbeing. Located in Mattapan, HAPHI was founded in 1989 by a group of Haitian-American health care professionals to address pressing public health issues confronting Boston's Haitian community.

HAPHI provides a comprehensive range of prevention, education, and direct service programs to Haitian-Americans from the greater metropolitan area of Boston. Several of its programs serve Haitian Americans throughout New England.

Cover design and layout: Susan Sutherland

Table of Contents

Acknowledgments

MAC and the Autism Center deeply appreciate the long-standing generosity, commitment and guidance provided by the Nancy Lurie Marks Family Foundation, which has been pivotal to our efforts to reach underserved families. Our ability to work in the Haitian community would not have been possible without the additional funding support provided over the years to the Autism Center by many other generous foundations and individual donors. Current additional funders supporting the Autism Center are the Doug Flutie Jr. Foundation, DLA Piper Foundation, Ronald Ansin Foundation, the Edwin Phillips Foundation, Foundation M, Massachusetts Bar Foundation, Boston Bar Foundation and Whole Foods Market. We and the families we serve appreciate their very generous support.

We would like to thank Carrie Normand for generously volunteering to edit one of the initial drafts of this manual. Thank you to Kavita Padiyar for her contributions and edits and to Leonardine Pacombe for her creativity and involvement. Partners In Health was also kind enough to review selected sections of the manual and Elizabeth Stringer Keefe generously provided valuable technical assistance. And of course many thanks to MAC's autism center staff, past (including Ann Guay, Beth Simon, Julia Lavine, and Valerie Prosper) and present, who contributed much legal, autism, and special education expertise. And finally, we would like to thank most of all the dedicated Haitian families that enthusiastically participated in MAC's workshops to learn to advocate for their children with autism.

This training manual is dedicated to **Maule Laventure** and **Dr. Renald Raphael. Maule Laventure** is a parent of a child with autism who introduced us to HAPHI and the numerous Haitian families whose lives are affected by autism. It was with Maule that our intensive education about the needs and barriers faced by these families began. Maule advocates tirelessly for her son despite the many obstacles she has faced. We thank **Dr. Renald Raphael**, HAPHI Family Support Program Supervisor, for his passion and resolute commitment to Haitian families who have children with autism and other disabilities.

Foreword

In the last ten years, the number of children diagnosed with autism has skyrocketed. The sheer increase in numbers has been accompanied by increased awareness about autism. Family members, once isolated from each other, now network, march, raise funds, and raise their voices in schools and state legislatures seeking services for their children. Increased funding for research has resulted in a consensus among experts that early and effective treatment for children with autism enables them to grow, thrive and achieve at levels once unimaginable.

Autism does not discriminate. It impacts families from all walks of life. However, in order to obtain the services their children need to reach their full potential, families of children with autism must have the resources to be able to navigate complex legal and educational systems. While the condition of autism is not constrained by race or class, access to effective intervention is limited. In particular, children with autism in families who live in immigrant communities and face barriers of language, class and culture often remain concealed in a shroud of misunderstanding and stigma. And while schools everywhere have struggled to deliver services consistent with an understanding of the potential of children with autism, it has been particularly difficult in under-resourced school districts serving the many low-income, recent immigrants, such as in the Haitian community.

MAC's mission has always been to advocate for the most vulnerable children in our society. With the high numbers of MAC Helpline calls from parents of children with autism desperate for services, it was clear over a decade ago that we needed to do something different. In response, we established the Autism Special Education Legal Support Center ("Autism Center"), the first disability-specific program in our then-30+ year history, to respond to the complex needs of the burgeoning number of children with autism spectrum disorder (ASD).

Shortly after we established the Autism Center, a Haitian parent came in to our office seeking help for her son with autism. Maule Laventure was not satisfied with the education and services her son, Ali, was receiving in school, and we immediately agreed to represent him. But in coming to our door seeking help for her son, she in turn opened a door for the Autism Center by introducing us to the Boston Haitian community. Soon after taking on Ali as a client, MAC staff began to

attend monthly Sunday evening support group meetings for Haitian families run by Dr. Renald Raphael of the Haitian American Public Health Initiative (HAPHI). Dr. Raphael worked tirelessly, and still does, to help Haitian families obtain services that they need.

While the Sunday support group was open to parents of children with any type of disability, in fact most of those in attendance had children with autism. Dr. Raphael was already breaking down the barriers of isolation and misunderstanding within his community, but realized that he needed the expertise of an advocacy organization to get the children the services they needed from the local school district. And so our partnership was formed. Working together with HAPHI has given us the good fortune to learn how to better address the needs of the Haitian community in Boston where families struggle with the barriers of literacy, language, culture and poverty which impacts access to necessary services.

This training manual is designed to share with similarly situated advocacy or community-based organizations the strategies developed to empower Haitian parents to speak and advocate on behalf of their children with autism. While we were pleased that so many children from the Haitian community obtained better services and supports in school as a result of our advocacy, we were personally and professionally enriched by our partnership with the Haitian community in Boston. We stand in awe of the dedication of the HAPHI staff and the incredible resilience and commitment of the parents we spent many hours with, sharing and learning.

It is our hope that you, the reader, will be moved and inspired to investigate the prevalence and circumstances of autism spectrum disorder in your Haitian community so that you can start the process of empowering parents, advocating for legal entitlements and achieving school success for these children. Their very future depends on it.

Jerry Mogul
Executive Director

Julia Landau
Autism Special Education
Legal Support Center Director

1 Charles' Story

A family learns the value of advocating for their son

"Charles" was a five year-old Haitian boy with autism spectrum disorder (ASD) who lived in Boston. His parents emigrated from Haiti, were low-income, and Haitian Creole was their primary language. Charles' parents had never heard of autism when he first received the diagnosis from doctors at Boston Medical Center when he was two years old.

Charles received intensive in-home services through the Early Intervention program. However, the local school district failed to provide a special education program when Charles turned three, as required by federal law. Instead, Charles was placed on a wait list and was out of school without *any* services for three months. During the months he was without services, Charles lost critical new behavioral, and communication skills that he had acquired through Early Intervention and his behavioral difficulties became significantly worse. Boston Medical Center doctors expressed concern to school officials about the loss of services at such a critical time in Charles' development. Charles' parents were not at all familiar with special education programs, legal timelines, and federal laws. Their background was one where public entities and officials were not questioned for fear of persecution.[1] They did not speak or read English, and in Haiti, children disabilities do not have the right to an education. In fact, many are hidden away because of shame and lack of understanding. The barriers that Charles' parents faced in order to help their child were daunting. They saw, however, that their child had potential to learn, to make progress.

In Haiti, children with disabilities do not have the right to an education. In fact, many are hidden away because of shame and lack of understanding.

Our community partner, the Haitian American Public Health Initiative (HAPHI), contacted Massachusetts Advocates for Children's (MAC) Autism Special Education Legal Support Center (the Autism Center) on behalf of Charles' parents. MAC met with the family and agreed to represent them.

We learned that when Charles entered school at age 3 after being on the wait list, he had been placed by the district in a substantially separate classroom that, by its own admission, was a "disaster." No behavioral evaluation was conducted, no home services were provided, and despite the requirement for a summer program in Charles' educational plan, none was provided. As a result, his behavioral issues significantly worsened: Charles became increasingly physically aggressive towards his mother and younger brother if he was required to do something other than his preferred activity.

The following school year, Charles was placed in the same inappropriate classroom as the prior school year. During the first two months, Charles' parents were repeatedly called to the school to pick him up because his behavior was out of control, including hitting, biting, and kicking of adults and other children. In that same time period, Charles, now four years old, was suspended for being a safety risk to himself and other students (he had bitten another child in his class). At a Team meeting later in the year, Charles' parents reported that his behavior was unmanageable at home. Charles was reportedly a bright boy with significant potential, yet his behavior was interfering with his ability to progress.

Independent evaluations, including observations in the classroom obtained in the course of MAC's legal representation, revealed that Charles' school program was woefully inadequate in meeting his needs and that his behavioral difficulties continued to interfere with his education. Therefore, MAC attorneys filed a complaint at the Bureau of Special Education Appeals (BSEA) that resulted in an order to place Charles, for the summer, at a private school with programming specially designed for children with autism who have severe and challenging behaviors. The hearing officer found, in part, that the district's failure to provide Charles with an education for three months after his third birthday, despite a timely referral, was "egregious." MAC attorneys ultimately negotiated a favorable settlement of the remaining issues of Charles' case. Charles was able to attend school in a program where he demonstrated progress for the first time in two years. Both his parents and school staff reported that even in the first two months he had gained verbal skills.

At the same time that MAC's Autism Center was working on individual cases with Haitian clients, such as Charles, we were also actively collaborating within the Haitian community, in particular with HAPHI's Haitian Family Support Program. HAPHI is a Haitian community-run, non-profit agency in Boston committed to providing members of the Haitian-American community with culturally and linguistically accessible information and services. The Haitian Family Support Program works with families who have children with disabilities; the majority of families in the program have children with autism. These families meet monthly in a parent group to gain information and training around disability issues.

MAC partnered with HAPHI in order to train and educate Haitian parents of children with autism about their legal rights related to special education.

MAC partnered with HAPHI in order to train and educate Haitian parents of children with autism about their legal rights related to special education. Charles' mother, during the long litigation process, joined the parent group. It was very important to her that she help and give back to her community. Charles' mother talked to the parent group during MAC trainings about her experience advocating for her child. She talked about the difficult but necessary process of speaking up to public officials on behalf of her child and how her efforts, with MAC's help, ultimately helped her child succeed. She described the process and the concrete outcomes and services that her child received and the specific progress her son was finally making.

Charles' Story

Our work with Charles and his family reflected the huge inroads MAC made gaining not just access to, but also trust from the Haitian community. During the course of the legal process, Charles' parents learned the value of overcoming barriers and advocating for their son. They served as an example and inspiration to other Haitian families who were similarly situated in Boston. Unfortunately, after Charles had demonstrated significant progress in his new placement, his family made the difficult choice of moving to another country where they would not face problems with their immigration status.

For reasons having to do with literacy, cultural barriers and immigration status of many families, the advocacy process with Haitian families is never simple. While Charles and his family had to move, he did make progress in the years that MAC was advocating for him. But beyond the benefit to himself alone, his case was invaluable in teaching us how to better advocate with families in communities that face cultural and linguistic barriers. Further, Charles' case raised many important systemic compliance issues faced by young children with autism in school districts, like Boston, throughout the country.

During the course of the legal process, Charles' parents learned the value of overcoming barriers and advocating for their son. They served as an example and inspiration to other Haitian families who are similarly situated in Boston.

2 Introduction

The Haitian Experience / History and Barriers

Introduction

The life of a parent raising a child with autism can be full of joy as well as fraught with challenging demands, whether at home or in school, in the classroom or in the family room. Beyond guiding their children through the turbulence of everyday life, these parents are faced with the often daunting responsibility of ensuring that their children receive appropriate special education programs, services, and supports. While equal educational opportunity is guaranteed by law, too often it is not a reality for children with autism. Their parents, operating on pure passion and perseverance, must serve as their champions, their advocates, and their voice.

Navigating the legal landscape of education can be challenging for any parent of a child with autism. Even those with a substantial base of knowledge and resources may find themselves confused, ignored, or defeated. Autism does not discriminate – any child can be affected, regardless of race, economic status, or educational background. Where the challenges to any parent may prove incredibly difficult, the additional barriers for a member of an underserved population are staggering. Parents are underserved when they cannot exercise their rights due to differences in language, culture, ability, or race. In the end, it is the child that suffers, and a system that has failed.

For over forty years, MAC has used a multi-strategic approach to obtain results and change the conditions that limit children's opportunities. These strategies include building coalitions, empowering parents and community leaders, providing technical assistance and training, conducting case advocacy, advocating at the administrative and legislative levels, writing reports, and, when necessary, litigating. Following in this tradition, the Autism Center, a project based within MAC, has recognized barriers within underserved populations and strived to overcome these obstacles. For over ten years the Autism Center has worked with thousands of parents of children with autism. This work has provided invaluable insight into the nature of these obstructive barriers. In response, MAC launched a new initiative focused on the needs of low-income Haitian parents of children with autism.

An early, yet crucial, lesson came with the realization that addressing a non-traditional situation with traditional means of instruction did not yield constructive results. To educate and empower Haitian parents, to make them equal and effective members of their child's special education team, it was imperative for us to reinvent and redefine our approach. Our usual presentations and handouts that assumed a moderate to high level of literacy were not effective; addressing the needs of this community required a willingness to start from the beginning. MAC began by hiring a Haitian parent of a child with autism as a consultant, hoping to gain a better understanding of the barriers that these families face in the United States. With a broader grasp of these issues, we were able to devise more productive and interactive trainings and materials. Later, MAC worked with a Haitian-American consultant, fluent in Haitian Creole, who was not only very familiar with disability issues but also quite experienced in group trainings. With the help of this consultant, the trainings became more participatory and more effective. We developed this manual to share the fruits of these efforts.

This training manual describes MAC's outreach, training, and advocacy efforts, providing information and strategies to assist other organizations working with Haitian families who have children with autism. The experiences of many Haitian families are similar to Charles, demonstrating the need to inform others how to empower parents and raise expectations that their child with autism can succeed in school. The manual assumes the reader has a basic level of knowledge regarding special education law and autism, however additional background information can be found by visiting the resources listed in the Appendix. This training manual can be used by Haitian organizations with clients who have children with disabilities, parent and legal services organizations, hospitals, community health centers, and any community organization working with Haitian families – in fact, any person or group hoping to partner with the Haitian community in the most effective and productive manner possible.

This manual is divided into five sections. Section two describes in detail the extensive barriers faced by Haitian parents who have children on the autism spectrum – barriers that are essential to acknowledge, as they permeate all aspects of life in the Haitian community. The manual particularly targets barriers related to language, literacy, cultural norms, and race. Other sections discuss the importance of community partnerships, the role of a Haitian consultant or Haitian staff member, trainings, the advocacy process, and effective strategies for reaching the Haitian community.

Ultimately, helping any child with autism can be an on-going, difficult process, full of questions, challenges, and obstacles. However, cultivating an awareness and understanding of the additional barriers faced by underserved communities in this situation is critical as we all work together to ensure that our services are effective, that parents are heard, and that their children are educated and reach their potential.

The Haitian Experience: History and Barriers

A crucial first step in helping Haitian families to access services in your community is to have some understanding of their country of origin as well as an awareness of challenges encountered upon arriving in this country. The following section will describe the barriers to accessing services faced by Haitian families who have children with ASD, while also providing the historical context of their country and their culture. This information is of critical importance when developing successful outreach, training and/or advocacy programs.

The History

Haiti, along with the Dominican Republic, occupies the Caribbean island of Hispaniola. It is located just south of Cuba. Haiti is one of the poorest countries in the western hemisphere. Its culture derives from a mixture of African, French, and Native American perspectives, with the African and French influences being the most prevalent.[2]

Haiti has a long history of class differentiation, with the majority of Haitians experiencing poverty and a small number of wealthy elite.[3] The first wave of Haitian immigration to the United States occurred in the 1960s. This population was from a wealthy and educated class, leaving their country of origin in search of opportunity, higher education, and to escape the political and economic constraints of a corrupt dictatorship. The second immigration wave came in the 1970s. This group primarily came from a "middle class background;" they had literacy skills and worked hard and long to attain visas to come here for reasons similar to the first wave.[4]

The most recent group of Haitian immigrants began to make their way to the United States in the 1980s. During this time Haiti's political situation had become worse, beginning a period of political upheaval, violence, and extreme economic instability which has continued until the present day. These immigrants tended to come from a poorer class, and many of them had not received opportunities for work or school. In addition, a large percentage of these individuals suffered incredible loss and witnessed crimes against humanity. During this period, community-based non-profit organizations were established by Haitian leaders to assure these new immigrants access to health care, housing, employment, immigration, and literacy services.

Haiti experienced a catastrophic earthquake in 2010 which has had a huge ongoing impact on immigrants in the United States. The Haitian government reported that an estimated 220,000 people perished, 300,000 were injured and at least 1 million lost their homes. Many Haitians are still unaccounted for.[5] This earthquake destroyed much of Haiti's fragile infrastructure and caused tremendous economic and political strife in a country with no organized governing body and whose inhabitants' basic needs were not being met. In the midst of all of this despair, the Haitians strong sense of faith and spirituality has helped them to remain united and to start the process of rebuilding.[6]

Haitians in the United States have been greatly impacted by their personal experience and the larger political environment in Haiti. These circumstances, combined with the barriers that Haitians are already facing in the United States (discussed below), have resulted in an overwhelming sense of stress and anxiety within the Haitian community.

The Barriers

The difficulties that any parent of a child with autism encounters when dealing with a school system denying supports or services can be overwhelming. Haitian families experience a host of additional barriers when accessing services, as described below.

Linguistic and Literacy Barriers

Haitian natives, regardless of region or class, speak Haitian Creole, a mixture of French and African languages. However, in Haiti, Haitian Creole was only considered to be an oral language, as it was not formally written until 1975.[7] French, on the other hand, was the only official language of Haiti until 1987 when Haitian Creole was also made an official language.[8] Thus, prior to 1987, most education, written information, and official business were conducted in French, which disenfranchised a large percentage of the populace, as only the upper class and well-educated spoke French. (For example, it was only in 1979 that Haitian Creole was included as a language of instruction in the first through the fourth grades.)

Over sixty percent of Haitians living in Haiti are illiterate due to poverty and lack of resources.[9] As a result, the population immigrating to the United States faces enormous difficulties dealing with public agencies that rely on written communications that are often not translated or on oral communications mostly in English. Haitians can fall anywhere on a broad linguistic spectrum including: 1) fluent in Haitian Creole only, but without the ability to read or write; 2) fluent and literate in Haitian Creole only; 3) fluent in both Haitian Creole and French, but only able to read and write French; or 4) fluent and literate in both Haitian Creole and French. Consequently, many Haitian parents face significant barriers effectively communicating their child's needs and interests to school officials. Additionally, due to cultural norms that will be discussed later in this section, parents may not disclose challenges with literacy until after a trusting relationship has been developed, as illustrated in this scenario.

> *Mrs. B immigrated to the U.S. about four years ago with her then six-year-old son. He was diagnosed with autism after his teacher in the U. S. referred him to a neuropsychologist for an evaluation. Mrs. B is 45 years old and received her high school education in Haiti during the 1970s, when French was the official language of Haiti and all educational services were conducted in French. Mrs. B speaks Haitian Creole and French fluently and can also read and write French. During the process of her son's evaluation, she requested an interpreter who spoke Haitian Creole. The evaluator had the results of the evaluation translated into Haitian Creole, assuming that this was what Mrs. B would prefer, as she had originally requested a Haitian Creole interpreter. When Mrs. B received the document, she informed the evaluator that she was unable to read it, but did not give a full explanation as to why. The evaluator was left confused and frustrated.*

Cultural Beliefs Related to ASD and/or Other Disabilities

In Haitian culture, shame and guilt are generally associated with disabilities. There is a general lack of understanding about disabilities and lack of provision for accommodations. It is assumed that people with disabilities are incapable or less capable of contributing to society. Having a child with a disability is viewed as a failure from a social perspective and is looked upon as shameful for the entire immediate and extended family. Family members internalize that shame, as many parents do not want others to know that they have a child with a disability. Individuals with ASD or other cognitive or learning disabilities are often perceived as being lazy, slow, or socially inept, and, through the lens of certain religious and spiritual beliefs, perhaps even cursed or possessed. The general population's lack of education and biases around such "hidden disabilities" are significant, particularly as compared to a greater tolerance of disabilities that are outwardly visible.[10]

These cultural beliefs about disability are incompatible with the manner in which service providers in the United States work with families impacted by disabilities; as a standard, families are expected to take pride in their children and accept them for who they are. However, for some Haitian families, a disability is not something to be accepted, but rather a malady that hopefully will be cured through prayer and other indigenous healing practices.[11] Thus, a dilemma can emerge: service providers try to teach the child how to adapt to and overcome the limitations of the disability, while the family can deny the reality of the disability and expend their energy trying to wishfully or otherwise "cure" their child. In addition, pride and desire for privacy, mingled with these feelings of shame and guilt, can often result in under- or inaccurate reporting of problems that might arise due to a child's disability.

Though borne out of a desire to be extremely protective of family issues, it inevitably serves to further hinder the child's ability to move forward in his or her life with a disability.

Other aspects of Haitian culture impact the community's response to disability. For example, lack of eye contact is very common in children with ASD, and establishing eye contact is often a suggested goal for the Individualized Education Program (IEP) of children with ASD. Yet, many Haitian children are taught that making direct eye contact with an adult is disrespectful and defiant.[12] This is but one example of why evaluators and educators need to be aware of cultural norms when developing IEP goals for Haitian children with ASD.

The history of dictatorship in Haiti further complicates parent-advocate interactions. Many Haitians suffered severe consequences for questioning or challenging authority. As a result, parents of children with ASD tend to accept whatever is told to them by professionals or school administrators about their child – even if they disagree – and generally do not seek alternate professional opinions.[13]

> *Mrs. G had a daughter diagnosed with ASD at the age of three. At the time of diagnosis, she was told by her daughter's doctor and teacher that her daughter would never speak. Mrs. G was confused upon hearing this information, as her daughter was only three, and she felt it was too early to make such a prediction. Mrs. G set aside her doubts, however, believing that her daughter's providers knew best.*
>
> *Two years later, Mrs. G had a second child. When this child began to speak, Mrs. G noticed that her daughter with ASD would try to mimic her younger sibling. Soon her daughter with ASD started speaking in short sentences. Mrs. G was amazed to see her daughter's progress and proceeded to tell her teachers about it. She then requested that her daughter receive speech services in school, but the school refused. It was at this point that Mrs. G was referred to a MAC advocate.*
>
> *The advocate provided Mrs. G with information about ASD in a form that was easy to understand and accessible to her. The advocate then educated Mrs. G about her rights and what options she had in obtaining special education supports and services. After learning more about her daughter's diagnosis, Mrs. G was disappointed to learn that she had initially been misinformed about her child's prognosis, and that so much time had lapsed with her daughter receiving inadequate services. Through the advocate's guidance and direction, Mrs. G was able to fight for the services that she now knew her daughter was entitled to receive.*

Finally, religion and spirituality play a paramount role in everyday Haitian life. When problems arise, prayers, consultation with spiritual leaders, or alternative medicines tend to be the first step in attempting a resolution.[14] By the time those "solutions" have failed, there is frequently a significant lapse between the first signs of a disability and medical diagnosis. This is important to consider when working with a child with ASD, since earlier treatment is critically important to achieve better outcomes.

Discrimination

America has an unfortunate history of both racism toward people of color and intolerance of immigrant groups that directly impact Haitians. Stereotypes of Haitians being "boat people," refugees, infected with AIDS, "voodoo worshippers," along with many other negative associations have penetrated the American consciousness. This has detrimentally affected how Haitians are perceived as a group, and perhaps even how they are treated in the medical and education systems. One must be fully aware and prepared to confront these untruths when navigating the system with a Haitian family.[15]

3 Building the Foundation

Community Partnering

Identifying barriers, discussing problems, empowering parents, and dispelling the stigma are themes addressed throughout this manual. Collaboration among parents, lawyers, and advocates are required components for securing a better education for the children involved. However, when working with Haitian parents of children with autism, or any similarly-situated population, a preliminary requirement is first gaining meaningful access to the community itself.

The need for a community partner to effectively reach Haitian parents with children on the autism spectrum reflects best practice in any field (e.g., public health, politics, business and marketing) attempting to reach individuals of an underserved community that faces cultural, linguistic, racial or class barriers. Organizations unfamiliar to the community can be stymied in achieving their goals, principally due to the lack of trust. This is especially true for organizations which utilize attorneys and/or promote an advocacy approach designed to empower parents. Often families have legal issues beyond those of their children with disabilities. For example, many families do not have legal immigration status; families don't want to get involved with an unfamiliar organization (especially a legal one) due to fear of deportation. In addition, Haiti is an example of a politically repressed country where it is not safe for individuals to stand up for their rights.[16] Thus the idea of working with an agency that encourages parents to express a view that is opposed to that of an authoritative organization (the school system) can evoke fear and resistance.

MAC developed a successful relationship with our community partner through a client already closely associated with HAPHI. Our client was in desperate need of advocacy for her young son with autism. This parent knew that the special education system was not working for her child, and she sought help to ensure her child received the services he needed to make progress. This client faced countless barriers already described for Haitian parents with children with autism. Putting her fears aside, she fought diligently to overcome these obstacles, especially her fear of authority, and asked MAC for help. Working with this client illuminated the incredible barriers faced by Haitian parents. Our client introduced us to the supervisor of the HAPHI Family Support Program (described above on page 6), and we learned that this community organization had the best potential for us to reach other children and families. We learned that many of the HAPHI parents were in urgent need of education, advocacy, and support that wasn't offered anywhere in a manner that was accessible.

At the onset, HAPHI's Family Support Program supervisor emphasized that collaboration would only have a chance of success if MAC was invested in a long-term relationship. HAPHI leadership knew from experience that it would take a considerable time investment by MAC for parents to develop the trust and confidence necessary to make a real difference in their children's lives. After careful consideration, we signed up for the long haul.

Once we formed an alliance with HAPHI, we hired our Haitian client as a consultant. The consultant helped us to learn about Haitian culture and beliefs, as well as the barriers Haitians faced in this country. She also provided important guidance and assistance, working with us to conduct outreach to other parents as well as other Haitian community organizations such as community health centers,

churches, and adult service agencies. Soon, our presence in the community was recognized by Haitian community leaders who were willing to help with additional outreach.

MAC conducted workshops at HAPHI on a regular basis (and continued to refine and adapt our trainings, so that they were culturally sensitive and accessible, see training section pages 35-76), but this wasn't enough to become interconnected. A more personal effort was required that was very rewarding, though time- and labor-intensive. The parents welcomed us to share dinners with them after the trainings, and we slowly got to know each other. Soon, we were invited to special events and other activities hosted by the parents of the support group. For example, we attended special Father's Day events at the homes of some of the parents each year and were welcomed and honored at a Mother's Day ceremony at a local church.

We worked closely with the supervisor and social worker at HAPHI to plan all parent training and advocacy activities. They became a partner and an advisor in all aspects of our work, including case work with individual families, development of the workshop material, and strategizing for how to most effectively achieve results for the children. We incorporated their valuable feedback into our work.

We were able to identify parent leaders within the group who worked with us to deliver workshops and to speak to the parents in the group about successes they experienced as they learned to advocate for their children. When families saw the positive outcomes of others in their community, they became more engaged and developed more trust. Parent leaders also volunteered to participate in a "parent-to-parent" program where they would provide valuable support, encouragement, and inspiration to other parents in need. These parent leaders demonstrated that "knowledge is power" and that parents needed to help each other to ultimately help their children. We also offered intensive training and tutoring to one parent leader with the use of an interpreter on very specific aspects of special education laws so that she could become a stronger support for these parents during their child's special education process.

Working with parents in the manner in which they are most familiar and comfortable was important to our success. At first, we met the parents requesting legal assistance at the HAHPI location they were accustomed to visiting. We utilized our Haitian consultant and HAPHI partners to contact parents, help schedule meetings, accompany parents to their children's independent evaluations and school system IEP meetings, and explain situations and answer questions. But we often found that visiting the homes of Haitian families with children on the spectrum was a more fruitful manner to conduct our outreach and follow-up. Some parents faced additional barriers making it unfeasible for them to meet with us outside their home, for example, lack of transportation or childcare for young children. Visits to homes for outreach, intakes, and follow-up was one of the strategies that enabled us to reach and maintain relationships with the parents who needed our advocacy assistance.

Based on the advice of our community partner, MAC later launched a small parent group for those interested in more intensive training, and this built even more cohesion and camaraderie within the group. A more intimate and trusting relationship developed between the parents and MAC staff. It is critical for advocates and attorneys to understand the barriers faced by Haitian parents of children with autism in order to develop practical strategies at each step of the advocacy process.

4 Embarking on the Process

Advocacy Efforts

Intake

The advocacy process usually begins with an intake, generally conducted over the phone. However, in MAC's experience, Haitian parent intakes are more productive and efficient when they occur in person, and, if possible, during a home visit. Additionally, if the advocate or attorney is not Haitian, participation of a Haitian Creole-speaking individual familiar with both Haitian cultural norms and special education laws is incredibly important. Ideally, this partnership would be with a person who is known and trusted within the Haitian community, as the gradual establishment of trust between the parent and advocate/attorney is essential for successful outcomes. This is true for all parent/advocate relationships, but the cultural barriers that Haitian parents face makes this particularly important. It is essential to directly consider the barriers of pride, literacy, language, shame surrounding disability, authority issues and immigration status when moving forward in the process, as they will be a consistent presence influencing the relationship.

For example, during the intake process, parents may be reticent to provide accurate information about their child's disability or school problems they are having due to various cultural norms, including the sense of shame that generally surrounds disability in Haitian society. Many Haitian parents will initially present their child in the best light possible rather than reveal some of the child's most significant needs. Therefore, the advocate or attorney who asks a parent to list the issues faced in school or at home may not elicit an accurate portrayal of the child's situation. A more productive approach would be asking parents to describe their biggest current worries for their child, as well as those five or ten years down the road, which may draw out more usable and valuable information to advocate for the child.

Technical Assistance

A critical goal of all special education advocacy efforts is to educate and empower parents to advocate for their children as independently as possible. Parents will need to stand up for their children for the many years they are in school, and there are not enough pro bono lawyers or advocates to meet the need. We begin our education of parents by providing them with technical assistance through much of the intake process. But technical assistance for parents who face language and/or cultural barriers needs to be more intensive. For example, because of the cultural barriers surrounding literacy, language, and distrust of authority,[17] it can be a daunting challenge for parents to write and deliver letters to school district officials (e.g., requests for school records). Many advocacy organizations may initially want to review records before deciding whether to provide advocacy assistance, and so it may be necessary to supply intensive legal technical assistance just to obtain these records. Additionally, the attorney or advocate may also be called upon to write and translate letters for the parent, ensure delivery to appropriate school district staff, and/or monitor district compliance with required special education timelines.

Because the advocacy process involves many steps with unexpected "curve balls" along the way, it is important to clarify to parents that each step works toward a broader goal, and that while one

obstacle may be handled or resolved, the process must continue to march forward. The parent may need frequent reminders that even after agreements are made with the school district, parent follow-up and compliance monitoring are essential. Again, the cultural reluctance to challenge authority presents a difficult barrier for Haitian parents to overcome.

For children with autism, as with many other disabilities, independent evaluations are frequently essential to help determine necessary programs and services. However, accessing appropriate medical and therapeutic clinicians can be overwhelming, if not impossible, for many Haitian families. Haitian parents may require assistance throughout the independent evaluation process, not just the typical support of identifying the appropriate expert, but also help with making appointments, filling out forms, and generally facilitating parent/clinician meetings. Again, working in partnership with the aid of trusted Haitian Creole-speaking individuals/community partners who are knowledgeable about special education, disability issues, and the barriers that these parents face is essential to ensure that the child receives a thorough, independent evaluation where all areas of need are assessed.

This process, from beginning to end, can be tedious and exhausting for attorneys, advocates, and parents. Typically, hospitals, private clinics, and evaluation centers send parents an information packet about the assessment process, detailing this multi-day undertaking. The initial information packet includes consent forms and/or insurance waivers to sign and lengthy complex questionnaires to complete. Many organizations will not schedule an appointment for the child until they receive the signed forms and required documentation. The evaluation itself can require an initial parent interview, and an additional parent feedback session may take place when the testing has been completed. The process requires parent follow-through at every step, and, as such, it is essential that the advocate or attorney, with the assistance of a community partner, carefully and continuously assess the level of support that the parent needs along the way.

Advocacy

Facilitating the advocacy process with this population is labor intensive. As a result of living under a dictatorship, Haitians find the concept of advocacy to be very unfamiliar culturally. Advocating necessitates asking questions and challenging individuals in leadership positions, something with which many Haitians do not initially feel comfortable. Additionally, the concept of "process," a progression of activities aimed toward a specific purpose, can be unfamiliar as well. In Haitian culture, if there is a problem, one goes to the appropriate person or organization to fix it, not to hear about the process of fixing it, of all the steps involved to rectify a situation or come to the desired end result.[18] However, advocating for children with disabilities in the United States is a multi-layered process that can take many years to complete. It requires planning, scheduling, and ensuring evaluations are conducted. The special education process has complicated timelines that must be monitored by parents and advocates and usually includes an array of meetings, where frequently, even after all of these steps, consensus isn't met and the process can start all over again. It is important to make it clear and to remind parents frequently that advocating is indeed a lengthy complicated process, as they are likely to become discouraged before they see any results.

Interpretation, translation, and support services are critical, though most low literacy and linguistic barriers not only necessitate interpretation, but also require accompanying explanation and patience. There is no direct translation in many situations because there are no Haitian Creole words for

concepts that do not exist in Haiti. For example there is no word or phrase that accurately defines and differentiates between various types of mental illnesses or of neurological or cognitive deficits, including those in the autism spectrum. These types of "hidden disabilities" tend to be generalized and grouped together without any way of discerning one from another. In addition, they also tend to be described with a negative connotation. This makes it increasingly challenging to work with Haitian families who have children on the spectrum, as there is no word in their native language that defines the nature of the diagnosis.[19] As Haitian law does not provide special education, communication and understanding of these American protections may prove difficult.[20] The structure and substance of in-depth legal policies and procedures must be explained with culturally relevant examples. Thus, providing an interpreter and/or having documents translated is not sufficient. The interpreter must comprehend the barriers these parents face and be familiar enough with special education law in order to determine if the client understands the complicated tasks at hand.

The advocacy process with Haitian families can be complicated. Even a legal advocacy organization's initial attempts to engage a client may be met with hesitation. For example, some families may not initially disclose their immigration status requiring sensitivity toward their situation. Frequently there are other important underlying concerns that the family may not reveal that ultimately could affect the case. For example, a parent may be reluctant to report their employment status or income because they are working at a job where their work is not documented, and they fear they will run the risk of losing their job or being reported. A family might also be nervous about working with a legal advocacy agency in America because of child discipline reasons. For example, in Haiti, physical discipline is a common form of punishment.[21] It is a prevailing belief in the Haitian community that a child advocacy organization or state-run agency will immediately take away your child if it believes that the child is being inappropriately disciplined, or if the agency disagrees with your parenting style in any way.[22]

At times, problems are not even discussed within a family or with members of the church. However, once a trusting relationship between advocates/attorneys and families is established, and as parents increase their knowledge about the special education system, families often convey an immense sense of gratitude and relief that is very rewarding.

5 The MAC Training Blueprint

Ice Breakers / Workshops

This section provides examples of some successful training curricula and introductory icebreakers used with Haitian families. They are easily accessible and ready to use. The workshop topics were parent-selected. We conducted a needs assessment to ascertain issues of interest and concern, so we could then tailor and develop participatory workshops to address those concerns. All training activities had to take into consideration the parents' literacy level, and we always offered options for verbal participation.

The following were the goals we established for training parents: 1. To conduct workshops that increase awareness of the existence of special education laws for Haitian parents of children with ASD; 2. To help them understand that the promise of the laws are meaningless if parents aren't informed; and 3. That voicing disagreement is vital to the special education process.

MAC's initial training focus was broad. Project staff addressed general provisions and procedures required by special education law. Later MAC began coordinating monthly workshops for a smaller group of Haitian parents with children on the autism spectrum.

Initially, before gaining an appreciation of Haitian culture and the barriers faced by families, we utilized the Autism Center's standard PowerPoint training materials. However, it was immediately apparent that these training strategies were not effective for Haitian parents (as would be true for any ethnic group comprised largely of recent immigrants facing language and cultural barriers). Although the Autism Center's training materials were effective for English–speaking parents, the translated PowerPoint handouts were not as helpful for Haitian non-English-speaking parents. Furthermore, the usual PowerPoint presentations coupled with multi-page handouts did not resonate with these parents. We were challenged by very little parent participation and a general reticence to work with attorneys due to cultural barriers, despite the urgent need for advocacy.

In order to effectively teach Haitian parents basic special education rights and strategies, different training strategies had to be developed. Over the first two years, MAC learned a great deal about Haitian culture as we adapted and revised our workshops for this population. Initially we employed a Haitian interpreter and simultaneous interpretation equipment for our trainings. Eventually we learned that some parents didn't like to use the bulky equipment and thus used it sporadically.

We developed new trainings strategies with the project's bi-lingual, bi-cultural Haitian-American consultant, who was knowledgeable about disabilities and special education. MAC staff developed training modules that accommodated the parents' cultural, linguistic, and literacy barriers. Hands-on materials and concrete examples were used, and trainings were held in small groups. Project staff created role-play scenarios, and with the expertise of the project's Haitian consultant, staff learned to successfully incorporate Haitian spiritual reflection into the parent workshops, resulting in increased, dynamic group participation. These training modules also attempted to address the low literacy of families learning to access the paper-driven special education system, which is built upon IEPs, evaluation reports, progress reports, and other written documents.

Our efforts weren't confined to trainings/workshops for parents. As project staff continued to develop culturally sensitive and participatory workshops, we also made sure to maintain a presence in the greater Haitian community. Gradually, parent involvement began to increase and trust developed. With the Autism Center's intensive and sustained efforts over the years, parents in the Haitian community became willing to discuss and address issues related to their children's autism. Our experience has demonstrated the time-consuming, labor-intensive, yet fundamentally rewarding nature of the work necessary to effectively reach these underserved families.

Workshops

This manual provides templates of parent workshops developed to increase knowledge of special education laws. The workshops were successful because strategies were employed to engage parents from the outset, utilizing icebreakers and activities often incorporating spirituality and cultural context, to increase parent participation and engagement.

Icebreakers were developed to initiate each workshop in order to familiarize group members with the facilitator and to provide an opportunity for the parents to learn, share, and bond in an accepting, comfortable environment. They also introduced the topic of the day and/or reviewed prior workshop concepts. Some of the Icebreakers are specific to particular workshops while others can be used for any of the workshops. Parents previously absent from the conversation were now active participants, infused with enthusiasm. More importantly, we found that the icebreakers directly addressed and defused barriers that were hindering the parents from fully participating , e.g., hesitations linked to privacy and deference for authority figures, as well as feelings of shame, guilt, and pride. This resulted in an increased interest in the training, more active participation, a more cohesive group, and an open exchange of ideas and personal information.

MAC's Haitian-American consultant, who was both trained in group facilitation and experienced in working with the Haitian population, played a pivotal role. The consultant assisted MAC staff with revamping our presentations to make the information more accessible to Haitian parents. By developing culturally sensitive and relevant lesson plans that included interactive activities, we were able to actively engage parents.

The workshop to address *Parent Concerns* was developed in response to parents' many worries about their children's progress and focused on skills necessary to clearly articulate their children's primary needs resulting from autism to the IEP Team (e.g., concerns about their child's safety, inability to communicate, lack of daily living skills, or inability to get a job). Massachusetts has a section in its IEP where parents can document all of their concerns (the Parent Concerns section). Though IEPs in other states may not have this specific section on the IEP form, it is still critically important for parents to learn how to articulate priority concerns which relate to the child's need for special education services. Parent concerns can be incorporated into other sections of the IEP (such as "present levels of performance") and orally communicated at IEP meetings.

The two-part *Parent Training and Services* series was developed because many parents were unaware that districts may be required to provide parent training and other home services through their child's IEP, depending on their child's special education needs. Many parents said that their children exhibited dangerous behaviors at home (e.g., bolting, self-injurious) and were without safety awareness, social skills, self-care, and communication skills. The parents did not know how to effectively communicate with their children to get desired outcomes nor could they handle behavioral concerns at home. These parents urgently needed parent training and, in some cases, direct home services for their children. Parents first needed to learn about the parameters of the school district's obligation to provide parent training and other services in the home. Many parents associated 'home services' with caretaker services or respite instead of special educational services; these services were differentiated in the trainings. In the second part of this series, parents were also taught how to address the need for services in an IEP; most importantly, they needed to know that even if the services were verbally agreed upon at an IEP meeting, this agreement must be written in the IEP in order to hold school districts accountable for specific service agreements.[23]

The *Independent Evaluation* workshop was prompted by parents' belief that school district conclusions and recommendations were unchangeable. They assumed that district evaluators knew what was best for their children because they were educators in positions of authority. However, parents also knew that their children weren't making progress and felt conflict between what they were told by school district officials and what they believed their children could accomplish. They did not know that they had the right to a second opinion in the form of an independent educational evaluation. MAC developed a highly interactive training to teach parents about their rights to an independent evaluation, emphasizing that the process for exercising this right was a lengthy one and required them to remain highly involved.

The *Barriers and Special Education* workshop engaged parents in a discussion about the cultural and linguistic barriers they faced when attempting to navigate the special education system in the US. Project staff orchestrated special education-related role plays that demonstrated examples of unique barriers faced by Haitian parents and then engaged the group in an interactive discussion. Alternate ways of meeting children's needs and overcoming barriers were developed by the group, making concepts concrete and accessible.

The last training in this section, *Autism Awareness Training and Outreach*, was developed in order to help identify Haitian parents with children on the autism spectrum. Staff conducted this training for Haitian adult English Language Learner classes as a way not only to conduct outreach but also to raise autism awareness in the community. Particular focus was given to impressions and expectations of people with disabilities in Haiti and in the US, Haitian views about people with hidden disabilities such as autism, and the impact of special education laws in this country.

The MAC Training Blueprint

Table of Contents

This section provides templates for the introductory ice breaker activities and for the workshops. Because of the parents' varying literacy levels, it is important to consistently offer the option for verbal participation when providing an optional written aspect of the workshop. These topics can also be adapted for other subjects.

Ice Breakers

Workshops

Ice Breakers

(NOTE: Icebreakers can be adapted to meet the needs of specific parent groups and must take into consideration literacy level – always offer option of verbal participation.)

1. Thank You Circle

Objectives:

- Directly appeals to the importance of religion and spirituality, often at the forefront of Haitian parents' lives
- Allows group members to feel more comfortable and relaxed with each other
- Provides group members with the opportunity to share in a bonding experience
- Places group members in a positive state of mind

Materials Needed:
None

What to do:

- Have participants stand quietly in a circle, close their eyes, and hold hands.
- The facilitator starts the exercise by stating that we have all come together to give thanks to the entity or higher power in whom or in which you believe.
- The facilitator should be the first to participate to provide a model for other group members.
- The facilitator states what he or she is thankful for. One suggestion is that the facilitator gives thanks for having the opportunity to work with the group, and additionally for the existence and participation of the group.
- Other group members can then follow in any order, and express their appreciation however they choose.

EXAMPLE #1
F= Facilitator / P= Participant

F: *Good afternoon, everyone, I would like to begin our training today with an activity we call an "icebreaker." An icebreaker activity is a way for us to get to know each other a little before we begin working together. This icebreaker is called the "Thank You Circle." Could everyone please get into a circle and hold hands?*

(after everyone follows these directions and settles into the circle, the facilitator continues…)

F: *Thank you, everyone. Now this activity requires everyone to stay silent while another person speaks. The purpose of this activity is to give thanks to God, or whatever higher power or entity in which or in whom you might believe, and share these sentiments with the group. This can relate to anything that is happening in your life, big or small, happy or sad. Everyone is encouraged to participate, but nobody should feel like they are required to do so. I will begin, but first, could everyone please close their eyes?*

(wait for a few seconds of silence to pass)

F: *I would like to thank God for the existence of this group, and for the opportunity for me to be here and share with everyone. I would also like to ask God to help everyone feel comfortable and to arrive at the group with open minds and open hearts.*

F: *Anyone should feel free to jump in whenever they would like.*

P1: *I am thankful for being able to make it here despite the fact that I was not feeling well this morning.*

P2: *I am thankful for the fact that my son ate all of his breakfast this morning independently.*

P3: *I am thankful for my daughter getting a good report card.*

(after everyone has had an opportunity to share, the facilitator will close the activity…)

F: *Thank you, everyone, for your openness and honesty. We are now going to return to our seats to start the second part of our training; still, let's try to continue to keep our hearts and minds open for the rest of our time here together.*

Question: What if no one volunteers to speak after the facilitator speaks?

When you find yourself in a situation where no one is participating, the facilitator can use an example to which everyone can relate, thereby making everyone feel more connected. The facilitator may also acknowledge that people in the group have sentiments they are not ready to share with the rest of the group, and close with a general "thank you" encompassing all sentiments spoken and unspoken. Using humor can also help in this situation.

EXAMPLE #2

F: *I would like to thank God for the existence of this group, and for the opportunity for me to be here and share with everyone. I would also like to ask God to help everyone feel comfortable and to arrive at the group with open minds and open hearts.*

(there is a long pause and no one is offering to speak)

F: *Lord, I am also thankful for you bringing everyone here safely. I know that everyone here has busy lives and definitely could be doing something else during this time, but instead you all chose to be here… who here can relate to having a busy life?*

P1: *I sure can! I was in such a hurry this afternoon that I almost forgot my driver's license…*

F: *So maybe you might have something you are thankful for, like maybe the fact that you have a warm car you can drive during these cold winter days. We seem to have at least one or two of them around these parts. Does anyone else here have any other ideas of what they are thankful for?*

2. Sharing Memories

Objectives:

- Provides the facilitator with an understanding of the skill level of the parents' children with ASD, and how this impacts them
- Provides the facilitator with an idea of the group's knowledge base regarding ASD
- Allows group members to feel more familiar and comfortable with each other
- Establishes what these parents have in common

Materials Needed:

None

What to do:

- Have parents sit/stand in a circle.
- Ask each parent to share a memory describing how and when they were informed of their child's autism diagnosis.
- The facilitator should go first to provide a model for the group. If the facilitator does not have a child with ASD or any other diagnosis, or does not have a child at all, he or she can share a childhood memory or a friend's story.
- The facilitator can also describe how he or she imagines the diagnosis experience would unfold.

EXAMPLE

F= Facilitator / P= Participant

F: *Today we are going to start off the training with a small activity that will require everyone to share a little about themselves with the group. Those who do not want to participate can just listen. I would like to go around the group and ask each person to recount the memory of how you learned of your child's ASD diagnosis. Please remember that everything we say in this group is kept confidential. I personally do not have any children, let alone any children diagnosed with ASD, but I can imagine what the experience might be like, based on what other parents have shared with me. I think that if I had been told that my child had autism, I would probably be very confused at first. I wouldn't have known what it meant, and I would most likely be very scared. Once I recovered from the immediate shock, I'd start asking questions. I would want to know if this meant that my child would be physically sick or if they would suffer all their lives. I'd want to know if there was a cure. I'd also really need to know how it happened and whether it was somehow my fault. I really think that there would be so much going on in my head that I wouldn't know what to do or where to begin. Am I way off base, or does this resonate with anyone else in this room?*

P: *Yes, when Sam was diagnosed I felt…*

(The facilitator will close the icebreaker by thanking everyone for sharing and reviewing some of the ideas and stories that people shared in common)

3. One Positive Thing

Objectives:

- Allows the facilitator to learn more about the participants and their children
- Places group members in a positive state of mind and allows them to focus on the strengths of their children, rather than only the challenges
- Enables group members to be more comfortable with each other
- Encourages group members to share personal stories
- Builds bridges between group members as they grow to understand that their issues are very similar

Materials Needed:

None

What to do:

- Have everyone sit in a circle or in rows if a circle is not possible.
- The facilitator will ask everyone to share one positive thing that their child did that week.
- Examples may include something the child learned or said, or an action the child performed or refrained from performing.
- The facilitator will participate first to provide a model for the rest of the participants.
- The facilitator should go first to provide a model for the group. If the facilitator does not have a child with ASD or any other diagnosis, or does not have a child at all, he or she can share a childhood memory or a friend's story.

EXAMPLE

F= Facilitator / P= Participant

F: *Good morning, everyone. Today we are going to start off our workshop by challenging everyone to think about their child in a different light. What is the one thing that all of our children have in common?*

P1: *They all have autism.*

F: *That's right -- they all have been diagnosed with autism. We've spent a lot of time talking about IEPs and special education law, about your concerns and frustrations, and just generally about the difficulties that our children are facing in the schools; it goes without saying that all of this is very important, but we haven't yet talked about the strengths of our children, which deserve just as much focus and attention. From the time that your child received his or her diagnosis, I am sure that you have participated in conversation after conversation about what your child cannot do. While it is necessary to know the extent of the difficulties that your son or daughter faces, it is not easy and it can be heartbreaking. That is why having the opportunity*

to talk about your child's strengths is equally necessary. Every accomplishment, small or large, matters. So for this activity, I would like each person to share with us one positive thing that your child did this week. Some examples may include something your child learned or said, or an action your child performed or refrained from performing. I will start. On Monday, my daughter said "thank you" to me after I served her breakfast.

P2: *That actually reminds me of something my daughter did this week. Normally during breakfast she will only eat pancakes, but she actually tried cereal and eggs this week.*

P3: *My son shook my friend's hand when I introduced her to him.*

P4: *My son finally learned how to tell me when he needs the bathroom.*

P5: *My son played nicely with his brother on Friday.*

F: (closing) *Thank you everyone for participating and for your honesty. I know that having a child on the spectrum can be extremely challenging. However, in the midst of those challenging moments, it is important to remember the positive things that are happening in our children's lives.*

(The facilitator will close the icebreaker by thanking everyone for sharing and reviewing some of the ideas and stories that people shared in common)

4. Role Play: Autism and Social Skills

Objectives:

- Introduces the workshop topic
- Educates parents on the importance of social skills training for students with autism
- Inspires a discussion about the social challenges that children with autism face
- Allows group members to feel more comfortable and relaxed

Materials Needed:

- Two facilitators
- Three or more scripts

What to do:

- In advance, write at least three role play scenarios including one in which an individual with ASD is conversing in a social scenario.
- Before the role play, have a short discussion on the different modes of communication (i.e., verbal and non-verbal, such as body language, facial expressions, tone of voice or augmentative and alternative communication).
- Open up the group to a short discussion of some of the social barriers that people with autism commonly have.
- The two facilitators will then act out each scenario.
- After observing each role play, the group will determine which modes of communication were used and discuss some of the social difficulties exhibited in the scenarios.

EXAMPLE

Sally, who is diagnosed with Asperger's Syndrome, sits next to George in the school cafeteria. George makes a facial expression that indicates that he is not happy that Sally has chosen the seat right next to him.

S= Sally / G= George

G: (in a feeble voice, while rolling his eyes) *Hi, Sally.*

S: *Hi, George, what did you get for lunch today?* (Sally leans over closely to look at George's lunch tray)

G: *I just got a hot dog and some juice.*

S: *It's not right that they never have any healthy options for lunch here. Did you know that over 80% of high school students are obese? This is a tragedy.*

G: *Ummmm….Sure….*

S: *I mean last week I tried to get something healthy and so I bought a salad, but when I opened it, it was all wilted and rotten… I was so mad that I wrote a letter to the board of education. This school should be written up for harming its students. Did you know that if we do ever get written up there is a chance that the school could get shut down for making all of our students overweight and sick? This would actually be helpful because this food is horrible. The fruits here are mostly rotten and expired. You should be upset about the food situation here..*

G: *It really doesn't bother me* (George is leaning away from Sally and looking around the cafeteria)

S: *Well, I guess it probably wouldn't bother someone like you because you obviously like junk food…judging from what you chose to eat today…hotdogs are bad for you…*

G: (speaking in an aggravated tone) *I actually like hotdogs. I need to get going. I am going to be late for class.*

S: *You still have 7 minutes before class starts. Hotdogs should be taken off of the school lunch menu. Hot dogs are made of several ingredients that can cause harm in lab rats, not to mention humans.*

G: (speaking while gathering his belongings and leaving the table) *I really have to get going. See you later.*

Facilitator process with the group –

- What types of communication were used in this role play (answer – verbal, body language, facial expression, tone of voice)
- What were some of the social challenges that Sally experienced/did not pick up on? (answer: sitting too close to George and his lunch, that he is uninterested in the topic of discussion, he doesn't want to be seen with Sally, seems embarrassed and offended, and when he gets up to leave Sally keeps talking, not picking up that George wants to end their interaction.)

The next 3 icebreakers are used for reviewing material from the previous training.

5. Pre-training Ice Breaker (specific for Parent Training and Services workshop)

Objectives:

- Assesses group members' comprehension of the workshop topic
- Enables group members to understand and appreciate the skills that their child currently possess
- Reminds group members that all children with ASD are different, drawing upon the various skills that group members' children possess

Materials Needed:

- 3 bowls – each a different color
- Snacks (or other food or non-food item) to put in the bowls (e.g., small individually wrapped candy)
- 3 self-adhesive labels that read social, self-help (daily living skills), and safety

What to do:

- Affix one label to each of the bowls and fill each bowl with snack or other incentive items
- Explain to the group that autism can result in needs in many functional (non-academic) areas including, social, communication, self-help (daily living skills), and safety. Parents should recognize that these are needs that children with autism can identify and learn about.
- Ask group members to think about their child's positive skills in these areas
- Taking turns, each group member provides an example of a skill that their child demonstrates in one of the three areas, though they should not identify which area
- After each group member speaks, the other members in the group must identify if the given example is from the social, self-help, or safety category
- Those who guess correctly can take an incentive item from the corresponding bowl
- This process repeats until all group members provide an example

Note: Members may not take an incentive item unless the example given accurately corresponds to one of the three categories.

EXAMPLE

F= Facilitator / P= Participant

P1: *My child washes his hands before meals without being asked or reminded.*

P2: (guessing skill category) *Self- help!*

P3: (guessing skill category) *Self- help!*

P4: (guessing skill category) *Self- help!*

F: *Those of you who guessed "self-help," you are correct! You may take an item from the bowl labeled "self-help."*

P2: *My child looks both ways when crossing the street*

P3: (guessing skill category) *Safety!*

P4: (guessing skill category) *Social!*

P1: (guessing skill category) *Safety!*

F: *Those of you who guessed "safety," you are correct! You may take an item from the bowl labeled "safety." Can somebody who guessed correctly explain why this is a safety issue? (If nobody volunteers, Facilitator explains).*

6. General Lesson Review I (specific for Parent Training and Services workshop)

Objectives:

- Reviews information from the previous *Parent Training and Services, Part 1* (i.e., skill and Personal Care Assistant (PCA)[24] assistance), see training section, page 48.
- Indicates to the facilitator how well the group comprehended the information from the previous training
- Energizes group members and gets them ready to learn
- Builds group cohesion

Materials Needed:

- One bowl
- Snacks (or other food or non-food item) to put in the bowls (e.g., small individually wrapped candy)
- Index cards with written examples of a *skill* or *PCA assistance*

What to do:

- Briefly review definition of a skill and PCA assistance, see training section, pages 49 and 50.
- Inform participants that you will be reading examples of a skill or PCA assistance from an index card and instruct them to raise their hand if they know the answer..
- Facilitator reads example from index card.
- Participants raise hand and states what they think the correct answer is.

(Ask 3-4 questions maximum, depending on the size of the group)

- If a group member correctly answers, they can choose an incentive item from the bowl.

EXAMPLE

F= Facilitator / P= Participant

F: (reading from card) *Someone washing your child's hair*

P1: *PCA*

F: (reading from card) *Someone teaching your child how to cross the street safely*

P2, P3: *skill*

F: *P1, 2, and 3 can take an incentive item from the bowl*

(The facilitator will close the icebreaker by thanking everyone for participating and introduce and move on to the training topic.)

7. General Lesson Review II (specific for How to Include Services in an IEP Service Delivery Section workshop)

Objectives:

- Reviews prior information
- Gives facilitator an indication as to how well the group comprehended the information from previous training
- Energizes group members and gets them ready to learn
- Builds group cohesion

Materials Needed:

- Snacks (or other food or non-food item) to put in the bowls (e.g., small individually wrapped candy)
- Sheet of paper, dry erase board, or chalk board
- Empty bag or hat
- Something to write with (e.g., dry erase markers or chalk)
- Small strips of paper
- Pen/pencil to label strips of paper

What to do:

- The facilitator will write questions on a sheet of paper, a dry erase board, or a chalk board related to whatever information needs to be reviewed; these questions would typically be about the information that was covered during the last meeting.
- Questions can range from true or false to multiple choice or open-ended. All questions should be numbered. This can be done ahead of time.
- The facilitator should then number each strip of paper according to the number of questions written. Place strips of numbered papers in empty bag or hat.
- Divide group members into two teams. Each team will have one team leader who is chosen collectively by the team.
- Each team will have the opportunity to choose a number out of the bag or hat. The facilitator will then read the question that corresponds with the number that was drawn.
- After the team discusses, the leader will provide their answer. If the answer is correct, each team member gets an incentive item.
- If the answer is incorrect, then the other team gets an opportunity to answer the question and take the incentive item.

- If both teams are incorrect, no one gets the incentive item.
- At the end of the icebreaker, the team that receives the most incentive items is the winner.

EXAMPLES

- Schools are solely responsible for teaching your child academic skills; they are not responsible for teaching your child any skills that apply to home and community. T or F (answer: F)
- When is the appropriate time for a parent to request an IEP meeting? (answer: C)

  A. during an IEP meeting

  B. in the beginning of the school year

  C. a parent has the right to request an IEP meeting at any time

  D. right before summer break

- What is the purpose of a service delivery section grid?

  (possible answer) The purpose of the service delivery grid is to document services, location, provider, and frequency and duration of services to be sure the school district provides what is needed.

(The facilitator will close the icebreaker by thanking everyone for participating and introduce and move on to the training topic.)

Workshops

(All activities must take into consideration literacy level – always offer option of verbal participation.)

1. Barriers to Special Education

The *Barriers and Special Education* workshop engaged parents in a discussion about the cultural and linguistic barriers they faced when attempting to navigate the special education system in the US. Project staff orchestrated special education-related role plays that demonstrated examples of unique barriers faced by Haitian parents and then engaged the group in an interactive discussion. Alternate ways of meeting children's needs and overcoming barriers were developed by the group, making concepts concrete and accessible.

Objectives

- Group members will partake in a discussion about barriers to their involvement in the educational process of their child(ren) with a disability.
- Group members will identify specific barriers from their personal experiences.
- Group members will identify specific barriers after observing a skit.

Materials

- Ice breaker – materials vary, depending on selected ice breaker.
- Training activity
  - Skits for role plays (to read from)
  - Dry erase board and markers (or black board, poster paper, etc.)
  - Prepared list of major barriers

Procedures

- Ice breaker - Varies, depending on selected ice breaker
- Presentation

  Tell the group that you understand there are many barriers for Haitians in this country. You've learned a great deal about the many obstacles they face. You would like to learn more about the barriers that have prevented group members from being fully involved in the educational process of their children with disabilities.

  For the group discussion, define barrier:

  Barrier: an obstacle that gets in the way of a person accomplishing a certain goal. For example, not having your child's evaluation results or lack of translation for a team meeting can prevent you from fully participating in the meeting.

Ask group members to share with the group the barriers that they experience. Have a prepared list available. This list can be consulted if no one readily participates or to get the process going. The facilitator can read a barrier from the list and ask the group if they've ever experienced this issue. For example, "Has language ever been a problem for you when you work with your child's school?"

Write each barrier that group members share on the dry erase board or its equivalent. Ask group members to give an example of the barriers that they list.

Below is the list that was generated by Haitian parents at a previous training:

List of Barriers from Parent Group Discussion

- Language
- Work/job
- Lack of childcare
- Discipline differences

  For example, spanking, child kneeling in a corner for long lengths of time. In the Haitian culture it is socially accepted for all adults to have the authority to discipline any child, even if the child is not their own. These means of correcting inappropriate behavior are also commonly used in schools. Additionally, for Haitians, the process of discipline tends to be focused on the child's deficits, and what the child is doing wrong.
- Limited access to technology
- Respect (teachers and parents – expectations are different in this country)
- Self-advocacy
- Complicated system
- Privacy
- Disagreement with school system
- Poverty
- Discrimination (this was a big one)
- Pride (e.g., even if a parent doesn't understand something, they say that they do anyway when asked)
- Special education system is complex and confusing

Prepared List of Major Barriers

- Privacy/ legal issues/ not wanting to air out dirty laundry
- Literacy
- Language
- System too complicated
- Self-advocacy/ fear of authority figures
- Lack of time, or having a job
- Shame around having a child with a disability
- Not understanding or having misinformation about what a disability is
- The way that Haitian parents raise their children does not parallel the way American children are raised (the school might discipline a child differently than the family does, as a result there is no consistency).

Tell group members that you are going to do some role playing of situations related to their child's IEP meeting and that when you are done, you'll be asking parents to identify which barrier(s) are depicted in the role-playing scenarios.

Each skit requires two or three volunteers to play the roles involved.

Describe the setting for each skit. Do not tell parents which barriers are being depicted, as this will be discussed at the end of the skit.

SKIT 1

- **Setting:** everyone meeting at the beginning of an IEP meeting
- **Roles to be played:** school district employee, parent, and security guard
- **Barriers:** privacy concerns, issues with authority figures or self-advocacy, and language barriers

School District Employee	*Hello, Ms. Lacombe. It's great to finally meet you.*
Parent	*Thank you, it's nice to meet you, too.*
School District Employee	*I know that you had requested an interpreter, and it just so happens that we are lucky enough to have our security guard, Mr. Joseph, who is also Haitian, translating for us today.*
Parent	(reluctantly) *Okay.*
	Then a 3rd party (the **Security Guard**) walks in.
Security Guard	(to the parent) *"Oh my goodness, Christine Lacombe, it's you! I didn't know your daughter went to this school!"*

End of skit

PARENT INPUT

Identified barriers: privacy concerns, issues with authority figures or self-advocacy, and language barriers

Solutions: before the meeting, request a professional interpreter (not a school employee)

SKIT 2

- **Setting:** telephone conversation, school district employee calls parent to set up IEP meeting.
- **Roles to be played:** school district employee and parent
- **Barriers:** lack of time, self-advocacy, and complicated system

School District Employee	*Hello, may I speak with Ms. Baptiste, please?*
Parent	*Yes, this is Ms. Baptiste.*
School District Employee	*Hello, my name is Elizabeth Carter and I am the IEP Coordinator at your son's school. Did I catch you at a bad time?*
Parent	*Well… I guess I have a minute. This is actually my cell phone and you are calling me at work.*
School District Employee	*I have actually left you several messages at home but I haven't been able to reach you.*
Parent	*Yes, I think I have heard a couple of those messages but by the time I get home from work, it's too late to call you back.*
School District Employee	*Well, maybe it might be easier if I email you. What's your email address?*
Parent	*I don't have an email address*
School District Employee	(in an impatient voice) *Well, what would be the best way to reach you?*
Parent	(in a reluctant voice) *I guess on my cell phone.*
School District Employee	*Well, since you said you were busy, I'll make this quick. I just wanted to set up a time for your son's IEP meeting. How about Thursday, October 5, at 10 00 AM?*
Parent	*Excuse me, what type of meeting is this?*
School District Employee	*Your son's IEP meeting.*
Parent	*IEP? What will the meeting be about?*
School District Employee	*IEP is his individual educational plan. In this meeting we will be deciding what classes he will be taking next year; and it will also give you an opportunity to meet his teachers.*
Parent	(sounding a little confused) *What time is this meeting again?*
School District Employee	*10 AM on October 5.*

Parent	*10:00 doesn't work for me because I have to work.*
School District Employee	*Well, is it possible for you to go in late or take some time off?*
Parent	*That will be very difficult because I have already requested some time off to make my other children's doctor's appointments.*
School District Employee	*Well, would you like to pick another day?*
Parent	(reluctant voice) *I am not sure how this is going to work… is it possible to schedule this meeting in a month or so, when all of my children's doctor's appointments are over?*
School District Employee	*Normally our IEP meetings are done on an annual basis during the same time of year, so we would hate to throw off the schedule. Well, anyway, according to his records, your son is doing very well, so there really isn't a pressing need for you to be there. We can have the meeting without you and then fill you in on what happened afterwards. How does that sound to you?*
Parent	(in a reluctant voice) *I guess that's okay…*
School District Employee	*In a couple of months you will have an opportunity to meet his teachers at the parent/ teacher conference anyway, so I think everything should be all set. I am going to send you some forms that you have to send back to me. They are just some papers you have to sign saying that you will not be able to make it to the meeting and that you agree to your son's schedule changes for the year. Can I fax these forms to you so that we can have them back ASAP?*
Parent	(sounding confused) *Fax??*
School District Employee	*Or I can just send them home with your son?*
Parent	*No, please don't do that; sometimes he loses things that are in his book bag.*
School District Employee	*Then I'll just mail them to you, but please make sure we get them back right away.*
Parent	*Okay, thanks. Good bye*

End of skit

PARENT INPUT

Identified barriers: no time, work, complicated system, technology

SKIT 3

- **Setting:** IEP meeting, school district employee presenting many papers to parent
- **Roles to be played:** school district employee and parent (other school district employees are present)
- **Barriers:** authority issues/self-advocacy, literacy, shame, complicated system

School District Employee *Welcome, everyone. We are all here to talk about the results of James Francois's testing, and to figure out what would be the most appropriate next steps. Present, we have Pamela Dumova, our consulting psychiatrist, Jim McCarthy, the school psychologist, Jill Arnold, the school Social Worker, Diane Smith, the school nurse, Judi Eisenberg, our Behavioral Specialist, James's teachers; oh and, of course, his PT, OT, and Speech Therapist.*

First, we will discuss the results of James's testing on the Wechsler, his neuro-psych eval, and how he did on concrete vs. abstract thinking. Any questions, Ms. Francois?

Parent (looking confused) *No….*

School District Employee *As shown on page 3, the results of the testing show that even though James is 14 years old, he is reading at a 3rd grade level and doing math at a 4th grade level. He also is a concrete thinker and has difficulty understanding abstract ideas. Are you seeing any of this at home, Ms. Francois?*

Parent (reluctantly) *No, not really…*

School District Employee *We are also seeing some oppositional behavior in James. When he is frustrated, he kicks and screams and will not listen to his teachers. I am curious to know if you are also seeing some of this behavior at home?*

Parent *Well he usually listens to me and when he doesn't, he is punished.*

School District Employee *How do you normally punish him?*

Parent (reluctantly) *Well…I can't think of anything right now…*

School District Employee *We have found that one way to work with James when he is upset is to give him options.*

Parent *What do you mean by that?*

School District Employee *For example, if he refuses to eat a sandwich for lunch, rather than make him eat a sandwich, we give him an option for one other food.*

Parent	*You mean that I should basically give into his demands and accept his behavior? If I did that he would never listen to anything I ever told him to do. I am his mother and he should listen to me without any questions asked.*
School District Employee	*Well, given everyone's input and the results of his test, I would say that James has a learning disability and he is probably also on the Autism Spectrum, though we would need more testing to truly determine that.*
Parent	*Disabled! What do you mean by that?? My son is not disabled; he just needs extra help at school.*
School District Employee	*Well, Ms. Francois, with this diagnosis we will be able to give him the extra help he needs.*
Parent	*Diagnosis? What do you mean by that? My son is not sick!*
School District Employee	*We are not saying he is sick, we are just trying to help him out in the best way possible. Unfortunately, the bell is about to ring and this meeting will almost be over. Ms. Francois, if you sign these forms we can give James extra help and services. We can't give him the extra help until you sign so he'll be without services until then. It's your choice.*
Parent	*Just show me where to sign…*

End of skit

PARENT INPUT

Barriers: complicated system, pride, discipline differences

Parent didn't seem interested in helping her child

Parent didn't understand the word "disability" and what was going on

Parent was not comfortable asking about things with everyone at the table–too complicated

Parent didn't understand what was going on in IEP

Parent didn't know what any of the terms were

Parent was generally embarrassed

→ **Get group feedback and answer questions**

2. IEP: Parent Concerns

The workshop to address *Parent Concerns* was developed in response to parents' many worries about their children's progress and focused on skills necessary to clearly articulate their children's primary needs resulting from autism to the IEP Team (e.g., concerns about their child's safety, inability to communicate, lack of daily living skills, or ability to get a job.). Massachusetts has a section in the IEP where parents can document all of their concerns (the Parent Concerns section). Though IEPs in other states may not have this specific section on the IEP form, it is still critically important for parents to learn how to articulate priority concerns which relate to the child's need for special education services. Parent concerns can be incorporated into other section of the IEP (such as "present levels of performance") and orally communicated at IEP meetings.

Objectives

- Participants will understand that the IEP must be developed with consideration of the parents' concerns about their child's education.
- Participants will be able to state which areas of concern can be addressed in the parent concerns section (academic, social, emotional, safety, etc.).
- Parents will begin to think about their own concerns and priorities for their child.

Materials

- Enlarged poster-sized IEP page 1 – parent concerns
- Marker
- Blank IEP page 1 – make sure to have translated IEPs available (determine what language(s) material should be translated to)
- Prepared list of parent concerns (attached)

Procedures

- Ice breaker - Choose appropriate ice breaker (we used Thank You Circle, page 23.)
- Presentation

  Explain the parent concerns section of the IEP. This is the part of the IEP where parents document their concerns. In Massachusetts this section is for parent input only. Parents can write whatever they want in this section, for example, the concerns can be academic, social, and emotional. While indicating concerns in this section does not necessarily mean that your child will receive services to address these concerns in the IEP, this documentation gives the school district notice that you have specific worries. While some states do not have this specific IEP section, when developing a student's IEP, school districts must ensure that there is parent participation and must consider this input about special education concerns.

Activity

- Affix large parent concerns page to the wall/board
- Explain to parents that you are going to pass out smaller version of this page to each of them to refer to, but they will not be writing on it until later in the exercise
- Pass out blank IEP page 1
- Ask parents to call out what their concerns are
- Presenter starts with own examples: head banging, taking off clothes at inappropriate times/ places, etc.
- Presenter uses checklist (attached) for additional examples and to encourage participation
- Presenter writes concerns that parents call out or examples facilitator uses on enlarged IEP page for group to see
- Suggest that parents can think about or write their own concerns on the blank IEP page
- Group discussion follows regarding how the concerns that the parents bring up are appropriate to put in the parent concerns section.
- Remind group that autism is a disability that affects all aspects of the child's life and that concerns don't have to be just academic but can also be about functional skills.

→ **Get group feedback and answer questions.**

PAGE ONE OF THE IEP - HANDOUT-

School District Name:

School District Address:

School District Contact Person/Phone #:

Individualized Education Program

IEP Dates: from _____ to _____

Student Name: **Jessie** _____ DOB: _____ ID#: _____ Grade/Level: _____

Parent and/or Student Concerns

What concern(s) does the parent and/or student want to see addressed in this IEP to enhance the student's education?

Student Strengths and Key Evaluation Results Summary

What are the student's educational strengths, interest areas, significant personal attributes and personal accomplishments?
What is the student's type of disability(ies), general education performance
including MCAS/district test results, achievement towards goals and lack of expected progress, if any?

Vision Statement: What is the vision for this student?
Consider the next 1 to 5 year period when developing this statement. Beginning no later than age 14,
the statement should be based on the student's preferences and interest,
and should include desired outcomes in adult living, post-secondary and working environments.

Non distrik lekòl-la:

Adrès distrik lekòl-la:

Nimewo telefòn kontak nan distrik-la:

Pwogram edikasyon pèsonèl

Dat IEP: depi le _____ rivele _____

Non elèv-la: _____ Datifèt _____ ID#: _____ Klas/ nivo: _____

Enkyetid paran oswa elèv-la
Ki enkyetid paran-an oswa elèv-la ta renmen yo diskite nan IEP-sa-a pou anrichi edikasyon elèv-la?

Konpetans elèv-la ak rezime prensipal rezilta evalyasyon-an
Nan ki matyè elèv-la pi fò, ki domenn ki enterese-l plis, ki sa ki distenge-l plis epi ki sa li reyalize?
Ki kalite andikap elèv-la genyen, ki pèfòmans-li nan etid jeneral epi
ki rezilta tès MCAS distrik-la, ki pwogrè lap fè pou atenn bi-li oswa èske li pa fè pwogrè ki espere?

Deklarasyon de bi: Ki bi elèv-sa-a pou akonpli?
Konsidere yon tan ant yon anne ak senk anne le wap prepare deklarasyon-sa-a. Pa kòmanse nan laj pi wo pase 14 anne.
ou dwe baze deklarasyon-ou-an sou sa elèv-la prefere ak sa ki enterese-li.
epitou ou dwe konsidere ki sa ki anvizaje pou lavi granmoun-ni epi nan anviwonman lekòl secondè ak anviwonman travay.

Nom du secteur scolaire :

Adresse :

Personne à contacter/ No. de téléphone :

Programme d'Education personnalisé (IEP)

Date IEP : du au

Nom de l'élève : _____ DDN : _____ No. : _____ Classe/Niveau : _____

Préoccupations du parent et/ou de l'élève

Quelles sont les préoccupations que le parent ou que l'élève aurait souhaitées voir aborder dans ce Programme d'éducation personnalisé (IEP) afin d'améliorer l'apprentissage de cet élève?

Résumé des points forts de l'élève et des résultats clés de l'évaluation

Quels sont les points forts de l'élève sur le plan scolaire, ses centres d'intérêt, ses qualités et ses grandes réussites?
Quel est le type de handicap(s) dont souffre l'élève, ses performances scolaires, y compris les résultats de ses tests (MCAS), ses réussites vis à vis des objectifs, au besoin, ses manques vis à vis des progrès escomptés?

Exposé de la vision : Quelle est la vision que vous avez pour cet élève?

Lors de la rédaction de cette déclaration, prendre en compte la période entre l'année suivante jusqu'au 5 prochaines années. En commençant au plus tard par l'âge de 14 ans, la déclaration doit être basée sur les préférences et les centres d'intérêts de l'élève, et devra inclure les résultats escomptés dans sa vie à l'âge adulte, post scolaire et professionnelle.

Massachusetts DOE/ Individualized Education Program IEP 1/French Page 1 of 8
Massachusetts DOE/ Programme d'Education personnalisé (IEP) Page 1 sur 8

Examples of Parent Concerns

Because of cultural norms already discussed, group members may not readily participate. Help this process by giving them examples from the non-exhaustive list of Parent Concerns list below. Ask them if they have any of these or similar concerns.

Academic

- ☐ Can't read or write
- ☐ Can't add or subtract numbers, can't do math

Social

- ☐ No friends
- ☐ Can't start conversations with others
- ☐ Can't keep conversation going once started
- ☐ Doesn't know how to share
- ☐ Is picked on or made fun of, bullied

Behavior – in school, home, community (church, grocery store, neighborhood)

- ☐ Hits
- ☐ Kicks
- ☐ Bites
- ☐ Screams
- ☐ Swears
- ☐ Scratches
- ☐ Takes off clothes
- ☐ Pulls hair
- ☐ Head banging
- ☐ Inappropriate touching
- ☐ Can't stay seated in the car or bus
- ☐ Doesn't sleep at night
- ☐ Transitions

Communication

- ☐ Doesn't talk
- ☐ Has no way to communicate
- ☐ I can't communicate with my child
- ☐ Talks with memorized phrases, but not interacting

Safety

- ☐ Runs away or bolts
- ☐ Escapes from home or school
- ☐ Is not safe around home items like the stove or knives
- ☐ Does not know how to safely cross the street

Emotional

- ☐ Nervous all of the time
- ☐ Sad – cries a lot
- ☐ Doesn't feel good about him or herself (no self-confidence)

Sensory

- ☐ No tolerance for sounds – for example: beeping, buzzing, alarms, sirens, barking, crying, other noises
- ☐ No tolerance for lights
- ☐ No tolerance for the way things feel – for example, scratchy clothing, tags on the back of shirts/pants, sticky hands or face, the way food feels in the mouth

Transition (Vocational)

- ☐ What is my child going to do after High School?
- ☐ Transition assessment
- ☐ Will my child be able to go to college?
- ☐ Will my child have a job?
- ☐ What are my child's interests?
- ☐ Where will they live and work?
- ☐ How do I work effectively with the school on a transition assessment and services - they are telling me that they have made the referral to determine the need for adult services and supports for when my child leaves high school but I'm worried about my child being prepared *before* he/she leaves high school.
- ☐ Travel training
- ☐ How do we work with our child to write a vision statement that includes our child's voice, dreams and vision?

Independence

- ☐ Activities of Daily Living (ADLs)
- ☐ Stranger danger/safety in the community
- ☐ Does not dress by themselves
- ☐ Does not shower, comb hair, brush teeth etc.
- ☐ Is not fully toilet trained
- ☐ Can't participate independently in the community (store, church)

3. Special Education Parent Training and Services, part 1

The two-part *Parent Training and Services* series was developed because many parents were unaware that districts may be required to provide parent training and other home services through their child's IEP, depending on their child's special education needs. Many parents said that their children exhibited dangerous behaviors at home (e.g., bolting, self-injurious) and were without safety awareness, social skills, self-care, and communication skills. The parents did not know how to effectively communicate with their children to get desired outcomes nor could they handle behavioral concerns at home. These parents urgently needed parent training and, in some cases, direct home services for their children. Parents first needed to learn about the parameters of the school district's obligation to provide parent training and other services in the home. Many parents associated 'home services' with caretaker services or respite instead of special educational services. We realized that initially it was first important for parents to be able to differentiate these services, which was a focus of the initial workshop. In the second part of this series, parents were also taught how to address the need for services in an IEP; most importantly, they needed to know that even if the services were verbally agreed upon at an IEP meeting, this agreement must be written in the IEP in order to hold school districts accountable.

Objectives

- Participants will differentiate between addressing their child's special education needs resulting from autism and their need for Personal Care Attendant (PCA)/respite services
- Participants will learn that special educational needs can, in some cases, address a child's needs to develop social, safety and self-help/daily living skills

Materials

- Ice breaker
  - 3 bowls – each a different color if possible (Each bowls is for a different skill category: social, self-help, safety)
  - Snacks (or other food or non-food item) to put in the bowls (e.g., small individually wrapped candy)
  - Put snacks/incentive items in each of the 3 bowls
  - Each of the 3 bowls is for a different skill category: social, self-help, safety
- Activity
  - Index cards – A skill or PCA task is written on each card (refer to learned skills and PCA lists, which are attached)
  - 2 bells
  - 2 small dry erase boards (or 1 large board divided into 2 sections): One board/section will be used as a score board, and the other should have the two categories ("Learned Skill" and "PCA assistance") written on it
  - Write examples from card on the white board under appropriate category

- Keep score: team 1 and team 2
- Poster board: write definition of a learned skill (for the purposes of this training)
- Learned Skills list (attached)
- PCA* Activity list (attached)

**The occupation of attending to the physical needs of people who are disabled or otherwise unable to take care of themselves, including tasks such as bathing, management of bodily functions, and cooking.* www.medical-dictionary.thefreedictionary.com

Procedures

- Ice breaker - Choose appropriate ice breaker
- Presentation

What are special education parent training and services?

We will talk about home/parent training services and give examples. We will also talk about how to include them in your child's IEP and the specific service options available based on individual need. Home services are usually needed to teach a child a new skill or to help generalize already learned skills. To generalize means to be able to do a skill in more than one environment. Skills are usually taught/reinforced using a specific teaching methodology (e.g., Applied Behavior Analysis or ABA). This is a direct service to the child. Home services can include parent training where a parent gets trained how to teach the child a new skill.

School districts must be responsive to a child's needs resulting from a disability; this includes social and emotional needs as well as academics. The goal of education is to help the child learn the skills necessary to work and live in society, including those essential to obtaining employment. A child with autism may have needs that go beyond the school day outside of the classroom and may need services in these other environments.

When home services to work with your child directly are in the IEP, the parent usually is required to be at home when those services are being provided. Individuals that come to work with you or your child are not there to babysit or provide respite. They do not help with daily routines such as bathing or feeding unless teaching your child skills in these areas. However, activities of daily living (ADLs) may be addressed in order to teach a child a skill (service is not care taking) or to learn a routine (e.g., morning routine - getting ready for school). Safety skills (crossing the street, avoiding dangerous objects, etc.) can also be taught in the home and in the community.

The team determines if there is a need for home services. You are part of this team.

Think back to your parent concerns discussed earlier. To help show that there is a need for a home service to address specific areas of necessity; you must first state these concerns. It is helpful to have an evaluator (teacher, psychologist, doctor, etc.) provide written recommendations for home services in a report that the school district will read. Specific evaluations will be needed to support the need for services.

What does "skill" mean when talking about students with autism? A skill is what a student learns to do that is developed through teaching, training, or experience. Developing skills can help a student be more independent at home, at school, in the community, and at work.

Activity

- Form 2 teams
- Facilitator writes the learned skill definition on the poster board, and then reads this definition aloud to the group.
- Facilitator selects and reads one index card – examples: making eye contact (skill), brushing child's teeth for them (PCA).
- When the group hears the description, a group member must ring the group's bell (the first team to ring the bell gets to answer first), be called upon, and state if the card read is a learned skill or a PCA assistance; if the team is correct, they get to select an incentive item, but if the team is incorrect, the other team gets an opportunity to answer the question and win the prize.
- Categories - "Learned Skill" and "PCA assistance" are written on a dry erase board; as the activities are identified, write them under the appropriate category.
- Score is kept on a dry erase (white) board.
- The team that wins the most incentive items is the winner.

→ **Get group feedback and answer questions.**

Learned Skills and PCA Assistance Lists for Training: Special Education Home Services

Learned Skills

- ☐ Joining a conversation
- ☐ Joining a game
- ☐ Starting a conversation
- ☐ Using pictures to communicate
- ☐ Asking for directions
- ☐ Asking for help
- ☐ Crossing the street safely
- ☐ Making eye contact
- ☐ Staying on topic
- ☐ Learning to play alone
- ☐ Staying on task
- ☐ Learning about time
- ☐ Learning about math
- ☐ Learning what body language means
- ☐ Learning how to interrupt a conversation
- ☐ Ignoring distractions
- ☐ Taking turns
- ☐ Attending to simple tasks
- ☐ Accepting transitions
- ☐ Follow non-verbal commands
- ☐ Following playground rules
- ☐ Expressing anger appropriately
- ☐ Talking about current events
- ☐ Recognizes personal space
- ☐ Learning to comb/brush hair

PCA Assistance List

- ☐ Brushing a child's teeth for them
- ☐ Bathing child
- ☐ Combing child's hair
- ☐ Taking child out for a walk
- ☐ Washing child's hair
- ☐ Cooking for child
- ☐ Folding child's clothing
- ☐ Feeding child
- ☐ Physically transferring child out of the bath tub
- ☐ Physically transferring child from his or her bed to the floor
- ☐ Ironing child's clothes

4. Special Education Parent Training and Services, part 2

Direct Services to Child and Parent Training

Objectives

- Group members will understand the difference between direct services to a child and parent training
- Group members will understand the link between parent concerns and the range of special education service options

Materials

- Ice breaker
  - Index cards – A skill or PCA* task is written on each card
  - Snacks (or other food or non-food item) to put in the bowls (e.g., small individually wrapped candy)
  - Bowl or container for snacks
- Training activity
  - Poster-sized parent concerns page of the IEP – *preferably with parent concerns of the group written in from previous "Parent Concerns" training*.
  - Blank parent concerns page

**The occupation of attending to the physical needs of people who are disabled or otherwise unable to take care of themselves, including tasks such as bathing, management of bodily functions, and cooking.* www.medical-dictionary.thefreedictionary.com

Procedures

- Ice breaker
  - Brief review of learned skills and PCA assistance
  - Read card- 3-4 questions maximum
  - Pick participants to answer if stated activity is a learned skill or PCA assistance.
  - If participant gets answer correct, they can choose a snack.

EXAMPLE

Question: Someone washing your child's hair **Answer**: PCA

Question: Someone teaching your child how to cross the street safely **Answer**: learned skill

- Presentation

Direct and indirect services

When referring to home training services provided by the school district, this can mean that someone provides direct services to your child or it can mean that someone will teach you how to help your child. Each school district can have a different title for the person who would come to your home. "Home Trainer" or "ABA provider" are two examples of titles. A home trainer can work with your child to teach him/her a certain skill, such as how to take turns or cross the street safely and then provides training to you so that you can continue to teach the skill in the same.

While we talk about this, think about the concerns you have for your child:

1. What do you need to learn and what does your child need to be taught? We had a workshop a while ago where the group brainstormed a lot of different parent concerns. We wrote them on this big parent concerns page (refer to poster-sized parent concerns page of the IEP).
2. I'm going to pass out a blank parent concern page – looking at this big list of concerns, write down or just think about any that you share, or think of new ones that aren't listed here.
3. As I read these concerns off, raise your hand as you hear one that you can identify with.

- Activity
  - Affix poster-sized parent concerns page to wall
  - Pass out blank parent concern page
  - Parents think about their own concerns – can write down on blank page
  - Read concerns from poster-sized parent concern page (from previous Parent Concerns training, if this training has not been done, facilitator should prepare this in advance)
  - Participants raise hand if they have the concern that is read aloud

Direct Special Education Service to Child in the Home

The methods for teaching your child that are the most successful are the ones that are specific to how your child learns. The goal is to identify some areas of concern in the home/community or issues of generalizing school to home skills. Generalizing means the ability to demonstrate a skill learned in one environment, such as school, in another environment such as in the home. Once the special education team determines the areas of concern, the home trainer will develop a plan to teach skills to the child that will address the issue.

EXAMPLES

Concern: *"my child runs across the street without looking for oncoming cars"*

Response: the home trainer will work with your child to understand and use safety precautions when crossing the street

Concern: *"my child cannot stay on task when doing his homework"*

Response: the home trainer can develop a plan that teaches your child to stay on task.

Concern: *"my child does not know how to use the communication device"*

Response: the home trainer can work with your child to help master the device and help you understand how it is used.

Special Education Home Parent Training

The goal of **home/parent training** is to teach a parent some skills so that he or she can work with and potentially help the child learn.

Sometimes programs are not successful at first and changes have to be made. A skilled home trainer, or one supervised by someone with expertise, can ensure that this happens.

A child with ASD has a better chance of making progress when family members reinforce the skills that they learn at school and home, as this offers consistency and less confusion.

Some strategies that can be taught to parents by the home trainer:

1. how to reinforce desirable behavior (ex. when a child sits in a chair for a certain amount of time, this desired behavior is rewarded – rewards are determined by assessing child's likes/interests)
2. how to ignore undesirable behavior (a home trainer helps parents to define what an undesirable behavior is in a given situation)
3. how to redirect a child
4. what to do when a child has a tantrum
5. how to tell when a child needs a sensory break
6. activities to do with a child during sensory breaks or to reinforce skills
7. how to support a child's ability to communicate (e.g., communication systems and/or devices)

→ **Get group feedback and answer questions.**

5. How to Include Services in an IEP

Objectives

- Group members will learn what information should be contained in the service delivery section of the IEP using special education parent training and services as an example.

Materials

- Ice breaker - Varies, depending on ice breaker
- Presentation
  - Blank IEP service delivery page
  - Blank IEP
- Activity
  - Index cards with skill or PCA task is written on each card (refer to skills and PCA training)
  - Dry erase board
  - Dry erase markers
  - Dry erase board eraser or something to clean off board
  - Incentive items

Procedures

- Ice breaker - Procedures will vary depending on ice breaker
- Presentation

  Review questions for Home Service Training parts 1 and 2:

  - What is home training on an IEP? (services provided by someone employed by the school district to come to your home to either teach you , your child, or both of you a skill).
  - A Home Trainer can provide services to a parent by teaching the parent how to teach the child a specific skill or skills. He/she can come to your home/community to directly teach your child a skill. In some cases, the home services will be for both the child and parents.
  - Does a Home Trainer dress your child or perform hygiene tasks for your child? (No)

Service Delivery Section of the IEP

The services your child will receive are listed toward the end of the IEP in the Service Delivery section. Home training services will be listed here too. When a service is described as "parent training" in the IEP, this can be confusing because frequently the service won't indicate if it is training for the parent or direct services for the child. Ask the team to ensure that the IEP state specifically if the training is to be a direct service to the child, to the parent, or both.

IMPORTANT – This is crucial to understand, as you might very well be **expecting** someone to work with your ***child***, but instead someone comes to your house to teach ***you*** how to work with your child.

Remind participants that the IEP is a legal contract – whatever is written in the Service Delivery section must be provided to your child (or you, in the case of parent training). Make sure that whatever services are agreed upon at the team meeting are written down (as agreed) in the Service Delivery section.

The Service Delivery section is one of the sections of the IEP. Show participants a whole IEP and indicate the Service Delivery section and where it is in the document.

Service Delivery page - Has three sections – A, B, and C (Massachusetts forms).

A. Consultation (indirect services to school personnel and parents)

This is not a direct service to your child (meaning no one is working with your child). It is called an indirect service. This is a team member or service provider sharing their expertise with another team member or service provider to help your child. The consultation could also be a team member or service provider meeting with you, the parent.

For example:

- The speech therapist consulting with the classroom teacher or other member of the team.
- The occupational therapist consulting with an aide.
- Team members consulting with each other about the student

B. Special Education and Related Services in General Education Classrooms (direct services)

These are direct services to your child (meaning that someone is working directly with your child) that take place in the classroom. The IEP should list any necessary direct services provided in the regular classroom setting.

For example:

- Speech therapy in the classroom
- OT in the classroom
- Reading or math instruction
- Social skills group

C. Special Education and Related Services in Other Locations (direct services)

These are direct services to your child (meaning that someone is working directly with your child outside of the classroom. The IEP should list any necessary direct services provided outside of the regular classroom. These direct services are often called "pull out services" (because your child is pulled out of his/her classroom to receive the service).

For example:

- Speech therapy in the speech therapy room
- OT in the OT room
- Reading or math instruction in the resource room
- Social skills group in a separate room
- Home training

☑ Focus on Goal # (this section is in Massachusetts IEP forms)

Each Goal in the IEP should have a service attached to it. If your child has a goal for speech and language, then the service delivery grid should reference speech therapy and the goal # to which it corresponds.

☑ Type of Personnel

The specific type of service provider is listed here. Though it does not have to include the name of the individual that is providing the service, it needs to be specific:

- In Massachusetts, "Special education staff" or "Sped staff" are both too vague, as they do not indicate who will be providing the service.
- It must state if the service is to be provided by a special education teacher (e.g., "Sped Teacher," "Sped tutor," "Sped asst," "OT," "OT asst," etc.).
- It must clearly be noted when a service is provided by an assistant rather than a fully-certified provider, and the law requires that anyone not fully certified must be supervised and trained by a certified provider in that field (OT, SLP, etc.).

☑ Frequency and Duration Per Cycle

- This section lists the number of sessions (frequency) of the service your child will have per week (or cycle) and also the amount of time (duration) your child will receive the service for each session.
- **Make sure you understand the amount of time your child will be receiving a service. "On-Going" or "As Needed" are both too vague and fail to establish a time commitment.**

☑ Start date/end date

- Start and end dates must be listed for the time period that the services will span. In most cases, the time period will be one year, as IEPs must be reviewed/renewed every year.
- In some cases, the team may agree that the service will be time limited (e.g., a 3-month trial period).
- **Always check the dates that are listed for the service time period.**

Activity

- Draw blank service delivery section on the dry erase board
- Fill in information provided by cases example below (see "Service Delivery Grid Activity: What is missing?" sample following)
- Ask parents to identify what's missing in the grid on the dry erase board
- In the sample grid provided, the first 2 examples are complete/correct, and the remaining examples have various components missing
- Offer incentive to parents that can identify missing components

→ **Get group feedback and answer questions**

Service Delivery Section Activity: What is missing?

Case 1

Kelty does not use eating utensils the way they were intended. She plays with them and throws them on the floor or at other individuals at the table. Kelty also has weak fine motor skills and has difficulty holding the eating utensils as well as pencils when writing. A parent trainer will teach Kelty's parents in the home to use behavioral strategies and to reinforce Kelty when appropriately using forks, spoons, and knives (Goal #1). She also receives occupational therapy (OT) services at school in a small group to address her fine motor skills (Goal #2).

Information in the service delivery section: **COMPLETE**

1. **Section A** – Consultation to parent (correct)
2. **Goal**: #1
3. **Type of Service**: Consultation Home Trainer/Parent (or Parent Training)
4. **Type of Personnel**: Home Trainer
5. **Frequency (how often) and duration (how long)**: 1 session of 2 hours per week
6. **Start Date**: September 15, 2008
7. **End Date**: September 15, 2009
8. **Section C** - Special Education and Related Services in Other Settings (Direct Service) (correct)
9. **Goal**: #2
10. **Type of Service**: Occupational therapy
11. **Type of Personnel**: Occupational therapist
12. **Frequency (how often) and duration (how long)**: 1 session of 30 minutes per week
13. **Start Date**: September 15, 2008
14. **End Date**: September 15, 2009

1 A. Consultation (Indirect Services to School Personnel and Parents)					
Focus on Goal #	Type of Service	Type of Personnel	Frequency and Duration/per Cycle	Start Date	End Date
2 1	3 Parent training	4 Home trainer	5 1 session, 2 hr per wk	6 9/15/08	7 9/15/09
B. Special Education and Related Services in General Education Classroom (Direct Service)					
8 C. Special Education and Related Services in Other Settings (Direct Service)					
9 2	10 OT	11 Occupational therapist	12 1 session, 30 min per wk.	13 9/15/08	14 9/15/09

Case 2

Viviane has difficulty completing her homework because of her difficulty concentrating and gets frustrated. When frustrated, Viviane will injure herself and throws and breaks items in the home. In the home, the Home Trainer will teach Mr. and Mrs. Pacombe behavioral strategies to keep Viviane on task and to reduce injurious and destructive behavior (Goal #4). Viviane also receives behavioral services in her general education classroom working with an autism specialist for 60 minutes each day (Goal #5).

Information in the service delivery section: **INCOMPLETE**

1 **Section A** – Consultation to parent (correct)

2 **Goal**: MISSING (Goal #4)

3 **Type of Service**: MISSING (parent training - direct service for student)

4 **Type of Personnel**: Home Trainer

5 **Frequency (how often) and duration (how long)**: 1 session of 120 minutes per week

6 **Start Date**: MISSING (the start and end dates are usually for the time span of one year)

7 **End Date**: MISSING (the start and end dates are usually for the time span of one year)

8 **Section B** - Special Education and Related Services in General Education Classroom (Direct Service)

9 **Goal**: MISSING (Goal #5)

10 **Type of Service**: Behavior

11 **Type of Personnel**: Autism specialist

12 **Frequency (how often) and duration (how long)**: 1 session of 60 minutes each day

13 **Start Date**: September 15, 2008

14 **End Date**: MISSING (September 15, 2009)

1 A. Consultation (Indirect Services to School Personnel and Parents)					
Focus on Goal #	Type of Service	Type of Personnel	Frequency and Duration/per Cycle	Start Date	End Date
2	3	4 Home trainer	5 1 session, 120 hr per wk	6	7
B. Special Education and Related Services in General Education Classroom (Direct Service)					
8 C. Special Education and Related Services in Other Settings (Direct Service)					
9	10 Behavior	11 Autism specialist	12 1 session, 60 min each day	13 9/15/08	14

Case 3

Timafi runs away from his parents or other adults when at the store or playground.

The IEP Goal #1 addresses this concern and states that Timafi will stay with the adult in charge when out in the community and that a Home Trainer will teach him in the home the skills needed to meet this goal. Timafi also has social skills needs and does not communicate effectively with others. The school speech therapist is working with him twice a week on appropriate language and other social skills in a small group during the day when at school. The IEP Goal #4 addresses these issues.

Information in the service delivery section: **INCOMPLETE**

1. **Section C** – Special Education and Related Services in Other Settings (Direct Service) (Correct)
2. **Goal**: MISSING (Goal #1)
3. **Type of Service**: MISSING (parent training - direct service for student)
4. **Type of Personnel**: Home Trainer
5. **Frequency (how often) and duration (how long)**: 3 sessions per week DURATION MISSING (1 hour per session)
6. **Start Date**: MISSING (the start and end dates are usually for the time span of one year)
7. **End Date**: MISSING (the start and end dates are usually for the time span of one year)
8. **Goal**: #4
9. **Type of Service**: Social skills training
10. **Type of Personnel**: Speech therapist
11. **Frequency (how often) and duration (how long)**: 2 sessions per week for 30 minutes each session
12. **Start Date**: September 15, 2008
13. **End Date**: September 15, 2009

A. Consultation (Indirect Services to School Personnel and Parents)					
Focus on Goal #	Type of Service	Type of Personnel	Frequency and Duration/per Cycle	Start Date	End Date
B. Special Education and Related Services in General Education Classroom (Direct Service)					
1 C. Special Education and Related Services in Other Settings (Direct Service)					
2	3	4 Home trainer	5 3 sessions per week	6	7
8 4	9 Social skills	10 Speech therapist	11 2 sessions of 30 minutes per wk	12 9/15/08	13 9/15/09

6. Independent Evaluations

The ***Independent Evaluation*** workshop was prompted by parents' misunderstanding that the conclusions and recommendations provided by school district evaluators were unchangeable. They assumed that the evaluators knew what was best for their children because they were educators in positions of authority. However, they also knew that their children weren't making progress and felt conflict between what they were told by school district officials and what they believed their children could accomplish. They did not know that they had the right to a second opinion in the form of an independent educational evaluation. MAC developed a highly interactive training to teach parents about their rights to an independent evaluation, emphasizing that the process for exercising this right was a lengthy one and required them to remain highly involved.

Objectives

- Parents will understand the process of getting an independent evaluation for their child, including their ongoing role throughout.
- Parents will understand that the process of getting an independent evaluation can take many months from beginning to end.
- Parents will understand that they can use independent evaluations to help get the services that their children need in order to make progress.

Materials

- Ice breaker - Materials vary with ice breaker used
- Training Activity
  - Dry erase board
  - Dry erase markers
  - Time frame schema for independent evaluations (see illustration below in section IV)
  - Skits for role plays (to read from)

Procedures

- Ice breaker - Procedures vary with ice breaker used
- Presentation

  Explain to the group that you will review the independent evaluation process and then will conduct a series of role-play scenarios to illustrate the many steps involved. After the role plays, the group will discuss the information. Below are the important points to cover with the group.
  - Getting an independent evaluation is a multi-step process that can take several months.
  - An independent evaluation is like going to a doctor for a second opinion.
  - The school district must do their own evaluations first.
  - If you disagree with the school district's evaluation findings, you can then request an independent evaluation.

- Explain that it is acceptable not to agree with the school district evaluation and common and expected that parents get another opinion from an outside objective specialist.
- This request must be done in writing.
- You can request that the school district pay for the evaluation.
- In Massachusetts, the school district must pay for the evaluation if you meet income guidelines (if your child qualifies for free and reduced lunch then s/he automatically qualifies)
- Parents can also use private insurance or Medicaid to secure independent evaluations.
- Not all evaluators will accept this rate
- Make an appointment for your child with the evaluator selected
- It can take several months to get an appointment
- After you and the school district have received the report from the independent evaluation, in Massachusetts, the school district has 10 schools days to schedule an IEP meeting to discuss and consider the findings
- The following role-play scenarios are about a parent who wants parent training and services to address some of her child's concerning and self-injurious behaviors
- Presenters will play the roles of the special education facilitator, parent, and advocate
- Note: One of the presenters will provide explanations between the role-play scenarios; this is under the heading of "Narrator Comments"

Activities

- Use the dry erase board to illustrate the Independent Evaluation request steps and time from requesting the independent evaluation to conclusion. See illustration on page 73.
  - Role-play scenarios and narration of independent evaluation process and timeline:

    Etienne is a 5-year-old Haitian boy with autism. He attends his local public school in a self-contained special education class for children with autism. His mother, Mrs. Gauthier, is concerned about the self-injurious behaviors he exhibits in the home and community and his need for constant support to decrease these behaviors in school.

SKIT 1

Etienne's IEP meeting
September 8, 2008

- Mrs. Gauthier expresses concerns about her child's head banging and inability to complete morning routine. She is happy to hear that he is not doing these behaviors in school anymore as much but is concerned that he can't be successful without supports and structure in school. He is not independent in school and unable to carry over skills to his home and community. She is worried because while he is doing better in school, he is not going to have these supports his whole life. Mrs. Gauthier requests (in writing) that her son be evaluated for the need for parent training and services.
- School district agrees to conduct evaluations and will get back to parent.
- School district gives parent consent form.
- Parent signs the consent form at the meeting.

Beginning of skit 1

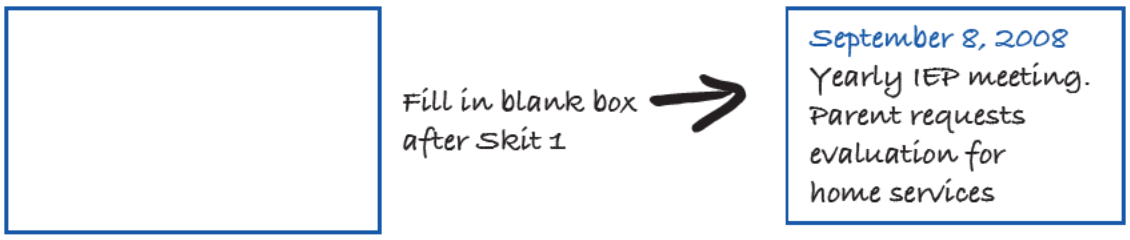
Setting: IEP meeting at school

Note: All members of the IEP Team are required to attend Team meetings unless excused by the parent. For the purposes of these skits, the special education facilitator will be the only Team member speaking.

Special Education Facilitator	*Good Morning, Mrs. Gauthier, I am glad that you were able to join us today.*
Mrs. Gauthier	*Thank you. I am happy to be here.*
Special Education Facilitator	*Well, after listening to all of the teacher and staff comments, it looks like Etienne is doing very well and we will continue to work on the goals that we had set for last year.*
Mrs. Gauthier	*I actually had some concerns that I wanted to bring up and add to his IEP goals.*
Special Education Facilitator	(with hesitation) *All right, what did you have in mind?*
Mrs. Gauthier	*Well, Etienne has a horrible habit of banging his head on the wall and sometimes on the floor when he gets frustrated. He does this at home and when we are out shopping. It's really scary and I am afraid he is going to hurt himself. I am also having a hard time with him in the morning. It is difficult to get him up, and then when he finally does get up, he does not know what to do. I tell him to brush his teeth and when I go to check on him, he is just playing in the water and there is toothpaste everywhere. And getting him to get dressed is even worse - he puts everything on the wrong way and sometimes he even forgets to put on underwear or socks.*

Special Education Facilitator	*Maybe you should try to get him to bed earlier - it sounds like he is probably tired.*
Mrs. Gauthier	*No - he goes to bed early and he gets plenty of sleep. And what about the head banging? I am really concerned about it…*
Special Education Facilitator	*Well, we are not seeing that behavior in school - is there anyone at home that he does not get along with?*
Mrs. Gauthier	(in a frustrated voice) *No- he gets along well with everyone. I'm happy that Etienne doesn't have this behavior at school as much and it makes sense that he doesn't because he has significant supports and services to help him with this. I would like to know if I could have someone come to my home and work with him to address these problems outside of school.*
Special Education Facilitator	*It sounds like you think he needs support in the home.*
Mrs. Gauthier	*Yes, that would be helpful. I have a letter here requesting parent training and services and it also explains what I am looking for.*
Special Education Facilitator	*Oh… I see you came prepared… well, here is a consent form that you have to sign and then we can conduct an evaluation to see what level of services Etienne needs.* (Mrs. Gauthier signs the form)

End of skit 1 – summarize information in timeline box on dry-erase board.



Narrator comments

While this is Etienne's annual meeting, remember that you can ask for an IEP meeting whenever you have a concern. Unscheduled meetings are common and it's your right as a parent and team member to ask for meetings when there is a concern.

It's always best to ask for an evaluation in writing, but in our skit, the parent asks for the evaluation in person at the meeting. This is OK too. The School District gives the parent a consent form at the meeting. It's important that the parent makes sure that she is signing a consent form for the type of testing she asked for. If she's not sure, she can ask the team more questions or take the consent form home and contact someone knowledgeable for help. Remember: the sooner the signed consent form is returned to the school, the sooner the evaluation can begin.

SKIT 2

NOTE: After the consent is signed, in Massachusetts, the School District has 30 school days (not counting weekends and school vacations) to conduct evaluations, and 15 days to have an IEP meeting. This means the IEP meeting must take place a total of 45 school days after the consent is signed with an IEP developed (The IEP process conforms to specific federal and state timelines. These are MA timelines; please check your state special education law for your own specific timelines).

November 10, 2008 - meeting

- School presents the results of evaluations: classroom observation, other testing that shows child's ability to follow directions and sequence, and behavior.
- School doesn't feel there is a problem. Student did well in testing, exhibited no self-injurious behavior, followed commands, and generally was able to carry out daily schedule at school without incident…. no home services necessary.
- Parent states that evaluations were only conducted in school and the problems she described are prevalent at home and in the community.
- School District disagrees -- any home issues are the parent's responsibility.
- Parent asks for an independent evaluation in writing.

Beginning of skit 2
November 10, 2008
Setting: school

Special Education Facilitator *Good morning, everyone. We are here this morning to review and discuss the results of Etienne's evaluation. We will also discuss Mrs. Gauthier's request for parent training and services. Well, Mrs. Gauthier, I have great news! It seems that Etienne did great on our assessments. We conducted a series of tests that assessed his problem-solving skills, and with some staff support he did very well. There were some moments during our evaluation where Etienne grew frustrated, but he kept calm and did not bang his head once. In fact, his teachers have never seen this type of behavior recently in school.*

Mrs. Gauthier *I already told you - Etienne is a very different person when he is not in school. He bangs his head when he does not get his way at home and when we are out! It sounds like he had staff support and structure during the testing and that he doesn't have these skills independently.*

Special Education Facilitator *Well, maybe you should consult with an outside specialist about this if it is really bothering you because, again, we are not seeing him do it here. And with regard to him getting ready in the morning, the results of the test show that he should not have any problems in this area because he was able to follow directions very well, and he has no problems following his schedule at school.*

Mrs. Gauthier	*School is very different from home! His day is very predictable and consistent at school. What would it be like if he didn't have any individual support at school? And what about Etienne getting dressed? He can barely put his clothes on by himself!*
Special Education Facilitator	*Well, unfortunately we cannot help you in this area because these are issues he is having at home, and not at school. There is a local autism support center nearby. Maybe you can call someone else to help you with this.*
Mrs. Gauthier	*I don't know anyone else that can help. Is it possible for someone to come out and observe him at home or maybe in a store?*
Special Education Facilitator	*Unfortunately we don't really have workers travel outside of school.*
Mrs. Gauthier	*I know my rights and I would like to have someone who is not from this school observe him at home. I have a letter here that requests an independent evaluation.*
Special Education Facilitator	*Mrs. Gauthier, I hope we have not upset you. We all want what is best for Etienne. You are certainly entitled to a second opinion if you think that would help, but I should tell you that often times getting a second evaluation can take a lot of time, and more often than not, the results come out to be the same as our results. I would just hate for you to waste your time and energy.*
Mrs. Gauthier	*No, if it is for my child, I can never be wasting time or energy. I will be in touch with you when the evaluations are completed.*
Special Education Facilitator	*I can provide you with a list of evaluators, if you would like.*
Mrs. Gauthier	*No, thank you, I will find one myself through my own health insurance.*
Special Education Facilitator	*Well, all right, I look forward to hearing from you at a later date.*

End of skit 2 – summarize information in timeline box on dry-erase board.

Narrator comments

If you disagree with the school district's testing results you have the legal right to an independent evaluation or second opinion. If you're not sure if you disagree, show the test results to someone who you trust or can explain them to you.

You can arrange a second opinion by yourself or through the school. If you have health insurance or Medicaid, you can set it up yourself. Sometimes it is easier to do the evaluations through your health insurance, as it usually doesn't take as much time.

For second opinions, in certain special circumstances, the school will pay. Or you can use health insurance. No matter how you get it done – health insurance or school-pay or self-pay – you have the right to have this done and **the school must consider the findings/results in decision-making about services for your child.**

→ Evaluation information

May 2008 - six months later: Independent evaluation takes place at Children's Hospital

Narrator comments

Note that six months have passed since the mother, Mrs. Gauthier, has requested the school testing at the school. If the mother had known that it would take this long and/or been aware of her rights, she could have made the appointment at the same time she requested the school perform their own evaluations. In this case, if the mom ended up agreeing with the school's testing and didn't feel the need for a second opinion, she could have simply cancelled the appointment.

Ask for an interpreter when you set up the appointment if you need one. Even if you speak English, some of the terms and questions the doctors may use may be unfamiliar to you. They are unfamiliar to most people, so it's completely fine not to understand. Additionally, it's always helpful to bring a friend – similar to how we stress bringing someone to an IEP meeting. Friends can take notes, help you remember things, and assist you with processing the evaluation and what the doctor said after the appointment.

These evaluations can take more than one visit, frequently requiring 3 visits on average. The meetings usually consist of a parent interview and various evaluations of your child. During the parent interview, you'll be asked questions about your child's abilities and behavior. This is a very important process, as providing accurate and representative information to the evaluator will allow him/her to make better and more responsive recommendations for services to meet your child's needs.

These are important points that should be emphasized throughout the workshop:

- When you make the appointment, sometimes the date will be set far in advance
- You can ask to be put on a cancellation list. This means that the evaluator's office will put your name on a list. If someone cancels their appointment and a space opens up sooner than your scheduled appointment, the office will call you to give you the appointment. However, this is often at the last minute, so you have to be prepared to drop everything to get to the appointments if possible.
- If you need an interpreter, tell them this when you make the appointment.
- In addition to a potential interpreter, also consider bringing someone you trust to the appointment with you.
- You may have paperwork and questionnaires to fill out. Again, seek help with this.
- Return all of the paperwork as soon as possible – sometimes the evaluator's office won't even make an appointment until you get the paperwork back to them.
- Make copies of <u>everything</u>. You can ask the evaluator's office staff to make copies for you.
- Send the evaluator your child's IEP and any other evaluation reports that you have. This is important information for the evaluator.
- Each appointment may take 2 hours or so.
- It can take over a month to get the final report.

SKIT 3

June 11, 2008

IEP meeting – to discuss independent evaluation results

- In the interim, Mrs. G consulted an advocate recommended by a child advocacy agency. The advocate reviewed testing results along with Etienne's school records.
- The advocate agreed to attend the team meeting.
- During the IEP meeting, the school still disagreed with the need for home services
- The advocate skillfully reviewed independent evaluation and brought up important points from school testing that showed Etienne's difficulties in several areas.
- Parent and advocate asked for home training and direct services based on IE evaluator's recommendations.
- The School District finally agreed to home services and an IEP was written with a new goal for behavior included. School District agreed to provide, for one year, parent training once per week for 45 minutes, and direct services with the child twice per week for 60 minutes.

Beginning of skit 3
June 11, 2008
Setting: school

Special Education Facilitator *Good Morning, everyone. We are here to discuss the results of Etienne's independent evaluation. The staff and I have reviewed the results and our stance has not changed. We disagree with the independent evaluator's recommendation for home services. We believe that since the independent evaluator had only seen Etienne over the span of a couple of weeks – as opposed to us seeing him every day - we would have a better understanding of Etienne's needs. He is thriving at school, and we are not seeing any of the issues that Mrs. Gauthier sees at home.*

Advocate *Yes, it is true that the evaluator only saw him for a span of a couple of weeks, but it is also true that along with you, Mrs. Gauthier sees Etienne every day as well. In fact, out of everyone in this room, Mrs. Gauthier probably knows Etienne the best. The evaluator and Mrs. Gauthier are saying the same thing, and making valid points that should be considered.*

Special Education Facilitator *Yes, of course, we should always listen to the parent's concerns.*

Advocate *And with regard to Etienne's head banging, I see that Mrs. Gauthier has written this concern down in the parent concern section in the IEP for the past 3 years and it has never been addressed in Etienne's goals.*

Special Education Facilitator *Where do you see that?*

Advocate *On page 2 of the last 3 IEPs.*

Special Education Facilitator *We have created some goals around Etienne's inappropriate behaviors.*

Advocate *Yes, but the IEP never spells out specifically* what *behaviors. There was never a specific goal written to address Etienne's head banging. And with regard to Etienne's morning routine at home, the school had previously mentioned that Etienne has good problem-solving skills with some support, that he follows directions well, and that he has no problem following his schedule.*

Special Education Facilitator *Yes, Etienne has no problem with routines at school.*

Advocate *Well isn't it true that all of the routines that you have implemented in school have taken Etienne at least one academic year to learn? For example, it took a year for Etienne to learn his class schedule on his own, and even now he still needs some prompting. Don't you even use a picture chart with him in order for him to follow what is going on in the day? Isn't it true that if there is a change to his routine that he makes refusals and has a tantrum?*

Special Education Facilitator *Well, yes, he does need some prompting, and picture charts do help him follow what's going on.*

Advocate *The school has also previously mentioned that Etienne has good problem-solving skills, but that he requires some staff support in this area. The IE results say that Etienne's problem-solving skills are very poor. Isn't it true that Etienne has required significant staff support in the past because of his inability to follow through on tasks and resolve conflicts? This is a child who may require a residential placement if he is unable to function independently.*

Mrs. Gauthier *I want him to live at home.*

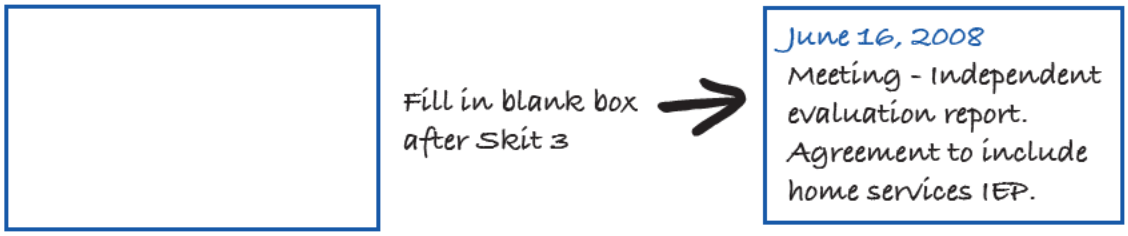
Advocate

With all of these issues going on, it is understandable why Etienne would have difficulty with his morning routine. If Etienne responds well to picture charts, wouldn't it be great if perhaps a home trainer could work with the Gauthier family to develop a picture chart to tell Etienne what to do in the morning, just like the way his school schedule is set up? Children with autism really benefit from things being the same across the board. If Mrs. Gauthier could set up things in her home similar to the way they are in school, then Etienne would not be so confused and it would help everyone. The bottom line is that the purpose of special education is to teach the child skills that he or she can demonstrate in all areas of life, including home and the community. Although you claim that Etienne is doing well in school, he clearly still needs services at home and in the community.

Special Education Facilitator

I think you have made your case- let's adjust the current IEP to include home services and then we will reconvene in 3 months to assess if it has been helpful and how things are going.

End of skit 3 – summarize information in timeline box on dry-erase board.



Narrator comments

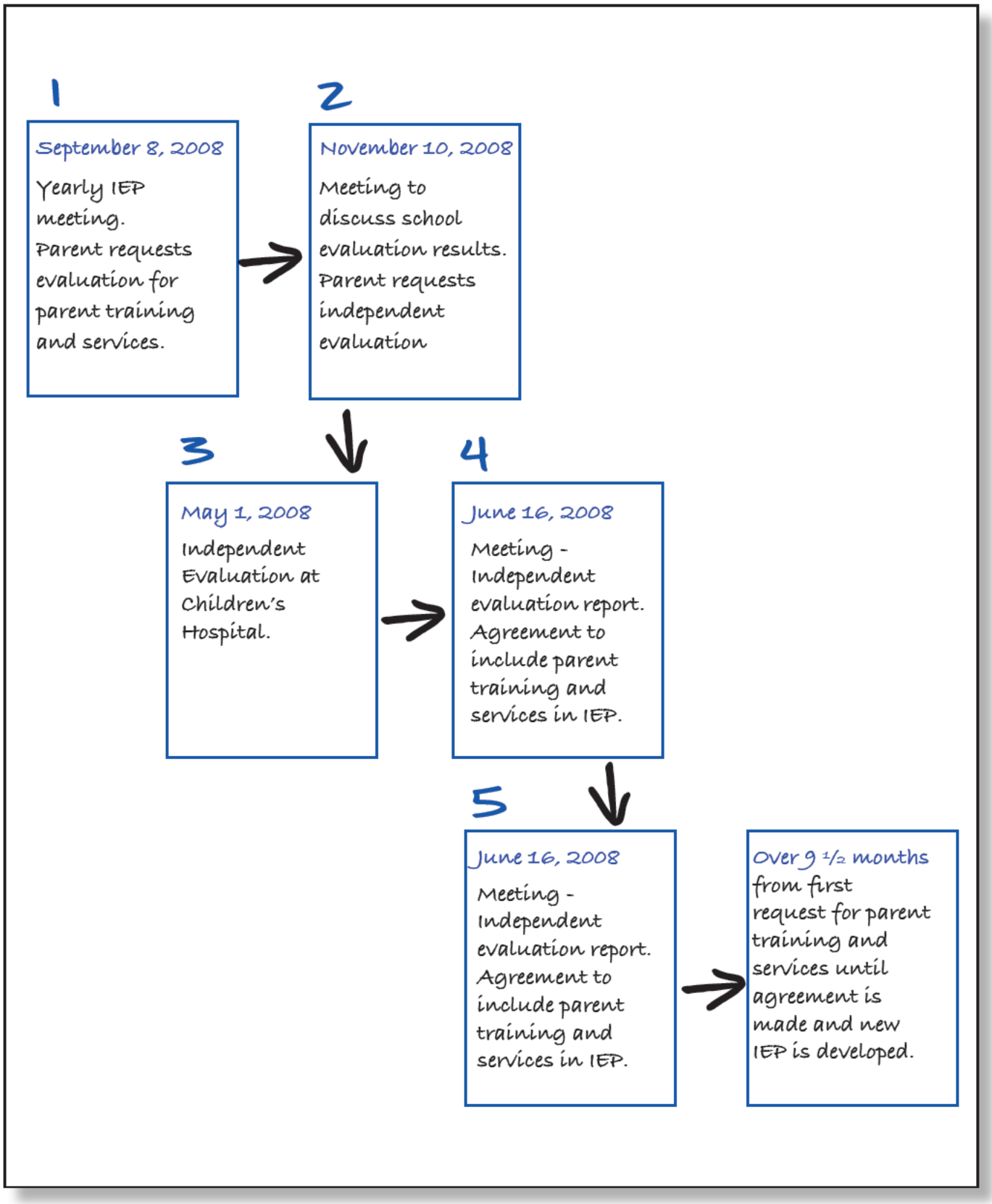
We used a very short time line considering that it can take more than 6 months to get an appointment for an evaluation at Children's Hospital or other hospitals. If so, this meeting wouldn't take place until September (meetings don't take place over the summer). If this were the case, it would be a whole year before any decisions were made about the parent's concern for home services.

→ **Get group feedback and answer questions.**

Some possible questions for the group:

- What did you think about the timeline?
- Note how long it took – even with the help of an advocate.
- What do you think about all of the steps and meetings needed to get services for your child?
- Did you learn anything new today?
- Is it easier to understand the information when we do role-play scenarios and skits?

Time frame schema – for dry erase board



7. Autism Awareness Training and Outreach (target audience - Haitian adults in the community who do not have children with autism)

This workshop, ***Autism Awareness Training and Outreach***, was developed as part of the community outreach strategy to help identify Haitian parents with children on the autism spectrum. Staff conducted this training for Haitian adult English Language Learner classes as a way to not only conduct outreach but also to raise autism awareness in the community. Particular focus was given to impressions and expectations of people with disabilities in Haiti and in the US, Haitian views about people with hidden disabilities such as autism, and the impact of special education laws in this country.

Objectives

- Educate and perform outreach with members of the Haitian community about autism
- Inform group members about an autism parent group

Materials

- Ice Breaker - Materials vary, depending on selected ice breaker
- Training - None

Procedures

- Ice Breaker - Procedures vary, depending on selected ice breaker
- Presentation

  We conducted this training with two facilitators (trainers): the Haitian consultant and a MAC autism center staff member. Facilitators alternated sections of the training.

  The consultant targeted the concept of disability from a cultural perspective and disability type (e.g., hidden vs. not hidden). MAC staff member focused on "what is autism" and the purpose of the training.
- Introduction

  Introduce yourself, other presenters, and the organization that you represent. Give some details about your organization and why you are there to talk to the group.

  We work with the Autism Center where we do outreach and provide training to Haitian parents of children with autism. Our goal today is to provide some background about autism; a disability that I'm sure you're aware is impacting increasing numbers of children, as well as tell you about a parent group we are forming for Haitian parents of children with autism.

What is a disability?

The definition of disability set forth in the Americans with Disabilities Act of 1990 (ADA)

"The term 'disability' means, with respect to an individual–

(a) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;

(b) a record of such impairment; or

(c) being regarded as having such an impairment." (P.L. 101-336, Sec. 12102)

- A disability can be physical, learning/ cognitive, sensory, related to mental health- does anyone here know a person with a disability?
- Encourage group members to talk about what they know about disabilities
- In our experience, our Haitian consultant talked about her own disability

Hidden and unhidden disabilities

- Hidden – you can't see a hidden disability the way you can a disability that is not hidden; for example, someone with autism versus someone in a wheel chair
- Hidden disabilities besides autism can include learning disabilities, mental health issues, and cognitive disabilities
- Discuss lack of understanding around hidden and unhidden disabilities in the US and in Haiti

Cultural beliefs around disability

- The Haitian consultant spoke more about her own disability
- Does anyone in the group know anyone with a disability? Friend? Relative?
- How are disabilities perceived or treated in your country? Possible responses:
  - disabilities are seen as a deficit
  - individuals with disabilities are viewed to be less capable
  - there are no accommodations
  - in Haiti, there are special schools for children with disabilities and parents have to pay for this. these special schools are for disabled children only so they are separated from children without disabilities
  - most parents of children with disabilities cannot afford to send them to a special school and the children are forced to stay at home
- Have you seen a difference in the US?
  - there are more opportunities here
  - the government supports persons with disabilities – financially and in various other ways
  - there are laws here against discrimination
  - people with disabilities in the US are more independent here because of accommodations; furthermore, they have the opportunity to be mainstreamed in school
  - education is free for all in the US

Discuss how having a disability does not make you less capable, but rather simply means that you do things in a different way

- Stress the importance of understanding the disability and providing accommodations
- Include that the lack of understanding (due to no fault of their own) can cause people to misinterpret behavior to be defiant or disrespectful- as a result these children are subjected to punishment or negative judgments

Autism

- Today we'd like to focus on one type of disability: autism

- Does anyone know what autism is? Have you heard of it?
- Autism is a disability that affects communication, social development, and behaviors. It causes problems with a person's ability to understand what is seen, heard, and touched. Autism is different for every person that has it. Some may be able to talk can interact with others, while others may stay to themselves and are not able to talk and might use a computer or device to communicate.
- Children with autism can have a lot of inappropriate behaviors.
- Give personal example if appropriate: My son has autism. He had difficulty with communication – no speech when he was little, couldn't communicate – frustrated, banged his head really hard on the floor or objects. Because he couldn't talk he showed his frustration by banging his head. He didn't like to be around other children and would scream or spit at them if they got too close to him – another inappropriate behavior.
- You can look at it this way: communication problems + social skills problems + sensory problems = a recipe for behavior problems.
- Autism usually stays with a person his or her whole life. A person with autism can learn how to communicate in an appropriate way and how to relate to people. All children on the autism spectrum have significant potential and competency if provided with needed supports and services. Many people with autism don't learn the same way that people without autism do so they have to be taught in a special and individualized way. Some have severe autism, while others can have mild autism. Some individuals with severe autism may, with a lot of help with learning and other therapies, see the severity of their disability lessen.
- Give personal example: my son has had a lot of help learning how to talk and behave. Now he talks and loves to be around other kids. He still has some problems with communication and knowing how to act around people, but he has come a long way and he doesn't spit at people or bang his head anymore.
- The help my son got was not easy to come by. When a child with autism turns 3 years old, the public school system must provide services to help the child with behavior and communication. Sometimes this system doesn't work the way it's supposed to and parents need help to learn what to do. It can be very difficult and confusing especially if you speak a different language or come from a different culture.
- MAC's autism project teaches parents how to get their children with autism the help they need from the school system.

What is MAC's outreach effort?

- We are forming a group of Haitian parents who have children with autism. The purpose of the group is to build unity and provide an opportunity to interact and learn from other parents, including understanding that you are not the only person who goes through some of the things that you do raising a child with autism.
- Another purpose is to work closely with the group to teach and empower parents, providing them with a forum to discuss the issues and barriers they face.
- If any of you have a child with autism or know anyone that does, please refer them to us so that we can tell them more about the group.

→ **Get group feedback and answer questions.**

Examples of questions asked by the group:

- Is autism contagious?
- How do you know if someone has it?
- Can adults get autism?
- Can autism be cured?

Glossary

Autism

Individuals with Disabilities Education Act definition: Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences.

http://idea.ed.gov/explore/view/p/,root,regs,300,A,300%252E8,

Asperger Syndrome

Asperger Syndrome is an autism spectrum disorder characterized by difficulty with social interactions and restricted range of interests and/or repetitive behaviors. There are usually no significant delays or difficulties in language or cognitive development.

http://www.autismspeaks.org/what-autism/asperger-syndrome

Early Intervention Program

Early intervention is a system of services that helps babies and toddlers with developmental delays or disabilities. It focuses on helping eligible babies and toddlers learn the basic and new skills that typically develop during the first three years of life. It is available in every state and territory of the United States and is required by The Individuals with Disabilities Education Act (IDEA), part C.

http://nichcy.org/

Special Education

Specially designed instruction to meet the unique needs of the eligible student and related services necessary to access the general curriculum and shall include the programs and services set forth in state and federal special education law.

http://www.doe.mass.edu/lawsregs/603cmr28.html?section=02#start

Substantially Separate Classroom

A small controlled classroom separate from the general school population for students with disabilities for all academic subjects with a special-education teacher.

http://specialchildren.about.com/od/specialeducation/p/specialedrooms.htm

Individualized Education Program (IEP)

A written statement, developed and approved in accordance with federal special education law that identifies a student's special education needs and describes the services a school district shall provide to meet those needs.

http://www.doe.mass.edu/lawsregs/603cmr28.html?section=02#start

Glossary

Bureau of Special Education Appeals (BSEA)

The agency in Massachusetts that conducts mediations and due process hearings to resolve disputes among parents, school districts, private schools and state agencies. The BSEA derives its authority from both federal law and regulations (the Individuals with Disabilities Education Act, "IDEA") and Massachusetts law and regulations. (MGL ch. 71B)

http://www.mass.gov/anf/hearings-and-appeals/bureau-of-special-education-appeals-bsea/

Hidden Disability

Disabilities that cannot be recognized through observation.

Applied Behavioral Analysis (ABA)

Behavior analysis is a scientifically validated approach to understanding behavior. ABA is the use of specific techniques and principles to bring about meaningful and positive change in behavior. ABA also applies these techniques to help reduce behaviors that may interfere with learning or behaviors that may harmful. ABA therapy is used to increase language and communication skills. It is also used to improve attention, focus, social skills, memory, and academics. ABA is recognized as a safe and effective treatment for autism.

http://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba

IEP Team

A group of persons, meeting participant requirements of federal special education law as provided at 34 CFR §§300.321 and 300.116(a)(1), who, together, discuss evaluation results, determine eligibility, develop or modify an IEP, or determine placement meeting.

http://www.doe.mass.edu/lawsregs/603cmr28.html?section=02#start

Assessment

Methods used to determine if a child has a disability and what typeof the special education and related services are needed.

Independent Evaluation

An evaluation conducted by a qualified examiner who is not employed by the public agency responsible for the education of the child in question.

http://www.wrightslaw.com/info/test.iee.steedman.htm

Outreach

An activity of delivering services and/or information to people who might not otherwise have access to those services. Frequently the services and/or information are provided in the locations where those in need live or work.

Additional Autism and Special Education Resources

Nancy Lurie Marks Family Foundation
http://www.nlmfoundation.org

Autism Speaks
http://www.autismspeaks.org

The Autism Society
http://www.autism-society.org

The Online Asperger Syndrome Information and Support (OASIS) center
http://www.aspergersyndrome.org

The Asperger's Association of New England
www.aane.org

National Autism Center
http://www.nationalautismcenter.org/index.php

Special Education
http://idea.ed.gov

Wrightslaw
www.wrightslaw.com

US DOE Office of Special Education Programs (OSEP)
http://www2.ed.gov/about/offices/list/osers/osep/index.html?src=mr

US DOE Office for Civil Rights (OCR)
http://www2.ed.gov/about/offices/list/ocr/index.html

Reference List

1. Allyn Gaestel. "Baby Doc's return to Haiti revives dark memories of Duvalier era". *Los Angeles Times.* 1/26/2011. Web. http://articles.latimes.com/2011/jan/26/world/la-fg-haiti-ghosts-20110126

2. The World Factbook. *Central Intelligence Agency*, Web. www.cia.gov/library/publications/the-world-factbook/geos/ha.html Haitians, Their History and Culture, Refuge Fact Sheet No. 10. Cultural Orientation Resource Center. Web. http://www.cal.org/co/haiti/hhist.html

3. The History of Haiti. *MedaliaArt, Caribbean and Latin American Art,* Web. http://www.medalia.net/hhistory.html St. Hill, Patricia; Lipson, Juliene; Meleis, Afaf Ibrahim. Caring for Women Cross Culturally, A. Davis Company, 2002, p. 171

4. Haitian Immigrants in the U.S. migration and identity *Education Resource Information Center*. Web. http://www.eric.ed.gov/PDFS/ED314952.pdf
Colin, J. M. Cultural and clinical care for Haitians. *U. S. Public Health Services. 2010*. Web http://www.state.nj.us/humanservices/dmhs/disaster/Haiti_cultural_and_clinical_care.pdf

5. Haiti Earthquake facts and figures. Disaster Emergency Committee. Web. http://www.dec.org.uk/haiti-earthquake-facts-and-figures

6. Uma Viswanathan. "Having Faith in Haiti". *The Washington Post.* 1/12/ 2011. Web. http://onfaith.washingtonpost.com/onfaith/guestvoices/2011/01/having_faith_in_haiti.html

7. Haitians, Their History and Culture, Refuge Fact Sheet No. 10. *Cultural Orientation Resource Center.* Web. http://www.cal.org/co/haiti/hhist.html

8. Haitians, Their History and Culture, Refuge Fact Sheet No. 10. *Cultural Orientation Resource Center.* Web. http://www.cal.org/co/haiti/hhist.html

9. Haitians, Their History and Culture, Refuge Fact Sheet No. 10. *Cultural Orientation Resource Center.* Web. http://www.cal.org/co/haiti/hhist.html

10. Erik Jacobson. "An Introduction to Haitian Culture for Rehabilitation Service Providers". *Center for International Rehabilitation Research Information and Exchange (CIRRIE)* 2003. Web. http://cirrie.buffalo.edu/culture/monographs/haiti.php
Colin, J. M. Cultural and clinical care for Haitians. *U. S. Public Health Services*. 2010. P. 39-40 Web. http://www.state.nj.us/humanservices/dmhs/disaster/Haiti_cultural_and_clinical_care.pdf

11. Erik Jacobson. "An Introduction to Haitian Culture for Rehabilitation Service Providers". *Center for International Rehabilitation Research Information and Exchange (CIRRIE)* 2003 Web. http://cirrie.buffalo.edu/culture/monographs/haiti.php

12. Haitians, Their History and Culture, Refuge Fact Sheet No. 10. *Cultural Orientation Resource Center.* Web. http://www.cal.org/co/haiti/hhist.htm
St. Hill, Patricia; Lipson, Juliene; Meleis, Afaf Ibrahim. Caring for Women Cross Culturally, A. Davis Company, 2002, p. 174

13. Colin, J. M. Cultural and clinical care for Haitians. *U.S. Public Health Services.* 2010. p. 12 Web. http://www.state.nj.us/humanservices/dmhs/disaster/Haiti_cultural_and_clinical_care.pdf

14. Colin, J. M. Cultural and clinical care for Haitians. *U.S. Public Health Services.* 2010. p. 5-6; p. 120. Web. http://www.state.nj.us/humanservices/dmhs/disaster/Haiti_cultural_and_clinical_care.pdf
St. Hill, Patricia; Lipson, Juliene; Meleis, Afaf Ibrahim. Caring for Women Cross Culturally, A. Davis Company, 2002, p. 182, 186, "Haiti - Sabine's story". Autism Around the Globe. 2010. Web. http://www.autismaroundtheglobe.org/countries/haiti.asp

15. Colin, J. M. Cultural and clinical care for Haitians. *U. S. Public Health Services.* 2010. p. 31 Web. http://www.state.nj.us/humanservices/dmhs/disaster/Haiti_cultural_and_clinical_care.pdf

16. Allyn Gaestel. "Baby Doc's return to Haiti revives dark memories of Duvalier era". *Los Angeles Times*. 1/26/ 2011. Web. http://articles.latimes.com/2011/jan/26/world/la-fg-haiti-ghosts-20110126

17. "Tip Sheet on Haitian Culture". *State University of New York Institute of Disaster Mental Health*. Web. www.in.gov/isdh/files/Hatian_Culture_tip_sheet-IDMH.pdf

18. Erik Jacobson. "An Introduction to Haitian Culture for Rehabilitation Service Providers". *Center for International Rehabilitation Research Information and Exchange (CIRRIE)*. 2003 Web. http://cirrie.buffalo.edu/culture/monographs/haiti.php
Colin, J. M. Cultural and clinical care for Haitians. *U. S. Public Health Services.* (2010). Web. http://www.state.nj.us/humanservices/dmhs/disaster/Haiti_cultural_and_clinical_care.pdf

19. Jennifer Browning. "Emory Medical Students Study Mental Health In Haiti's Central Plateau". *Project Medishare*, 2010, Web. http://www.projectmedishare.org/blog/2010/06/emory-medical-students-study-mental-health-in-haitis-central-plateau/
John H. Stone. Culture and Disability: Providing Culturally Competent Services., Sage Publications, 2005.

20. "Haiti. Country Reports on Human Rights Practices". *Bureau of Democracy, Human Rights, and Labor* March 4, 2002. Web. http://www.state.gov/j/drl/rls/hrrpt/2001/wha/8332.htm

21. Lisl Doscher Phelps, RN, BSN, MSN . "Cultural Competency and Haitian Immigrants". *Salisbury University, Department of Nursing, 2004.* Web. http://www.salisbury.edu/nursing/haitiancultcomp/references.htm

22. Cook Ross, Inc. "Background on Haiti & Haitian Health Culture". *A Cultural Competence Primer from Cook Ross Inc.* 2010. Web. www.cookross.com/docs/haiti.pdf

23. In Massachusetts this section is designated as the Service Delivery Grid.

24. The occupation of attending to the physical needs of people who are disabled or otherwise unable to take care of themselves, including tasks such as bathing, management of bodily functions, and cooking. Web. www.medical-dictionary.thefreedictionary.com

outreach training education advocacy

Autism Special Education Legal Support Center

Massachusetts Advocates for Children

MAC MASSACHUSETTS ADVOCATES *for* CHILDREN

United Way
United Way of Massachusetts Bay and Merrimack Valley

Massachusetts Legal Assistance Corporation