Introduction

The Hillsborough HIPPY Parent Involvement Program (HHPIP) - Center for Autism and Related Disabilities (CARD) collaboration was established to serve young children with Autism Spectrum Disorder (ASD) and their families who were enrolled in the HHPIP. The idea for the collaboration was initially formulated by the Executive Director of the Center for Autism and Related Disabilities at the University of South Florida (CARD-USF) who identified a gap that typically exists for children with ASD who are between ages three and five. The Executive Director explained this gap in an interview in these terms:

“...Early Steps is out there for kids that are zero to three. And then you go into either the VPK/Voluntary Prekindergarten system or kind of no man's land until you enter kindergarten...For children diagnosed with ASD that time frame between three and five is really, really important to put kids and their families on a learning and engagement trajectory to create an enriching environment with set curricular activities. And (HIPPY) had already done that piece of it...”

Identifying HIPPY as a potential avenue to help fill this gap, CARD-USF Executive Director, HIPPY State Office Director, and Hillsborough HIPPY Parent Involvement Program (HHPIP) Coordinator began meeting to brainstorm and discuss collaborating to serve children with ASD in HHPIP. After months of discussions a framework for collaboration between CARD-USF and HHPIP was developed with funding from the Children’s Board of Hillsborough County. HHPIP-CARD was formed with staff from both entities who worked together to serve children with ASD in HHPIP. Today, this collaboration has evolved into a strong, formalized structure and service system that is integrated into both programs service delivery systems. The collaborative itself is not independently supported, but rather exists as a focus within regular operations of each program.

This case study examined the collaboration between HHPIP and CARD-USF. The researchers attempted to answer several questions pertaining to the study objectives:

- Describe the collaboration between HHPIP and CARD-USF.
- Document the process that HHPIP uses to serve children with autism spectrum disorder (ASD).
- Summarize stakeholder perceptions regarding the effectiveness and impact of the HHPIP and CARD-USF collaboration on children with ASD and their families.
- Assess the effect of the program on children's outcomes and progress using available documents, including assessments, progress reports, and other historical data available through HHPIP and CARD-USF.
Methodology

A case study method was selected for this study because it allowed researchers the best opportunity to take an in-depth look at how the HHPIP-CARD collaboration has impacted families with a child with ASD.

Case Study Design, Recruitment, and Case Selection Process

Case study design

Case studies provide a way of carefully investigating systems and processes and allow the researcher to use different tools and methods to examine a particular phenomenon in its real-life context (Yin, 2014). The phenomenon being studied is the HHPIP-CARD collaboration and its impact on families with a child with ASD. The HHPIP-CARD collaboration case study used an embedded multiple-case design where each family selected was an individual case. This approach requires a replication, not a sampling, logic and the researcher must choose each case carefully. In other words, each family or case within this multiple case design will serve in a manner similar to multiple experiments (Yin, 2014).

Recruitment

After the decision was made to use the case study design to research this topic, IRB approval was sought and received. Upon approval, the research team began the recruitment and selection process. The recruitment strategy included distributing recruitment flyers (Appendix A) to the 21 families in HHPIP with children with ASD who were in the HHPIP-CARD database. Families who met study criteria indicated their interest in participating in the study and returned their flyers to the research team. Study participation criteria were as follows:

- A parent with a child that has been diagnosed with ASD.
- A parent with a child that has been enrolled in the HHPIP program for at least one fiscal year and has completed at least 15 weeks of the HIPPY curriculum (Year 1, Year 2, or Year 3).
- A parent with a child who was enrolled in HIPPY between July 1, 2013 to June 30, 2016.
- Parents’ willingness to participate in the study.

Case selection

A total of four families were identified through recruitment flyers. Researchers relied on HHPIP and CARD-USF staff expertise to help make the final selection of the three families for the case study. These staff had in-depth knowledge about the families. The case study design allows for selection of the cases that will provide the best information to meet the study objectives (Yin, 2014). Therefore, the selected families were the ones who were the most appropriate and who were actually willing and able to participate at the time the study was conducted. The final selection of the three families (cases) was based on ensuring that all families met the study criteria (listed above). Researchers also ensured that there was diversity in family types in terms of race, socioeconomic status, backgrounds, and that the three cases selected covered various levels on the autism spectrum.

The three families eventually selected had male children who had moderate and severe ASD diagnoses, which ensured that the study included families with children with diagnoses that varied in terms of severity. The families also differed in terms of their residential geographic location within Hillsborough County. There was diversity in terms of income, educational, and career/professional background.
While two of the children were still enrolled in HHPIP, one child had graduated from the program and was attending school. Two of the three children in the study were African-American and the third child was White. Although attempts were made to include a Hispanic family, unfortunately the selected family was not able to participate due to personal family challenges. Therefore, a limitation of the study was that none of the families were Hispanic and that all three children were males. However, as described in the Results section, the majority of children in the HHPIP-CARD collaboration are non-Hispanic and male.

**Data Collection**

A team of University of South Florida researchers worked in pairs to conduct case studies. The study included the following methods:

- A comprehensive document review of both programs (HHPIP and CARD-USF). This comprised reviewing information and records, both paper and electronic, of the three families (children) selected for the study. Documents included enrollment information, child assessments, and implementation materials such as records or notes that summarized child diagnosis and history, as well as referrals and other records pertaining to the child. All documents were reviewed by at least two researchers in order to triangulate the information obtained from the document review. (See comprehensive list of documents reviewed – Appendix B). Each researcher completed a HHPIP-CARD Case Study Document and Electronic Review (Appendix C).

- 60-90 minute in person, in-depth, semi-structured stakeholder interviews (Appendix D) with the following staff:
  - Executive Director of CARD-USF
  - HHPIP Coordinator
  - Two HHPIP Lead Autism Home Visitors
  - Two CARD-USF Consultants

- 60-90 minute in person, in-depth, semi-structured interviews (Appendix E) with the three parents of children with ASD selected for the study.
Results

This section is subdivided into three parts:

1. **The HHPIP-CARD collaboration**, which outlines several different components of the collaboration, including the structure, the collaboration process, and the service delivery. This section ends with a detailed case summary of each of the three children.

2. **Strengths and Opportunities**, which outlines main observations noted by researchers regarding implementation challenges and strengths of the HHPIP-CARD collaboration.

3. **Lessons Learned and Implications for the Future** provides a list of lessons learned from this study as well as brief recommendations for future studies and/or possible implications for future collaboration projects that focus on children with ASD.

The HHPIP-CARD Collaboration

**Stakeholders**

The Executive Director of CARD-USF, the HIPPY State Director, and the Coordinator for HHPIP initially worked together to determine how best to support families with children on the autism spectrum who are also enrolled in the HHPIP program. The HHPIP-CARD collaboration's current structure, major stakeholders, and main processes are depicted in Figure 1. Main stakeholders include the Executive Director of CARD-USF who oversees the CARD-USF Consultants. There are three CARD-USF Consultants working with the collaboration with HHPIP Home Visitors. The Florida HIPPY State Office Director for the HIPPY Training and Technical Assistance Center oversees the Coordinator for HHPIP. The Coordinator for HHPIP oversees the HHPIP Home Visitors. All HHPIP Home Visitors have the potential to work with children with autism and are considered part of the collaboration. There are 12 total HHPIP Home Visitors. Six of them work closely on the collaborative alongside the CARD-USF Consultants.

At the time of the study there were 21 families in the HHPIP-CARD collaboration. Of the children, 15 are White (71%), 4 are African-American (19%), and 2 are Asian (10%). There are 12 Non-Hispanic (57%) and 9 Hispanic (43%) children. There are 14 males (67%) and 7 females (33%).

**Collaborative Processes**

**Trainings**

CARD-USF staff hold trainings for HHPIP staff several times a year. These trainings include general strategies for working with families who have a child with autism, as well as more specific topics as needs arise. CARD-USF Consultants also attend the beginning of the year HHPIP trainings to better understand the HHPIP curriculum.

**Monthly meetings**

Once a month, the CARD-USF Consultants and HHPIP Home Visitors who have shared clients meet with the Executive Director and Coordinator. During these meetings HHPIP home visitors have the opportunity of sharing the family needs that are unrelated to the HIPPY curriculum that could be addressed through CARD-USF services. CARD-USF consultants can then contact the identified families to offer technical assistance and resources. Technical assistance typically is provided by offering parents strategies on how to better engage children with ASD while using the HIPPY curriculum. Examples of specific strategies include: Reinforcement strategies, hierarchy of support (ranging for highest level of support to the lowest levels of support), the first-then board and the
enhancement book. It also includes teaching in a more direct manner and making concepts in the HIPPY curriculum more concrete. For example parents are taught to use a physical item instead of just showing a picture of that item. Technical assistance is also provided by working with parents to identify which abilities might need to be developed before getting into the HIPPY curriculum tasks (e.g. developing bonding between parent and child to facilitate the child's responsiveness to a HIPPY activity that might require both extensive child and parent interaction or working on a child's ability to sit still for a period of time to enable them to be able to sit for the duration of a HIPPY activity.)

Joint home visits

A CARD-USF Consultant may also go on home visits with a HHPIP Home Visitor. This most typically happens during an initial HHPIP home visit when the Home Visitor is conducting assessments with the child and getting to know the family. The CARD-USF consultant can assist in conducting the assessments and provide strategies that are specific to the child's abilities and behavioral needs prior to starting the HHPIP curriculum. On some occasions, after monthly update meetings, it may be recommended that a joint home visit is necessary to help resolve a particular issue.
Development of the HIPPY curriculum supplement (enhancement/ASD add on)

As the collaboration progressed beyond the initial year, through the collaborative meetings and discussions, CARD-USF and HHPIP identified the need to develop an enhancement book to help families complete the HIPPY curriculum. The enhancement book was specifically designed to provide an alternative response system for children who have limited expressive communication skills.

Service Delivery

A variety of supports and services are provided to families through the HHPIP-CARD collaboration. These services, unlike the collaborative processes, are provided independently of each other with each entity providing its own set of unique services. These services are described by entity below.

Enrollment in the HHPIP-CARD collaboration

Enrollment in the collaboration can come through HHPIP or through CARD-USF. HHPIP and CARD-USF refer families to each other’s programs. For example, a family may hear about CARD-USF in the community or through its website. Once the family contacts CARD-USF for resources related to autism, CARD-USF may provide information about HHPIP as part of the resources parents can access. Alternatively, a family may be enrolled in the HHPIP program, and the HHPIP Home Visitor may know that a child either has an autism diagnosis or the family needs resources to determine if a child may have autism. Then, the HHPIP Home Visitor can provide the family who has a child with an autism diagnosis with contact information for CARD-USF. Other families who may not have had their child formally diagnosed with autism can be referred for case management services to assist in having the child evaluated and diagnosed.

After CARD-USF receives a diagnosis, the family qualifies to become a CARD-USF constituent. Ideally, the family will connect with CARD-USF and then will be officially put in the HHPIP-CARD collaboration. However, sometimes families may not be able to receive a diagnosis right away or do not want a diagnosis for their child for personal reasons. If this is the case, the family will not receive services from CARD-USF, but will still be able to participate in the HHPIP program.

CARD-USF services

Outside of the HHPIP-CARD collaboration, each program provides individual assistance to parents. A parent may contact CARD-USF for information about a variety of needs, including information about specific doctors or therapeutic centers that will take the child’s health insurance, safety information, and ways to assist the child with daily routines. CARD-USF also has resources, training and strategies that consultants use with families to help support and assist children with ASD. Assistance from CARD comes in the form of phone calls, emails, and home visits. CARD-USF only interacts with a family if a parent makes contact with their assigned CARD-USF Consultant. Therefore, families receive CARD-USF services on an as-needed basis and some families will have more interactions with CARD-USF than others.

HHPIP services

The HIPPY model comprises four major components: three year home-based curriculum; professional coordinator and staff of home visitors; role playing instructional technique; and home visits and group meetings. The HIPPY curriculum is a 30-week home based curriculum that uses the parents as the child’s first teacher. Targeted for children three to five years old, this educational curriculum is used nationally and internationally. Although it is targeted for children, the model primarily works directly with the parent and teaches them how to implement the HIPPY lessons each week so that they can deliver the curriculum to the child. Home Visitors carry out these instructions weekly through role play during each weekly home visit.
Home Visits
Home Visitors are responsible for delivery of the HIPPY curriculum and referring families for case management and other support services. HHPIP Home Visitors typically visit the home every week to deliver the HIPPY curriculum to parents. Therefore, by design, HHPIP Home Visitors have much more interaction with families than CARD-USF Consultants.

During the home visit, the HHPIP Home Visitor may observe family needs that should be addressed that fall outside the scope of HHPIP. Home visitors can then refer these families to a local agency—Gracepoint—for services. This agency’s mission is to educate and advocate for people who encounter behavioral health, substance abuse, and developmental challenges. Gracepoint can assist families with utilities, rent, furniture, relocation fees, and other family needs. In order to help families become self-sustaining, Gracepoint also helps families formulate goals along with strategies for meeting those goals.

Through the HHPIP contract with Gracepoint, many of the children with ASD are able to receive an official diagnosis through the assistance of Gracepoint, which helps families connect with the appropriate entities that can make such diagnoses. This is critical as USF-CARD requires that a child have a diagnosis before they can begin working with that child and family. Additionally, families can receive service assistance that falls outside CARD-USF or HHPIP’s service scope. For example, a Gracepoint case manager is able to pick up a parent and child and drive them to the child’s doctors’ appointments, which assists parents in getting a faster diagnosis for their child. Once children enter school, case managers are also able to attend Individual Education Plan (IEP) meetings with the child’s parent at the parent’s request. Thus, through the HHPIP-CARD collaborative, a broad range of a family’s service needs can be met.

Assessments & Surveys
Another key service provided through the home visitors are child assessments and program surveys. In order to determine the child’s developmental needs and to track the child’s progress in the program, HHPIP Home Visitors conduct four assessments:

1. The Ages and Stages Questionnaire, Third Edition ([ASQ-3], Squires, Twombly, Bricker, & Potter, 2009)
   The ASQ-3 is a series of questionnaires spanning from one month to five and a half years. There are 21 questionnaires total, covering specific age intervals, with intervals between questionnaires being closer the younger the child is. The ASQ-3 is typically completed by parents and focuses on age-specific communication, gross motor, fine motor, problem solving, and personal-social developmental expectations. Scoring on the questionnaire indicates if a child is developmentally on schedule (white), close to the cutoff for being on schedule and would benefit from additional learning activities and close monitoring of progress (gray), or below the cutoff and may be in need of further assessment with a professional (black). The ASQ-3 corresponding to the child’s chronological age is completed at the beginning of each HIPPY curriculum (Year 1, Year 2, and Year 3).

2. The Bracken School Readiness Assessment, Third Edition ([BSRA-3], Bracken, 2007)
   The BSRA-3 is a school readiness screener for children aged three to six years, eleven months that evaluates a child’s understanding and knowledge about foundational educational concepts relating to colors, letters, numbers/counting, size/comparison, and shapes. To assess these skills, the child looks at a set of pictures and is asked to point to stimulus items. The BSRA-3 is administered by the Home Visitor upon enrollment into a new HIPPY curriculum and at week 25 of the curriculum each year. The HIPPY state office summarizes all BSRA-3 assessments and rates whether the child is very advanced, advanced, average, delayed, or very delayed based on their age and the scores achieved on the test.
3. The Get Ready To Read!-Revised (GRTR!-R) screening tool (Whitehurst & Lonigan, 2009)
   The GRTR!-R is a 25 item early literacy skills screener for children aged three to five years that evaluates knowledge of letters and sounds, and books and print. To assess these skills, the Home Visitor guides children through a series of questions and hands-on activities. The raw score is used to determine if the child is below average, average, or above average based on their age. The GRTR!-R is administered upon enrollment into a new HIPPY curriculum and at week 25 of the curriculum each year.

4. The HIPPY Skills Test (HST) developed by HHPIP to assess three-, four, and five-year-olds’ learning
   The HST is a 10 item assessment designed to evaluate program effectiveness by assessing three-, four-, and five-year-olds’ progress and mastery of skills taught in the HIPPY curriculum. It was developed by the HHPIP Coordinator with assistance from HIPPY staff members from the Tampa, Pinellas, and Gainesville HIPPY programs. The HST assesses the child’s understanding of Prekindergarten readiness skills such as: parts of the body, working memory, spatial relationships, patterns, shapes, colors, numbers, and letters. To assess these skills, the Home Visitor guides children through a series of questions and hands-on activities. There are separate assessments based on the child’s age (three, four, or five). The HST is administered upon enrollment into a new HIPPY curriculum and at week 25 of the curriculum each year.
CASE STUDY 1: Malik

Socio-demographic background
Malik is an African-American, six-year, nine-month-old boy who lives with his family in Hillsborough County. Malik lives with his mom and dad, his maternal grandmother, his five-year-old sister, his one-year-old brother, his nine-year-old male cousin, and his four-year-old female cousin. The couple is not married. Malik’s mother is the primary caregiver and a stay at home mom who was responsible for delivering the HIPPY curriculum to Malik before he graduated from the program in September 2015. The family is eligible to receive Temporary Assistance for Needy Families (TANF). He is currently attending an elementary school outside his neighborhood so that he can be served in an ASD program.

Community and family/life connections
The house in which Malik’s family lives belongs to his maternal grandmother. Malik, his grandmother, mother, father, siblings, and cousins have lived there for two years. Malik’s mother describes the neighborhood as a Spanish-dominant neighborhood with a mix of younger and older families that is quiet and safe. The family is friendly with, but does not have a close relationship with their neighbors. There are no apparent ties and connections to the local churches or any community organizations. The mother states that she has a strong support system within her family, which includes her mother, aunt, sister, brother, cousins, and other extended family members.

Personality and characteristics
An in-depth interview and a recent assessment of Malik’s progress provided insight into Malik’s personality and strengths. Malik’s mother describes him as full of joy and life. Various aspects of Malik’s personality contribute to his strengths, including being very funny, having infectious laughter, being outgoing and friendly, and a love of trying new things. Malik is a hands-on/tactile learner, needing to touch everything to learn. Because he is outgoing, he is now able to grasp concepts quickly.

Diagnosis and functioning level
According to Malik’s mother, the family was referred to CARD-USF by HHPIP. Malik enrolled in the HHPIP program in 2012, when he was three years old. Malik’s mother first noticed that he had some challenges at this same time. He was nonverbal, made little eye contact, cried, and had tantrums. His mother had difficulty connecting with him and understanding his needs. Although she took Malik to a pediatrician, the doctor informed her that there were no concerns and he just needed more time to develop.

At the time, Malik’s mother stated that she struggled completing the HHPiP curriculum with him because it was difficult to get him engaged, and the activity packets at the time had fewer hands-on activities. Through the HHPIP Home Visitor, Malik’s mother was referred to Gracepoint (described in the Service Delivery section). This agency provided Malik’s mother with information about neurological specialists. According to document review, when Malik was five years old, he was assessed by a neurologist. Malik’s mother reported that neurologist had diagnosed Malik with ASD/Attention Deficit Hyperactivity Disorder (ADHD) and had determined that he was “high functioning.” The document review of doctor’s report suggested that Malik was more interested in inanimate objects than people, failed to identify pictures, lacked sustained eye contact, produced mild echolalia and unrelated language, and answered questions inappropriately.

Through the HHPIP Home Visitor, after Malik received the ASD diagnosis, his mother was paired up with CARD-USF. The mother’s first contact with CARD-USF was in April 2015, and she became a CARD-USF constituent in July 2015. Upon enrollment into CARD-USF, indications from CARD-USF documents were that Malik had behavior, social, and other problems. Specifically, at enrollment in CARD-USF, Malik had a difficult time focusing and listening at home, had difficulty learning sight words at school, and his mother was concerned about him leaving the home on his own without notifying a caregiver. These challenges were evaluated as being of moderate concern. At the time of the study, Malik’s mother reported that he still finds academics, including learning the alphabet and colors, reading, and writing difficult.

Service plan/network (HHPIP/CARD)
Malik has graduated from the HHPIP program. Although Malik’s younger sister is now enrolled in HHPIP, their mother is no longer doing HIPPY activities with Malik. His mother continues to receive CARD-USF services on an as needed basis. CARD-USF developed support services to assist Malik and his family with resources, tools,
and techniques to address the major areas of need and concern noted in the initial enrollment documents. Table 1 provides a brief summary of Malik’s CARD-USF services.

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<tr>
<th>Need/Challenge</th>
<th>Service Strategy</th>
<th>Agency</th>
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<tbody>
<tr>
<td>Difficulty focusing on tasks and listening at home</td>
<td>Provided visual schedule and First/Then board</td>
<td>CARD-USF</td>
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<tr>
<td>Cleaning up</td>
<td>Provided visuals to label drawers and put clothes away</td>
<td>CARD-USF</td>
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<tr>
<td>Leaving home on own without notifying caregiver</td>
<td>Provided safety kit and training on safety procedures</td>
<td>CARD-USF</td>
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<tr>
<td>Difficulty learning sight words at school</td>
<td>Sight word flash cards</td>
<td>CARD-USF</td>
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The mother’s assessment on Malik’s level of progress since joining HHPIP and the collaborative was noted as Excellent. Malik’s HHPIP Home Visitor and CARD-USF Consultant also rated his level of progress since joining HHPIP and the collaborative as Excellent.

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<tr>
<th>Stakeholder’s Assessment on Malik’s Progress</th>
<th>1 Very Poor</th>
<th>2 Poor</th>
<th>3 No Change</th>
<th>4 Very Good</th>
<th>5 Excellent</th>
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<td>Parent</td>
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<td>HHPIP Home Visitor</td>
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<td>CARD-USF Consultant</td>
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Malik’s Results

All of Malik’s HHPIP assessments were examined during the document review and covered two fiscal years: Fiscal Year 1 (2013-2014) and Fiscal Year 2 (2014-2015). These assessments were conducted while Malik was enrolled in HIPPY Curriculum Years 1 and 2.

Get Ready To Read!-Revised Assessment

Malik demonstrated progress on the GRTR!-R assessments in both years moving from 0 to 7 in Year 1 and from 7 to 8 in Year 2.

Bracken School Readiness Assessment

On the BSRA-3, Malik showed improvement in color identification, letter identification, size/comparisons and shapes; he did not improve in numbers/counting.

Ages and Stages Questionnaire

For the ASQ-3, Malik made 5 point gains in the communication and gross motor domains, and a 30 point gain in the social personal domain; he did not make gains in the fine motor or problem solving domains.

HIPPY Skills Test

Progress was made on the HST in Year 1 going from 0 to 2, but no progress was made in Year 2, when he scored zero on both the pre- and post-assessments.
Summary of Malik’s case

Malik’s mother’s rated his overall progress since being involved with the collaboration as excellent. This rating is consistent with the assessments of the CARD Consultant and the HHPIP Home Visitor.

Initial issues relating to him being unfocused, maintaining eye contact, and relating to others had significantly improved over time. She reported that his social interaction has improved and that he is playing more with his siblings and cousins at home. This improvement was confirmed by Malik’s social personal score improvement on the ASQ-3, which showed a 30 improvement in the ASQ-3 from Year 1 to Year 2. This type of improvement is significant considering that in the neurologist’s initial assessment Malik was described as “roaming around engaged in conversation by himself,” having “insufficient eye contact” and showing “interest in inanimate things.”

Overall his mother appears to be pleased with the resources that are being provided, rating all of them as “extremely helpful.”

Malik’s mother ranked the helpfulness of Malik’s support services

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<td>HHPIP</td>
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<td>CARD-USF</td>
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<td>Malik’s Elementary School</td>
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<td>Extended Family</td>
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Socio-demographic background
Jack is a Caucasian, four year, ten-month-old boy who lives with his family in Hillsborough County. Jack lives with his mom and dad, who are married, and a younger sister who is one year old. Jack's mother is the primary caregiver and a stay at home mom who is responsible for delivering the HIPPY curriculum to Jack. His mother stopped working as an ICU nurse in order to attend to Jack and keep up with his schedule and therapy appointments. The family is not eligible to receive TANF. His mother is currently home schooling him.

Community and family life/connections
The family has lived in their current neighborhood for about 11 years. They live in a quiet neighborhood, which the mother describes as “…a good little neighborhood.” It is relatively safe and the family takes walks in their neighborhood. Jack's mother reported that although she knows some of her neighbors, the family keeps mostly to themselves. There are no apparent ties and connections to the local churches or any community organizations.

Personality and characteristics
An in-depth interview and an up-to-date assessment of Jack's progress provided insight into Jack's personality and strengths. Jack's mother describes him as “…a very sweet, a very bright boy. He's extremely reserved with other children still, but he will interact here and there. He's trying to learn how to socialize. He's still very delayed with that particular aspect, but at least he's interested now in trying to learn.” Among noted strengths is Jack's love of reading and talking to people he knows well. He enjoys swimming and playing with fire trucks. Jack is described by his mother as being “academically gifted” with some things coming really easy for him and him performing at a very high level. She describes Jack as follows: “Academically he's actually quite gifted. He is reading about two years above his level. He's learning some basic fractions, addition, subtraction.”

Diagnosis and functioning level
According to document review, the family was referred to CARD-USF by HHPIP. Jack enrolled in the HHPIP program in February 2015, when he was three years old. According to the in-depth interview with Jack's mother, she first noticed that he had some challenges when he was about nine or ten months old. He would scream as if in pain when his diaper was changed, he would not sleep unless pressure was consistently put on his head, and would regurgitate what he ate after he transitioned from breast milk to baby food. By 12 months old, Jack lost the ability to say all of the words he knew, except for ‘mamma,’ and he did not start walking until about 15 months old. Although Jack's mother took him to a pediatrician, the doctor did not indicate that Jack showed any characteristics of autism. However, according to his mother, Jack started feeding therapy at about 11 months old to help desensitize his gag reflex. When he was almost finished with feeding therapy at about 16 months old, the feeding therapist suggested that Jack might be on the autism spectrum. After being evaluated by a medical doctor at All Children's Hospital in Tampa in 2014 when Jack was approximately two years, seven months he was diagnosed with ASD, moderate to severe, at a severity level 3. Initial diagnosis recorded in reviewed agency documents suggested that social and communication skills were significantly lacking and that Jack's restricted, repetitive behaviors and cognitive delays would require substantial supports to address these challenges and limitations.

Prior to joining CARD-USF, Jack had been assessed in 2013 by Early Steps, a state early intervention organization that provides services to families with children from birth to 36 months who have significant developmental delays. Services include screening for developmental delays, developing an Individual Family Service Plan (IFSP) to meet family and child outcomes and goals, and connecting families to therapeutic services. The organization found that Jack had communication and language disorders, including mild to moderate receptive language disorder. Speech therapy had been recommended and was already being received.

According to Jack's mother, although she was aware of CARD-USF prior to enrolling in HHPIP in February 2015, she was not formally connected with a CARD-USF Consultant until after the Home Visitor referred her for services. The mother enrolled in CARD-USF in May 2015. Upon enrollment into CARD-USF, indications were that Jack had behavior, social, and other problems. Specifically at enrollment in CARD-USF, Jack was reportedly scaring animals, needed dental hygiene specifically relating to him not wanting to brush his teeth, and was also very afraid of getting his hair cut. There were also concerns around him running away. These challenges were evaluated as being of moderate concern.
At the time of the study, Jack’s mother reported that he still struggles with his fine motor skills and finds things like cutting and even putting on his clothes quite challenging. Jack’s mother reported that he has difficulty using a spoon, holding a pencil, and bathing. She reported that Jack continues to have difficulties knowing “what to do with other children.”

**Service plan/network (HHPIP/CARD)**

Jack receives services from both the HHPIP and CARD-USF programs. His mother receives CARD-USF services on an as needed basis. CARD-USF developed support services to assist Jack and his family with resources, tools, and techniques to address the major areas of need and concern noted in the initial enrollment documents. Table 2 provides a brief summary of CARD-USF services.

**Table 2: Jack: CARD-USF Services**

<table>
<thead>
<tr>
<th>Need/Challenge</th>
<th>Service Strategy</th>
<th>Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scaring animals</td>
<td>Social story about animals</td>
<td>CARD-USF</td>
</tr>
<tr>
<td>Dental Hygiene</td>
<td>Provide a list of dental providers</td>
<td>CARD-USF</td>
</tr>
<tr>
<td>Fear of hair cut</td>
<td>Social story about getting a hair cut</td>
<td>CARD-USF</td>
</tr>
</tbody>
</table>

With regard to HHPIP, Jack is in HIPPY Year 2, and receives the HIPPY curriculum. He completed Year 1 of the curriculum. Information from interviewing Jack’s mother and document reviews provided information about the HHPIP service plan. Many of the academic activities, such as letter and number recognition, are far below Jack’s academic knowledge. However, his mother stated that he struggles with many of the fine motor activities. According to her, this balance of easy and difficult works really well for Jack.

Document review provided “weekly check in” forms that showed which strategies caregivers are using with their children to help them learn and function. According to documents provided through CARD-USF, weekly check in provided from HHPIP staff showed that many of these strategies were being used to assist Jack with the HIPPY curriculum: Hand over Hand, First/Then Board, Timer, Rewards, and Social Experience. The Home Visitor role plays with Jack’s mother weekly and is a source of much needed emotional support. Weekly check in forms also indicated that Jack struggled with HIPPY activities for the following reasons: the activity was too easy for him, he could not focus, he had difficulty understanding concepts that were not concrete, he had sensory issues pertaining to the activity (e.g., certain textures and loud sounds), he had fine motor difficulties, he had a particular expectation about how an activity should be completed or objects should be manipulated and had difficulty when his expectations were not met, and he was not interested in an activity or he was bored.

**Other networks and supports**

In order for Jack to continue receiving therapy services throughout the day, Jack’s mother stated that she home schools him and does so with aid from a state education scholarship. According to the CARD-USF Consultant, she was able to provide Jack’s mom with potential curricula Jack’s mother can use in addition to HIPPY to continue to support Jack’s learning in the home.

In addition to HHPIP and CARD-USF services, Jack receives speech, occupational, and physical therapies through private insurance. Jack is part of the ELKS Program, which provides licensed in-home physical and occupational therapy to children for free through funding from a fraternal order and public donations. Jack receives additional occupational therapy through the ELKS Program. Jack and his mother also attend programs at Layla’s House, which provides programs, resources, and activities that promote child development and support for families of young children. Within this program, he and his mother attend a Preschool Readiness Program twice a week for two hours. Additionally, Jack receives swimming sessions to help with sensory issues.

**Impact of HHPIP and CARD-USF services**

When asked about the impact of services on Jack’s performance and progress, his mother revealed the following:

1. CARD-USF provides ideas on how to help Jack function on a daily basis with the ASD diagnosis. Social experience stories helped reduce anxiety with getting haircuts and reduced his aggressive behavior towards dogs.

2. HHPIP is a consistent, weekly support for Jack’s mother. His mother described the CARD-USF Consultant as a backup support; someone she can call on when she has nowhere else to turn to and talk about specific autism-related issues and resources.
The mother’s assessment on Jack’s level of progress since joining HHPIP and the collaborative was noted as EXCELLENT. Jack’s HHPIP Home Visitor and CARD-USF Consultant also rated his level of progress since joining HHPIP and the collaborative as EXCELLENT.

<table>
<thead>
<tr>
<th>Stakeholder’s Assessment on Jack’s Progress</th>
<th>1 Very Poor</th>
<th>2 Poor</th>
<th>3 No Change</th>
<th>4 Very Good</th>
<th>5 Excellent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
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<tr>
<td>HHPIP Home Visitor</td>
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<td></td>
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<td></td>
<td>✓</td>
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<tr>
<td>CARD-USF Consultant</td>
<td></td>
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<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

Jack’s Results

All of Jack’s HHPIP assessments were examined during the document review and covered two fiscal years, Fiscal Year 2 (2014-2015) and Fiscal Year 3 (2015-2016) when Jack was enrolled in HIPPY Curriculum Year 2.

**HIPPY Skills Test**

Jack completed the HST pre- and post-assessments in fiscal year 2. Jack demonstrated progress on the HST assessment improving from 4 at pre, to 7 at post.

**Bracken School Readiness Assessment**

Jack completed the BSRA-3 pre- and post-assessments in fiscal year 2. On the BSRA-3, Jack showed improvement in numbers and shapes. He obtained the highest score possible for colors (10) and letters (15) at pre-assessment and maintained these scores for the post-assessment. His raw scores on size/comparisons decreased.

**Ages and Stages Questionnaire**

Jack’s mother completed the ASQ-3 42 Month Questionnaire in fiscal year 2 and the ASQ-3 54 Month Questionnaire in fiscal year 3. For the ASQ-3, Jack made gains in all five categories, with a 15-point increase in his fine motor skills and 10-point gains in communication, gross motor, and social personal skills. A 5-point gain was seen in the area of problem solving.
Summary of Jack’s case

Jack’s mother rated his overall progress since being involved with the collaboration as excellent. This rating is consistent with the assessments of the CARD-USF Consultant and the HHPIP Home Visitor.

Among Jack’s initial issues was difficulty with his fine motor skills. His ASQ-3 scores show that he made the most gain in this area, receiving a 15-point gain in fine motor skills. However, his mother still identifies this as one of Jack’s main issues, reporting that he still finds it difficult to hold a spoon, pencil, or to wash his hands and body. His mother also readily acknowledges that she has seen improvements overall in his communication and social personal skills. These improvements are reflected in ASQ-3 10-point gains from Fiscal Year 2 to Fiscal Year 3 assessments. Making strides in this area is of significance as behavior and social problems were among the issues noted upon enrollment into CARD-USF. Jack’s mother recognizes there is still room for improvement, but the progress made thus far is encouraging.

She is satisfied with the resources that are being provided rating 4 of 7 services (CARD-USF, Layla House, ELKS, and private speech therapy) as being extremely helpful, and HHPIP and private occupational therapy as being very helpful. She was neutral about her private physical therapy services.
Case Study 3: Damarcus

Socio-demographic background
Damarcus is an African-American, six-year, seven-month-old boy who lives with his family in Hillsborough County. Damarcus lives with his mom and dad, who are married, a 13-year-old older brother, and a four-year-old younger sister. Damarcus’s mother is the primary caregiver and a stay at home mom who is responsible for delivering the HIPPY curriculum to Damarcus. The family is eligible to receive TANF. Damarcus is currently in a classroom for children with disabilities.

Community and family life/connections
The family has lived in their current neighborhood for about 10 years. They live in a neighborhood that is very diverse, comprised of working class families, home owners and renters, and a mix of young families, older couples, and immigrant and non-immigrant families. Damarcus’s mother describes her community as being quiet. There is a large immigrant population in the neighborhood and, although it may look unsafe from an outsider’s perspective, the mother feels it is a very safe neighborhood. She also reported that she does not have any close relationships with her neighbors. There are no apparent ties and connections to the local churches or any community organizations.

Personality and characteristics
An in-depth interview and an up-to-date assessment of Damarcus’s progress provided insight into Damarcus’s personality and strengths. Damarcus’s mother describes him as a happy child, who is loving and gives hugs and kisses to his mom. She describes him as being “sweet most of the time.” He is an independent child who likes to be by himself. Among noted strengths is Damarcus’s love for puzzles, running, and playing soccer with his dad. His mother also noted an ability to find defects or faults in day-to-day objects and take them apart. His mother described this trait as follows: “He’s pretty good at finding the weakness in any piece of technology, any kind of construction he could find. I mean he’ll find the weakness in the wall. You will think there isn’t any weakness, but he will find it. He will take remote controls apart [and even] your TV if he could get to it. Like everything. People would say he’s destructive, but I would say that he will be an engineer or a quality control inspector when he grows up. Because when you think things are built really well, he’ll find a weakness in it in a minute or two.”

Diagnosis and functioning level
According to Damarcus’s mother and CARD-USF document review, the family involvement with CARD-USF started as a self-referral when the mother contacted CARD-USF herself when looking for resources for her son. CARD-USF then referred Damarcus’s mother to HHPIP and she enrolled in HHPIP in 2013, when he was four years old. Damarcus’s mother first noticed that he had some challenges when he was around 15 months old because she felt he was sleeping too much and he was no longer able to express any of the words he knew after the family went on vacation out of the country. At the time, Damarcus’s pediatrician recommended that his mother enroll him in speech therapy services. This led her to Early Steps. Damarcus’s mother stated, and the documents reviewed confirmed, that Early Steps assessed him and found that he had communication and language disorders, including mild to moderate receptive language disorder. Speech therapy was then provided through Early Steps and his mother also chose to pay for speech therapy out of pocket through another provider. When Damarcus was approximately two years old, an Early Steps case manager suggested that his mother have him evaluated for autism within six months.

An official diagnosis was made by Early Steps when Damarcus was three years old, and according to the Autism Diagnostic Observation Schedule (ADOS) he fell in the moderate category. Initial diagnosis suggested Damarcus had no words or gestures and would make only occasional eye contact. Records from a qualified service provider who conducted Damarcus’s assessment stated that he displayed stereotypical and restricted behavior, including flapping hands and jumping around the room. Damarcus’s mother confirmed many of these behaviors during an in-depth interview. Once Damarcus received the autism diagnosis, his mother stated that he was linked to Child Find, an organization that works with local school districts to identify children who are eligible for services under the Individuals with Disabilities Education Act (IDEA). After being assessed by Child Find, Damarcus qualified for early admittance to school and received an IEP and placement in an autism ESE classroom full time.

Damarcus’s mother’s first contact with CARD-USF was in December 2012, and she became a CARD-USF constituent in October 2013. Upon enrollment into
CARD-USF, indications were that Damarcus had behavior, social, and other problems. Specifically, at enrollment in CARD-USF, Damarcus reportedly was aggressive towards people, and would hit his sister, family members, and other people. Additionally, Damarcus was non-verbal. All issues related to his aggressive behavior identified at intake were reported as demanding a high level of urgency. Communication urgency was noted as being moderate as Damarcus was already receiving some speech therapy when he was enrolled in CARD-USF.

At the time of the study, Damarcus’s mother reported that he still has a hard time holding pens and completing other activities that require him to use fine motor skills. He cannot dress himself and he has sensory issues, including feeling pain while wearing clothes. Additionally, he is still non-verbal, but is able to take his mother to what he wants and communicate with approximations of some basic sign language. She reported that his physical aggression has decreased and that over time she has been able to relate Damarcus’s outbursts and aggressive behaviors of biting, scratching, kicking, or slapping correlating to when he is tired, sleepy, thirsty, or feeling unwell.

**Service plan/network (HHPIP/CARD)**

Damarcus receives services from both the HHPIP and CARD-USF programs. His mother receives CARD-USF services on an as needed basis. In response to his needs, CARD-USF developed support services to assist Damarcus and his family with resources, tools, and techniques to address the major areas of need and concern noted in the initial enrollment documents. Table 3 provides a brief summary of CARD-USF services.

<table>
<thead>
<tr>
<th>Need/Challenge</th>
<th>Service Strategy</th>
<th>Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hitting, biting and being aggressive</td>
<td>Provide general behavior strategies including redirecting, hands down strategy</td>
<td>CARD-USF</td>
</tr>
<tr>
<td>toward others</td>
<td>paired with redirecting, posting rules using pictures</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Refer to HHPIP</td>
<td></td>
</tr>
<tr>
<td>Non-verbal – no verbal</td>
<td>Speech therapy in school</td>
<td>School</td>
</tr>
<tr>
<td>communication skills</td>
<td></td>
<td></td>
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</tbody>
</table>

With regard to HHPIP, Damarcus is in HIPPY Year 3, and receives the HIPPY curriculum. He completed both Year 1 and Year 2 of the curriculum. Information from interviewing Damarcus’s mother and documents reviewed provided information about the HHPIP service plan. Even though he was four when he first enrolled in HHPIP, because of Damarcus’s developmental level, his mother was given the choice to start in him the HIPPY curriculum Year 1 (three-year-old) or Year 2 (four-year-old) program and, after reviewing both curricula, she chose to begin him in the HIPPY Year 1 curriculum. The HIPPY curriculum at first and at times is not as helpful because Damarcus’s mom sometimes feels that he “is not getting it.” With additional support of the Home Visitor, the mother has stuck through, in part because the Home Visitor is very professional, reliable, and finds answers to questions the mother has. Additionally, the weekly presence of the Home Visitor provides a break for the mother who is sometimes bombarded by Damarcus’s younger sibling, who is very demanding of the mother’s attention. CARD-USF has been able to add an additional layer of support, providing resources such as information about behavioral health support.

Document review provided “weekly check in” forms that showed which strategies caregivers are using with their children to help them learn and function. According to documents provided through CARD-USF, weekly check in provided from HHPIP staff showed that many of these strategies were being used to assist Damarcus with the HIPPY Curriculum: Hand over Hand, Rewards, and First/Then Board. Weekly check in forms also indicated that Damarcus struggled with HIPPY activities for the following reasons: he could not focus, activities had too many instructions or details, activities were too difficult for his level (cognitively and motor skills), activities required him to follow steps, which he could not do, he wasn’t interested in the book/activity, and he had challenges with sensory activities.

Damarcus’s mother stated that the picture schedule has not been very helpful for them. She confirmed that the HIPPY activities in particular help her with structure and consistency, which she admits is lacking in the household and which Damarcus really needs: “The activities are way above Damarcus’s level, I’ll admit, but sometimes it gives like a structure. You know that, ‘OK Damarcus, let’s spend 10 minutes or 20 minutes together doing something.’ So I guess it just gives us something to do together.”

**Other networks and supports**

In addition to HHPIP and CARD-USF services, Damarcus receives speech therapy at school and additional speech therapy through private insurance. He also receives private occupational therapy and just finished behavioral
therapy after three years. Additionally, through HHPIP, the mother was also able to receive case management services from Gracepoint via referral from HHPIP. His mother stated that a case manager came to their house on several occasions and was very helpful in finding resources and services that matched Damarcus’s insurance.

Impact of HHPIP and CARD-USF services

When asked about the impact of services on Damarcus’s performance and progress, his mother revealed:

1. CARD-USF helps with specific behavior strategies and tools (e.g., Hand over Hand, First/Then, etc.). CARD-USF is there when the mother is overwhelmed and has nowhere else to turn.
2. HHPIP has helped the mother be more structured and accountable for sitting down and completing practical activities with Damarcus every week.
3. Since HHPIP began incorporating CARD-USF staff and suggestions into monthly group meetings, Damarcus’s mother now feels like she has a place she can take the whole family to and enjoy activities together. She described the notable change in group meetings as follows:

“The activities [at HHPIP group meetings] are even better now [since the collaboration began]. Damarcus could actually participate in some of them—not all of them—but there are things that he could do… Whenever I go somewhere I always think, ‘How is Damarcus going to respond to the environment? How is he going to adjust to it?’ The meetings actually really helped as a family because there aren’t that many places where we could go as a family together with Damarcus that won’t annoy normal people. Because Damarcus gets loud sometimes. He gets overwhelmed and he’ll start screaming and not too many people could handle that.”

The mother’s assessment on Damarcus’s level of progress since joining HHPIP and the collaborative was noted as GOOD. Damarcus’s HHPIP Home Visitor and CARD-USF Consultant rated his level of progress since joining HHPIP and the collaborative as VERY GOOD. The mother acknowledges that Damarcus has made progress and that overall Damarcus is better able to follow instructions and is able to sit and attend to activities a little bit longer than he was able to a year ago. However, she also acknowledges that trying to adapt the HHPIP curriculum has been challenging and that a ranking of Good best reflects the progress that has been made to date.

<table>
<thead>
<tr>
<th>Stakeholder’s Assessment on Damarcus’s Progress</th>
<th>1 Very Poor</th>
<th>2 Poor</th>
<th>3 No Change</th>
<th>3.5 Good</th>
<th>4 Very Good</th>
<th>5 Excellent</th>
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<tbody>
<tr>
<td>Parent</td>
<td></td>
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<tr>
<td>HHPIP Home Visitor</td>
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Damarcus’s Results

All of Damarcus HHPIP assessments were examined during the document review and covered three fiscal years, Fiscal Year 1 (2013-2014), Fiscal Year 2 (2014-2015), and Fiscal Year 3 (2015-2016) when Damarcus was in HIPPY curriculum Year 1, Year 2, and Year 3.

Get Ready To Read!-Revised Assessment

According to the documents reviewed, Damarcus was not given the GRTR!-R pre- and post-assessments at Year 1; he was given the GRTR!-R pre- and post-assessments for Fiscal Year 2, and a pre-assessment for Fiscal Year 3. On the GRTR!-R, he showed some improvement at Year 2 and continued improvement on the Year 3 pre-assessment.

HIPPY Skills Test

He completed the HST pre- and post-assessments in Fiscal Year 1 and Fiscal Year 2; and HST pre-assessment in Fiscal Year 3. For the HST, at Year 1, Damarcus showed some improvement. However, he did not show improvement on the HST at Year 2 or on the Year 3 pre-assessment.
**Bracken School Readiness Assessment**

Damarcus completed the BSRA-3 pre- and post-assessments at Fiscal Year 2; and BSRA-3 pre-assessment in Fiscal Year 3.

On the BSRA-3, Damarcus showed no progress in all skills at Year 2; the Year 3 pre-assessment indicated that Damarcus was beginning to learn colors, letters, and shapes.

**Ages and Stages Questionnaire**

According to the HHPIP Home Visitor, because Damarcus was functioning below his developmental level, his mother completed the ASQ-3 36 Month Questionnaire in Fiscal Year 1, when he was 48 months old; the 48 Month Questionnaire in Fiscal Year 2 when he was 60 months old. He was not given ASQ-3 to complete in Fiscal Year 3 because he was older than the assessment cut-off of 62 months.

For the ASQ-3, he did not show improvement in any domain.

**Summary of Damarcus’s case**

Damarcus's mother rated his overall progress since being involved in the collaboration as good. This rating is a little lower than the assessment of the CARD-USF Consultant and the HHPIP Home Visitor who rated his progress as excellent.

Based on his assessments, some progress is definitely being realized throughout his involvement with HHPIP-CARD collaboration. He has seen improvement in his GRTR!-R scores in Fiscal Year 2 and 3 and BSRA-3 scores in Fiscal Year 3. Damarcus's ASQ-3 assessment scores actually decreased, while his HST assessment scores improved in Fiscal Year 1 from pre to post, he showed no improvements in Fiscal Year 2 and 3 when he scored zeros in all three tests.

While some assessments showed little or no improvement, his mother’s observations suggest that Damarcus is making some gains especially in his behavior. Damarcus’s mother rated Damarcus’s support services from neutral to extremely helpful, with private behavior therapy being extremely helpful, private occupational therapy very helpful, and HHPIP helpful. CARD-USF, elementary school speech therapy, and private speech therapy were all rated as neutral.

**Damarcus’s mother ranked the helpfulness of Damarcus’s support services**

<table>
<thead>
<tr>
<th>Damarcus’s Resources &amp; Supports</th>
<th>1 No Help</th>
<th>2 Little Help</th>
<th>3 Neutral</th>
<th>3.5 Good</th>
<th>4 Very Helpful</th>
<th>5 Extremely Helpful</th>
</tr>
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<tbody>
<tr>
<td>HHPIP</td>
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Strengths and Opportunities

Strengths

» The collaboration has a positive impact on families. HHPIP provides structure, consistency, and the discipline that allows parents to work on educational and learning activities with their children. The HIPPPY curriculum’s structure and hands on nature of the curriculum activities allows parents a vehicle to interact, educate, and communicate with their children more effectively. The weekly assignments and activities provide much needed structure and a routine that appears to work well for children with ASD. CARD-USF has the expertise to provide autism-related resources, materials, and strategies to teach families how to work one on one with their children. The collaboration helps prepare children with ASD for kindergarten and through CARD-USF families continuing to receiving supports after their children complete HHPIP and enter into the school system.

» The HHPIP-CARD collaboration is clearly defined in terms of its structure, roles and responsibilities. Under the leadership of CARD-USF and the HIPPPY State office Training and Technical Assistance Center, staff roles and responsibilities are well defined. The HHPIP-CARD collaboration has clear roles, responsibilities, and expectations of its staff. All major responsibilities and assignments of key staff are clearly delineated (pgs. 13-14).

» Both entities have strong leadership and expertise, which allows for more effective service delivery. Each entity has an expertise: HHPIP has the HIPPPY curriculum, and CARD-USF has autism expertise. Leadership and guidance is provided through the CARD-USF Executive Director and HIPPPY State Director. The HHPIP Coordinator provides direction and leadership for the Home Visitors, and the CARD-USF Executive Director provides supervision for the CARD-USF Consultants, with one lead Consultant providing support on a daily basis to other consultants involved in the collaborative.

» Monthly meetings provide an avenue for staff from both entities to work together by providing updates on child progress and giving input on how to better support and serve families. These meetings serve as a major way to ensure constant dialogue and communication between HHPIP Home Visitors and CARD-USF Consultants. This helps ensure that collaborative partners are fully informed about families in the program.

» The collaboration of the two entities provides a wider and more integrated array of services for families which would not have been available if the family was being served by these entities independently. HHPIP provides the educational curriculum for families and is able to refer families for case management services to have a wider array of needs met. CARD-USF provides autism-specific support services for families. Collectively families receive a richer range of supports.

» The collaboration is mutually beneficial to both entities. The following are among some specific advantages of this partnership:
  • CARD-USF provides specific tools and strategies for families with a child with ASD that HHPIP could not have been able to provide.
  • HHPIP staff connects CARD-USF more directly to families who may not otherwise reach out to them for help. This allows CARD-USF to provide more help and assistance to families than it is able to reach because of HHPIP.
  • Staff from both entities receive professional development, learning, and growth as a result of the collaboration.
Opportunities for Growth

» One parent would like to see a more direct link from the CARD-USF website that shows them exactly what to do as a first time visitor to the site. This appears to be an easy solution and would require just connecting the getting started section with the CARD-USF contact information.

» Like most service entities, CARD centers have legislative statutes that guide implementation of its services to the community. It provides information, resources, and referrals to anyone calling for assistance. However, it cannot provide in person consultation until the client provides a signed release of information in order to obtain an evaluation report from a licensed medical or clinical professional with a diagnosis of ASD or related disability. Sometimes this can take months because a parent does not return paperwork in a timely manner or they might encounter long waiting lists in getting a medical evaluation and diagnosis. Consequently, families can be left in a position where they are waiting to receive in person CARD consultation services as they wait for a diagnosis for their child and this can be frustrating to both families as well as collaboration staff. The issue is discussed by one HHPIP-CARD staff:

“It’s just about challenges in processes that we have to kind of figure out, but once we get a referral from CARD and the referral comes from CARD, our staff is assuming that CARD has a diagnosis, but they do not [in every case]. So then CARD is waiting for us to enroll the family and get the diagnosis from the parent, which delays their being served by CARD… They need to get a diagnosis [but] it takes longer for us to get them…”

It may be helpful for the collaboration to revisit the intake and referral processes to further clarify the limits and options available for families before an official ASD diagnosis and consider any additional ways that the collaborative might appropriately support families who fall in this category.

» Progress is being made in identifying assessments for determining child progress with the use of BSRA-3, GRTR!-R, and other assessments. The collaborative should continue working on identifying clear benchmarks and outcomes to be collected and tracked over time.

» The strategies that facilitate the use of the curriculum by children with ASD need to be simplified further. More adaptations need to be included to make abstract concepts more concrete for children with ASD. Though current strategies are helpful, at least one parent suggested that even these strategies needed to be broken down into simpler steps to accommodate her child’s challenges.

Damarcus’s mother described the process she uses to break down HIPPY instructions:

“Going through [the HIPPY curriculum] and reading all those words to Damarcus, that’s a waste of time. So I had to [adapt it], otherwise it wouldn't have been effective in any way. Because with Damarcus the language has to be simple and direct. The fewer words you use, the better. But if I open the HIPPY [packet] and read what I'm supposed to read to Damarcus, I'll lose him. Because I lose him. I mean, I do it through my own words doing my own stuff, and I still lose him and have to go get him back. Sometimes we take a few days to get one activity done. So I improvise. I work with it. Yes, I keep the basic theme of it. You know, the basic ideas. But I do not present it in the way that you're supposed to read from it. I can't do that with Damarcus, it's not going to work…Sometimes it's not the activity itself, but in just the instructions you use. So if we have a jumping activity, I mean I can't say to Damarcus, ‘Well Damarcus, we're going to walk over there and start jumping.’ I have to say, ‘Damarcus,’ take him, and then say, ‘Let's jump.'”
The collaboration should continue working on strategies to prevent families from dropping out of the collaboration. Both HHPIP and CARD-USF staff indicated that there was at least a 50% drop out rate when the collaboration first began. Through the collaboration, both entities explored reasons why families may drop from the collaboration and ways in which they can keep families from dropping. Both entities identified parents’ feelings of being stressed and overwhelmed as one of the main factors causing drop out. It was suggested that family circumstances should be considered to make sure it is the right time for the family to enroll in the collaboration. As both entities become more confident in the collaboration, they are also better able to explain each of the programs to families and how families could benefit from both programs. Once families are enrolled in the collaboration, one HHPIP Home Visitor suggested that requesting the CARD-USF consultant check in with the family can provide the encouragement and support families need to continue with the collaboration. The HHPIP Home Visitor also plays an important role in building rapport and making connections with the family in order to encourage families to persist and continue in the collaboration even when they are feeling overwhelmed or stressful situations arise.

The Executive Director of CARD-USF summarized the situation as follows:

“I think what we kind of started thinking about is who would really be the best candidates to participate. Who’s in a place where they’re not overwhelmed, where they’re not in dire poverty to the point where they are thinking more about feeding their kids than sitting down for 15 minutes and doing HIPPY. Trying to find families whose circumstance we could participate in and be a support to make this workable for them. And when they were kind of—I mean there are some people who didn’t have a phone for a while or their living circumstances were tenuous and they may not have been able to be in that environment anymore and they had to move or they were in a shelter. There’s so many different scenarios that we were dealing with at the beginning. But I think also as we put more information out and we’re more sure about what we’re doing, I think we can portray this program in a way that helps parents to better understand where the commitment lies, evaluate whether they’re in that place to take it on now, and I think we’re getting parents that are not dropping out with the frequency that we saw at the very beginning.”
Lessons Learned and Implications for the Future

Even minimal improvements constitute meaningful gains for children with ASD and their families

Small successes often translate into tangible outcomes and progress for children with ASD. While ASQ-3, BSRA-3, and other assessment gains may not be very large under normal circumstances, these small gains and outcomes help to develop parents’ confidence and belief in their child’s abilities. Progress may mean that a child who initially could not sit still for five minutes can now actually sit through and attend to an entire HIPPY activity. This type of progress translates into other areas of socialization that help the child function better on many different levels.

The Executive Director of CARD-USF provides her insight in these terms:

“…[As a result of the collaboration] definitely kids [are] reading. We’ve heard it from multiple families, their kid’s reading and enjoyment of reading and being able to learn from reading. Clearly their Prekindergarten academic skills have come along. Their cooperation in going through their daily routine at home, whether it’s becoming more independent within a routine or it may be just participating and cooperating and not having meltdowns as often. Coming to the table to do something can be really challenging at the beginning for some kids, and then their fully cooperating with, ‘We’re going to do this at the table and we’re going to have something fun waiting for us.’ I think all of those are things that have happened with our kids. Just the social communication piece for kids, being able to just hug your mom or being able to give a high five to your dad or feel like you are helpful in the house because your parents thought enough of your skill to give you a job to do, if you will. You could easily get sort of in this mindset of, ‘I don’t want to pressure him. I don’t want him to meltdown. So I don’t want to ask him to do anything he doesn’t want to do.’ And then kids just get into that mode and it’s really hard to undo it.”

Clearly Defined Roles and Expectations are Critical to Effective Implementation.

In order to implement this type of collaboration there must be clearly defined roles and expectations identified, and staff must receive the proper training on an ongoing basis. Strong leadership is also critical to direct and supervise staff from both teams. Staff from both entities are clear about their roles and responsibilities. However, it does not appear to matter whether or not family members have specific knowledge about the collaboration itself, as long as they know who provides what, and the services are effective, family members appear satisfied.

Collaboration positively impacts parents’ sense of isolation.

Information from parent interviews, highlight the sense of isolation that parents with children with ASD often feel. This study underscores just how overwhelming having a child with ASD can be and revealed that parents often feel isolated. Data suggest that HHPIP-CARD collaboration and its staff, along with other resources, provide a strong support network for parents and this helped to combat their feelings of being overwhelmed and/or isolated. Subsequently, HHPIP-CARD is playing a critical, much needed role in providing tools and strategies that help parents cope with some of their children’s challenging behaviors. This is making parents engage, interact with, and teach their children more effectively. But more importantly, through the collaboration, parents receive emotional supports that help decrease their feelings of isolation.
One of the parents described the impact of collaboration in this way:

“I think it's great to have somebody coming in your house once a week just checking on you. Autism can be very isolative and even though you have therapists coming in and things like that, you also have a schedule that makes it hard to get out. And you have a child that may or may not be able to handle every day activities. So having somebody coming into your house once a week that just says, 'How's everything doing? Are you OK?' And just can talk about things. They may not have answers, but it's still nice to have somebody that has seen your child, watched them grow, and can kind of relate to what's going on in a way that maybe family members that see him three times a year can't. So I really like that aspect of it.

And like I said, I love just having the, 'I don't know what else to do. You know what, I can call CARDs.'… When I do, I know that she's [CARD Consultant name] there and she will work hard to find an answer for me. So it's kind of like the weekly check-in [from HHPIP], 'Are you doing all right? Are things going OK?' And then if it gets bad, I know that I can immediately just pick up the phone and have somebody on the other end [from CARD], so it's kind of nice to have that.”

HHPIP-CARD collaboration provides responsive services that cater to the unique needs of children with ASD.

The collaboration has been responsive in providing activities that address the needs of families in the program. Children with ASD frequently respond to life experiences by engaging in behaviors that are challenging for parents. As such parents are often reluctant to attend social events or engage in activities that young children typically engage in. This leads to a sense of isolation for parents and their children. The HHPIP-CARD collaboration appears to have made some progress in addressing this sense of isolation. The collaboration was successful in hosting an educational, recreational event for children and their parents which was adequately staffed to ensure the safety of the children. This event was mentioned several times during the study as being useful and helpful. The event was educational and fun for the children and their parents, and provided an environment of respite, support, and learning. The HHPIP Coordinator summarized the value and impact of having events that specifically cater to the needs of children with ASD and their families:

“These families feel a lot of times like they can’t go out in public places because they don’t want their kid to have a meltdown, or they don’t want people to look at them strange, and all these other kinds of things. So it was really eye-opening for me. We did an event last October where it was just only for the CARD families. Bring your kids. It was just fun. We’re just going to have fun, and we’re going to have food. And we had a lot of staff there. And the parents were able to sit down and talk to other parents and they didn’t have to worry about their kids. And their kids just played and had a great time. And they were just like, ‘thank you.’ Because they don’t get that. That was done as a CARD Family Fun Day that we just wanted to do. It was like, ‘oh we’ll have to do this every year.’ Because it was two hours and they didn’t want to leave. We’re like, ‘ok, it’s time to go home now.’ But the kids had a ball. And the parents didn’t have to run behind them.”
Families require a wide array of supports to adequately address the different needs of children with ASD which requires strong coordination and organizational skills.

Although overall the HHPIP-CARD collaboration appears to be making a positive impact on family and child, it is also clear that these families need much more than just the collaborative services to make things work for the family. The three families in the study had a wide network of supports and all appear to be a valuable part of the service support network. This includes physical, occupational, and speech therapy, as well as educational and medical services. While the parents in all three cases were capable of adhering to the rigorous schedules of appointments and services for their children, it may be helpful to have someone available to assist them to manage and coordinate the different supports and services, if needed. Even though all three parents in the study were stay at home mothers, two of the mothers had previously worked in professional careers but had to stop working to more effectively care for their child with ASD.

Other barriers families face

All three mothers described various ways in which they had significant barriers with insurance and doctors. This included pediatricians initially down playing the families’ concerns about their child’s development and not mentioning autism as a potential diagnosis, requiring them to seek out other opinions. Another issue occurs when specialists no longer take their child’s insurance or the insurance company only pays for a minimum amount of services, forcing the parent to switch to a different provider or pay out of pocket, which was costly. For two of the families, gaps in services for their children happen routinely because of these insurance barriers. One mother described in detail how the gaps in services and the need to frequently switch providers negatively impacted her child’s progress:

“There was this place I used to take him [for speech therapy] and, I mean he was actually saying things like, ‘Hi’ and ‘Bye’ and ‘Go’. Unfortunately the insurance changed and the speech therapist left. But since then we don’t get the ‘Hi’ and the ‘Bye’ anymore and the ‘Go’. We still get the ‘No’. Which I was hoping he would have made a jump from that…Sometimes they tend to change the therapist. And then insurance in Florida is really horrible. They make it so that the kids have to be re-evaluated every three months. And then when you’re re-evaluated, then you have to submit and then wait for the insurance to get back to you before you can start therapy again. So every three months, there’s this gap in services. So he regresses because there’s a gap. Sometimes that gap goes on for at least two weeks, sometimes up to a month or more…So we changed [to a different behavioral therapist]…It was really expensive to the new one we changed, like $220 a session. And we had to pay most of it out of pocket [because of insurance barriers]…We paid almost $12,000 for behavioral therapy [but] it was worth every penny.”

Although these issues are beyond the scope of services the HHPIP-CARD collaboration can provide, they are important for both entities to factor in when working with families to provide resources and support.
Conclusion

Impact of HHPIP-CARD Collaboration

The case study provides an in-depth view of the services and impact the HHPIP-CARD collaboration has made on three children and their families in Hillsborough County. This study revealed that the HHPIP-CARD collaboration provides much needed services that have a positive impact on families who have children with ASD.

Data suggests some opportunities of growth, including:

» Developing solutions that might alleviate the waiting times between getting an actual ASD diagnosis and receiving CARD-USF services.

» Identifying clearer benchmarks and outcomes of success to be tracked.

» Establishing even simpler adaptations to the HIPPY curriculum.

The study also identifies numerous benefits received through participation in the HHPIP-CARD collaboration. These benefits include

» Providing some educational consistency for families to work with their children.

» Providing a broader array of services for families, assisting families in helping their child with ASD function better within the family.

» Improving educational HIPPY activities.

The study also revealed that the collaboration is mutually beneficial to both HHPIP and CARD-USF. Some of the collaboration strengths include training of staff regarding specific strategies that can help children with ASD and their families function more effectively, professional growth of staff as a result of their work on the collaborative, and improved agency ability in staying more connected with families.

The data underscores the importance of having activities that are more responsive to the needs of families with children with ASD and reveals the need for having more of these types of supports for families. Engaging, educating, and collaborating with other providers and professionals could significantly strengthen and expand supports to families with children with ASD.

Areas for Future Research

Because of the limitation of this case study (i.e. no Hispanic or female children in the study), similar studies that comprise a broader target perspective may need to be conducted to assess the service delivery process and effectiveness of services provided to children with ASD and their families in Hillsborough County. To get this broader perspective, research that include a larger number of racially diverse families with both male and female children with ASD need to be conducted. Such studies may include Hispanic and/or immigrant families whose first language is not English and whose experiences with the system may differ from English speaking, non-immigrant families. Future studies could also include interviews of other service providers and other extended family members (identified by the parents), to get a broader, more in-depth assessment of the children with ASD, and the supports that their families receive.
HHPIP–CARD Collaboration Case Study

Background and Study Objectives
This research study is funded through the University of South Florida’s, Department of Child and Family Studies in the College of Behavioral and Community Sciences. Three families who meet specific criteria (listed below) will be included in the case study. No names or identifiable data from this study will be used in any published articles, reports or presentations. Study objectives include:

- To describe the collaboration between HHPIP and CARD-USF
- To document the process that HHPIP uses to serve children with autism.
- To summarize stakeholder perceptions regarding the effectiveness and impact of the HHPIP and HHPIP-CARD collaboration on children with autism and their families.
- To assess the effect of the program on children’s outcome and progress using available documents including assessments, progress reports and other historical data available through HHPIP-CARD collaboration.

What does participation in the case study research involve?
- Participating in one in-person, audio-recorded interview (60 and 90 minutes long). For parents-interviews will include questions about your child’s diagnosis and abilities; the benefits and challenges related to your participation in HHPIP; and the impact of HHPIP-CARD collaboration on your child and your family. For staff this interview will include questions about your role and experiences in the HHPIP-CARD collaboration; working with the child and family; and your perspectives on the benefits and challenges of this collaboration.
- Participating in one additional follow-up call (if necessary) to clarify information obtained during the interview. The maximum amount of time for this call is 30 minutes.
- The total maximum amount of time that you will be expected to participate in the study (in-person interview and follow-up phone call) is 2 hours.
- Permitting USF researchers to review HHPIP-CARD information and records (paper and electronic) of your child (e.g. assessments, HIPPY implementation materials, diagnosis etc.)

Who can participate?
1. A parent with a child that has been diagnosed with autism spectrum disorder
2. A parent with a child has been in the HIPPY program for at least one year (Oct-Sept)
3. A parent with a child who has had at least 15 weeks of the HIPPY curriculum (Yr1, Yr2 or Yr3).
4. A parent with a child who was enrolled in HIPPY during July 1, 2013 to June 30, 2016 period.
5. A HIPPY or CARD staff who has been involved in the HHPIP-CARD collaboration

Why you should consider participating in the study?
- You will have the opportunity to tell your story and provide information that can improve the process, effectiveness, and impact of the HHPIP on children with autism.
- Your information will contribute to the general body of knowledge relating to the early education of children with autism. Your information can enhance various strategies to support the successful educational and social development of children with autism.
- Parents participating in the case study will receive a $25 gift card.

Please check one of the boxes below to indicate your level of interest
☐ I am interested in participating in the case study research
☐ I am not interested in participating in the case study research

If you have any questions contact:
Mary Lindsey, Ph.D. - Principal Investigator
Florida Center for Inclusive Communities
Department of Child and Family Studies
College of Behavioral and Community Sciences
13301 Bruce B. Downs Blvd. MHC 2113A
Tampa, FL 33612-3807
Tel: (813)974-4858 | Fax: (813)974-6115
Email: lindsey@usf.edu
### Appendix B: CARD-USF Documents Reviewed for the HHPIP-CARD Case Study

<table>
<thead>
<tr>
<th>Document</th>
<th>Malik</th>
<th>Jack</th>
<th>Damarcus</th>
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# HHPIP-CARD Case Study
## Document and Electronic Review

Name of researcher(s) completing document review

1. 
2. 

Date document review was completed: 

Name(s) of document(s) reviewed:

1. 
2. 

Was information from other electronic sources reviewed? □ Yes □ No

If yes, name the electronic source: 

Target child's name: 

Parent's/primary caregiver's name: 

## Child Demographic Information

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## Child and Family Enrollment Summary

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<th>Date Child Dropped out or Completed Program</th>
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</table>
**Presenting Problem/Status**
What were the circumstances surrounding the target child being enrolled in the HHPIP or CARD program.
Identify any referring agency or person (Check all that apply)

- [ ] Self: ____________________________
- [ ] Family Member: ________________________
- [ ] Other: ____________________________
- [ ] Pre-K/VPK/Head Start: ____________________________
- [ ] Primary Care Physician: ____________________________
- [ ] Hospital: ____________________________

Identify any specific problems upon enrollment (*Check all that apply*)

- [ ] Behavioral/Social
  Explain: ____________________________

- [ ] Medical
  Explain: ____________________________

- [ ] Other
  Explain: ____________________________

**HHPIP-CARD Collaboration Services**
Service/Treatment Strategy Employed (identify who or what agency is responsible for each service)

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<tr>
<th>Service/Strategy</th>
<th>Agency</th>
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2
Assessments
List assessments have been completed on the target child since enrollment (include any other assessments that may have been completed and are evident in the document/electronic review):

<table>
<thead>
<tr>
<th>Assessment Type</th>
<th>Date</th>
<th>Scores</th>
<th>Interpretation of Results</th>
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Other Summary Findings & Notes
Please summarize any other relevant findings/information obtained through this review.
HHPIP-CARD Case Study
Semi-Structured Staff Interview

Introduction

Good Morning/Good Afternoon my name is (Name of Interviewer) and this is (Name of Co-Interviewer) and we are both with the USF research team that is conducting the HHPIP-CARD case study research. I'd like to first of all thank you for agreeing to participate in the case study. As a participant, I will be asking you questions about the HIPPY Parent Involvement Program (HHPIP)-CARD collaborative, your involvement and role in this collaborative, the strengths and challenges of the collaborative, and your opinions regarding the impact that the collaboration has had on educational and social progress of children on the autism spectrum in general and specifically about the children enrolled in this case study.

Your opinion as staff/executive director, coordinator on this collaborative is very important to us and we anticipate that the information we obtain through our case study research will help to highlight some of the strengths of the collaborative and provide data that can improve other HIPPY programs in Florida. In addition, the information we collect will contribute to the broader general body of knowledge on how programs, agencies, schools and other educational systems can serve families with children with the Autism Spectrum Disorder (ASD) more effectively.

I thank you for your time and appreciate your willingness to share your opinions and experiences with us. This interview will last between 60 to 90 minutes and will be audio-recorded to ensure that your comments are captured accurately. We will also be taking notes as we conduct the interview. I may call you at a future time at a time that is convenient for you, to follow up and clarify some things. This follow-up call will last between 15 to 30 minutes.

Any reports or articles presentations developed as a result of this case study will be anonymous – your name will not be identified or included in any reports, articles or presentations. However, because the information we obtain through the case study will be used in these ways you will be required to sign an informed consent form as a participant in this case study. I will go over this document with you in a few minutes and answer any questions you may have about the study or informed consent form.

Before we do that I'd just like to remind you again that we will be audio recording the interview and that the interview questions don't have right or wrong answers. The questions generally relate mainly to your experiences, perspectives and your personal opinions.
## Assessments

List assessments have been completed on the target child since enrollment (include any other assessments that may have been completed and are evident in the document/electronic review):

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## Other Summary Findings & Notes

Please summarize any other relevant findings/information obtained through this review.
June 2016
Ruby Joseph, MPA,
HIPPPY Researcher
Mary Lindsey, PhD,
Director, Florida HIPPY Training & Technical Assistance Center

HHPIP-CARD Case Study
Semi-Structured Staff Interview

Introduction
Good Morning/Good Afternoon my name is (Name of Interviewer) and this is (Name of Co-Interviewer) and we are both with the USF research team that is conducting the HHPIP-CARD case study research. I'd like to first of all thank you for agreeing to participate in the case study. As a participant, I will be asking you questions about the HIPPY Parent Involvement Program (HHPIP)-CARD collaborative, your involvement and role in this collaborative, the strengths and challenges of the collaborative, and your opinions regarding the impact that the collaboration has had on educational and social progress of children on the autism spectrum in general and specifically about the children enrolled in this case study. Your opinion as staff/executive director, coordinator on this collaborative is very important to us and we anticipate that the information we obtain through our case study research will help to highlight some of the strengths of the collaborative and provide data that can improve other HIPPY programs in Florida. In addition, the information we collect will contribute to the broader general body of knowledge on how programs, agencies, schools and other educational systems can serve families with children with the Autism Spectrum Disorder (ASD) more effectively.

I thank you for your time and appreciate your willingness to share your opinions and experiences with us. This interview will last between 60 to 90 minutes and will be audio-recorded to ensure that your comments are captured accurately. We will also be taking notes as we conduct the interview. I may call you at a future time at a time that is convenient for you, to follow up and clarify some things. This follow-up call will last between 15 to 30 minutes.

Any reports or articles or presentations developed as a result of this case study will be anonymous – your name will not be identified or included in any reports, articles or presentations. However, because the information we obtain through the case study will be used in these ways you will be required to sign an informed consent form as a participant in this case study. I will go over this document with you in a few minutes and answer any questions you may have about the study or informed consent form. Before we do that I'd just like to remind you again that we will be audio recording the interview and that the interview questions don't have right or wrong answers. The questions generally relate mainly to your experiences, perspectives and your personal opinions.
I’m going to start by asking you about your work on the HHPIP-CARD Collaborative.

1. What is your background working in early childhood and with children who have autism spectrum disorder?

2. How did you get involved in the HHPIP-CARD collaboration and what is role in this collaborative?

3. How would you describe the HHPIP-CARD collaboration/partnership and what processes and structures support this collaborative? (meeting, roles, trainings, etc)?
Implementation Strengths and Challenges

4. What are main strengths of the HHPIP and HHPIP-CARD collaboration?

5. What are the main implementation challenges of the HHPIP and HHPIP-CARD collaboration and what do you think can be done to improve these challenges? *(should relate to process implementation as well as any implementation service challenges parent, child and family services)*

6.a) How many families did you start out with? _______

   b) How many families have dropped out? _____ Talk about the reasons why these families dropped out.

7. What overall impact do you think the HHPIP-CARD collaboration has had on children in HHPIP with autism spectrum disorder?

Autism Spectrum Disorder Diagnosis and Services

*This next question is dealing with challenges of diagnosis not necessarily related to the HIPPY curriculum in general.*

8.a) What are some of the things _______ *(Target Children in the study)* generally finds difficult to do as a daily part of his/her life?

   Child 1. __________________________________________________________
   __________________________________________________________
   __________________________________________________________

   Child 2. __________________________________________________________
   __________________________________________________________
   __________________________________________________________

   Child 3. __________________________________________________________
   __________________________________________________________
b) How does the HHPIP-CARD collaboration specifically help _________ (Target Children in the study) deal with these issues?

**HIPPY Curriculum Delivery**

*This next questions deals with curriculum delivery*

9. a) How does the HHPIP-CARD collaboration specifically help in the delivery of the HIPPY curriculum for ________ (Target Child)?

b) What are some of the extra supports, enhancements that the HHPIP-collaboration provides you and _________ (Target Child)?

c) What are some of the tools and techniques that HHPIP-CARD collaboration provides to families who have a child with Autism Spectrum Disorder?

*I'm going to talk to you about the progress that _________ (Target Child) has made since being involved with HHPIP-CARD*

10.a) Please rate the level of progress that (targeted children) have made since becoming involved in HHPIP?

(Check one for each child)

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<thead>
<tr>
<th></th>
<th>Very poor</th>
<th>Poor</th>
<th>No change</th>
<th>Very good</th>
<th>Excellent</th>
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b) Explain your rating (i.e. what specific reasons made you give this rating?)

Child 1. ____________________________________________

__________________________________________________

Child 2. ____________________________________________

__________________________________________________

Child 3. ____________________________________________

__________________________________________________
11. Please list and rank the resources/services (including HHPIP-CARD collaborative has provided to the family).

   Rate with interviewee.

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<tr>
<th>Child 1 Resources/Services</th>
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<th>3</th>
<th>4</th>
<th>5</th>
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Lessons Learned

Now let's talk about lessons learned and what you might recommend to others who may be considering this type of partnership.

12. What are some of the lessons you've learned professionally and personally from being involved in the HHPIP-CARD collaboration?

   Professionally
   1. 
   2. 
   3. 

   Personally
   1. 
   2. 
   3. 

13. What key elements do you think are critical for the successful implementation of this type of collaboration?

14. Is there anything that you feel is important for me to know that would help us understand how HHPIP-CARD collaboration has been implemented in Hillsborough county? Please explain.

Thank you so much for taking the time and providing this information.
HHPIP-CARD Case Study In-Depth Parent Interview

Introduction

Good Morning/Good Afternoon my name is ___ (Name of Interviewer) and this is ___ (Name of Co-Interviewer) and we are both with the USF research team that is conducting the HHPIP-CARD case study research. I’d like to first of all thank you for agreeing to participate in the case study. As a participant, I will be asking you some questions about the HIPPY Parent Involvement Program (HHPIP)-CARD collaborative, your involvement in the HHPIP and the effects of the collaboration and HHPIP on your child’s educational and social progress. I will be also be asking you about your family’s overall network of resources, services and supports for you to share how these resources and HHPIP assist you and your family. You will be asked to identify and describe any strengths and challenges you’ve experienced as a result of using HIPPY curriculum, specifically to help educate your child.

Your opinion as a parent/primary caregiver is very important to us and we anticipate that the information we obtain through our case study research will help to highlight some of the strengths of HIPPY and provide data that can improve other HIPPY programs in Florida. In addition, the information we collect will contribute to the broader general body of knowledge on how programs, agencies, schools and other educational systems can serve families with children with the Autism Spectrum Disorder (ASD) more effectively.

I thank you for your time and appreciate your willingness to share your opinions and experiences with us. This interview will last between 60 to 90 minutes and will be audio-recorded to ensure that your comments are captured accurately. We will also be taking notes as we conduct the interview. I may call you at a future time at a time that is convenient for you to follow up and clarify some things. This follow-up call will last between 15 to 30 minutes.

Any reports or articles or presentations developed as a result of this case study will be anonymous - you or your child’s name will not be identified or included in any reports, articles or presentations. However, because the information we obtain through the case study will be used in these ways you will be required to sign an informed consent form as a participant in this case study. I will go over this document with you in a few minutes and answer any questions you may have about the study or informed consent form. Before we do that I’d just like to remind you again that we will be audio recording the interview and that the interview questions don’t have right or wrong answers. The questions generally relate mainly to your experiences, perspectives and your personal opinions.
Carefully go over the informed consent form.

In-Depth Interview Guide for Parents/Primary Caregivers
HHPIP-CARD Collaboration Case Study

Parent Name: __________________________________________________________
Child’s Name: __________________________________________________________
Interviewer: __________________________________________________________
Date of Interview: ______________________________________________________

I’m going to start off by asking you some general questions about your neighborhood and community.

Community and Family Life
1. How long have you lived in this community?

2. What is it like living in this community? How would you describe life in your community?
   Probe: How involved are you and your family in your community?

Family and Target Child
Now that I’ve heard a bit about your community. Let’s talk a bit about your family and ______ (Target Child).

3. Tell me about your family? (How many children, ages, etc.)

4. Tell me about ______ (Target Child). What are some of the characteristics that you would use to describe ________ (Target Child)’s personality?

5. What are some of ________ (Target Child) strengths?
Autism Spectrum Disorder Diagnosis and Services
6. What are some of the things that ________ (Target Child) finds challenging to do?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

7. When did you first begin to notice that ________ (Target Child) had some challenges?

8. When did you receive your child’s diagnosis of Autism Spectrum Disorder?
   Date: MM/DD/YEAR
   _____/_____/_____

9. What did you do and what happened?
   a. What was his diagnosis?

   b. Who made that diagnosis?

   c. What plans or services were put in place as a result of the diagnosis?
HHPIP and HHPIP-CARD collaboration Services

Now I'm going to talk to you about HHPIP and CARD.

10. How long have you and your child been involved in HHPIP?

11. How did you become involved in the HHPIP/HIPPY program?

12. What services does HHPIP/HIPPY provide you and your family?

13. Do you know about HHPIP-CARD collaboration/partnership?  □ Yes  □ No
   If no, go to question 15.

14. How would you describe HHPIP-CARD/CARD/HHPIP collaboration (partnership)?

   a. Often times the home visitors are the liaisons between HIPPY and CARD for families. How would you rate their role as being liaison?

      1  2  3  4  5
      No Help Little Help Neutral Very Helpful Extremely Helpful

15. How does the HHPIP-CARD/CARD/HHPIP collaboration specifically help _________ (Target Child)?

   a. How does the HHPIP-CARD/CARD/HHPIP collaboration specifically help you deliver the HIPPY curriculum to your child?

   b. What are some of the extra supports, enhancements that the HHPIP-collaboration provides you and your child?

   c. What are some of the tools that HHPIP-CARD collaboration provides you and your family?
16. How has the HHPIP and the HHPIP-CARD collaboration impacted you as a parent?

17. How has the HHPIP and the HHPIP-CARD collaboration impacted your child's development and progress?

18. How has the HHPIP curriculum and the HHPIP-CARD collaboration impacted your family as a whole?

19. Tell me about some of the strengths of the HHPIP and HHPIP-CARD collaboration?

20. Tell me about some of the challenges of the HHPIP and HHPIP-CARD collaboration- what can be done to improve these challenges?

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<th>Challenges</th>
<th>How it can be improved/addressed</th>
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21. Please rate the level of progress that your child has made since becoming involved in HHPIP? (Check one)

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Explain your rating (i.e. what things/ reasons specifically made you give this rating?).

**Other Resources and Supports**

Now let’s talk about some other supports and resources that you use to help you take care of _____ (Target Child)

22. What are some other formal and informal supports and resources that you have that help you support your child? (e.g. Teacher, Church, Child Welfare Agency and Other).

*Please list*

1. __________________________________________
2. __________________________________________
3. __________________________________________
4. __________________________________________
5. __________________________________________

23. How have these resources helped you?

24. Please list these resources (including HHPIP-CARD/CARD/HHPIP) and rank their order of helpfulness.

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25. Is there anything that you feel is important for me to know that would help us understand more about your child’s progress or life that you I have not asked about? Please explain.

*Thank you so much for taking the time and providing this information.*
References


For More Information

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FloridaHIPPYSateOffice
FloridaHIPPY

Florida HIPPY is a program of

Florida Center for Inclusive Communities

University of South Florida - College of Behavioral & Community Sciences