

**Our Kids...**

***Their Future***



Strengthening Pottstown's children and families for a brighter future

Pottstown School District in collaboration with W.K. Kellogg Foundation

**March 2016**

Report to the  
Pottstown School District  
by the  
Penn Project for Civic Engagement

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## **Our Children ... Their Future: Strengthening Pottstown's children and families for a brighter future**

### **Introduction:**

This is a report of the two *Let's Talk* community forums, one entitled "*Let's Talk - Be Your Child's Champion*" and the other one, "*Let's Talk - Be Your Special Needs Child's Best Advocate*." The first forum focused on a general approach to advocating for your child around issues such as discipline, homework help and bullying. The second forum focused on advocating for children with special needs.

These foci were identified through conversations in Family Advisory Committee meetings. Committee members identified a need to discuss how to help parents and guardians advocate for their children. Some parents wanted a forum solely on the topic of advocating for children with special needs. The purpose of the forums was to provide an opportunity for participants to connect around issues of advocating for their children, in order to:

- Give parents/caretakers an opportunity to talk with each other about the successes they were experiencing advocating for their children this school year and what supported those successes.
- Enable parents/caretakers to raise questions and concerns about advocating for their child around discipline, homework help and bullying and work with other parents to address those concerns.
- Enable parents/caretakers to share information about a broad range of strategies that support more effective advocating.

This report is divided into three sections: an overview which describes who participated in the forums, a summary of key learnings about advocacy from the forums, and a summary of overall take aways from the forums

The two forums were held as follows:

- March 12, 2016, 12:00 pm, Olivet Boys and Girls Club at Ricketts Center, 26 participants
- March 16, 2016, 5:30 pm, Kingdom Life Church, 20 participants

The structure of the forums was similar with the exception of the opening plenary. On March 12 during the plenary session, Mary Rieck of PEAK welcomed everyone, Michael Ryan, Pottstown family-based therapist with Creative Health Services discussed the meaning of advocacy, and Harris Sokoloff of Penn Project for Civic Engagement introduced the work for the evening. On March 16, Pottstown School District leaders in Special Education gave presentations including, Shante Forrest: Program Administrator Montgomery County Intermediate Unit, Pam Bateson: Director of Special Education Pottstown School District, Robin Romero: Special Education Teacher Pottstown School

## District and Holly Lee: Family Services Coordinator Pottstown School District

At both forums, after the plenary, participants moved into small groups where they introduced themselves and shared responses to several questions related to advocacy posed by group moderators. This discussion focused on examples of successful advocacy, and challenges when advocating did not go as well, which generated ideas and strategies for how to better support your child with the district.

Each small working group was led by a team of moderators –one or two trained community members with an equal number of PPCE moderators. In some small groups a community member served as a Spanish interpreter to ensure that those participants in need of translation would be able to participate fully in the forum. The moderators took notes on large flip-chart paper of the conversations. Those notes are the basis for the forum reports on which this report is based, and which were posted on the PPCE and PSD web sites. The forum closed with a plenary session in order to surface some key ideas from the small group discussions. Reports from moderators of the small group conversations at each location, which include rough descriptions of demographic information, are attached (appendix 1). Participants included parents whose children were enrolled in Pottstown Schools and Pre-K programs and members of the community, and local business owners. There was representation from each of the primary demographic groups living in Pottstown. Spanish interpretation services were provided for participants at each forum.

Generally, groups were talkative and energetic, conversing back and forth about successes and challenges in advocating for their children and about ideas and strategies.

In reflecting on the experience, participants noted the following learning outcomes of the forums:

- The importance of talking and sharing experiences with other adults
- The importance of being involved, consistent and following up in advocating for your child.
- Learning about specific social supports and resources available to support challenges around children with special needs.

### **Participant Summary**

A. 46 Pottstown residents participated in the two forums, as follows:

- Demographic information
  - March 12, 2016
    - Total participants: 26
      - 10 Latino
      - 3 White
      - 11 African American
  - March 16, 2016
    - Total participants: 20

- 2 Latino
  - 6 White
  - 12 African American
- Attendees included:
  - Parents of school aged children (PreK, elementary, and middle school primarily), foster parents and caretakers, local business owners and/or community members
  - Parents of children with special needs

## **Summaries of Key Learning**

- Knowledge and resources
  - Knowing what should be available to your child
  - Being connected to community and resources (e.g. your network)
  - Learned experience and knowledge (e.g. from going through process of advocating related to child with special needs, often easier after having gone through it once)
- Personal characteristics
  - Persistence
  - Patience
  - Ability to overcome adversity in life
  - Curiosity and willingness to learn
  - “Fearlessness” (e.g. not being afraid to look silly or offend others when advocating)
  - Organizational skills (e.g. keeping notes, coordinating meetings)
  - Self-acceptance and knowing that you are doing your best to support your child
- Interpersonal skills
  - Demonstrating support for others
  - Building relationships with others and working as a team in support of your child
  - Mobilizing others in support of your child
  - Effective communication and collaboration
  - Effective communication of expectations to both children and children’s teachers
  - Asking questions
- Relationship with your child
  - Knowing child and his/her needs
  - Ability to talk to, listen to, and understand child
  - Standing up for child & being his/her voice
  - Ability to calm children down

- Ability to “treat special needs kids as normal”

### **Issues parents had to advocate around**

- Inaccurate assessment of student’s learning level in classroom or diagnosis
- Classroom supports for students with special needs
- Perceived poor teaching practices
- Issues with peers at recess
- Behavior / discipline issues at school
- Neighborhood safety concerns related to middle school and high school dismissal

### **Supports in advocating**

- Knowledge and resources
  - Using an interpreter
  - Knowing “who’s who” in the district and who to talk to at the school
  - Intermediate unit workers who provide school-based support for children with special needs in school
  - Identifying programs / supports that are a best fit for children with special needs
  - Benefits of medical assistance for providing services for children with special needs
  - Benefits of Early Intervention in helping parents connect to resources and navigate the system for children with special needs
- What parents can do themselves
  - Being persistent / “Not backing down”
  - Being proactive (e.g. learning about opportunities, staying informed)
  - Being assertive in asking for what you think your child needs
  - Asking questions (there are no bad questions to ask)
  - Seeing an issue for yourself by visiting the school
  - Getting multiple opinions (e.g. from doctors related to a diagnosis)
  - Following up to check on progress in how an issue is being handled
  - Supporting children in advocating for themselves (e.g. teaching and modeling advocacy)
- What parents can do with others
  - Connecting with other parents to advocate collectively (e.g. creating a petition)
  - Support from others / reaching out for help / networking
  - Bringing a friend or advocate with you to school meetings (especially IEP meetings) to help be a second set of ears and provide emotional support
  - Communicating expectations clearly and highlighting differences in expectations between parents and the school when necessary

- Requesting face-to-face meetings with your child's teacher
- Seeking help from the programs presented by the panel

### **Challenges in advocating**

- School and district related challenges
  - Lack of cultural sensitivity from staff
  - Perception of discrimination or lack of respect (often based on race, ethnicity, or language abilities)
  - Differences in perception between parent and school related to supports children needed
  - Limited interpretation resources
  - Lack of follow through from school on next steps
  - Communication gaps with school staff
  - Parents are willing to help provide support but there is a lack of infrastructure for this (e.g. monitoring dismissal, walking school bus at other schools)
  - Lack of childcare at school board meetings
  - Lack of availability during weekdays to attend school board meetings
- Personal challenges
  - Limited English abilities
  - Lack of knowledge and information
  - Fear, lack of comfort with speaking up (especially with those perceived as “experts”)
  - Work schedule makes it difficult to be at school or attend meetings
- Family-related challenges
  - Disagreement between parents about what is best for child
- Challenges specific to advocating for children with special needs
  - Knowing what questions to ask in order to get the right information, resources, or supports
  - Understanding acronyms, paperwork, and overall confusing information
  - Negative perceptions from others around receiving medical assistance
  - The process of having a child identified as having a disability and getting services can be confusing and seem lengthy
  - Supports for students can be cancelled or changed suddenly
  - Not all schools or programs can meet your child's needs
  - Insurance doesn't cover all services
  - Lack of consistency and communication between different service providers for different age groups (especially as related to transitions after age 3)
  - “Revolving door of people” in schools and service provider agencies

## **Help that is desired**

- From schools
  - Easier way to connect with schools and teachers
  - Specific information about your child and your child's educational program
- From district
  - More information about how to navigate "the system"
  - Creation of a parent advocate / liaison position
  - Improved training for teachers on best ways to work with parents
  - Additional support staff (e.g. assistants, social workers)
  - Better ways to engage with the school board that might be more accessible for parents or other avenues for parents to provide feedback to the district
  - More information about how to support children at home (especially when there are differences in child's behavior or communication abilities at school versus at home)
  - Understanding what supports are available and how to access them for children who don't qualify for an IEP
  - Understanding the nature of a child's difficulties (e.g. for a bilingual child who may also have cognitive challenges)
- From other parents / what parents can do together
  - Sharing information and resources
  - Partnering for language needs (going to school together or offering language support to other families)
  - Volunteer (e.g. for walking school bus)
- Other
  - More information about parent and child rights
  - Information about resources and how to access those resources including those from outside the school
  - Support in navigating the system as related to children with special needs (e.g. "services coordinator")

## **Overall takeaways**

- Be more involved - this helps parents to get to know others who can provide support and to gain information that can also support their advocacy
- Be more consistent and follow up
- Know your rights
- Get to know other parents - hearing from other parents helps you to know you aren't alone in dealing with issues, helps you gain information, and helps you to think about supporting others in the community
- Parents want to be involved but don't always feel they have avenues to do so

# **Appendix**

## **Appendix 1 - Forum reports**

**Let's Talk...**  
***Be Your Child's Champion***

**MODERATOR REPORT**

LOCATION: Olivet's Boys & Girls Club

DATE: March 12, 2016

**Moderators:** Gina Cappelletti & Phoebe Kancianic

**Moderator's description of the group:**

- 40s White man (school board member & parent of Rupert 2<sup>nd</sup> grader- – first time at Let's Talk)
- 20-30s Black woman (parent of 20 year old and Rupert 2<sup>nd</sup> grader – has previously attended Let's Talk)
- 40s Black woman (foster parent with kids at Rupert, Franklin, Doylestown Autistic – has previously Let's Talk)
- 20s-30s Black man (single father of 8 yrd old at Franklin and 11 year old at Pottstown Middle – cousin of FAC moderator – first time at Let's Talk)
- 20s-30s Hispanic woman (4 year old at YMCA PreK – sister in law of Hispanic man in group – has previously attended Let's Talk)
- 20s-30s (biracial??) woman (6 and 10 year olds at Franklin- – first time at Let's Talk)
- 30s-40s Hispanic man (6, 11, and 20 year old – husband of FAC moderator)
- Black male high school student (youngest member of school board - – first time at Let's Talk)

The group had representation from a range of demographic groups including members of the Black community, members of the Hispanic community, and school board members (one White dad and one Black high school student). Approximately half of the participants had previously attended a Let's Talk event. While chairs were arranged in a circle, some group members chose to sit slightly outside of the circle, citing that they needed the tables behind them to take notes. There were empty chairs between participants. Generally, there was limited space around the outside of the circle. There was movement throughout the conversation with varied people entering and exiting the room including PEAK staff, PCCE staff, and the Black male high school student.

Overall members of the group were somewhat hesitant to participate and the conversation was influenced by the presence of a White male school board member and by the intermittent presence of a Black male high school student who was also a member of the school board. These participants moved the conversation away from "parents sharing with other parents" to parents providing feedback to the school district and/or the school district representatives

asking for increased participation from parents. These participants influenced the conversation through their positioning as “experts” on school-related topics and spoke about more broad system and community level changes.

Interactions were generally respectful, though there was some occasional crosstalk. 3 of the 8 participants spoke most often. The greatest involvement from all participants was around concerns related to behavior of students in the neighborhoods near the schools after high school and middle school dismissal – all participants commented on this issue. Two participants spoke only when invited directly by the moderators during the icebreaker and closing.

**Superpower or strength you have as an advocate for your child(ren):**

Participants were hesitant to share strengths, responding in some instances with “I don’t know” and “I don’t know if I have any”. Generally, parents described things that they had to overcome or deal with in their own personal lives or with their children. It was unclear whether or not parents were considering specific instances of advocacy that they had initiated or experienced when providing responses. Moderators helped to rephrase or paraphrase parents’ share-outs to reshape them into strengths from general examples or stories. Strengths shared included:

- Knowing one’s own children well
- Curiosity, willingness to learn
- Being fearless, having deal with issues in life and survived
- Developing relationships and seeking out resources
- Being patient and persistent (repeated by two participants)
- Being present in the school and classroom (i.e. showing up at the school)
- Dealing with being a single parent, asking for help
- Being an involved parent
- Being bilingual
- Surviving difficult situations personally and with children
- Communicating and collaborating effectively with schools and teachers

**Successes/supports: What are the things participants identified as part of their success in advocating for their child(ren) and where possible ideas for using those things in other settings.**

Generally, participants focused less on stories of advocacy and more on strategies or qualities that might contribute to successful advocacy.

- One parent said that her child participates in an after school program that has been helpful in supporting her academic growth. Through a brief discussion of this effort through the lens of advocacy, participants identified that the parent was advocating for her daughter by being proactive to learn about and get her daughter involved in supportive activities.
- A Black mom talked about how she dealt with an issue when the school/teacher said that her child was having behavior issues. She said that she went to the school herself to observe and said that the child acted differently when she was there. She then used that information to have a conversation with the teacher and to come up with a plan for how

to keep the child more actively engaged during class. She said that her success in this case was because she was proactive and persistent.

- A Hispanic dad talked about how his daughter had an issue at school when she was in a class with a substitute and got into a fight with another student. He said this behavior was unusual for his daughter and she got in trouble for it. He went to the school to talk to the assistant principal about what happened. He also asked his daughter for her side of the story. He called the school again and had a meeting with the principal. His daughter was then moved into a different classroom which he felt was a sufficient resolution to the problem.
  - The White dad raised the issue of what supports might be offered at the school to help the students who are doing the bullying or fighting.
- A Hispanic mom raised the issue of dismissal from the high school and middle school telling a story of when she was driving in the area and kids were running (or biking?) in the street. Several parents described this time of day as chaotic and dangerous for younger children and families. A Black dad said he lived near this area and he goes outside during this time of day to try to help with kids' behavior.
  - A Black mom said that something helpful in this situation might be a petition that parents can take to school. She said that a petition is effective because it brings parents together around an issue.
  - The Hispanic mom said that she is home during the day because she is working on her GED so that she would be willing to help deal with this issue.
  - There was a discussion of how parents vs. school representatives/staff might be used to help deal with this issue. There was evidence of parent willingness to help but questions about how to make that happen.
  - Other suggestions to deal with this issue included: the use of a peer buddy system in which older students would help walk younger students home, contacting school-based organizations (Home and School Association), more walking school buses, telling principals about the problem, getting more cameras installed in these problematic areas.
  - There was a lingering question of how efforts to deal with this issue might be lead or organized. It seemed like the Black mom was collecting contact information from other participants, but it wasn't clear how she planned to use it.
- Other strategies that support advocacy that were shared included: knowing who's who in the district/community and using those connections and supporting kids in sharing about things going on back to the school (i.e. advocating for themselves).

**Barriers : What are the things participants identified as part of their success in advocating for their child(ren) and where possible ideas for doing it differently next time.**

This discussion focused specifically on barriers to parents' participation in school board meetings as a potential venue for advocacy. Barriers included:

- Fear
- Feeling intimidated about how they might be perceived by others based on race/ethnicity

- Anxiety about English language limitations
- Limited availability due to work schedule
- Lack of childcare
- Timing of meetings during the weekday when parents have more availability on the weekends
- Being intimidated about talking in a large group of “experts” – parents find talking directly with other parents and/or talking in small groups to be easier

**Help: What are the things participants identified as specific areas where they might need support from others? What are the things that participants might need from the district (or early childhood programs) to be better advocates?**

- Parents said they were willing to help others by volunteering (e.g. walking school bus, PTO) which would allow them to support and advocate with others

#### **Final synthesis of key advocacy ideas**

- Parent takeaways from the conversation included:
  - Being more involved and informed can help support advocacy – parents can be more proactive and can connect with other parents
  - Getting to know each other more is helpful in a few ways – hearing from other parents helps you to know you aren’t alone in dealing with issues and that others are dealing with similar things; you can hear ideas from other parents; in talking to other parents, you start to think more about others and their kids so it’s not just about helping your kid but others in the community
  - If you see something, say something about it
- There was a discussion about school board meetings as a venue for advocacy and a subsequent discussion of barriers parents experience to participating in these meetings. A lingering question related to these barriers was: How can school board meetings be reconceptualized or restructured so that parents who are expressing a desire to be involved can be better included in these meetings?
- Overall, parents expressed a willingness to be involved but didn’t feel that they necessarily had avenues to do so.
- Parent advocacy in issue related to behavior/discipline in school seemed to be most successful when the parent proactively collected information about what occurred, communicated with the school, and was persistent in his/her efforts.

**Let's Talk...**  
***Be Your Child's Champion***

**MODERATOR REPORT**  
Saturday, March 12, 2016  
Olivet Boys & Girls Club  
Pottstown, PA

**Moderators: Brian Armstead, Duke Lynch and Alexis Didget**

**Description of the group:**

There were 10 participants. All were native English speakers. Five were men/five were women. Three were white; one was Latino; six were African-American. Eight of the participants had children in school. One participant is a foster parent; the foster children are in school. The last participant does not have children in the schools but owns a local business and works with children a lot. Two children attended PEAK. Ten children attended either elementary or middle schools in Pottstown.

**Question #1: What is your “superpower” in advocating for yourself or your child?**

- Stand behind kids 100%
- (Business owner) stand behind “my kids”; they have to deal with me as well s their parents.
- I “walk” with people and support them as long as they will go; a strong supporter
- Be there; “father-figure” for anyone & everyone;workout with neighborhood kids
- Help uplift them
- Don't need to know everything but stick it out
- Being present
- Figured it out on her own; never give up; look for resources.
- Being a parent (raised six (6) children of his own)

**Question #2: Think of a time you wanted to advocate for your child. What supported you?**

- Groups
- Faith
- Family & friends
- Spouses
- Desire to do better for your children (*i.e. Get better outcomes*)

- Desire to set a better example for your children
- Networking

**Question #3: Think of a time you wanted to advocate for your child. What got in the way?**

- Just don't have the info
- Lack of knowledge
- Behavioral health
- The school gets in the way (i.e. They drag their feet or don't do things, etc.)
- Pride
- Fear
- Parent not being there\*
- Co-parenting\*\*
- Lack of respect (i.e. Not respecting the parent, their opinions, or their rights)

*\* Comment: Regarding 'pride': A participant quoted the saying "A closed mouth don't get fed," and everyone in our group nodded and mumbled their agreement.*

*\*\* Comment: Regarding 'co-parenting': the other parent can hold things up if they are not on the same page, disagree with what needs to happen, or are just "contrary" to anything the other parent wants.*

**Question #4: What is a time your advocacy went well and why did it go well?**

- A student "came out" (about his/her sexuality). Honest conversation was a key to helping the student.
- 1<sup>st</sup> grader was diagnosed with ADD. He was bored and walked around class when his work was finished. Mom advocated against meds and instead wanted to use other interventions. It worked out well and she "got the desired effect a different way."
- Sometimes you need to take a child to several doctors, not just accept the first doctor's opinion.
- Oldest son had some developmental delays. The doctors just told them to wait but instead, they got early intervention services which helped out a lot.
- Mom was able to advocate strongly because she "knew her child best."

*Comment: We got into a side conversation about disciplining your child. The discussion was about the use of physical discipline, etc. It didn't directly relate to our topic but there was a lot of energy in the discussion. It might be something parents want to discuss in the future.*

**Question #5: What is a time your advocacy did NOT go well?**

- The parent was redirected away from the primary issue
- Lack of resources, not sure where to go
- Lack of interest from teachers
- Lack of communication between teachers and parents
- Teachers and/or aids not following up with parents
- Communication gaps

**Question #6: What can parents do differently to be better advocates?**

- Come down to the children's level
- Don't pre-judge
- Understanding children
- Networking; building stronger foundation
- Parents make appearance at school - stronger bond with the school

**Question #7: What would you like help with to do a better job advocating for your child?**

- Easier way to connect with school
- Seeing/speaking with teachers
- Peer mediation
- More education about advocating
- More information from school districts (their resources and information about the students' needs)
- Follow-up with teachers/schools
- Going outside of the school for help (more information about community resources and help to access those resources)
- Learn more about their rights so that they know what they can advocate for

**Question #8: What can the school district/early childhood program do differently to help parents be better advocates for their children?**

- How to learn about available resources
- Specifics about your child/programs (not generalized info)
- Better understand the system (who to talk to)
- Make a parent advocate position or assign someone to be a parent advocate maybe

the guidance counselor)? This would be someone that a parent can talk to to help them follow up with teachers/staff inside the school. The advocate could also visit the student in class and report back to the parent so they get a better sense of what's happening in the class, etc. This would help the parent avoid having to take off from work.

- Hire more educated and dedicated teachers (educated about how to treat parents and dedicated to working with parents)
- Train teachers about working with parents. (How to do it and why its important.)
- Hire more assistants, social workers, parents as middle people to fill the gaps
- Smaller school settings would allow teachers to be more on top of their students and to make better relationships with the parents.
- More after school programs to help kids learn

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**Entire group recap by Harris.**

**Question: What is one thing you learned today?**

- Be more involved
- Be more consistent
- Knowing your rights
- Talk/listen respond

**Let's Talk...**  
***Be Your Child's Champion***

**MODERATOR REPORT**

LOCATION: Olivet's Boys & Girls Club

DATE: March 12, 2016

**Moderators' names:** Laura Hinds MSW, LCSW & Kizmet Meade

**About the group**

Our group was comprised of 7 delightful participants! All were ladies who identified as being of Latin descent. This group was conducted in Spanish, with the help of 2 interpreters.

One mother had two children, 12 years apart- one in middle school and the other in elementary school (schools not captured).

One mother has a 5 year old and an 8 month old. Her eldest is in school (school name not captured).

One mother has 3 children 5yr-old and under (school name not captured).

One mother had two older children, elementary aged- school not captured.

One mother had a daughter in middle school- school not captured.

One mother has two elementary school aged children- school not captured.

One mother joined late and missed this piece, but she has one 6ish year old and appears pregnant.

**What are your "super powers" that enable you to be a good advocated for your child?**

- I know when something is wrong with my child. I am sensitive to his needs.
- I know how to help my child, what he needs to be successful
- I am good at teaching my child, I show him how to stand up for himself.
- I am my child's voice.
- I can tell when my child is "not ok." That helps me stand up for her.
- I am connected to the community, I know what is going on and what should be available to my child.

**What successes have you had in advocating for your child(ren)?**

- There was a time when a student was put in the “wrong level” of learning in the classroom, thought to be to have a learning disability. His mom reported that she pushed back with this assumption and highlighted the teaching methods and language challenges that were the issue, more so than the intellectual ability of her child. Through her advocacy, this mom was able to have her child properly assessed, and found to be “just fine”- and moved to the appropriate learning level.
- Another mother shared that her child was being pushed around and “mistreated” on the playground at recess. When she approached the school she was told that the student to recess monitor ration did not permit the level of oversight that felt sufficient. Mom felt she did a good job relaying her concern and expectation re: how the children should be managed. (It is important to note that at this point in time a short discussion re: the differences in expectation between Latin families and non-Latin families was part of the issue. It was reported that Latin families expect that part of “education” is the process of teaching manners and moral expectations (eg how we should treat one another)- as a result this mom felt she was able to impress this expectation that she held upon the school personnel that both her child and his peers be instructed in this way.
- Another mother shared that her child’s teacher would explain things 1 time and refused to repeat herself- which this mother thought was a poor teaching method. Mom noted that her child is completely bi-lingual and that she did not see this as a language issue vs a poor teaching process. Mom felt that by using an interpreter she was able to explain how she disagreed with this method.
- One mother shared that her daughter reported being pushed on the playground during recess and having her hair pulled by a peer. When this mom approached the school she was told “Kids will be kids.” This mom felt she was able to successfully advocate that this was not the expectation of safety she had for her child.

### **What are some challenges you have had in advocating for your child?**

Universally, the moms reported that language was the most challenging aspect of advocating for their children, but not all for the same reasons:

- Inability to speak the language as swiftly as the staff with whom they are engaging, and the staff refusing to speak slowly.
- Teachers blaming children’s delays on Learning Disabilities vs reflecting on their teaching methods, speaking slowly to accommodate ESL students, or offering additional support to Latin children.
- School not following the language support protocol.
- Staff evidencing behaviors that could indicate a lack of care for the needs of the non-english speaker (“Bad attitude”, “Dismissive Demeanor”, “Ignorant Behavior”).
  - This was such a point of discussion that it was determined that there was one staff person in particular that all could agree on was “very, very rude”- she was called “La Rubia” (The Blond), and the whole group seemed to instantly recognize and agree on poor engagement skills.

The other challenges were:

- A perception of racism against Latin families
- A lack of cultural sensitivity from auxiliary staff
- A perception of “blaming” language toward the parent from staff when needs or fears re: child’s progress were being highlighted
- Disproportionate need for advocacy with less resources available (1 Interpreter for the whole system, a language line that is not consistently staffed)
- Homelessness being the basis for discrimination
  - One parent shared that when she struggled with housing the staff gave her a hard time about not providing a “permanent address” for her child and tried to keep her from bringing her child to school.
  - When alerted by Kizmet that there was a protocol to support homeless families, the mothers said this was neither acknowledged nor offered to them.

### **How do you manage/overcome these challenges?**

- All the parents reported relying on Ada, older children, and some family members for help when Ada was not available.
- Others acknowledged planning their communication with the school around when the language line was supposed to be available- but that it was not consistently staffed at times.
- One mother shared that she would fight and fight and fight- without backing down. The mothers were very intrigued by this mom’s passion- though it was clear that this mother also had better language skills than most of the other moms.
- One mother shared that since there was such an age difference between her oldest and her youngest, she had learned some helpful skills when her oldest was in elementary school that she could use with her youngest. These included:
  - Knowing which instructors were most responsive, knowing how best to advise her child, being prepared with language support of her own at parent-teacher meetings/conferences.
- One mother was very relieved to report that her child is doing so well that she does not need to advocate, which she hopes will continue as she seemed anxious about some of the realities she was hearing from her fellow mothers.

### **How can you all support one-another with advocating for your children?**

- By partnering with other families, either by going to the school in groups with a shared interpreter, or offering each other’s language support to other families.
- By alerting each other when the language line is staffed/accessible.
- Sharing information about the resources (programs, summer opportunities) that they find.
- By insisting on the school teaching social skills (teaching children to be good people).
- Helping each other “Know your child’s rights” by sharing what you have learned.
- By remembering that it is “ok” to reach out and ask for help.

### **How can the district/programs support or help you in advocating for your child?**

- By providing bi-lingual announcements
- By providing directions re: how to join parent groups
- By having more respect for the b-lingual experience
- By understanding the expectations of “social and moral instruction” of children held by Latin families.
- By offering more recess aids to monitor/prevent aggressive behavior during recess.
- Parent Association advertising better (in multiple languages)

### **Final Synthesis:**

- Ask for help,
- Stand your ground,
- Know your rights

Since we had extra time, I asked the following 3 questions as well:

### **What are some aspects of your personality/traits that you need to “put aside” in order to be a better advocate for your child?**

- Fear and intimidation that I won’t be understood.
- To stop feeling like “Teachers are experts.” I am the expert on my child.
- Trusting my own expertise
- To keep pushing, even when authority figures say “No”\*\*
- To be “ok” with going outside of the chain of command.\*\*
- To not feel bad “insisting” on things\*\*
- To not be afraid to raise my voice.\*\*
- That asking for help is not a shameful thing- or going against your family’s privacy.\*\*

\*\*These were in keeping a brief conversation re: what are traditional Latin values that are hard to overcome when advocating for one’s child.

### **How can we teach our children to become better at advocating for themselves?**

- Teaching our kids how to negotiate disputes
- Teaching our children how to engage their teachers where there is an issue.
- Helping our students learn how to build relationships of trust with their teachers.
- Teach our kids more “solutions” to common problems (standing up for themselves, playing near the recess monitor, etc.)

### **What can I do to become a better advocate for my child?**

- Learn more about my family’s educational rights
- To check in more and support my child consistently
- To show teachers that I stand up for my child.

# Let's Talk...

## *Being Your Special Needs Child's Best Advocate*

### **MODERATOR REPORT**

LOCATION: Kingdom Life Church

DATE: March 16, 2016

**Moderators' names:** Josh Warner, Terrill Thompson, Ray Rose  
Translation – Ada Sykes

#### **About the group:**

Group 1 had nine members, eight female and one male. All participants had at least one special needs child or grandchild in the Pottstown schools, and many had multiple children with special needs. Three group members were African American, two were Hispanic and primarily Spanish speakers, two were Caucasian, one was West African, and one was of mixed race. The age range varied from several young mothers in their 20s and 30s to one great-grandparent. A few group members were primary caretakers for school-aged children that were not their biological kids. Ada, our translator, helped the two Spanish speaking mothers understand the group dialogue and contribute to the conversation.

#### **Advocacy Strengths, or what “superhero” strengths you possess for advocating**

- Great at calming children down
  - Both with her own children, and other family members' kids
  - Even for neighborhood kids, or over the phone
- Great at treating special needs kids as normal
  - Helping them understand they are part of the community, regardless of special needs
- Great at 1-on-1 help; talking to and understanding a single child
  - Requires a lot of listening
  - Having kids “show you” what’s wrong instead of communicating with words
  - Need to be very patient
  - Let the child do the talking
    - *Both the “listening” and the “patience” superhero skills were seconded by other parents*
- Great at knowing her own kids
  - Observing, knowing, and understanding kids' mannerisms, which often communicate sooner or more clearly than words
  - Have to show them love
- Great at communicating expectations to children
  - And also good at communicating these expectations with kids' teachers, to get them on board

- Great at teaching sharing as a skill and value for kids to uphold
- Great at “not being afraid to look like an idiot” when advocating for kids or talking to schools, teachers, providers, or the school district
  - Putting oneself out there to help kids, and not being embarrassed or shy

### What are your success stories advocating for your kids? What has worked?

- Having and requesting face-to-face meetings with a teacher
  - This takes persistence sometimes
  - You have to let the school know what you want to happen with the situation
    - Often, you have to go to the school
    - Request 1-on-1 meeting
  - Getting other parents involved helps too
  - **Barrier:** *one group member was frustrated that bullying done to her child wasn't being addressed. What can be done about bullying when it is hard to get the school to help?*
  
- The programs covered by the Panel presenters really work!
  - Over time, and with parent involvement, the organizations can choose the school, care sites, and other programs that best fit the child
  - This process of “getting things right” has really helped; great successes
  - The coordinators are really good at what they do
  
- The Intermediate Unit workers regularly come into the schools and work with a child on speech therapy, or other special needs
  - This is great
    - Things can happen in schools without need for separate sites or appointments
  - **Barrier:** *the process for getting this to happen can take time, and be confusing*
    - *It helps to have prior practice doing this (like struggling to make it happen for a older child)*
    - *It's much easier with second or third children*
  
- The ability to shift programs or locations to get the best fit and address challenging needs has worked very well
  - “Holcam” or “Holkham” – (we did not clarify what this was, or its spelling, but it seemed like a place or particular program)
  - Tailored programs
    - Several group members said their kids were doing much better given these
  - **Barrier:** *realizing that a certain school or program can't meet a child's needs can take a long time. Sometimes many months.*

- **Barrier:** IEPs can be cancelled (sometimes all of a sudden) for kids, despite the child having non-academic challenges or special needs that need to be addressed
      - One group member mentioned that the 504 Program is good for kids that have special needs, but don't have specific academic or learning needs that would be addressed through an IEP
- One participant noted that the family had pressing questions and needs relating to special needs advocacy for their kids a few months ago, but they asked the right questions, and the schools and other organizations provided the necessary information
  - The parents followed up after the info was provided, and "it all came together"

### **Challenges, or what hasn't worked (yet)**

- Preschool learning and communication growth for bi-lingual children
  - One parent noted that she sees different amounts of communication from her child at home vs. what is reported to her by the teacher at school
    - How much of this issue is due to the challenges of acquiring a new language (English) versus the specific needs of the child?
    - Mother was concerned, in that it is hard to tell if the child should have special needs assessments and help, or if all this is just due to new language learning
    - Mom is now in the process of getting the evaluations mentioned by the Panel presenters
- How can parents get tips & advice from schools or teachers about what works with kids?
  - Behavioral differences at home compared to school

### **Questions formatted to ask the Panel:**

1. What do we do if there is a difference in a child's behavior at school vs. at home
2. For bilingual children, how do we know if struggles at school are cognitive, or merely the challenges of second language acquisition?
3. For students who don't qualify for an IEP, what other options are there?

### **Panel's Answers:**

1. *What do we do if there is a difference in a child's behavior at school vs. at home*
  - This may be a good opportunity for a Wrap-around program mentioned by Holly
  - Investigate if there is a reward system being used at the school
    - Could just be social aspects and group mentality at school, too
  - Kids could just be tired from a long school day
2. *For bilingual children, how do we know if struggles at school are cognitive, or merely the challenges of second language acquisition?*

- *<One panelist helped with this question after the event ended, but I did not hear the whole answer>*
  - There are bi-lingual psychiatrists that work with bilingual children for the evaluation processes related to behavior and education plan needs
3. *For students who don't qualify for an IEP, what other options are there?*
- The 504 Program
  - The Multi-Tiered Systems of Support program/policy (formerly R.T.I.I.)

# **Let's Talk...**

## ***Being Your Special Needs Child's Best Advocate***

### **MODERATOR REPORT**

LOCATION: Kingdom Life Church

DATE: March 16, 2016

**Moderators:** Laura Hinds & Gina Cappelletti

**Moderator's description of the group:**

- 30-40s White man (pastor, parents of 4 kids at Pottsgove incl. those diagnosed with Autism)
- 30-40s White woman (2<sup>nd</sup> grader at Lincoln and 3 ½ year old with special needs)
- 40s Black woman (caretaker for 4 grandchildren, 2 at Rupert, 1 at Pottstown Middle, works as advocate and holds support group for parents of special needs children)
- 20-30s White woman (parent of baby)
- 30-40s White woman (7 year old at Franklin in Autistic support program)
- 30-40s White woman (3 sons incl. one with Autism, 2 at Lincoln)
- 30-40s Black woman (17 year old and 2 children in PreK)
- 30-40s Black woman (observer)
- 30-40s Black woman (limited participant)

Approximately half of the participants had previously attended a Let's Talk event. All participants had children or grandchildren with special needs (most commonly Autism). Participants sustained conversation throughout the discussion with all participants contributing experiences or ideas. The room was loud, making it hard for participants to hear each other at different points. Participants spoke to the facilitators directly, but also offered advice and support directly to each other. Two FAC members were seated behind the circle at a table in the back of the room and were not directly participating, though one woman commented at the end about her experiences with her son for whom she had recently initiated the process of identifying needs and services. Participants cited attending this particular Let's Talk because they had children with special needs and wanted to learn more about services and be involved in support their child(ren). Many spoke of challenges when their child(ren) were first diagnosed and of not knowing what to do. In addition, they share about the different ways in which they navigated the process of

**Strength you have as an advocate for your child(ren):**

Most participants were able to self-identify strengths. In some cases, participants shared about ways in which they handled various situations involving their children with special needs and Laura, as the moderator, was able to reframe this work as a strength. In advocating for their children with special needs, parents discussed the following strengths:

- The pastor said that his position as a school board president was a strength for him in being able to navigate issues and get what he needed for his children. He also shared that he was comfortable in speaking up and not being afraid to hurt others' feelings in the process in order to get what was needed for his child(ren). He used the term "being selfish" to describe the process of ensuring his children get what they need. Another parent agreed with this sentiment saying that she acts like a "mama bear" in being protective of her children.
- Two parents shared similar strengths related to accepting responsibility for their own role in the process (of diagnosis and support services), recognizing that it is their job to do more than just agree with what others are telling them. They believe it is their responsibility to "do more than just say 'OK'" to what is being told to them about their own child.
- There was agreement from several parents about working together as a team with those involved in their child's life as a strength. This included working as a team with a spouse, teachers, school personnel, and service providers.
- Other strengths echoed by several parents included: asking questions, working to get the information you need, keeping notes, requesting meetings, and coordinating meetings, people, and being aware of resources and how to access them.
- A mother who felt she was less successful in supporting and acting as an advocate for her oldest child was unsure of her strength. She talked about how she was here because she is working to do better with her youngest children. In a discussion with another mom and the moderator, her story was reframed to recognize her strength in self-acceptance and in trusting that she did/is doing her best to support her child(ren). Along with this, she shared that she was reflecting on how she could become a better advocate or better support her child(ren).
- One mom shared that she works to know the people her children interact with (teachers, support service providers) and build relationships with these people. This allows her to provide specific directions to the people her son interacts with based on her own knowledge of her child's needs
- One mom shared that though she didn't feel as though she had specific traits of an advocate, she was well engaged with her child's teacher and that relationship influenced the teacher's decision to engage larger systems on her child's behalf. The moderator highlighted that this mom clearly had effective skills in engaging relevant people in her child's educational sphere into mobilizing others in support of her child.
- One mom shared at the very end that her son has been diagnosed with Precocious puberty and as a result is bigger and looks older than other kids his age. She said her strength is in "talking reality" by reminding people not to jump to conclusions about her son and reminding them that he is still a child

**Successes/supports: What are the things participants identified as part of their success in advocating for their child(ren) or what they learned from their experiences of working to advocate for their child(ren) with special needs**

Generally, participants focused less on what they learned from the panel presentation and

more on what they've learned over time in their own experiences in working to support and in advocating for their child(ren) with special needs.

- One mom said she learned that medical assistance and outside services (which were talked about during the panel) were really important to her family. Even though her family had private health insurance, many of her son's issues were initially medically based and the family was not able to afford all the co-pays and deductibles associated with the care. Once accepted onto Medical Assistance their son was provided opportunities for services and supports that her family did not think about, did not think they had access to, nor could afford even with insurance. This mom shared that once her son was accepted into Medicaid, a world of services were available to him that she would never have known to pursue. Her family learned about medical assistance early in the process of her son's diagnosis through Early Intervention.
- Several parents, including the mom above, discussed the ways in which Early Intervention provides helpful support including: helping to facilitate connections to resources; helping families to understand milestones for kids and where their own child falls within this; providing support for filling out paperwork; and helping parents navigate the complex "rules" of the process of getting children supports. This mom also highlighted that this knowledge not only empowered her to address her son's needs, but educated her on things to monitor and correct with her younger children as well, putting her entire family "on the right track", stating that everyone is now doing "beautifully."
- Parents reiterated several times during the night the importance of asking questions and being assertive. Related was the sense that they as parents know their child better than anyone which should give them a sense of confidence in being able to ask questions. Later another parent stated that there are no bad questions to ask.
- A caregiver for her grandchildren who also works as an advocate herself shared that even though she is an advocate herself, it's really important to bring someone with you to meetings. She stressed the importance of a second set of eyes and ears in receiving information about your child or services. She said that in her own experience, she as the caregiver, tends to get emotional when receiving information. Having an advocate can provide emotional support and can help you to interpret information heard when you might feel emotional.
- The same caregiver also shared about the need to consistently follow up on the child's IEP, their progress, and next steps in the identification/support process for the child. Along with this is the need to ask for different things during the process if you are not seeing progress or if supports are not being provided. For example, she talked about asking the school for a functional behavior assessment (FBA) of the child if the child's needs were not being recognized by the teacher or school.

**Barriers : What are the things participants identified as part of their success in advocating for their child(ren) and where possible ideas for doing it differently next time.**

- One mom said that she had a lot of success in advocating for her child with special

needs prior to age 3 – she felt like she was able to work well with those providing support for her child and that things were going smoothly. She talked about challenges with transitions after age 3 when there is a different set of providers working with her child. She said that the transition is “not happening” and seemed frustrated by lack of consistency in services and systems.

- Parents talked about the challenge of many acronyms they are not familiar with being used at meetings and in paperwork and overall confusing information being shared about their child or services. The advocate said that she has a cheat sheet of acronyms that she can share to alleviate this concern.
- Other parents echoed frustration with different systems, rules, and personnel for different age groups. As children age and move to a different service, they have to adjust to new people who may not know the child or the system as well.
- In addition, parents talked about the “revolving door of people” within service providers and the overall lack of communication and disorganization within schools and support agencies among providers. Information related to their child(ren) and support services for their child(ren) was not consistently shared between the involved agencies.
- The woman who works as an advocate said that a challenge is that even with insurance not all services are provided and it is hard to deal with the red tape of the system.
- A parent shared that there was a barrier related to perceptions around receiving medical assistance and concerns about how others might view this as a handout rather than a service needed to support their child(ren).
- A FAC member sitting behind the circle shared at the end that her son is in the process of diagnosis and determination of services, but that it is frustrating when this process of “long and dragging” when her son needs help more immediately. She felt like he was “losing time”.
- In highlighting the need to “speak reality “ to providers, a mom shared that the inaccurate perceptions of her child by those tasked with serving him was a barrier to her child’s success.

**Questions/Help: What are the things participants identified as specific areas where they might need support or more information?**

- One mom shared that her older son had an IEP throughout school but that he never had a specific diagnosis that would require an IEP, only that he was below grade level. She also felt that this reality held her son back from his full potential and that to this day he is not as functional as she wishes he were. This mom felt this was a failure on her part in not advocating well enough for him in his youth. This raised the question of how much say you have as a parent and how parents might be able to speak up and fight for what they believe for their child when being told certain information by the teacher or school.
- A mom expressed frustration that the process of getting your child diagnosed and finding services is a long process and asked why it takes so long. Another mom raised the issue of timelines associated with different parts of the process of diagnosis and

securing support services and where parents might find this information so they might have a better sense of how long certain steps should take.

- A mom asked, in relationship to the challenges of “navigating the system” if there was someone who acted similar to a “patient coordinator” providing information and support to parents as their child(ren) went through the process of diagnosis and securing services and if this person exists what their title is.