



Changing the Way We Approach Medically Complex Children: A Screener for Unmet Needs

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Abstract

Medically complex children have at least one chronic condition resulting in high service needs, including medication, equipment and multiple subspecialist involvement. Evidence has shown that increased care coordination reduces the number and length of hospital stays, and decreases healthcare costs.

The Rainbow Medical Home Initiative (RMHI) at Children's Hospital Primary Care Center targets the medical and social care coordination needs of this population. In 2011, 91.3% of caretakers reported unmet needs in at least one of the following areas: medical equipment, medical supplies, educational and therapy services, mental health support, recreational/social opportunities and home caregiver support. 47.1% reported unmet needs in 3 or more areas. The objectives of this project are: 1) develop a screener for unmet needs amongst RMHI families; and 2) assess the acceptability and feasibility of incorporating this screener into routine care. If successful, this screener will allow providers to more proactively address patients' unmet needs.

Two focus groups and 4 individual cognitive interviews of families were performed to evaluate the completeness, format and literacy level of a draft of the screener. The screener was piloted during the summer of 2012 at patient visits. Feedback on the acceptability and feasibility of screener implementation was solicited through surveys from stakeholders (patient families, providers, social work and administrative staff). Qualitative feedback was solicited in group format from stakeholders to elicit process issues not accounted for by our surveys. Feedback was incorporated into a more refined screener that was distributed during the second half of summer. A similar feedback cycle was performed to develop the final screener.

Major unmet needs identified by the 70 completed screeners are: securing educational services (12/25, 48%), finding people or programs parents can trust to help care for their child

(22/68, 32%) and finding recreational/social opportunities (21/69, 30%). The 74 stakeholders queried generally agree that the screener helps identify needs and improves communication between providers and families. Most stakeholders believe that the screener is feasible to incorporate into routine practice.

This project will improve the effectiveness and efficiency of our medical home by enhancing our understanding of our patients' non-medical issues. Future directions include screener incorporation into routine practice; screener translation into Spanish; ongoing data collection of unmet needs; development of resources to respond to these needs; dissemination of results to clinical care teams and training on resources designed to address them.

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Glossary for Abbreviations/References

CHPCC	Children's Hospital Primary Care Center
RMHI	Rainbow Medical Home Initiative
Stakeholders	Patient families, providers, social workers and front desk workers

1. Introduction

Specific Aims

The Children's Hospital Primary Care Center (CHPCC) provides medical care for 14,000 infants, children and young adults. The CHPCC's Rainbow Medical Home Initiative (RMHI) was established in 2006 to coordinate the unique medical and social needs of children with special healthcare needs. The goal of this project is to improve the quality of care for RMHI patients by implementing a tool that screens proactively for unmet needs during routine primary care. The unmet needs for which we specifically screened include medical supplies, medical equipment, educational and therapeutic services, recreational/social opportunities, mental health and home caregiver support. We surveyed CHPCC providers, nurses, administrators, social workers and families to elicit feedback on the screening instrument. We also evaluated the acceptability and feasibility of the screening tool by administering questionnaires to families, providers, social workers and front desk staff to evaluate whether the screener can be incorporated into routine care and whether unmet needs were identified. We will use the continuous quality improvement methodology to refine the instrument over a time period of 7 weeks during the summer.

Significance:

Medically complex children or children with special health care needs can be defined as children with at least one chronic condition resulting in high service need for families, medication equipment addressing functional difficulties, multiple subspecialist involvement and/or elevated health service use. (Zuo, Cohen, Agrawal, Berry, & Casey, 2011). This is a vulnerable population as these children are at risk for having poor health outcomes, often as a

result of decreased care coordination (Cohen, et al., 2010). For example, during transitions in care, medically complex children are at higher risk for medication errors than typically developing children (Stone, Sabrina, Mundorff, Maloney, & Srivastava, 2010). Preliminary evidence has shown that increased care coordination leads to reduced length of hospital stays, number of admissions and healthcare costs (Hall, 2011).

The RMHI at CHPCC was established in 2006 to target the unique medical and social care coordination needs of this patient population. To this end, an interdisciplinary team composed of a medical director (Dr. Romi Webster), nurse practitioners, social workers and administrative staff was assembled. RMHI identifies medically-complex children (See Appendix 1: Rainbow Medical Home Initiative Criteria) and implements patient- and system-level supports designed to improve access, care coordination and service delivery for each child. To date, approximately 800 patients have been identified. Many RMHI patients have complex medical conditions including cerebral palsy, hydrocephalus, immunologic conditions, organ transplants and congenital heart disease. Neurodevelopmental conditions (including autism, developmental delay and cognitive disability) also are represented either as the qualifying chronic condition, or in addition to the medical complexity. Many Rainbow patients are dependent on medical technology such as feeding tubes, tracheostomies, supplemental oxygen and wheelchairs for daily living. RMHI has flagged these patients as Rainbow patients in their scheduling system. As a result, Rainbow patients have access to prioritized immunizations, longer visit times, and improved continuity of care with a dedicated Rainbow nurse practitioner who is able to see them when the PCP is unavailable.

Due to the medical and psychosocial complexity of CHPCC's patient panel, a reactive system has evolved where needs may not be identified until they are at a crisis point. During the

summer of 2011, second-year medical student Madeline Coquillette conducted a needs assessment amongst RMHI families regarding the type and extent of psychosocial needs that would impact care coordination. She found that a high number of caregivers (91.3%) reported unmet needs in at least one of the following areas screened: medical equipment, medical supplies, educational and therapy services, mental health support, recreational/social opportunities and home caregiver support. Notably, 47.1% reported unmet needs in 3 or more areas. Ms. Coquillette's project was the first to collect psychosocial data on the Rainbow population, and the prevalence and intensity of the unmet needs was concerning.

Since that time, I worked with Dr. Webster, Madeline Coquillette and the Rainbow Team to develop an Unmet Needs Screening Tool for Rainbow Families (See Appendix 2: Draft of Screening Tool). We gathered feedback from families about the instrument and determined the strategy for roll-out of the screening tool during 2011 to 2012. During the summer of 2012, I tested the feasibility of administering the screening tool and evaluated the needs that emerged from RMHI families.

Innovation:

Prior to this innovation, when RMHI patients came to CHPCC for a visit, they were presented with screening tools that were developed for typical children. These tools asked questions about major behavioral, emotional and social needs that typically developing children may have. As many medically complex children exhibit developmental delay or physical disability, providers noted that Rainbow caretakers and patients often found these questions irrelevant and sometimes even offensive. Furthermore, the ineffectiveness of current screeners to identify issues specific to RMHI patients was demonstrated by Madeline Coquillette's research as above. As a result, this project aimed to test the roll-out and utility of a screening tool

designed specifically for RMHI patients. The one-page screener was developed with the intention of maximizing proactive care coordination, while minimizing the burden of additional paperwork for providers, administrative staff, caregivers and patients. If successful, this screener would allow PCPs to proactively address patients' needs and improve quality of care for patients.

2. Methods

Based on an analysis of the unmet needs assessment performed by Madeline Coquillette on RMHI caregivers, the screener domains covered included education, therapy services, recreational or social opportunities, mental health and emotional support services, medical equipment, medical supplies and prescription refill needs. We also included a question on transition to adulthood as this is a time of increased vulnerability for these patients and one of the quality improvement goals of RMHI. The screener was drafted using Microsoft Publisher (See Appendix 2.1).

Two focus groups of 4-6 parents each and 4 individual cognitive interviews were conducted to integrate the perspective of families into our draft screener. A pre-established Rainbow Parent Advisory Board meeting was used as one of the focus groups, and the second focus group was recruited via PCP recommendation. The goal was to recruit a diverse group of participants covering a range of education levels, racial and ethnic backgrounds, socioeconomic status, ages of children and diagnoses of children. Dr. Romi Webster led the focus groups with 2 to 3 separate observers present. The sessions were audio-recorded to ensure our ability to identify themes generated after the focus groups. During this phase, only Dr. Romi Webster, Madeline Coquillette and I had access to data from the interviews. Data was stored in a locked cabinet in Dr Webster's office to which only Dr. Webster, Madeline Coquillette, Rachel Grant (a research assistant working on a separate project) and I had access. Digital recordings of the focus groups were downloaded onto CD's that were stored in the locked cabinet.

The 4 cognitive interviews were conducted with interested parents with a refined screener to ensure that the screener was clear, understandable and reliable. Interested parents were recruited when they came for their appointments at CHPCC. The feedback from the cognitive

interviews and focus groups was incorporated into a pilot screener that distributed during the first half of summer 2012 (See Appendix 2.2).

During the summer of 2012, the pilot screener was distributed to RMHI patients. The front desk staff provided the pilot screener to families as they checked in for their appointments at CHPCC. They were given instructions to complete it prior to seeing the provider. These were distributed to families at Rainbow Return and Rainbow Well Child Care visits. Screeners were not distributed to families at CHPCC for sick or urgent care visits. The providers then reviewed the screener with the patient and clarified any questions or concerns. Providers addressed the issues raised themselves or would make a referral to the social worker on call for assistance. The providers then put the screeners (complete and incomplete) into a box in the large conference room where providers were already sorting out billing sheets, developmental screens and other papers generated during the course of the visit. We collected the screening tools from the box.

In terms of evaluating feasibility and acceptability, surveys were administered to CHPCC stakeholders, which included providers, social workers, front desk and administrative staff, families and patients (See Appendix 3). For families and patients, I did a brief structured 1:1 interview at the end of the patient visit to inquire about the screener's usefulness in eliciting concerns and accessing resources, the screener's ease of use, the caretaker's willingness to use the screener in the future and ideas for improvement. For providers, social workers and administrators, we targeted staff members who had used the tool and asked them to respond to a brief survey (See Appendix 3) regarding whether the screener was helpful in identifying patient needs, the influence of the screening tool on workflow, productivity and referral generation as well as ideas for improvement. We attempted to receive feedback from at least 70% of the providers, social workers and administrators halfway through the summer and at the end of the

summer. The survey was anticipated to take the respondents 1 to 2 minutes to fill out. This feedback format was used because feedback has been collected from individuals in this proposed format with other implementation studies in CHPCC and worked well in the past. In addition to individual survey feedback from stakeholders, we sought group feedback on the implementation at pre-established provider, staff and social work meetings. The feedback solicited halfway through the summer was used to generate a more refined screener that was distributed throughout the second half of summer. Similarly, the feedback received from the second half of summer on the screener was used to generate the final screener.

In terms of patient medical record keeping, data from the screener was not entered into the electronic medical record unless the physician deemed the information pertinent to include in the medical record. In the course of this study, no screener was entered into patients' electronic medical records.

Summer 2012 Timeline:

	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7
Implementation of Screener Version 1	X	X	X				
Individual feedback from providers, social workers, administration, regarding Screener 1	X	X	X				
Group feedback from providers, social workers, administration regarding Screener 1			X				
Changes to Screener Version 1 Made			X				
Implementation of Screener Version 2				X	X	X	
Individual feedback from providers, social workers, administration, families regarding Screener 2						X	
Group feedback from providers, social workers, administration regarding Screener 2						X	
Data Analysis and Evaluation of Screener Impact, Acceptability and Feasibility	X	X	X	X	X	X	X

3. Results

Based on the focus groups and cognitive interviews, the main themes that emerged were that families wanted help with transitioning from Early Intervention to school, guardianship, opportunities to decrease social isolation, and greater awareness of possible assistance (including financial, respite and educational resources).

A total of 77 screeners were completed over the summer. The major unmet family needs identified were 1) Of the caretakers with children age 3 or older, 36% wanted help with educational services (14/39); 2) 32% of caregivers had concerns finding recreational opportunities (25/77); 3) 31% of caregivers had concerns finding people or programs that they could trust to help care for their child (24/77).

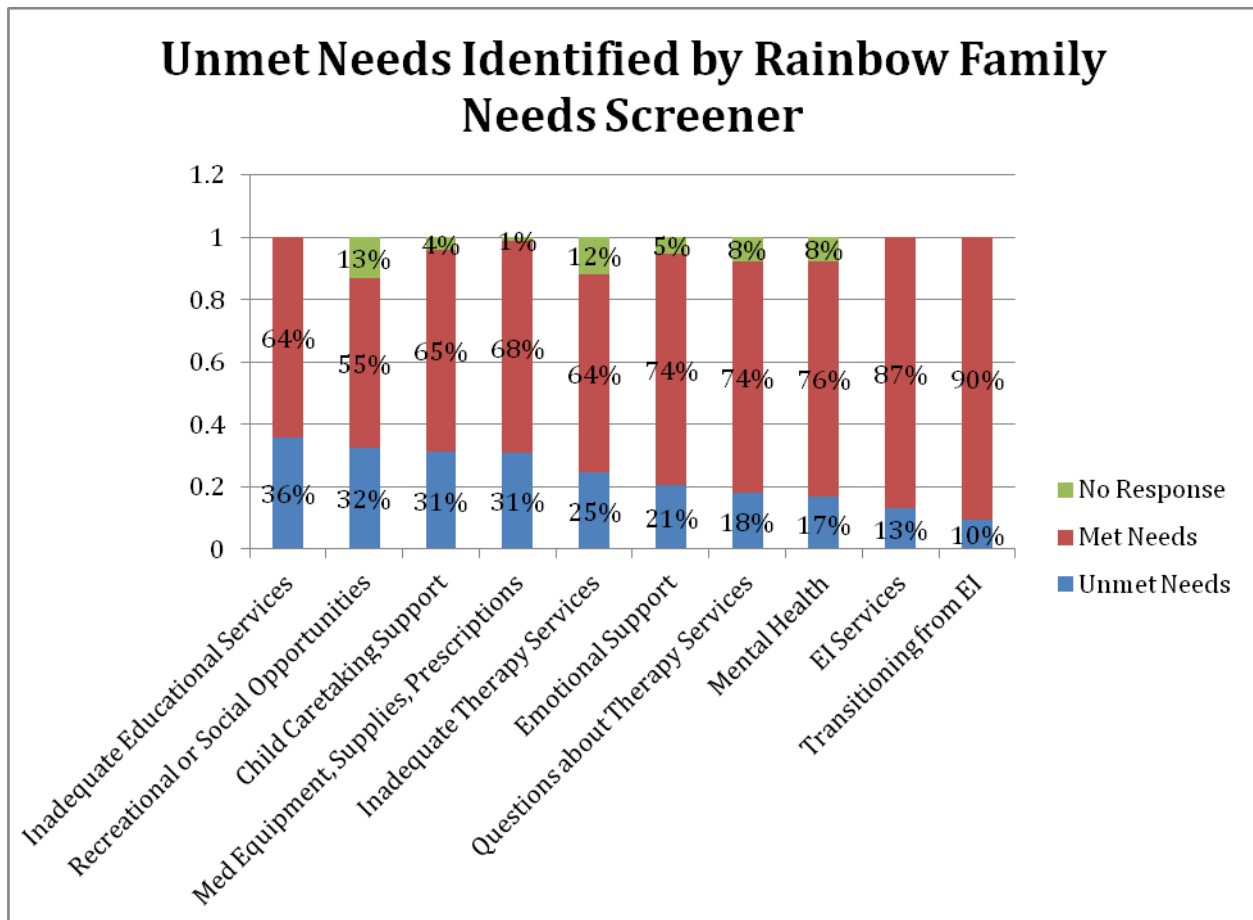


Figure 1. Needs Identified by Rainbow Family Needs Screener

In terms of stakeholders' feedback (patient families, providers, social workers and front desk staff), 74 stakeholders responded including 1 provider, 8 social workers, 7 front desk staff and 58 families. Of note, although all 9 providers who work at CHPCC were approached for feedback, only 1 of the 9 providers had patient families that used the screener and could therefore provide relevant feedback on the screener for this study's purposes. The stakeholders queried generally agreed on the following: 1) Stakeholders are comfortable responding to the needs identified. 2) The screener will improve communication between providers and families. 3) The screener is important in taking care of RMHI patients and families. 4) The screener seemed difficult to incorporate into routine practice for providers, in part due to time constraints and formatting issues (See Appendix 4). In addition, when Social Work was queried during their staff meeting, none of the social workers reported a significantly increased burden on their services due to screener implementation.

4. Discussion, Conclusions, and Suggestions for Future Work

The greatest unmet family need identified from the screener was that families wanted help with educational services. This could be addressed by referring patients who indicate this need to the Advocating Success for Kids (ASK) program that is already established at Children's Hospital. ASK consists of a multidisciplinary team that consists of staff in developmental medicine, social work, education and psychology. Given the medically complex nature of Rainbow children, ASK can uniquely help parents by making personalized recommendations regarding their children's education, educate parents about child development and ways to navigate school systems, and empower parents to become advocates for their children.

The second greatest unmet family need identified from the screener was a desire for help finding developmentally appropriate recreational opportunities. Currently available resources specific for medically complex children are mainly pamphlets for summer programs. While there are many recreational opportunities in Boston for medically complex children, there is no centrally compiled and constantly updated list of these opportunities. Therefore, one potential future direction is to compile a set of developmentally-appropriate recreational resources for medically complex children.

The third greatest unmet family need identified was finding people or programs that caregivers can trust to help care for their child. Through speaking with parents at the focus groups, we learned that respite homes and programs are available but are not widely advertised. In the future, through working with parents, a set of resources including respite home resources could be compiled and communicated with parents. This will potentially decrease caregiver stress while maintaining continuity of care for medically complex children.

One of the most salient themes that emerged from the feedback solicited from stakeholders was that although most stakeholders felt that the screener was important to proactively identify unmet needs amongst patients, a more efficient manner of reviewing the screener was needed. Some methods that were tried included rewording questions to ensure that pertinent answers were all marked as “yes” or “no.” However, this involved rewording some questions in a manner that was difficult to understand and would undermine our goal of having a user-friendly screener for patients’ families of most literacy levels. Another idea was to have an “answer sheet” with all the pertinent positive and negative answers printed on a transparency. This transparency could then be left in the large conference room at CHPCC where most residents present to attendings between patient appointments. However, this idea was used with a different research project with poor outcomes, including providers not being able to find the answer sheet in the room, or the answer sheet getting lost. Thus, the final version of the screener developed involved bolding the pertinent positives or negative answers on the screener (see Appendix 2.3). While we recognize that this may bias our patients’ families as they fill out the screener, we also feel that it is very important to have a screener that is user-friendly enough for all stakeholders to use to identify patients’ unmet needs proactively and intervene accordingly.

In conclusion, the main themes that emerged based on the cumulative feedback from the focus groups, cognitive interviews and feedback surveys from stakeholders are the following: 1) Families appreciate and expect their child’s medical home to address their non-medical unmet needs; 2) Screener incorporation into routine care may lead to more proactive identification, assessment and addressing of unmet needs; 3) Time constraints seem to limit the ability of providers to review the screener during patient visits; 4) There is a need to develop systems and resources to support screener implementation and respond to unmet needs.

One of the main limitations of this study was the low number of providers who could provide feedback for our study. While there are 9 providers who work at CHPCC, only 1 of the 9 providers had a Rainbow patient who used the screener during our study's timeframe and could provide feedback on the utility of the screener. This factor is potentially complicated by the fact that the principal investigator in this project is also the director of the Rainbow Medical Home Initiative and therefore often sees many of the Rainbow patients in clinic. Given the conflict of interest, the principal investigator's feedback on the screener was not counted in the feedback screeners provided to providers. However, this also significantly lowered the number of other providers who saw Rainbow patients during the short 6 week course of our screener implementation and from whom we could collect feedback from. In the future, the timeline of screener use could be lengthened to account for this limitation and increase the number of providers who can provide feedback on the screener.

Suggestions for future work include responding to the needs identified by the screener, evaluating the adequacy of existing support structures and developing resources to cater to needs identified by the screener. For example, with the implementation of team-based clinical care, a response system to the screener could include response specialists, patient navigators and social workers rather than relying solely on the medical provider. Other suggestions include translating the screener into Spanish and collaborating with the Online Advocate (<http://www.onlineadvocate.com/>) and the Department of Social Work to enhance response tools for frequently endorsed unmet needs (e.g. adaptive recreational/social community resources). Finally, the screener could be expanded to non-RMHI patients in CHPCC who have relevant chronic illnesses (asthma, obesity, ADHD etc) who may benefit from the screener.

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Rainbow Criteria


Child must meet one or more criteria below:

1. Severe single system disorder (*e.g., insulin dependent diabetes, seizure disorder, mental retardation, severe developmental delay*) -excluding patients with asthma and psychiatric disorders.
*Patients with asthma or mental health issues should be referred to the CHPCC Asthma Team or Mental Health Team for care coordination.
2. Biologically-based severe health problems involving **more than one** body system (*developmental, psychiatric or psychological disorders do count as a single system*)
3. Simultaneous involvement with more than one medical specialist (*M.D. level*) with each referral expected to last for more than 12 months
4. More than three hospitalizations in the prior year or a hospitalization in the prior year that lasted for more than 15 days
5. Dependence on medical technology:
 - Gastrostomies
 - Tracheostomies
 - CPAP
 - Ventilators
 - Oxygen
 - Mechanical Hospital Bed(Nebulizers alone for asthma do not qualify)
6. Dependence on a wheelchair
7. Ongoing need for home or school-based health care services in addition to one of the above:
 - Home Health Aides
 - Visiting Nurses
 - Block Nursing Hours
 - Physical Therapy
 - Speech Therapy
 - Occupational Therapy
 - Other

***Qualifies as a Rainbow Patient only if child has met criteria for the last 12 months or if the criteria/condition is expected to last for more than 12 months.**

This information was originally developed by: Palfrey JS, Sofis LA, Davidson EJ, Liu J, Freeman L, Ganz ML. The Pediatric Alliance for Coordinated Care: Evaluation of a Medical Home Model. *Pediatrics*. 2004;113;1507-16. It was modified by the Rainbow Team at Children's Hospital Primary Care Center, December, 2008.



Appendix 2.1: Draft of Screener Tool Prior to Focus Groups and Cognitive Interview Feedback




The Rainbow Team at CHPC

Patient Label

Rainbow Family Needs Screener

	Yes	No
Is your child enrolled in Early Intervention (EI)?	<input type="checkbox"/>	<input type="checkbox"/>
If yes, do you have any concerns about the services that your child gets from EI?	<input type="checkbox"/>	<input type="checkbox"/>
do you have concerns about your child transitioning from EI to public school services?	<input type="checkbox"/>	<input type="checkbox"/>
If no, are you interested in your child getting EI?	<input type="checkbox"/>	<input type="checkbox"/>
Does your child go to school (such as Head Start, preschool)?	<input type="checkbox"/>	<input type="checkbox"/>
If yes, does your child get any educational services at school?	<input type="checkbox"/>	<input type="checkbox"/>
do you feel your child needs educational services that they are not getting?	<input type="checkbox"/>	<input type="checkbox"/>
If no, would you like your child to be in school?	<input type="checkbox"/>	<input type="checkbox"/>
If your child receives therapy services (such as physical, occupational, speech or language therapy), do you have questions or concerns about those services?	<input type="checkbox"/>	<input type="checkbox"/>
If not, do you feel that your child needs therapy services they are not getting?	<input type="checkbox"/>	<input type="checkbox"/>
Do you have any questions about your child's transition to adulthood (such as legal guardianship, or the ability to make medical decisions)?	<input type="checkbox"/>	<input type="checkbox"/>
Would you like help finding recreational or social opportunities that are appropriate for your child?	<input type="checkbox"/>	<input type="checkbox"/>
Caring for a child can be stressful. On average, over the past two weeks, how stressed have you been feeling?		
 1 2 3 4 5 6 7 8 9 10 		
Would you like help finding emotional or other support for you, your child's siblings or other family members?	<input type="checkbox"/>	<input type="checkbox"/>
Would you like help finding mental health services or support for your child?	<input type="checkbox"/>	<input type="checkbox"/>
Do you have people who can help you take care of your child?	<input type="checkbox"/>	<input type="checkbox"/>
Do you need help with any medical equipment, supplies, or prescriptions today?		
What other questions or concerns do you have today?		
Would you like to talk to a social worker today?	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 2.2: Screener Pilot 1 with focus groups and cognitive interview feedback incorporated
(distributed during 1st half of summer 2012).

	<div style="border: 1px solid black; padding: 5px; min-height: 40px;">Patient Label</div>	
Rainbow Family Needs Screener Please fill out this form to help us better understand your needs.		
		Yes No
If your child is less than 3 years old, is your child enrolled in Early Intervention (EI)?		<input type="checkbox"/> <input type="checkbox"/>
If yes, do you have any concerns about the services that your child gets from EI? do you have concerns about your child transitioning from EI to public school services?		<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
If no, are you interested in your child getting EI (home-based developmental support)?		<input type="checkbox"/> <input type="checkbox"/>
If your child is 3 or older, does your child go to school (such as Head Start, preschool, elementary school, middle school, high school)?		<input type="checkbox"/> <input type="checkbox"/>
If yes, does your child get any educational services (such as IEPs) at school? do you feel your child needs educational services that they are not getting?		<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
If no, would you like your child to be in school?		<input type="checkbox"/> <input type="checkbox"/>
If your child receives therapy services (such as physical, occupational, speech or language therapy), do you have questions or concerns about those services?		<input type="checkbox"/> <input type="checkbox"/>
Do you feel that your child needs therapy services they are not getting?		<input type="checkbox"/> <input type="checkbox"/>
Would you like help finding recreational or social opportunities (including summer or afterschool programs) that are appropriate for your child?		<input type="checkbox"/> <input type="checkbox"/>
If your child is 12 or older, do you have any questions about your child's transition to adulthood (such as legal guardianship, or the ability to make medical decisions)?		<input type="checkbox"/> <input type="checkbox"/>
Caring for a child can be stressful. On average, over the past two weeks, have you felt stressed? If so, how often? Sometimes Often Always		<input type="checkbox"/> <input type="checkbox"/>
Would you like help finding emotional or other support for you, your child's siblings or other family members?		<input type="checkbox"/> <input type="checkbox"/>
Would you like help finding mental health services or support for your child?		<input type="checkbox"/> <input type="checkbox"/>
Do you have people or programs you can trust who can help you take care of your child (such as nursing, family, friends, respite homes)?		<input type="checkbox"/> <input type="checkbox"/>
Would you like to talk to a social worker about finances, food, housing, behavioral health services or other concerns?		<input type="checkbox"/> <input type="checkbox"/>
Do you need help with medical equipment, supplies, or prescriptions? If so, please specify:		<input type="checkbox"/> <input type="checkbox"/>
Do you need help getting an appointment with a specialist? If so, please specify:		<input type="checkbox"/> <input type="checkbox"/>
Do you have other questions or concerns? Please feel free to write on the back.		<input type="checkbox"/> <input type="checkbox"/>

V2

Appendix 2.3: Screener Pilot 2 (distributed during 2nd half of summer 2012)



Rainbow Family Needs Screener

Please fill out this form to help us better understand your needs.

Patient Label

Yes No

If your child is less than 3 years old, is your child enrolled in Early Intervention (EI) ?		<input type="checkbox"/>	<input type="checkbox"/>
If yes,			
do you have any concerns about the services that your child gets from EI?		<input type="checkbox"/>	<input type="checkbox"/>
do you have concerns about your child transitioning from EI to public school services?		<input type="checkbox"/>	<input type="checkbox"/>
If no,			
are you interested in your child getting EI (home-based developmental support)?		<input type="checkbox"/>	<input type="checkbox"/>
If your child is 3 or older, does your child go to school (such as Head Start, preschool, elementary school, middle school, high school)?		<input type="checkbox"/>	<input type="checkbox"/>
If yes,			
does your child get any educational services (such as IEPs) at school?		<input type="checkbox"/>	<input type="checkbox"/>
do you feel your child needs educational services that they are not getting?		<input type="checkbox"/>	<input type="checkbox"/>
If no,			
would you like your child to be in school?		<input type="checkbox"/>	<input type="checkbox"/>
If your child receives therapy services (such as physical, occupational, speech or language therapy), do you have questions or concerns about those services?		<input type="checkbox"/>	<input type="checkbox"/>
Do you feel that your child needs therapy services they are not getting?		<input type="checkbox"/>	<input type="checkbox"/>
Would you like help finding recreational or social opportunities (including summer or afterschool programs) that are appropriate for your child?		<input type="checkbox"/>	<input type="checkbox"/>
If your child is 12 or older, do you have any questions about your child's transition to adulthood (such as legal guardianship, or the ability to make medical decisions)?		<input type="checkbox"/>	<input type="checkbox"/>
Caring for a child can be stressful. On average, over the past two weeks, have you felt stressed ?		<input type="checkbox"/>	<input type="checkbox"/>
If so, how often? Sometimes Often Always			
Would you like help finding emotional or other support for you, your child's siblings or other family members?		<input type="checkbox"/>	<input type="checkbox"/>
Would you like help finding mental health services or support for your child?		<input type="checkbox"/>	<input type="checkbox"/>
Do you have people or programs you can trust who can help you take care of your child (such as nursing, family, friends, respite homes)?		<input type="checkbox"/>	<input type="checkbox"/>
Would you like to talk to someone from Primary Care about finances, food, housing, behavioral health services or other concerns?		<input type="checkbox"/>	<input type="checkbox"/>
Do you need help with medical equipment, supplies, or prescriptions ? If so, please specify:		<input type="checkbox"/>	<input type="checkbox"/>
Do you need help getting an appointment with a specialist? If so, please specify:		<input type="checkbox"/>	<input type="checkbox"/>
Do you have other questions or concerns ? Please feel free to write on the back.		<input type="checkbox"/>	<input type="checkbox"/>

V3 08/15/2012

Appendix 3: Stakeholder Feedback Surveys

Needs Screener Quick Survey Patient/Family



For the past few weeks, we've been using the Rainbow Family Unmet Needs screening tool at CHPCC. Please think about your experience using the screening tool and answer the following questions. Thank you!

1) Have you ever heard of CHPCC Rainbow Team or the Rainbow Medical Home Initiative?

- ☐ Yes
- ☐ No

Please let us know how much you agree or disagree with the following statements:

2) It was easy to fill out the screening tool.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

3) The screening tool helped me organize my thoughts before my child's visit.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

4) The screening tool helped me communicate with my child's provider during the visit.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

5) The screening tool made me aware of resources that I did not realize were available before (such as help with therapy services, mental health or school).

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

6) It would be useful to fill out this screener at my child's future CHPCC visits.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

7) Are there needs that we should be asking about that were not included in the screening tool?

- ☐ Yes
- ☐ No

If yes, please tell us what else you think should be included on the lines below.

8) Please list ideas you have for improving the Rainbow Screening Tool.

Needs Screener Quick Survey Providers



For the past few weeks, we've been using the Rainbow Family Unmet Needs screening tool at CHPCC. Please think about your experience using the screening tool and answer the following questions. Thank you!

1) Have you had any rainbow patients who have filled out the new screening tool?

- ☐ Yes
- ☐ No

If no, please end here. Thank you for your time.

If yes, please indicate to what extent you agree or disagree with the following statements

2) I found the screening tool to be useful in identifying family needs at the visit.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

3) I felt that the incorporation of the screening tool made the visit duration longer.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

4) The screening tool helped me communicate with the patient's family during the visit.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

5) The family's responses to the screening tool raised issues that I did not have time to address during the visit.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

6) I felt comfortable responding to the needs identified by the screening tool.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

7) Did you make any referrals in response to the screening tool?

- ☐ Yes
- ☐ No

If so, please indicate any referrals you made based on the screening tool:

- ☐ Social Work on call
- ☐ CHPCC Psychosocial Referral in Powerchart
- ☐ Referral to CHPCC Community Resources specialist (M. Jaikaran)
- ☐ Referral to community resource or agency outside Children's Hospital
- ☐ Referral to another program in CHPCC
- ☐ Referral to a medical subspecialist
- ☐ Referral to Rainbow Team for assistance/care coordination
- ☐ Other, please specify: _____

8) The Rainbow screening tool is important for taking care of our Rainbow patients and families in CHPCC.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

9) It would be manageable to incorporate this screening tool into routine practice with all Rainbow patients at Return and WCC visits.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

10) Please list ideas you have for improving the Rainbow Screening Tool.

Needs Screener Quick Survey Social Workers



For the past few weeks, we've been using the Rainbow Family Unmet Needs screening tool at CHPC. Please think about your experience using the screening tool and answer the following questions. Thank you!

1) Are you aware of having had a SW referral generated due to the Rainbow Unmet Needs Screening Tool?

- ☐ Yes
☐ No

If so, please indicate which of the following resources were requested (please check all that apply):

- | | |
|--|--|
| Assistance with <u>educational</u> services | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Assistance with <u>medical therapy</u> services (e.g. PT, OT, ABA) | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Assistance with <u>transition to adulthood</u> | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Assistance with <u>recreational</u> or social opportunities | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| In-home services to help with patient care or ADL's | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Mental health services for <u>parent</u> | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Mental health services for <u>patient</u> | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Mental health services for <u>siblings</u> | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Assistance with obtaining medical equipment/supplies | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| Other | <input type="checkbox"/> Yes <input type="checkbox"/> No |

If Other, please specify: _____

Please indicate how much you agree or disagree with the following statements:

2) The screening tool was useful in identifying patient and family needs.

- ☐ strongly agree
☐ somewhat agree
☐ somewhat disagree
☐ strongly disagree

3) Implementation of the screening tool in CHPCC has increased the number of pages that I am getting on call.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

4) I felt comfortable responding to the needs identified by the screening tool.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

5) From the social work perspective, it would be manageable to incorporate this screener into routine practice with all Rainbow patients.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

6) The Rainbow Screening Tool is important for taking care of our Rainbow patients and families in CHPCC.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

Please use this space to elaborate on any of your answers, especially the concerns you have with implementing the screening tool in CHPCC.

Needs Screener Quick Survey Administration



For the past few weeks, we've been using the Rainbow Family Unmet Needs screening tool at CHPCC. Please think about your experience using the screening tool and answer the following questions. Thank you!

1) On average, how much extra time is it taking for you to hand out the Rainbow screening tool when registering the patients?

- ☐ One minute or less.
- ☐ More than one minute.

Please indicate how much you agree or disagree with the following statements:

2) Handing out the Rainbow screening tool is making it harder to check in Rainbow patients and families.

- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

3) The Rainbow Screening Tool is important for taking care of our Rainbow patients and families in CHPCC.

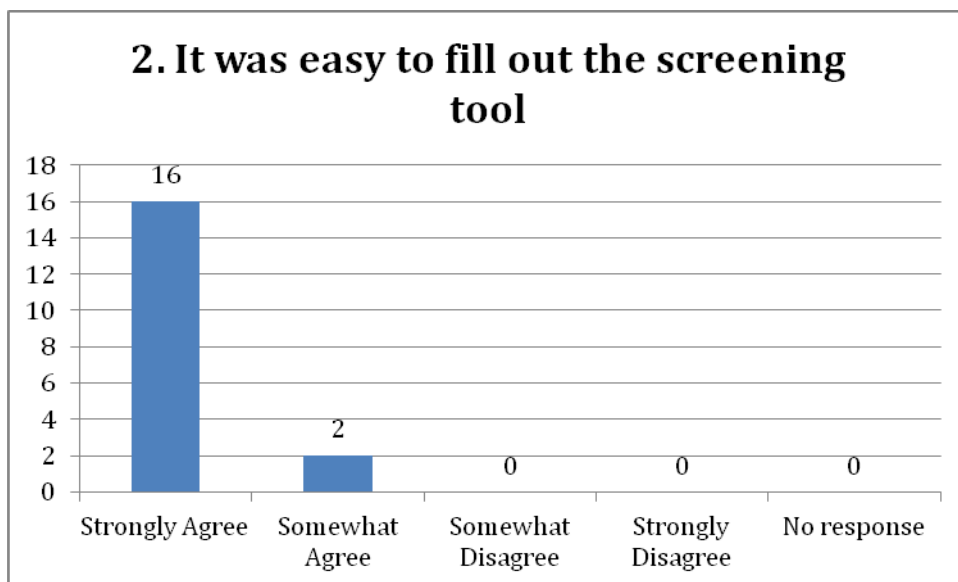
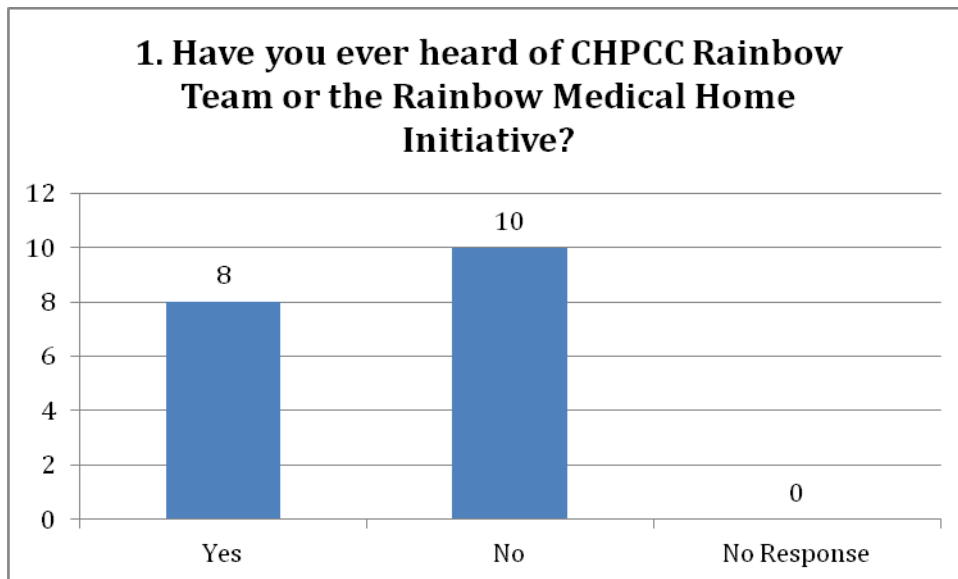
- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

4) It would be easy to incorporate handing out the Rainbow screening tool at all Rainbow Well Child and Return Visits on an ongoing basis.

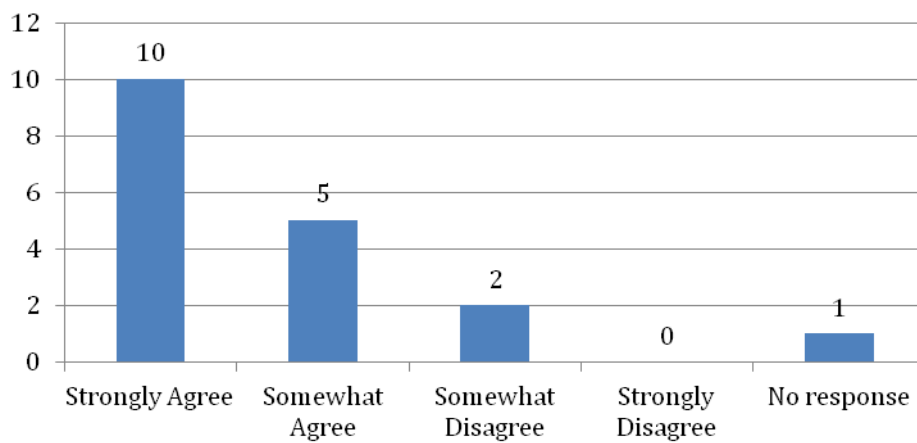
- ☐ strongly agree
- ☐ somewhat agree
- ☐ somewhat disagree
- ☐ strongly disagree

Please list ideas you have for improving the Rainbow Screening Tool.

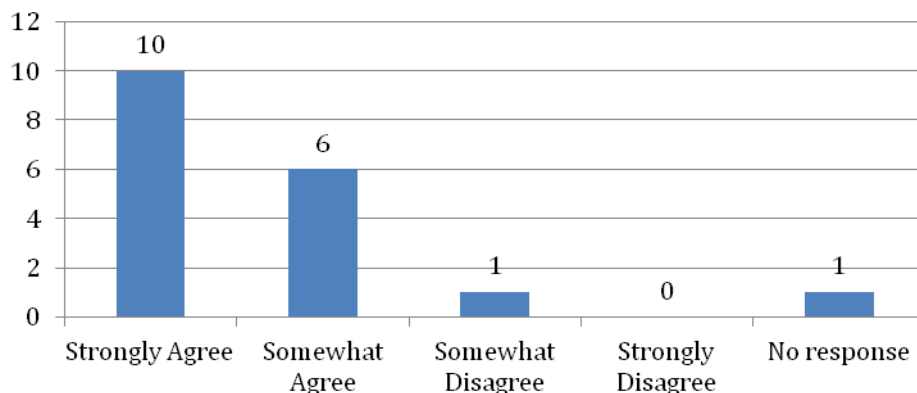
Appendix 4.1 – Tables and Results from Stakeholders’ Feedback Surveys (from patient families regarding Screener 1 distributed during the 1st half of summer)



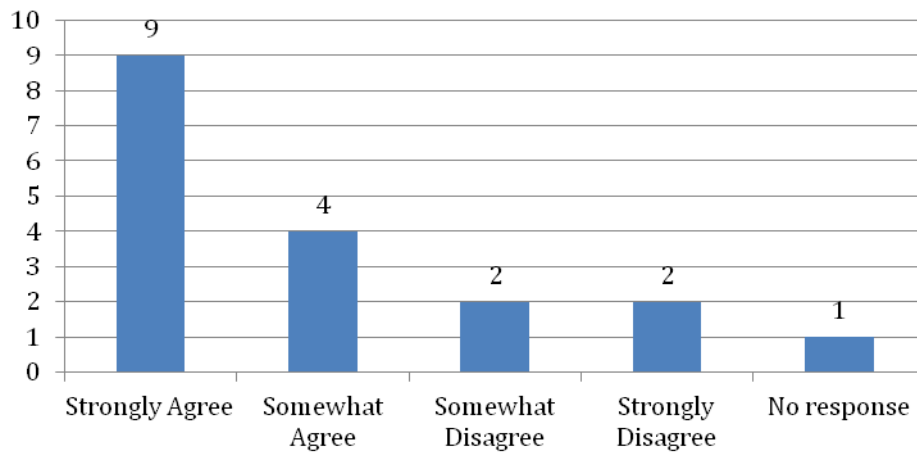
3. The screening tool helped me organize my thoughts before my child's visit



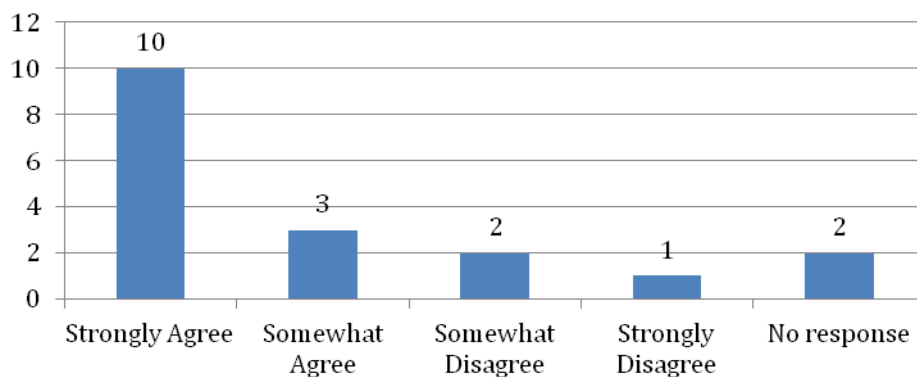
4. The screening tool helped me communicate with my child's provider during the visit

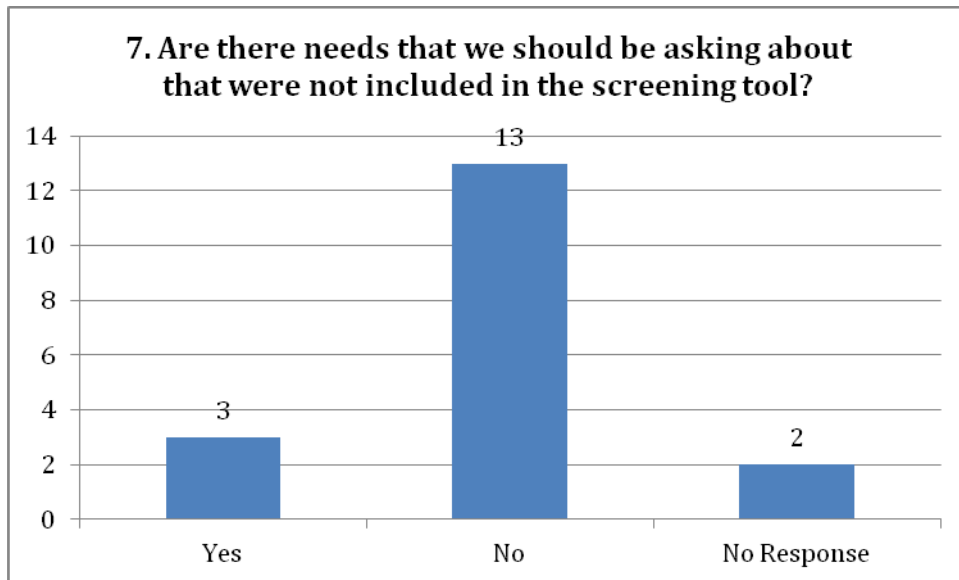


5. The screening tool made me aware of resources that I did not realize were available before

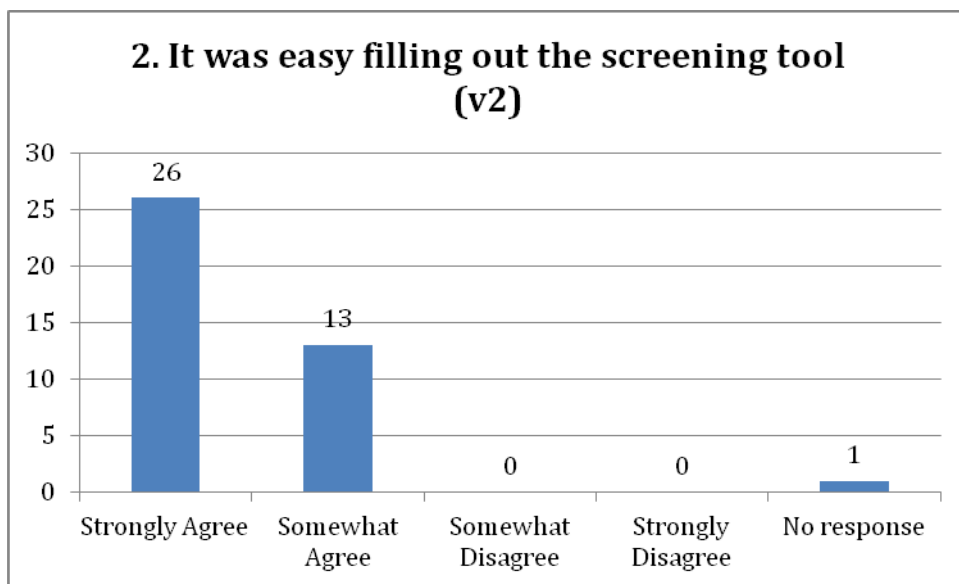
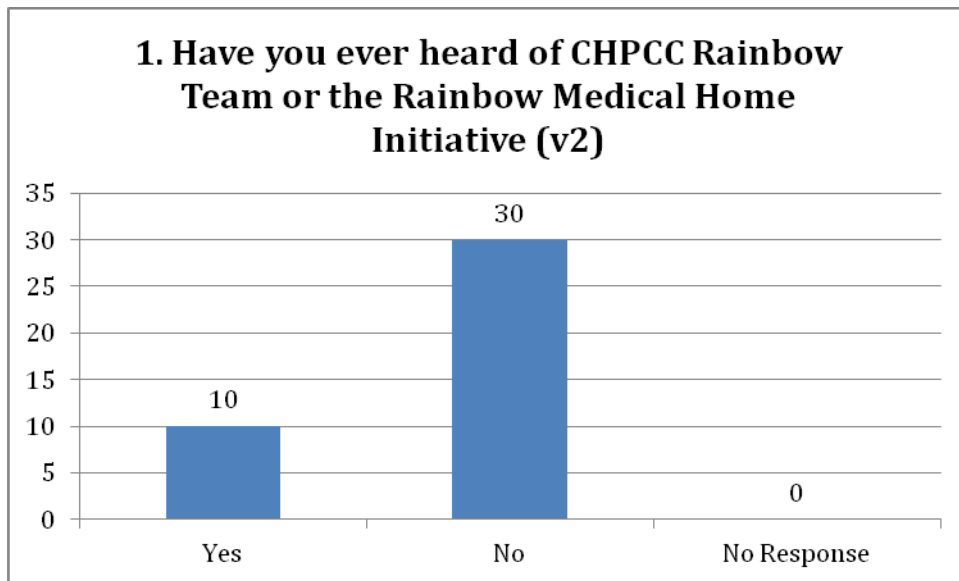


6. It would be useful to fill out this screener at my child's future CHPCC visits

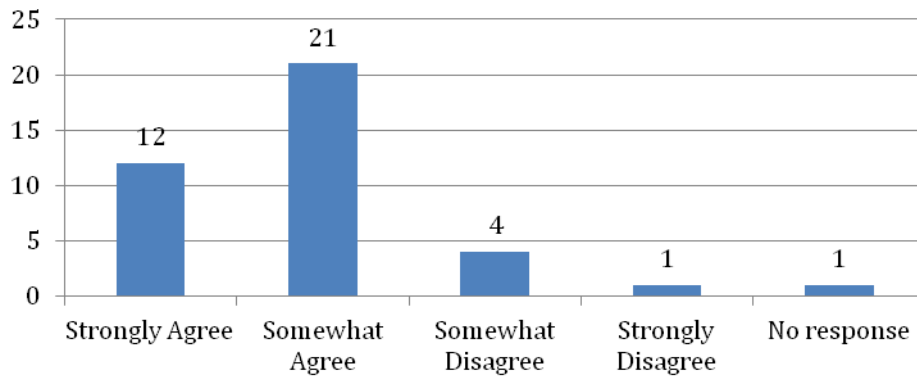




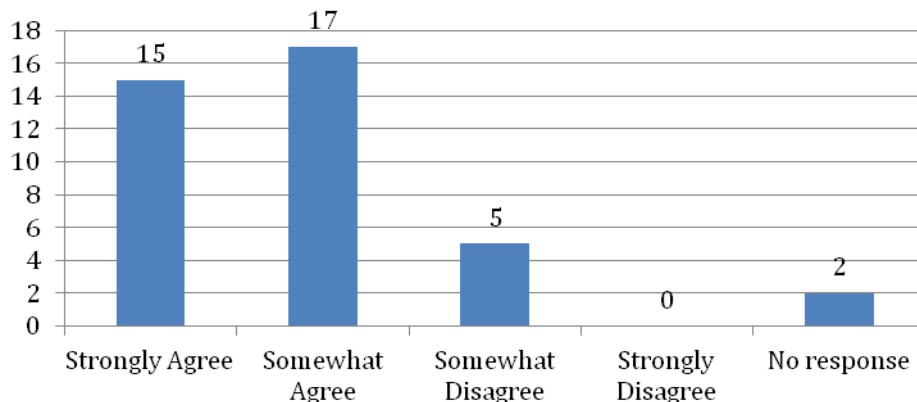
Appendix 4.2 – Tables and Results from Stakeholders’ Feedback Surveys (from patient families regarding Screener 2 distributed during the 2nd half of summer).



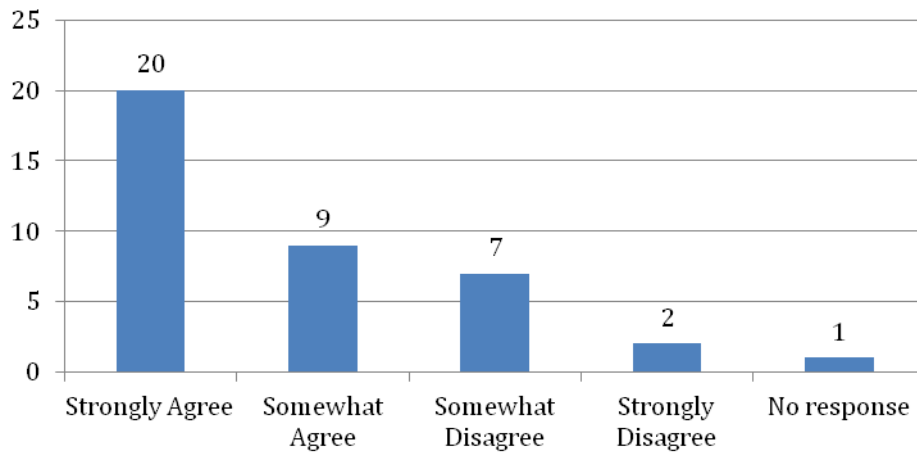
**3. The screening tool helped me
organize my thoughts before my
child's visit (v2)**



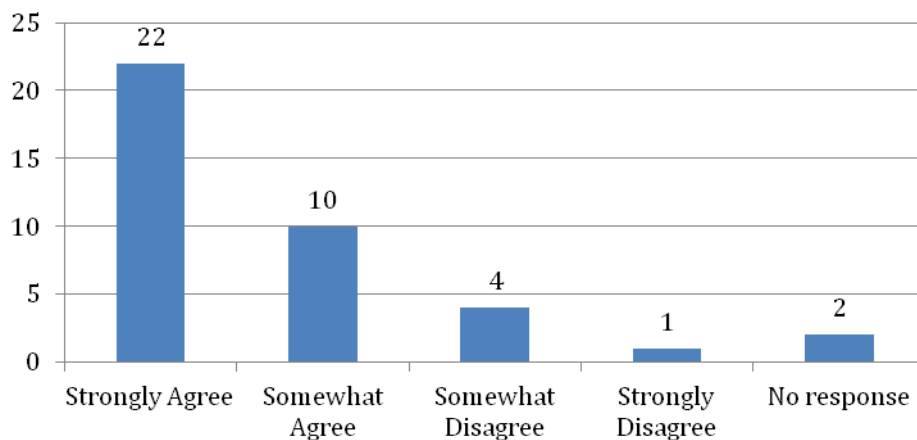
**4. The screening tool helped me
communicate with my provider during the
visit (v2)**

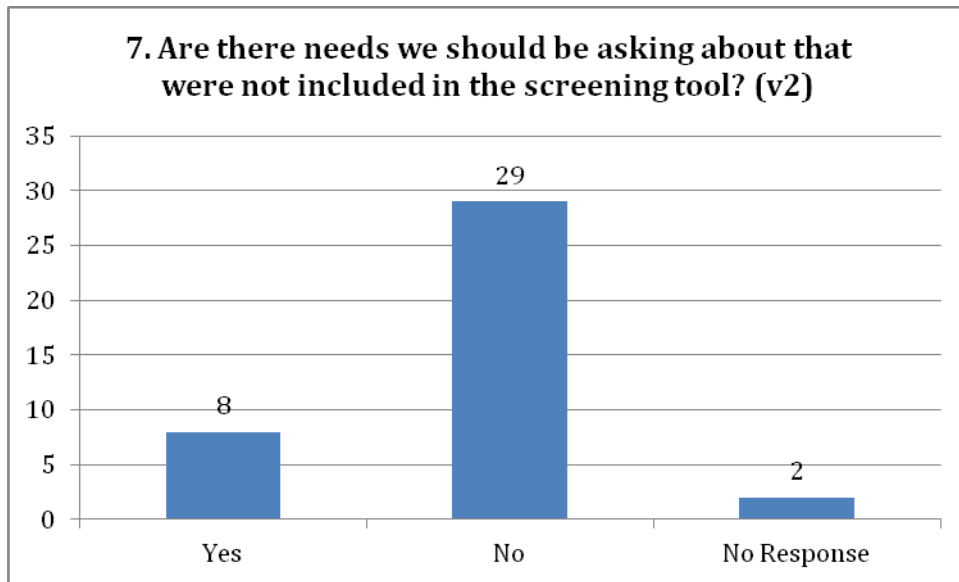


5. The screening tool made me aware of resources that I did not realize were available before (v2)

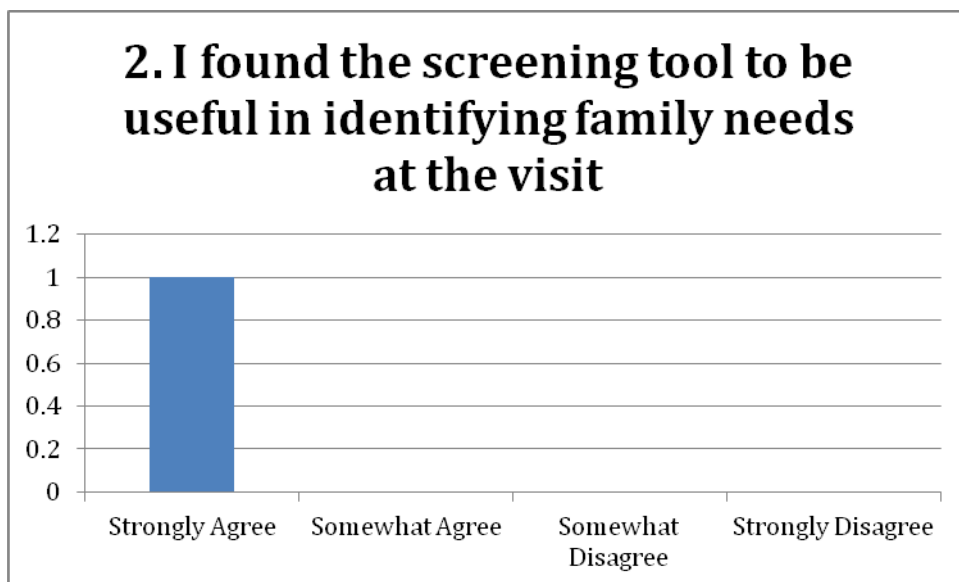
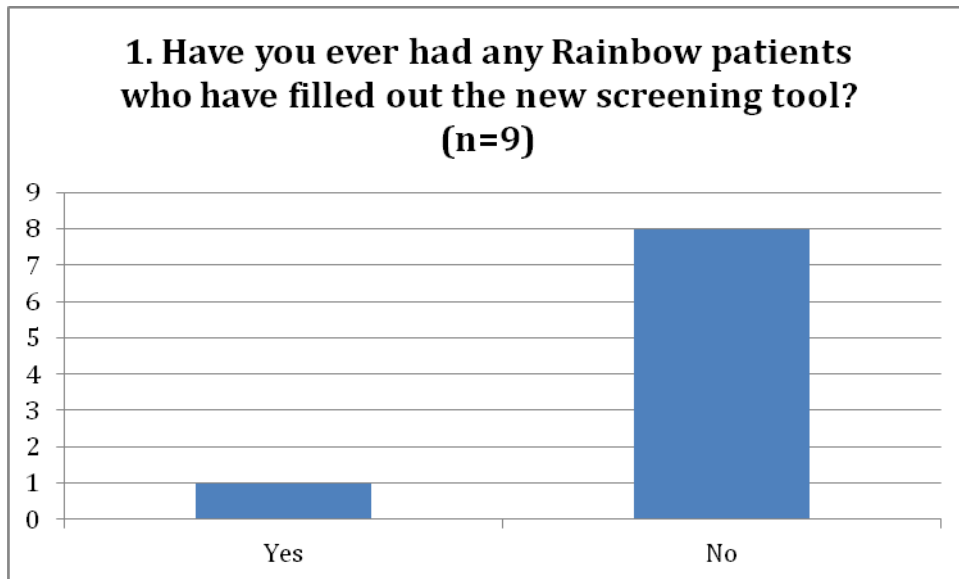


6. It would be useful to fill out this screener at my child's future CHPCC visits (v2)

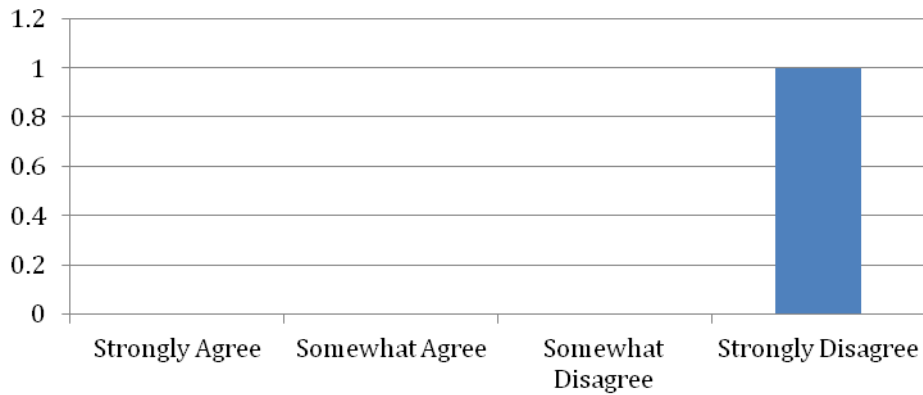




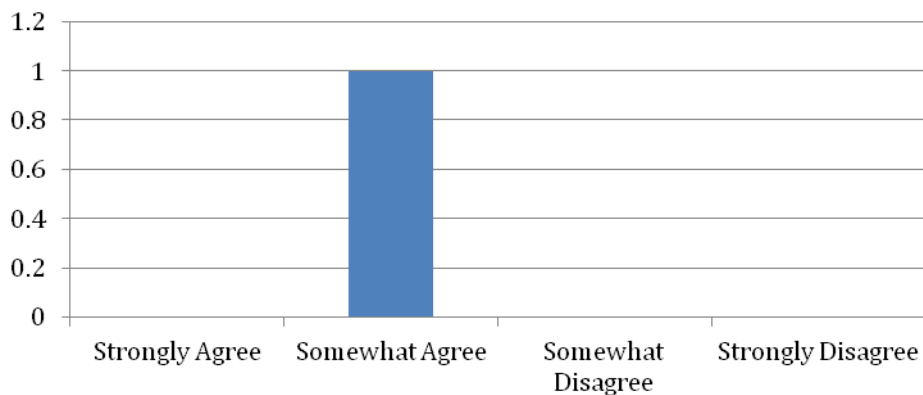
Appendix 4.3 – Tables and Results from Stakeholders’ Feedback Surveys (Providers)



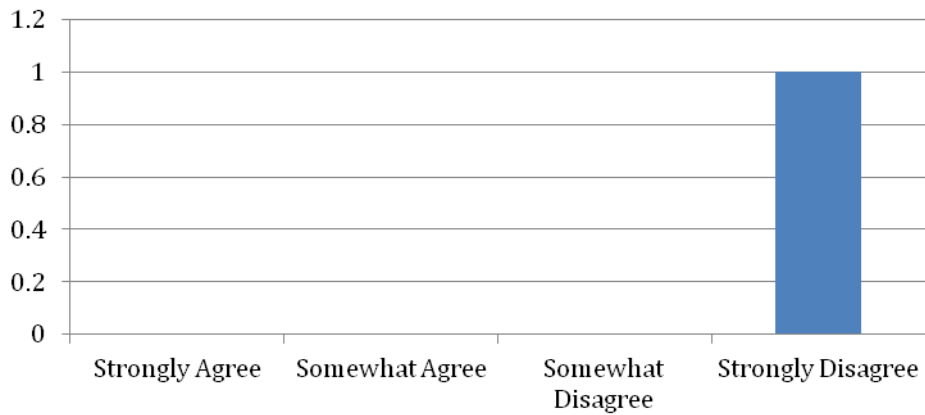
3. I felt that the incorporation of the screening tool made the visit duration longer



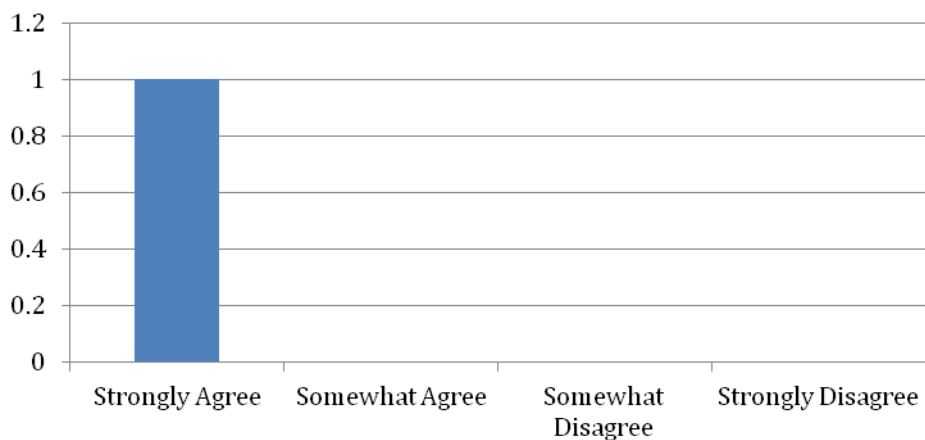
4. The screening tool helped me communicate with the patient's family during the visit



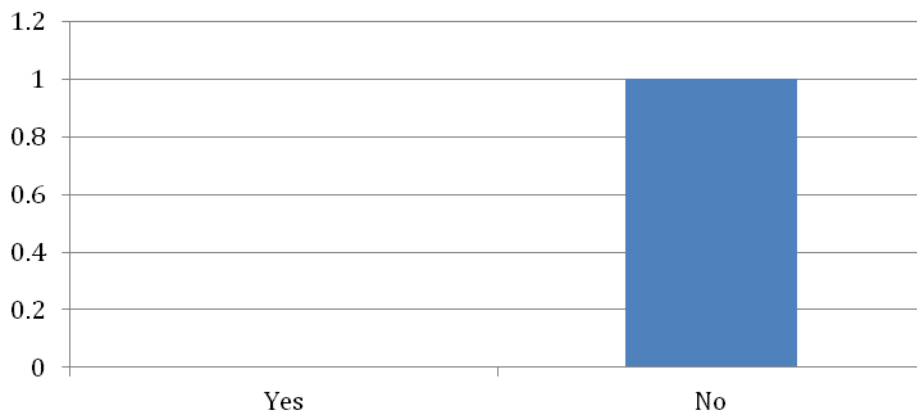
5. The family's responses to the screening tool raised issues that I did not have time to address during the visit



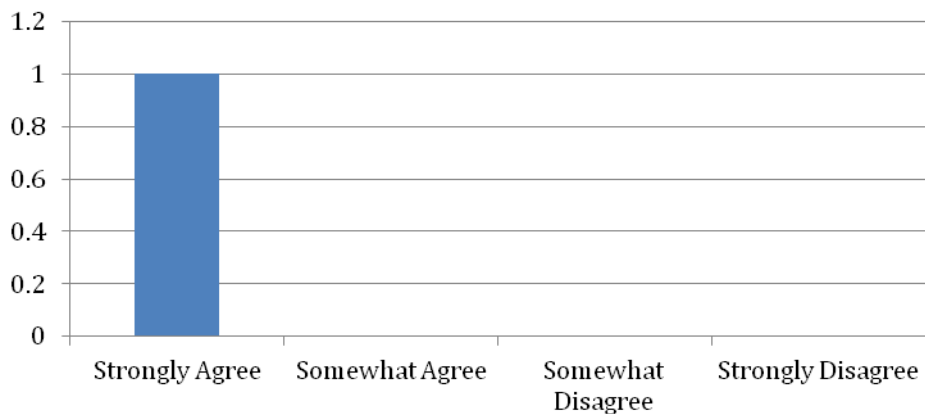
6. I felt comfortable responding to the needs identified by the screening tool



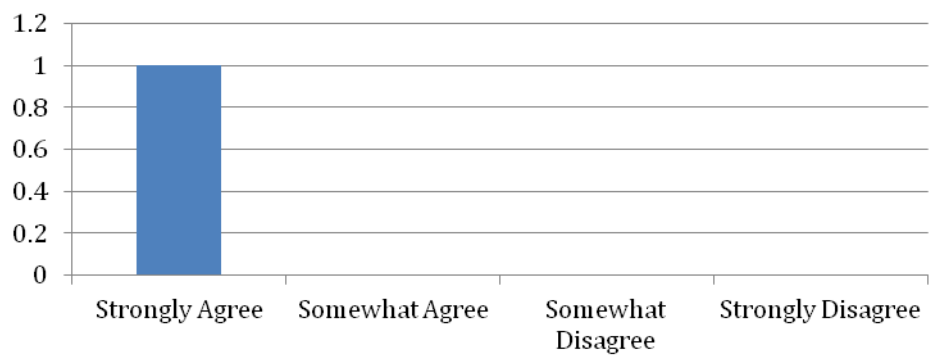
7. Did you make any referrals in response to the screening tool



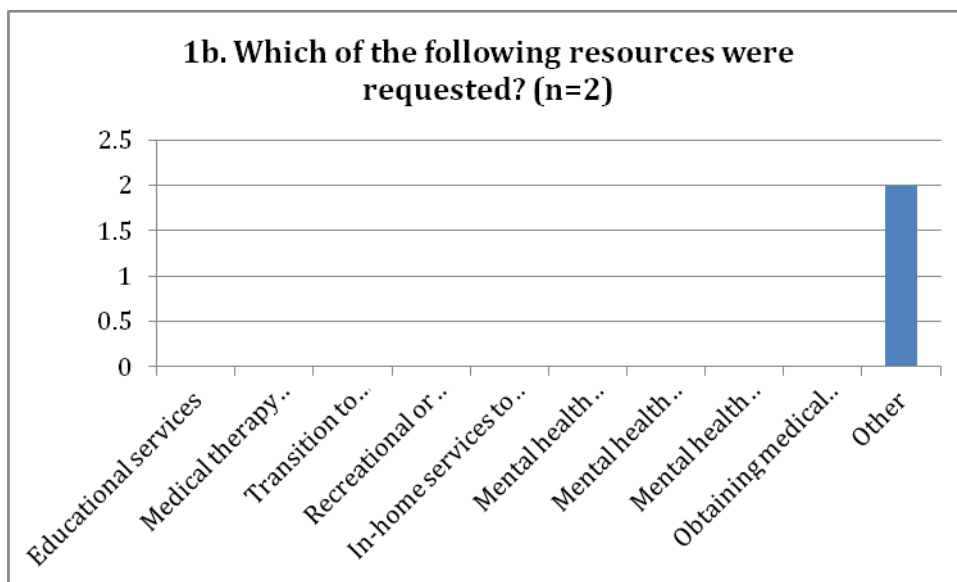
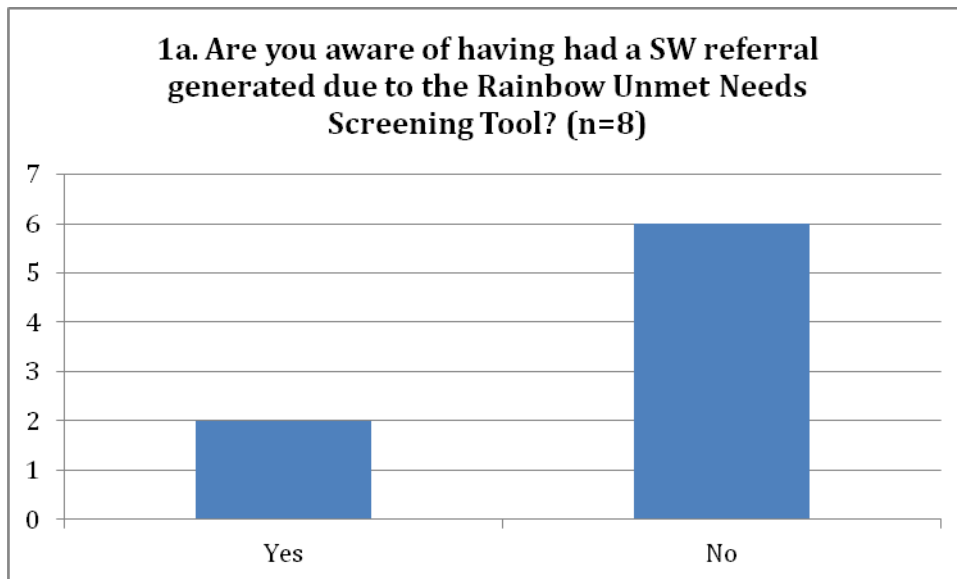
8. The Rainbow screening tool is important for taking care of our Rainbow patients and families in CHPCC



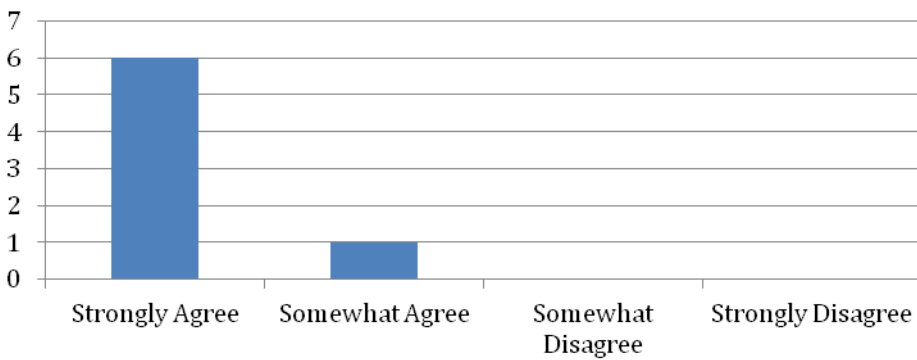
9. It would be manageable to incorporate this screening tool into routine practice with all Rainbow patients at Rainbow and WCC visits



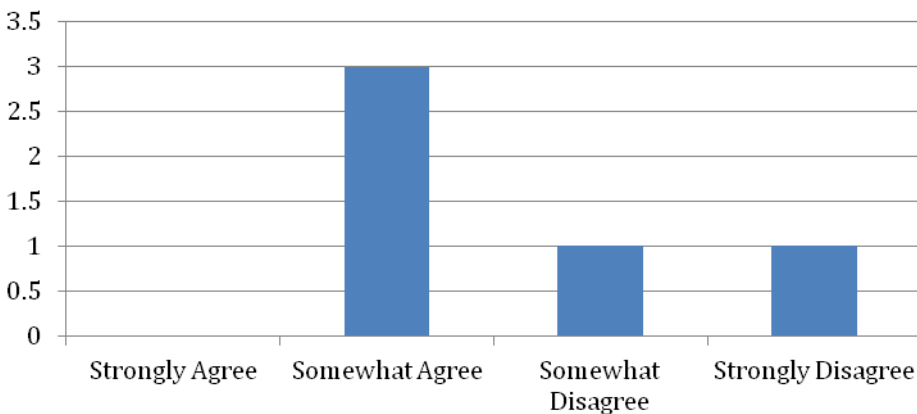
Appendix 4.4 – Tables and Results from Stakeholders’ Feedback Surveys (Social Workers). SW refers to Social Work.



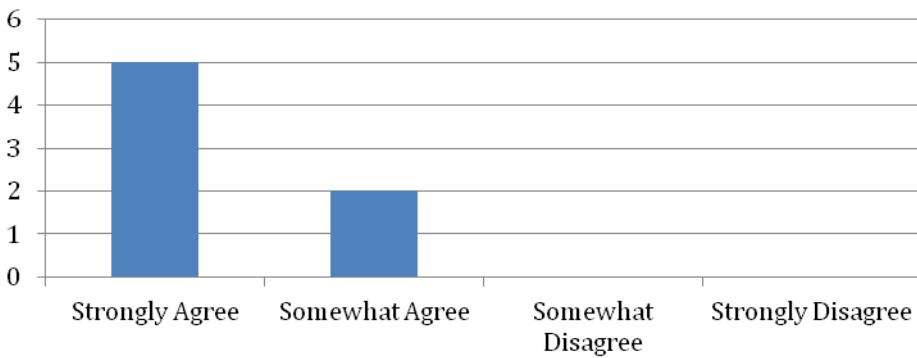
**2. The screening tool was useful
in identifying patient and family
needs (n=7)**



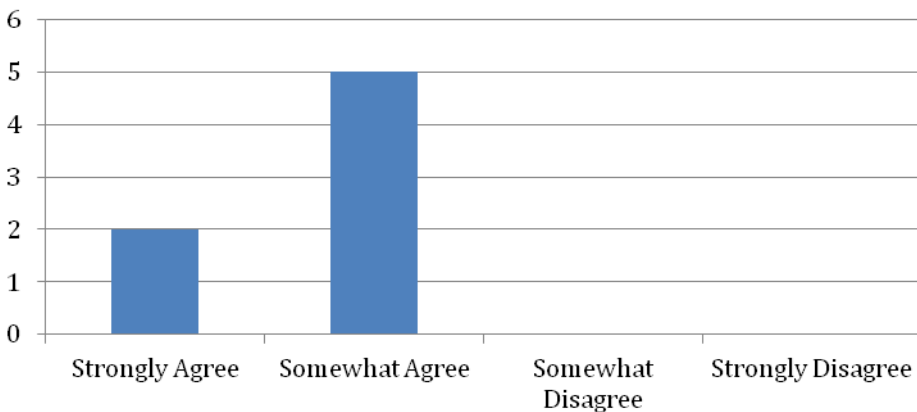
**3. Implementation of the screening tool in CHPCC
has increased the number of pages that I am
getting on call (n=5)**

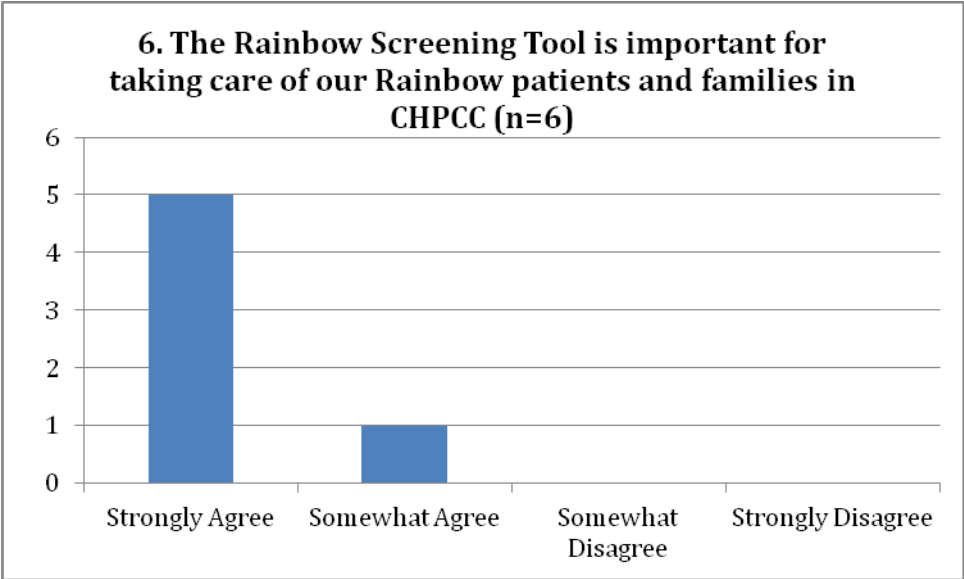


4. I felt comfortable responding to the needs identified by the screener (n=7)

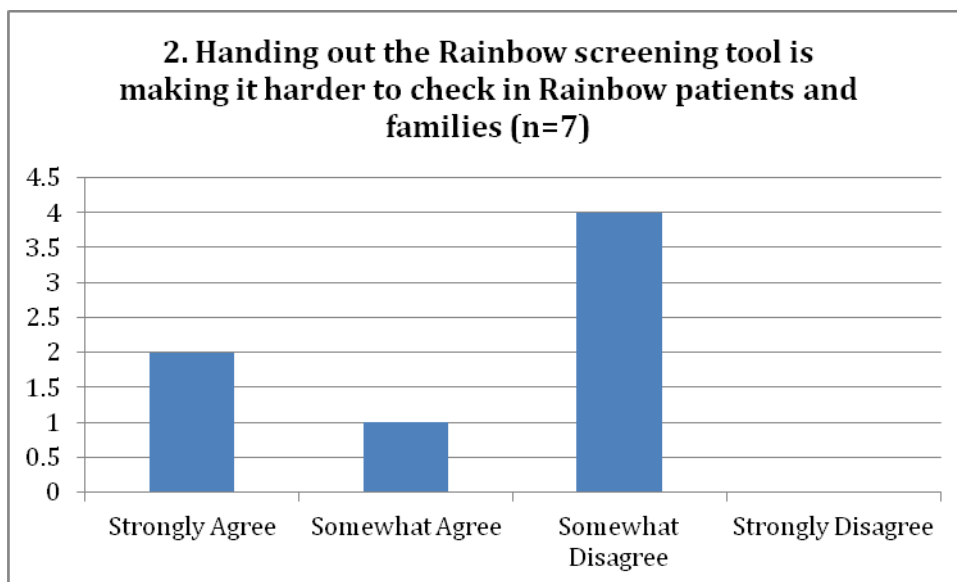
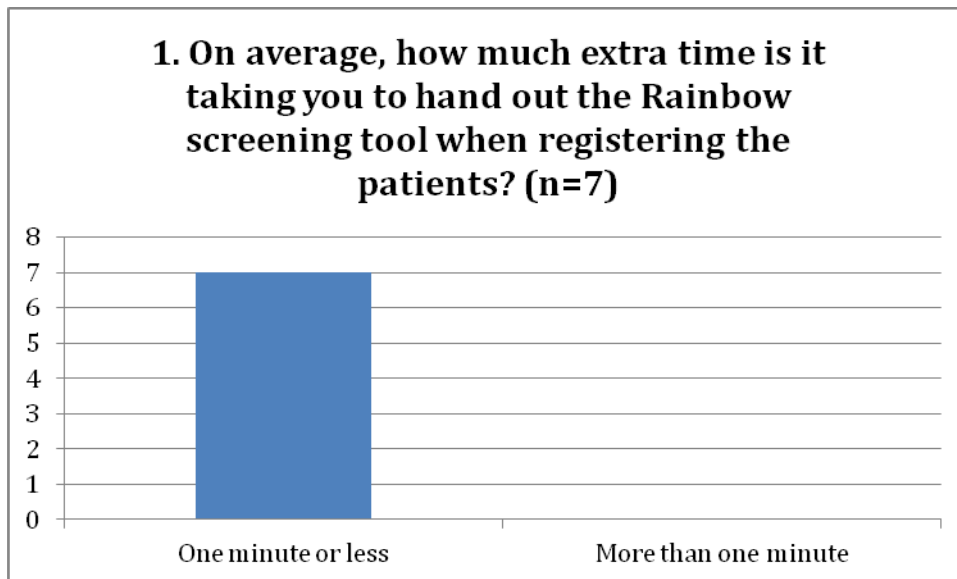


5. From the SW perspective, it would be manageable to incorporate this screener into routine practice with all Rainbow patients (n=7)

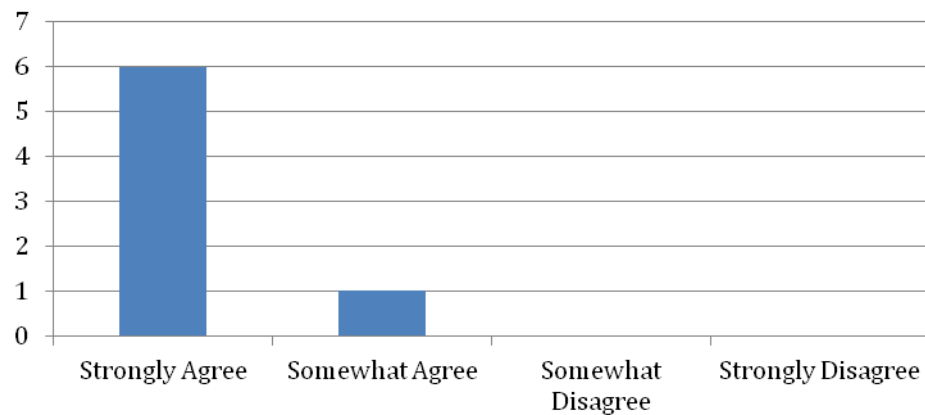




Appendix 4.5 – Tables and Results from Stakeholders’ Feedback Surveys (Front Desk Staff/Administrative Workers)



3. The Rainbow Screening Tool is important for taking care of our Rainbow patients and families in CHPCC (n=7)



4. It would be easy to incorporate handing out the Rainbow screening tool at all Rainbow Well Child and Return Visits on an ongoing basis (n=7)

