

# The Survey of Well-being of Young Children (SWYC) User's Manual

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All updates to this manual will be available for download at [www.theSWYC.org](http://www.theSWYC.org). Please check the website to make sure you are consulting the most recent version.

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## **Preface**

The critical importance of early child development, the long term effects of adverse childhood experiences, and the challenges of establishing a coordinated and comprehensive system of care are increasingly recognized by researchers, policy makers, and professionals who work directly with young children. The appreciation of these issues, which is congruent with the evolving concept of a pediatric “medical home,” has led to a focus on early identification of and screening for risks of developmental-behavioral disorders and family/social determinants of toxic stress.<sup>i</sup> The *Survey of Well-being of Young Children (SWYC)* was developed in response to these interests.

The SWYC is a freely-available, comprehensive, first-level developmental-behavioral screening instrument for children under 5 ½ years of age. It was designed to be completed by parents<sup>ii</sup> or other caregivers in the context of pediatric primary care visits, but can also be used in other settings, such as early child care and education, home visiting, and preschools. SWYC questions were written to be short, easy to read, and simple to answer from memory. The entire instrument takes most parents 10 minutes or less to complete. As a “first-level” screening instrument, the SWYC is designed to be used as an initial step in assessing children’s risk of developmental-behavioral issues, with positive screens followed up on through further conversation with the child’s caregiver.

The SWYC is appropriate for children between 1 and 66 months of age, and there is a different SWYC form for each standard well-child visit in this range. All scoring guides can be found in section 2D on “Scoring.” PDFs of all SWYC forms and scoring guides are available to be printed from our website: [www.theSWYC.org](http://www.theSWYC.org). Our website also contains the most up-to-date information on the availability of electronic versions of the SWYC and versions of all SWYC translations, research publications and presentations, psychometric data, and revision histories. Lastly, the website includes links for recommended readings, useful resources, and a FAQs and “Contact Us” page.

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<sup>i</sup> For more information on a pediatric medical home, please see the American Academy of Pediatrics (AAP) website: <http://pediatrics.aappublications.org/content/110/1/184.full.pdf>

<sup>ii</sup> Throughout the rest of this manual, the word “parents” will refer to any caregiver with enough knowledge about the child to complete the SWYC reliably, for the sake of simplicity.

## **How the “SWYC: User’s Manual” is Organized**

The *SWYC: User’s Manual* was written for a diverse audience: pediatric primary care providers (PPCPs),<sup>i</sup> nurses, researchers, community-based child-serving professionals such as child care providers, home visitors, and preschool teachers, and leaders of organizations who plan to implement the *Survey of Well-being of Young Children (SWYC)* system. These potential users have very different expectations and needs. We have tried to organize the chapters so that different users can easily find the sections most applicable to their needs.

### ***If you are interested in...***

- |   |                     |
|---|---------------------|
| • Using the <i>SWYC</i> in a pediatric practice or other setting        | Read Chapters 1 & 2 |
| • Electronic formats of the <i>SWYC</i>                                 | Read Chapter 3      |
| • Translations and cultural adaptations of the <i>SWYC</i>              | Read Chapter 4      |
| • Research using the <i>SWYC</i> , such as quality improvement projects | Read Chapter 5      |
| • More detail on how often to screen                                    | Read Chapter 6      |
| • More detail on evaluating a screening instrument                      | Read Chapter 7      |
| • More detail on the implications of setting screening thresholds       | Read Chapter 8      |
| • <i>SWYC</i> revisions and licensed works                              | Read Chapter 9      |

The appendices provide supplemental information for the *SWYC: User’s Manual*.

- Appendix (i) showcases how calculations were performed for statistical values discussed in chapter 8 on “Decision Thresholds: A Deeper Look.”
- Appendix (ii) includes frequently asked questions (FAQs) that appear throughout the manual in the form of “question and answer” cartoons.
- Appendix (iii) includes a glossary that defines all of the important terms and acronyms cited throughout the text.
- Appendix (iv) includes information about the authors of this manual.
- Appendix (v) includes acknowledgements.
- Appendix (vi) contains a list of all the references included in the manual.

Please note that up-to-date information about the *SWYC*, including the downloadable forms, any news or changes to materials, research updates, recommended readings, and psychometric data, can be found on our website: [www.theSWYC.org](http://www.theSWYC.org).

<sup>i</sup> Throughout this manual and the rest of the *SWYC* system, the umbrella term “pediatric primary care providers” (PPCPs) will refer to all types of child health care professionals, including, but not limited to: pediatricians, family physicians, nurse practitioners, and physicians’ assistants.

## **Executive Summary**

Below is a very brief summary of the *SWYC*. Before implementing the *SWYC* in a pediatric or family medicine practice or in a community setting, careful reading of at least chapters 1 and 2 of the *SWYC* Manual is essential.

### **Introduction to the *SWYC***

The *SWYC* is a freely-available, comprehensive, first-level developmental-behavioral screening instrument for children under 5 ½ years of age. It was designed to be completed by parents or other caregivers in the context of children's health supervision visits, but can also be used in child care, home visiting, and preschool settings.

*SWYC* questions were written to be short, easy to read, and simple to answer from memory. The entire instrument takes most parents 10 minutes or less to complete. As a "first-level" screening instrument, the *SWYC* is designed to maximize the amount of information available to a provider before a visit with a patient or client. It is therefore meant to be used as a first step in assessing children's risk of developmental-behavioral issues, with positive screens followed up by further conversation with the child's caregiver.

### **Components**

The *SWYC* assesses multiple domains of children's well-being:

- The *SWYC Milestones* assess the child's cognitive, language, and motor development.
- The *BPSC* and *PPSC* assess behavioral and emotional symptoms for children under 18 months and from 18-66 months, respectively.
- The *POSI* assesses risk for autism spectrum disorder for children from 16-36 months
- The *Family Questions* assess stress present in the child's family environment, including parental depression, discord, substance abuse, food insecurity, and parent's concerns about the child's behavior, learning, or development.

### **Age-Specific Forms**

There are 12 *SWYC* forms—one for each pediatric well-child visit up to 5 years. PDFs of all *SWYC* forms are available to be printed from our website: [www.theSWYC.org](http://www.theSWYC.org).

### **Validity**

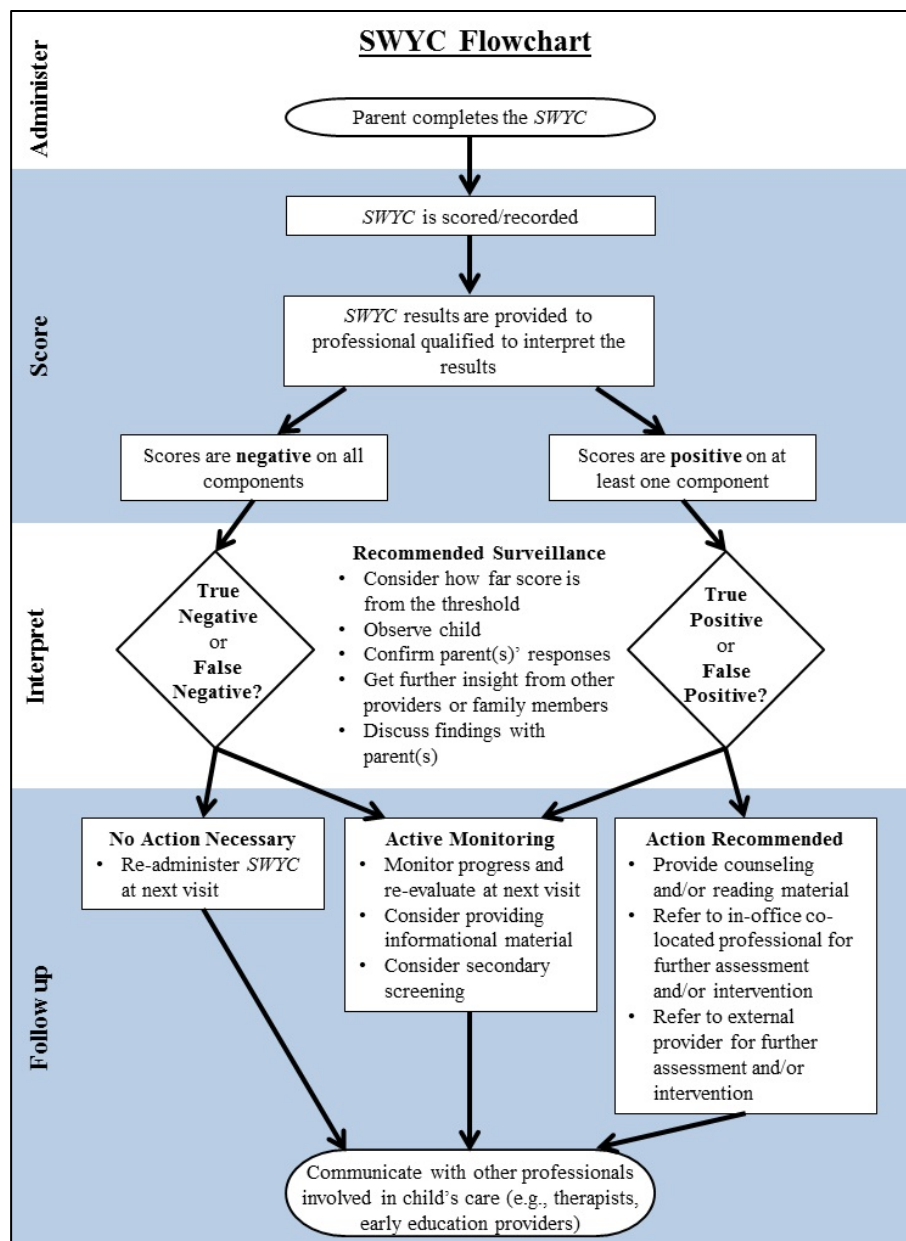
Initial research studies found the reliability and validity of the *SWYC* to be comparable to older and more familiar developmental screening instruments and in concordance with parents' reports of diagnosed developmental-behavioral disabilities in their child (see section 5A of the *SWYC* manual for more detail). Currently, we are evaluating its validity as compared to

standardized developmental and emotional/behavioral assessments. Translations into languages other than English have not yet been independently validated.

**Implementation**

For implementation of the SWYC or any screening instrument, it is important first to clarify the workflow: to whom, by whom, and how the instrument should be administered, how it should be scored, and who will receive and interpret the results. Note that in order to select the appropriate SWYC form, front desk staff must be trained on how to calculate a child's age in months and days and adjust for prematurity when necessary. You can download a customizable training handout (*SWYC 101: Quick-Start Guide for Front Desk Staff*) from our website, [www.theSWYC.org](http://www.theSWYC.org). You can also consult section 2B of the SWYC manual for suggestions on training staff.

The flow chart to the right summarizes subsequent steps in the screening process. Note that the critical professional responsibility is to consider the scores on all SWYC components in combination with observations of the child and discussion with the parent(s) to discern whether further monitoring or action is necessary. The goal of the SWYC is not to make a diagnosis or to dictate need for referral, but to add information to help guide professional judgments.





## Scoring Instructions

Examples and further information are available in section 2D of the SWYC Manual

### *Developmental Milestones*

1. Each form includes 10 items. Score each item using these values: "Not Yet" corresponds to "0"; "Somewhat" to "1"; and "Very Much" to "2." Missing items count as zero.
2. Add up all 10 item scores to calculate the total score.
3. On the SWYC scoring chart on page 8, the child's age in months is indicated in the "age" column. Check to be sure that the parent completed the correct form for the child's age (far left column labeled "form"). If not, the score will be misleading. **Please Note:** Cut scores are not available for the 2- and 60-month forms. The individual questions are valid and reliable and may be useful for surveillance.
4. See the SWYC scoring chart on page 8. Following along the age appropriate row, determine whether the child's total score falls into the "Needs Review" or "Appears to Meet Age Expectations" category.

Scoring for the *Milestones* can also be done in Excel. Please see the "Form Selector and Milestones Calculator" on our website: [www.theSWYC.org](http://www.theSWYC.org).

### *Baby Pediatric Symptom Checklist (BPSC)*

1. The *BPSC* is divided into three subscales, each with 4 items. Determine the *BPSC* subscale scores by assigning a "0" for each "Not at All" response, a "1" for each "Somewhat" response, and a "2" for each "Very Much" response, and then sum the results.
  - a. In the event that parents have selected multiple responses for a single question and are unavailable for further questioning, then choose the more concerning answer (i.e. "Somewhat" or "Very Much") farthest to the right.
  - b. In the event that there is a missing response, that item counts as zero.
2. Any summed score of 3 or more on any of the three subscales indicates that a child is "at risk" and needs further evaluation or investigation.

***Preschool Pediatric Symptom Checklist (PPSC)***

1. Determine the *PPSC total* score by assigning a “0” for each “Not at All” response, a “1” for each “Somewhat” response, and a “2” for each “Very Much” response, and then sum the results.
  - a. In the event that parents have selected multiple responses for a single question and are unavailable for further questioning, then choose the more concerning answer (i.e. "Somewhat" or "Very Much") farthest to the right.
  - b. In the event that there is a missing response, that item counts as zero.
2. A *PPSC* total score of 9 or greater indicates that a child is "at risk" and needs further evaluation or investigation.

***Parent's Observations of Social Interactions (POSI)***

1. Score each of the seven questions. Each question is assigned either a “1” or a “0”. If the parent selects one or more responses that fall in the last three columns, the question is scored as “1”; otherwise, it is scored as “0.”
2. For items where parents have selected multiple responses for a single question (i.e., multiple responses in each row):
  - a. Choose the more concerning answer (i.e., lower-functioning behavior) farthest to the right.
  - a. If the parent has selected multiple answers in the last three columns for one item, assign only one point for the item. Since there are seven *POSI* questions total, there is a maximum of seven potential points.
  - b. Missing items count as zero.
3. A result of three or more points in the last three columns indicates that a child is “at risk” and needs further evaluation or investigation.


## **Family Questions**

Positive endorsement of items on this list indicates that a child should be monitored further. *If after reviewing the Family Questions, a PPCP believes a child or family member may be at immediate risk of harm, appropriate steps should be taken to refer the child and/or family to the appropriate child protection agency for help as soon as possible.*

1. Question 1 Screens for tobacco use.
2. Questions 2, 3, and 4: At least one positive response suggests a substance abuse disorder
3. Question 5 screens for food insecurity.
4. Questions 6 and 7: Parental depression is assessed by the *Patient Health Questionnaire-2 (PHQ-2)*. Answers are scored such that "Not at All" is given a "0", "Several Days" is given a "1", "More than Half the Days" is given a "2", and "Nearly Every Day" is given a "3." A total score of **3 or greater**, suggests further evaluation.
5. Questions 8 and 9 screen for domestic violence. The score is considered positive if the most extreme choice, is endorsed on one or both items.
6. Parent's Concerns: If a parent endorses being "Somewhat" or "Very Much" concerned about his or her child on either of the two *Parent's Concerns* questions, pediatricians should use this as an opportunity for additional conversation.

## **Longitudinal Scoring Sheet**

On the next page, we have included a longitudinal scoring sheet that can be kept in a child's chart to track SWYC results over time. All subscales are included and the same chart can be used at each visit. This form is also available for download at [www.theSWYC.org](http://www.theSWYC.org).

SWYC Longitudinal Hand Scoring		Milestones		Irritability		BPSC		Routines		DOB:		MR#:		Parent Concerns					
FORM	Age (m)	Needs Review	Appears to meet age expectations	Appears ok	Needs Review	Appears ok	Needs Review	Appears ok	Needs Review	More than meant to	Needed to cut back	Had a bad effect	Hunger	Depression (2 Item Total Score)	Tension	Arguments	Dev. Behv.		
2m	1-3	No cut scores available	≥14	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
4m	4	≤13	≥16	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
6m	5	≤15	≥12	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
9m	6	≤11	≥15	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
12m	7	≤14	≥17	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
15m	8	≤16	≥11	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
18m	9	≤11	≥14	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
24m	10	≤13	≥15	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
30m	11	≤14	≥13	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
36m	12	≤13	≥14	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
48m	13	≤13	≥11	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
60m	14	≤14	≥13	<3	≥3	<3	≥3	<3	≥3	N	Y	N	Y	<3	≥3	-	+	N	Y
18m	15	≤10	≥11	<9	≥9	<3	≥3	 <p>www.TheSWYC.org</p>											
24m	16	≤12	≥12	<9	≥9	<3	≥3												
30m	17	≤11	≥12	<9	≥9	<3	≥3												
36m	18	≤12	≥13	<9	≥9	<3	≥3												
48m	19	≤13	≥14	<9	≥9	<3	≥3												
60m	20	≤14	≥15	<9	≥9	<3	≥3												
18m	21	≤15	≥16	<9	≥9	<3	≥3												
24m	22	≤16	≥17	<9	≥9	<3	≥3												
30m	23	≤17	≥18	<9	≥9	<3	≥3												
36m	24	≤18	≥19	<9	≥9	<3	≥3												
48m	25	≤19	≥20	<9	≥9	<3	≥3												
60m	26	≤20	≥21	<9	≥9	<3	≥3												
18m	27	≤21	≥22	<9	≥9	<3	≥3												
24m	28	≤22	≥23	<9	≥9	<3	≥3												
30m	29	≤23	≥24	<9	≥9	<3	≥3												
36m	30	≤24	≥25	<9	≥9	<3	≥3												
48m	31	≤25	≥26	<9	≥9	<3	≥3												
60m	32	≤26	≥27	<9	≥9	<3	≥3												
18m	33-34	≤27	≥28	<9	≥9	<3	≥3												
24m	35	≤28	≥29	<9	≥9	<3	≥3												
30m	36	≤29	≥30	<9	≥9	<3	≥3												
36m	37	≤30	≥31	<9	≥9	<3	≥3												
48m	38-39	≤31	≥32	<9	≥9	<3	≥3												
60m	40-41	≤32	≥33	<9	≥9	<3	≥3												
18m	42-43	≤33	≥34	<9	≥9	<3	≥3												
24m	44-46	≤34	≥35	<9	≥9	<3	≥3												
30m	47	≤35	≥36	<9	≥9	<3	≥3												
36m	48-50	≤36	≥37	<9	≥9	<3	≥3												
48m	51-53	≤37	≥38	<9	≥9	<3	≥3												
60m	54-57	≤38	≥39	<9	≥9	<3	≥3												
18m	58	≤39	≥40	<9	≥9	<3	≥3												
24m	59-65	No cut scores available	≥41	<9	≥9	<3	≥3												

# **Chapter 1**

# **Introduction**

**A) Overview of the SWYC**

Page 11

**B) Design Principles**

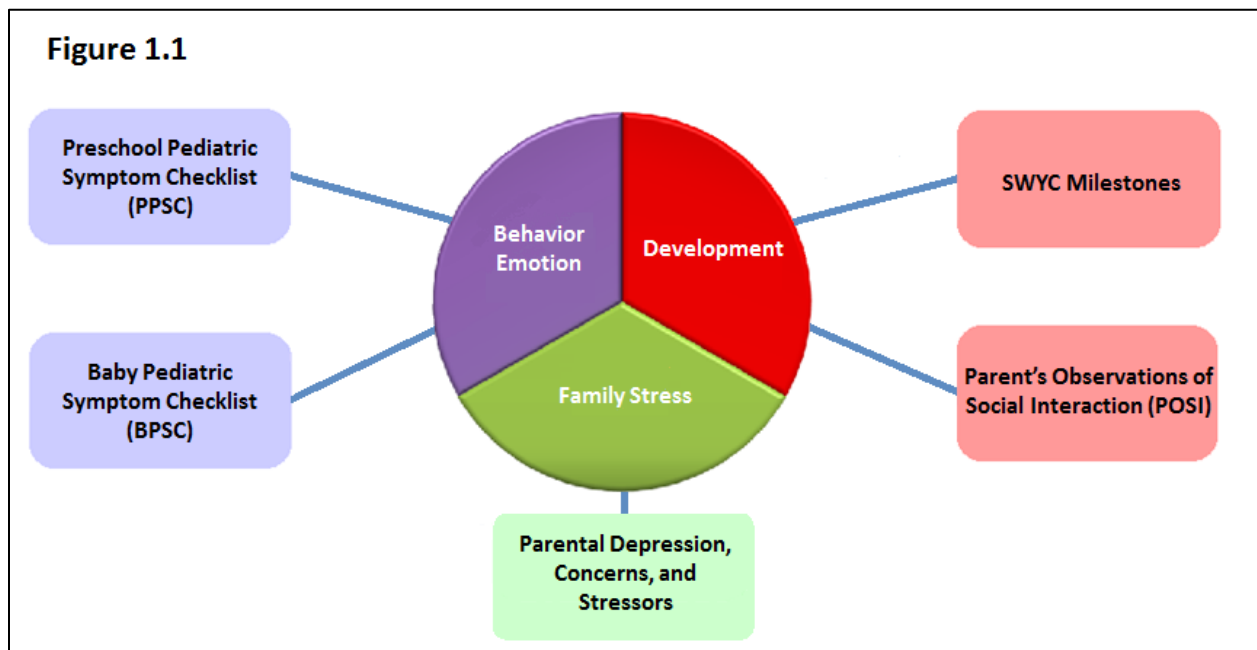
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## **A) Overview of the SWYC**

The *Survey of Well-being of Young Children (SWYC)* is a freely available, first-level screener that monitors risk for developmental-behavioral disorders in children up to 5 ½ years old. *It is not a diagnostic tool* – instead, the *SWYC* is a parent-report instrument primarily designed to maximize the amount of information that can be elicited reliably from parents before they meet with their child's pediatric primary care provider (PPCP). As such, it is intended to help PPCPs determine areas of the child's functioning that require further investigation. The *SWYC* questions were written to be short and easy to read. The entire instrument takes most parents 10 minutes or less to complete.

The *SWYC* assesses multiple domains of children's well-being: cognitive, language, and motor development; behavioral and emotional adjustment; autism risk; and family stress. In order to assess these domains, each *SWYC* form includes four components: (1) *SWYC Milestones*; (2) *Baby Pediatric Symptom Checklist (BPSC)* or *Preschool Pediatric Symptom Checklist (PPSC)* (depending on age); (3) *Family Questions*; and (4) *Parent's Observation of Social Interaction (POSI)* (for select age range). See Figure 1.1 below for an illustration of how the components fit into the respective domains of functioning:



- The *SWYC Milestones* assess the child’s cognitive, language, and motor development. It is important to know that among the 10 questions provided for each age level, some questions are expected to be easy for a child of that age, some average, and some difficult. Thus, parents should not expect that their child will be able to accomplish all ten of the skills listed.
- The *BPSC* and *PPSC* assess behavioral and emotional symptoms for children under 18 months and from 18 to 66 months, respectively.
- The *POSI* assesses risk for autism spectrum disorder (ASD) for children between 16 and 36 months of age. There are six questions that are conceptually similar to the “critical items” of the *M-CHAT* and an additional seventh question that asks parents to indicate their child’s favorite activities.<sup>1</sup>
- The *Family Questions* assess stress present in the child’s family environment, including parental depression, discord, substance abuse, and food insecurity, and two questions eliciting the parent’s concerns about the child’s behavior, learning, or development. Any positive response should be followed up to ensure whether a significant risk is present and if referral for intervention is warranted.

The American Academy of Pediatrics (AAP) and many state health departments recommend formal developmental screening at 9, 18, and 30 (or 24) months.<sup>2</sup> Other states, such as Massachusetts, require screening at every visit. We suggest that more frequent screening is advisable (please see chapter 6 on “When to Screen: A Deeper Look” for more detail). Therefore, we created 12 age-specific *SWYC* forms to be used at every well-child visit (i.e., one for each visit on the pediatric periodicity schedule).<sup>3</sup> Figure 1.2 depicts which *SWYC* components assess each domain of functioning at each age.

<b>Figure 1.2</b>												
<b>Visits on the Pediatric Periodicity Schedule</b>												
<b>Domains</b>	<i>2 mo</i>	<i>4 mo</i>	<i>6 mo</i>	<i>9 mo</i>	<i>12 mo</i>	<i>15 mo</i>	<i>18 mo</i>	<i>24 mo</i>	<i>30 mo</i>	<i>36 mo</i>	<i>48 mo</i>	<i>60 mo</i>
Developmental Functioning	<b>SWYC Milestones</b>											
							<b>POSI*</b>					
Behavioral/Emotional Functioning	<b>Baby Pediatric Symptom Checklist</b>						<b>Preschool Pediatric Symptom Checklist</b>					
Family Stress	<b>Parental Depression, Concerns, and Family Stressors</b>											
*Parent’s Observations of Social Interactions												



## **B) Design Principles**

We designed the *Survey of Well-being of Young Children (SWYC)* with several principles in mind. An understanding of these principles should help users better understand the strengths and limitations of the *SWYC* as well as guide users seeking to create adaptations or new translations of the *SWYC*.

As reflected in its name, the first principle of the *SWYC* has always been to promote young children's **well-being**. This implies longitudinally examining behavioral symptoms and developmental milestones over the course of the child's first 5 ½ years, in the context of his/her family. It also implies embedding the *SWYC* in a system of care that can translate this information into appropriate services, thereby improving children's well-being. As a result, the *SWYC* is intended for pediatric primary care providers (PPCPs) to use in pediatric offices. The *SWYC* may also be used by other professional groups who are part of a system of care for young children and their families (e.g., home visitors, child care providers, preschool teachers).

The second principle that underlay the original design of the *SWYC* was **comprehensiveness**. The historical separation of "developmental" from "behavioral" screening is outdated and no longer tenable. PPCPs need a comprehensive strategy to identify children at risk for the whole range of developmental and behavioral problems. In addition, as the social determinants of health and well-being have become more and more evident, it is also clear that PPCPs need an efficient and acceptable way to identify selected risks within the child's family that they, and others involved in early childhood services, have the capacity to address (e.g., parental depression, substance use, hunger).

A third foundational principle in the design of the *SWYC* was **feasibility**. PPCPs have always been clear that the instrument must be brief, easy for parents to respond to independently (either at home or in a waiting room), straightforward to administer and score, and amenable to delivery via an electronic platform – either freestanding or via an electronic medical record (EMR) system. The *SWYC* format is amenable to administration via the internet, so parents could conceivably complete it by computer, tablet, or smartphone either at home or in an office (please see chapter 3 on "Electronic *SWYC*" for more detail). Because it was specifically designed for use in pediatrics, the *SWYC* is also keyed to the standard pediatric periodicity schedule, making it easier to select the appropriate form for each child.

Attempting to achieve both comprehensiveness and feasibility places competing demands on an instrument. True comprehensiveness may be best achieved through a full clinical evaluation that involves developmental testing, structured observations, and interviews with the child's parents. Clearly, this approach requires significant resources of time and staff. In contrast, feasibility may be best achieved through use of a very brief questionnaire, which by necessity

omits many nuances and details. In designing the *SWYC*, we sought to strike a balance between these competing goals. Explicitly, we sought to *maximize the information that can be elicited reliably from parents of young children before they meet with their health care provider*. When risk is identified, further evaluation will be necessary to determine its nature and severity. Based on these principles, we made a series of decisions while designing the *SWYC*:

**Brevity and simplicity:** Parents and PPCPs have cautioned us repeatedly to keep the response time under 10 minutes in order to maintain optimal flow of patients through the pediatric office or another setting, and thus to minimize the burden on parents who have young children in tow. We also sought to keep sentences short, response options clear, and language simple. No pictures or diagrams are necessary to explain the questions we ask.

**Reliance on parents' observations:** To ensure that parents can complete the *SWYC* anywhere and anytime (including in waiting rooms), they should be able to answer the questions reliably from memory, without the need to “test” their child’s abilities or use any equipment. *SWYC* questions are also designed to be interpreted subjectively by parents. For example, some of the components of the *SWYC* have the response option “very much,” which can be interpreted to refer to either the frequency of a behavior, its intensity, or its severity. It is up to the parent to decide how much “very much” is to them when answering the question. These choices increase feasibility but place limits on the types of behaviors and milestones that the *SWYC* can assess.

**Prioritize sensitivity:** For most instruments, scoring thresholds (also known as “cut scores”) are set in a somewhat arbitrary fashion.<sup>i</sup> Of course, the goal of scoring thresholds is to strike a balance between sensitivity (i.e., accurately identifying as many children as possible who actually have developmental or behavioral problems) and specificity (i.e., identifying correctly as many children as possible who do not have a significant condition). In creating the scoring thresholds for the *SWYC*, we have chosen to favor sensitivity over specificity, a decision that results in minimizing the number of children who are truly at risk but are not identified through screening (i.e., “false negatives”). The “cost” of this decision is the identification of more false positive cases that require further evaluation. The “benefit” is that fewer children with significant disabilities will be missed. Please see section 2E on “Interpretation” for further discussion about this decision and chapter 8 on “Decision Thresholds: A Deeper Look” for even more detail.

**Freely available:** We provide the most updated forms and scoring guides on our website, [www.theSWYC.org](http://www.theSWYC.org), and any user is welcome to use them without further permission. Please

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<sup>i</sup> Ideally, thresholds are set based on cost-effective analysis; see: [Pauker, S.G., & Kassirer, J.P. (1980). The threshold approach to clinical decision making. *New England Journal of Medicine*, 302(20), 1109-1117.]. However, most instruments set thresholds using ad hoc methods based on receiver operating characteristic (ROC) curves.

note that the *SWYC* is protected under copyright law and we request that individuals interested in modifying the *SWYC* or administering it in a way for which the downloadable forms are not appropriate contact us for permission (see chapter 4 on “Translations and Cultural Adaptations” for more information specifically about translations of the *SWYC*).<sup>ii</sup>

Amenable to different formats: The *SWYC* can be downloaded from our website, [www.theSWYC.org](http://www.theSWYC.org), and printed on paper. Because questions are simply worded and do not require props or pictures, they are also amenable to administration by computer or telephone. We are working with electronic medical record companies to encourage them to include the *SWYC* in their standard patient portals and pediatric templates (see chapter 3 on “Electronic *SWYC*” for more information).

Longitudinal care: The *SWYC* forms are designed to coincide with the standard pediatric periodicity schedule<sup>3</sup> and are intended for use at each well-child visit in the first 5 ½ years of life. They thereby provide an overview of the child’s development over time. Although there is very little evidence about longitudinal screening performed with any screening instrument, we believe that administering the *SWYC* at every visit encourages parents to consider their child’s behavior and development as a focus of pediatric care and provides the best opportunity to monitor children’s behavior and development. For a more complete explanation of our rationale, see chapter 6 on “When to Screen: A Deeper Look.”

Validity: In our initial research, the reliability and validity of the *SWYC* was comparable to older and more familiar developmental screening instruments (see section 5A on “History of the Development of the *SWYC*” for more detail). Other evidence of validity derives from the *SWYC*’s concordance with parents’ reports of previous diagnoses of developmental-behavioral disabilities in their child. Currently we are evaluating its validity as compared to standardized developmental and emotional/behavioral assessments (see section 5B on “Ongoing Research” for more detail). Initial evidence suggests that responses to the *SWYC* are not unduly influenced by race, ethnicity, gender, or socioeconomic status (i.e., differences in *SWYC* scores between groups are best explained by observed true differences in children’s behavior and development). Further standardization and validation of *SWYC* scoring is in process, including among diverse populations (see section 5D on “Future Research” for more information).

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<sup>ii</sup> For questions or concerns about the *SWYC* or interest in translating the *SWYC* into other languages, please contact Kate Mattern at: [theswyc@gmail.com](mailto:theswyc@gmail.com).

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# **Chapter 2**

## **Implementation of the *SWYC***

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## **A) Chapter Summary**

Use of the *Survey of Well-being of Young Children (SWYC)* is part of a process by which a child's development and behavior are monitored, discussed, and evaluated. An important outcome of this process is the opportunity for a conversation about the child's well-being between the parent(s) and the pediatric primary care provider (PPCP) or other child care provider. Another important outcome is that, by filling out the questions, parents are often prompted to monitor aspects of their child's well-being that are covered in the SWYC.

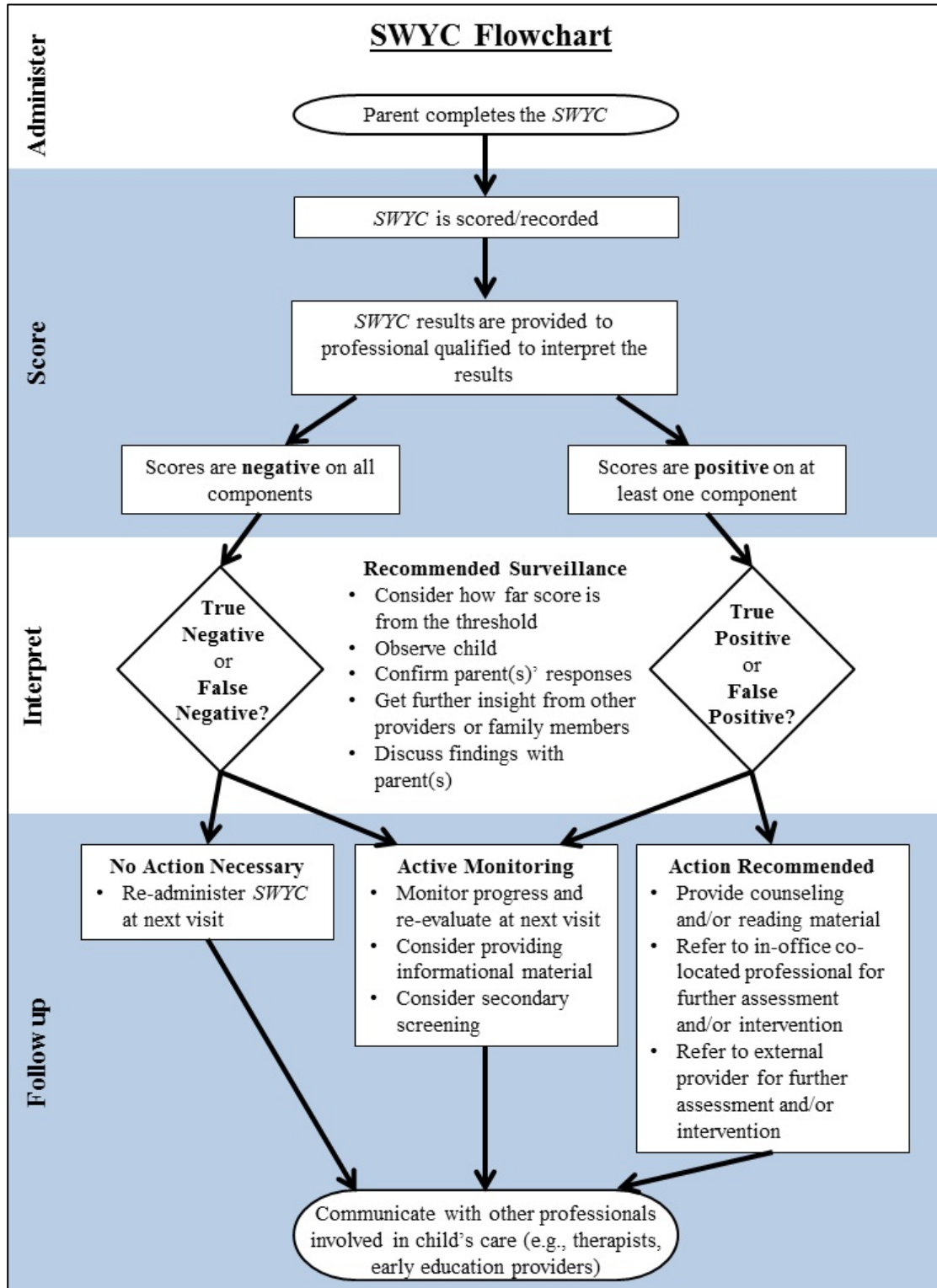
There are 12 SWYC forms, one for each age when well-child visits are typically scheduled. Each form includes a component about cognitive, language, and motor development, a component about behavioral and emotional adjustment, and a component about family stress. The 18-, 24- and 30-month forms also include a component to assess behaviors associated with autism spectrum disorder (ASD). Please see section 1A on "Overview of the SWYC" for more detail.

Parents of children between 1 and 66 months of age can complete the SWYC before regular well-child care visits to a PPCP, or may be asked to complete it by a home visitor, child care provider, or preschool teacher. Before administration, it is important to remind parents that the SWYC is a questionnaire designed to identify concern, not the presence of a particular disorder. Please see sections 2B on "Preparation" and 2C on "Administration" for more detail.

After the parent completes the form, each component is scored separately (please see section 2D on "Scoring" for more detail). If a child's score falls outside the expected range, this means that the child may be at risk for having a problem in that area of well-being. The SWYC scoring thresholds are designed to identify as many children who truly are at risk as possible, and to miss as few as possible. This means that some children will be identified who actually are not at risk (i.e., false positives). Scoring thresholds and interpretation of scores are discussed in section 2E on "Interpretation."

Interpretation of the meaning of SWYC scores involves observation of the child, discussion with the parent(s), and/or occasionally obtaining observations from another parent, grandparent, or other child care provider. If a developmental or behavioral risk is identified, the PPCP or other provider might decide on further evaluation, in-office counseling, or referral to a community resource (please see section 2F on "Follow-up and Referral" for more detail).

We provide a flowchart below to depict a step-by-step way in which the SWYC might fit into a comprehensive, regular screening and follow-through procedure. The next several sections describe the process depicted in the flowchart in greater detail.





## **B) Preparation**

Thoughtful preparation is a necessary first step to implementing a successful screening and monitoring program.<sup>4</sup> Although patterns of regular screening will depend somewhat on local risk factors, resources, and health insurance regulations, program personnel should consider the following before administering the *Survey of Well-being for Young Children (SWYC)*:

1. Identify which children will be screened.
2. Decide with what frequency and at what ages children will be screened.
3. Determine workflow considerations, such as:
  - a. Who will administer and score the screening instruments?
  - b. How and where will the information be stored and tracked longitudinally over time?
4. Determine how staff will be trained, including:
  - a. Educating staff about the goal and importance of screening.
  - b. Taking into consideration each staff member's specific role and qualifications.
5. Determine who will inform parents of children in the practice or program regarding:
  - a. The value of screening.
  - b. The procedures that will be followed.
  - c. What will be done with the information gathered.

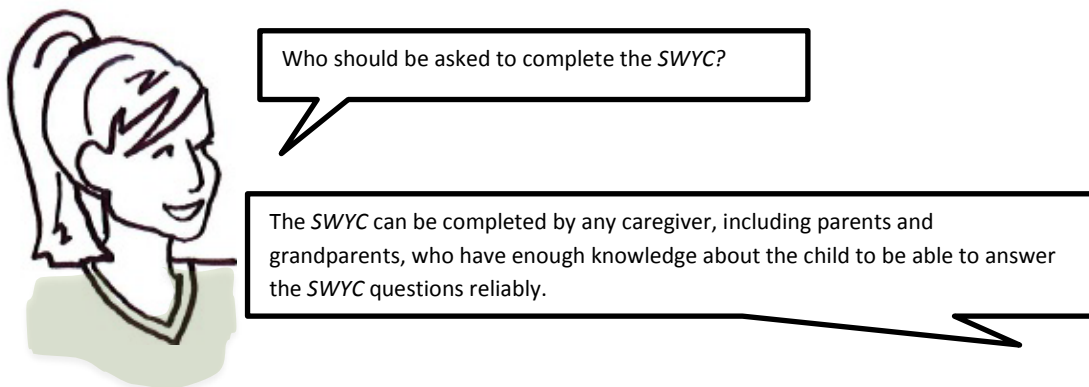


Where do I purchase the SWYC?

No purchase is required. All of the age-specific SWYC forms are freely available on our website: [www.theSWYC.org](http://www.theSWYC.org).

## **1. Target Population:**

The SWYC is intended to target a 'universal' population of children up to 5 ½ years old at all successive health supervision visits. This population also includes children with known disabilities, because new risks or concerns may emerge at any time. The SWYC may be used in special circumstances that make it necessary or prudent to be more selective, such as for professionals working with referred populations of children (e.g., foster children), but these individuals should be cautioned that the SWYC was developed and researched for use in a general population. Lastly, for those wishing to use the SWYC with non-English speaking populations, please refer to section 4D on "Current and Future SWYC Translations."



## **2. Administration Schedule:**

The SWYC is keyed to the standard periodicity schedule for health supervision visits and can easily be made a regular part of each pediatric visit for children up to 5 ½ years old. Although the American Academy of Pediatrics (AAP) suggests screening when children are 9, 18, and 30 (or 24) months old<sup>3</sup>, we believe there are notable advantages to implementing the SWYC at every visit. For example:

- Staff and parents become accustomed to developmental-behavioral screening as a routine part of care. Forms are given to every parent with young children regardless of age, and physicians expect screening to be completed prior to all well-child visits.
- Because attendance at each pediatric visit is well below 100%,<sup>5</sup> frequent screening ensures that a child who attends any visit will be screened. The lower the attendance rate, the more important this becomes.
- Recurrent screening encourages an ongoing conversation about children's behavior and development. This may be helpful in supporting not only the identification of problems as they arise, but also in building the trust necessary to motivate follow-up with outside referrals, when indicated.

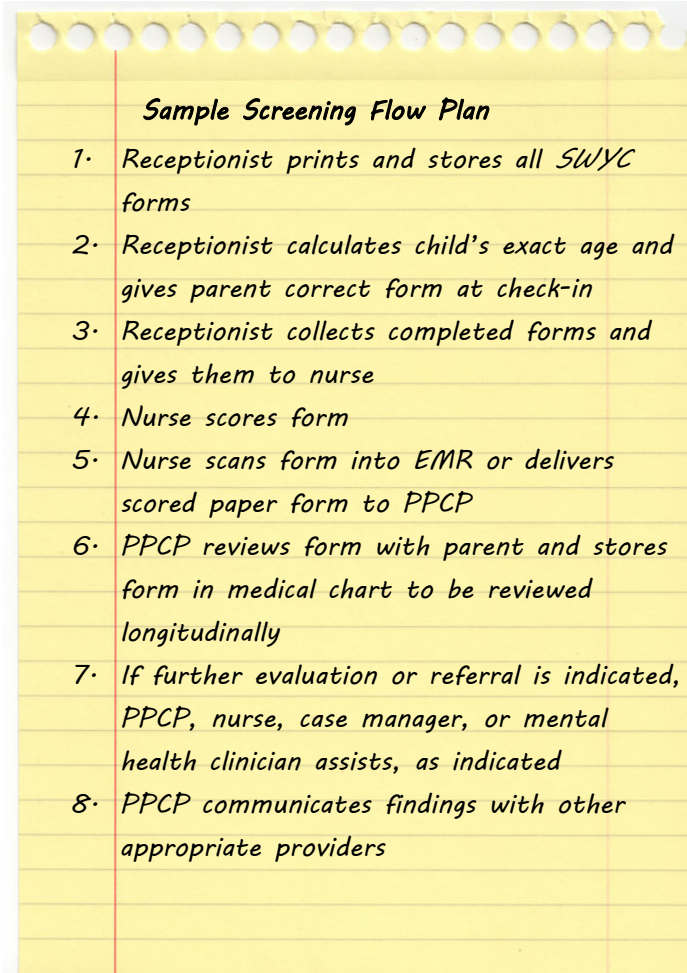
- Screening at younger ages is valuable, as even very early signs of developmental or behavioral symptoms can lead to supportive guidance and helpful interventions, and can be informative about later pathology.

Some pediatric primary care providers (PPCPs), home visitors, child care providers, and preschool teachers may choose instead to develop a different administration schedule, and may choose to administer different components of the SWYC at different ages. We encourage more rather than less frequent administration in order to ensure as few missed screenings and false negatives as possible. Please see chapter 6 on “When to Screen: A Deeper Look” for more detail.

### **3. Workflow Considerations:**

In order for the screening procedure to occur reliably, a workflow pattern must be developed individually for each setting, given that the needs and resources for each system will vary. However, thoughtfully detailing the workflow and writing a protocol for administration will be important in *any* setting to ensure that children are properly screened. Some general considerations include determining who will administer and score the SWYC as well as how and where the information will be stored. Furthermore, it is also important to maintain a list of appropriate community resources for parents in need of a referral. One possible system for a pediatric office might look something like this (see “Sample Screening Flow Plan” figure to the right).

Please note that the opportunity for electronic administration [both freestanding and embedded in electronic medical records (EMRs)] now exists through several platforms and will expand in the coming years (see chapter 3 on “Electronic SWYC”). These electronic formats offer the ability to expedite this procedure.



<i>Sample Screening Flow Plan</i>	
1.	<i>Receptionist prints and stores all SWYC forms</i>
2.	<i>Receptionist calculates child's exact age and gives parent correct form at check-in</i>
3.	<i>Receptionist collects completed forms and gives them to nurse</i>
4.	<i>Nurse scores form</i>
5.	<i>Nurse scans form into EMR or delivers scored paper form to PPCP</i>
6.	<i>PPCP reviews form with parent and stores form in medical chart to be reviewed longitudinally</i>
7.	<i>If further evaluation or referral is indicated, PPCP, nurse, case manager, or mental health clinician assists, as indicated</i>
8.	<i>PPCP communicates findings with other appropriate providers</i>

#### **4. Train Staff:**

Training should be designed to ensure that all staff understand: (1) how and why the *SWYC* is being implemented; and (2) how to execute their specific roles. Additionally, all staff members should understand the importance of confidentiality throughout the screening process.

##### ***Getting people on board:***

Before beginning to use the *SWYC*, all staff members should understand the rationale for screening and its role in assessing risk, not disorder. Perspectives on the use of screening questionnaires vary widely among clinicians, and it should not be assumed that all agree that it is a good idea. Providers might consider contacting other clinicians who are already using the *SWYC* to ask questions and learn from their experiences. During implementation, it may be useful to include time to discuss the process and any unexpected events – either positive or negative – so that they may be addressed in a productive fashion. When feasible, it may be advisable before implementation to get perspectives from parents (e.g., if a program has access to a parent-teacher organization/parent-advisory board).

##### ***Training for specific roles:***

Staff members should be identified for each subsequent stage of the implementation process, including administration, scoring, interpretation, and follow-up/referral. Although the specific responsibilities for each role will be discussed in detail in the corresponding sections of this chapter, we offer some broad considerations to begin thinking about the qualifications and criteria necessary for each position. For example:

- Front-line staff, who ask parents to complete the *SWYC*, should be prepared to succinctly present the *SWYC* and answer questions (e.g., tell parents who will see the results of the *SWYC* and how their scores will be used in the overall process of care). There is a handout available for separate download on our website that is intended to serve as a “*SWYC* 101 for Front Desk Staff.” You can fill in the specifics of your practice’s procedures and post this handout for easy reference. See an example on page 26.
- Staff should be taught how to determine which *SWYC* form is appropriate based on the child’s exact age.
- Other staff should be trained on how to accurately score the *SWYC*.

- Qualified staff should be trained to interpret *SWYC* scores, explain both positive and negative screening results to parents, and offer follow-up when necessary. If a referral for further evaluation and/or intervention is indicated, staff members should be prepared to help families to access appropriate resources in their community



What makes someone qualified to interpret the *SWYC*?

By “qualified,” we mean someone who:

- has the skills and experience to understand what a positive screen does and does not mean
- possesses the ability to explain results to parents in a way that enhances trust and benefits the child
- maintains patient confidentiality

Whether or not someone is qualified is not necessarily based on specific degrees or training. Ultimately, the criteria that determine whether or not someone is qualified to interpret *SWYC* scores are up to your team.

**Example SWYC 101 Quick-Start guide for Front-Desk Staff- download the template to customize for your practice at [www.theSWYC.org](http://www.theSWYC.org)**

# SWYC 101

## A Quick-Start Guide for Front Desk Staff

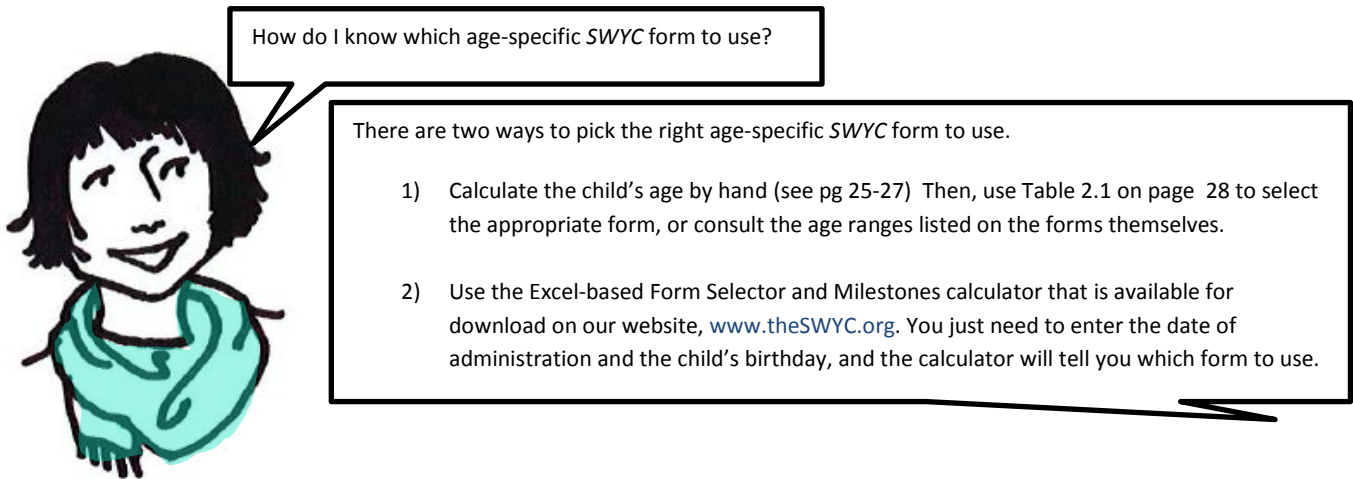


- We are using the SWYC at every checkup for children five and younger.
- The SWYC is a questionnaire that is designed to give pediatricians a better understanding of their patients' behavior and development.
- There is a different SWYC form for each well-child visit. Each form is one page, back and front. We have the SWYC available in English and Spanish.
- We keep the SWYC forms at the reception desk.
- The SWYC forms are grouped by age. If we are running low on SWYC forms, you can print more out by going to [www.theSWYC.org](http://www.theSWYC.org) and clicking on "Age-Specific SWYC Forms."
- When a patient checks in at the front desk for their well-child visit, ask yourself if they are the right age to receive the SWYC.
- Pick out the form that is correct for that child's age:
  - Go to [www.theSWYC.org](http://www.theSWYC.org) and click on "Choose a Form and Score the SWYC." Then click on "Form Selector and Milestones Calculator" to download it. You can save this on your desktop to use any time you need it.
  - Enter the current date and the child's DOB in the yellow boxes on the Excel sheet. If the child was born prematurely, enter that too.
  - The calculator will tell you what form to use.
- Hand the parent the SWYC form. Say, "Your child's physician has asked that you complete this form. Please answer every question and return it to me when you're done."
- When the parent returns the form, give it to the nurse to score.

## **C) Administration**

After completing the preparation stage of the screening process, designated personnel can begin administering the *Survey of Well-being of Young Children (SWYC)*. Given the ease of use, the *SWYC* does not require specific qualifications to administer or score. However, interpretation of the results requires careful consideration (see section 2E on “Interpretation”). The mechanics of the administration process require the following two steps:

1. Determine the child’s exact age (years and months)<sup>i</sup> and select the appropriate *SWYC* form
2. Introduce parents to the *SWYC*. You might wish to:
  - a. Discuss the value of completing the *SWYC*
  - b. Highlight the importance of answering all the questions
  - c. Answer any questions about specific *SWYC* items
  - d. Let the parents know that results are not diagnostic and only indicate need for further review.



<sup>i</sup> Please see our age calculator in the “Form Selector and Milestones Calculator” link in the navigation bar on our website: [www.theSWYC.org](http://www.theSWYC.org)

**1. Determine the Child's Exact Age and Select the Appropriate SWYC Form:**

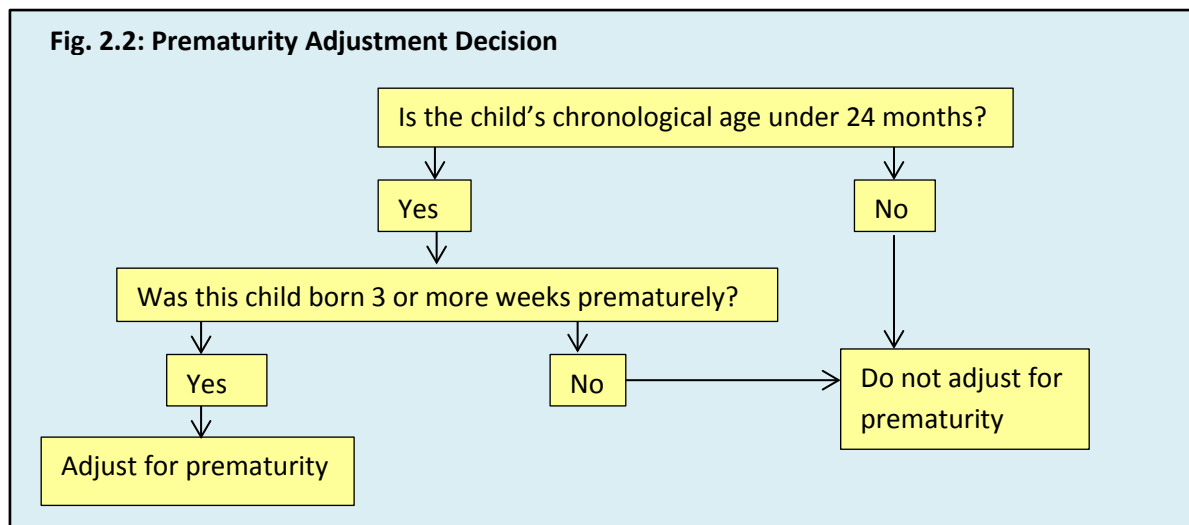
For results to be valid, each child must be screened using the correct age-specific form. Thus, it is essential to determine a child's exact age in months and days, and to select the appropriate SWYC form. There is a different SWYC form for each age on the pediatric periodicity schedule<sup>3</sup>. Specifically, there is an age band around the precise age on the periodicity schedule, which is indicated on Figure 2.1 below. You can use this chart to find the appropriate form.

For children under 24 months who were born 3 or more weeks premature, their age should be adjusted based on the number of weeks they were premature (see fig 2.2). For example, if a child was born 4 weeks premature and is 15-months-old at the time of screening, then s/he should be considered 14-months-old instead. Thus, that child should receive a 12-month SWYC form rather than a 15-month SWYC form.

Each of the 12 comprehensive age-specific forms contains components from all the domains of functioning to be assessed (i.e., developmental, behavioral/emotional, and family stress; please see section 1A on "Overview of the SWYC" for more detail). If desired, each individual component of the SWYC can be administered on its own. Individual forms for each component and complete SWYC forms can be found on our website: [www.theSWYC.org](http://www.theSWYC.org). In particular, we recommend viewing Figure 2.3 to gain a better understanding of which SWYC forms contain the *Parent's Observations of Social Interactions (POSI)* and for which ages the *POSI* can be used as a stand-alone tool.

**Figure 2.1**

Form	Minimum Age	Maximum Age
2	1 month, 0 days	3 months, 31 days
4	4 months, 0 days	5 months, 31 days
6	6 months, 0 days	8 months, 31 days
9	9 months, 0 days	11 months, 31 days
12	12 months, 0 days	14 months, 31 days
15	15 months, 0 days	17 months, 31 days
18	18 months, 0 days	22 months, 31 days
24	23 months, 0 days	28 months, 31 days
30	29 months, 0 days	34 months, 31 days
36	35 months, 0 days	46 months, 31 days
48	47 months, 0 days	58 months, 31 days
60	59 months, 0 days	65 months, 31 days





Can I use only the behavioral/emotional screener, or only the *SWYC Milestones*, or do all 4 components of the *SWYC* have to be used together?



The *SWYC* is designed to be a comprehensive first-level screening instrument for routine use in regular well-child care. It combines what is traditionally “developmental” with traditionally “behavioral” screening, and adds screening for autism and for parental depression and other family risk factors. As such, it is designed to be used as a single package, and to be used regularly over the course of health supervision. However, it is also acceptable to use individual parts of the *SWYC* separately to meet particular needs.

### How to calculate age:

To calculate the child's age, you can either use an electronic tool or do the math by hand. We would suggest using the downloadable Form Selector excel sheet on our website, [www.theSWYC.org](http://www.theSWYC.org). This excel sheet will calculate a child's age and tell you which *SWYC* form to use. All you need to do is enter in the current date, the child's birthday, and the number of weeks the child was premature, if applicable.

Doing the math by hand is complicated. If you do want to do the math by hand, however, here's how you do it. More information on when to adjust for prematurity and how to do so is included in example three below.

### Example One:

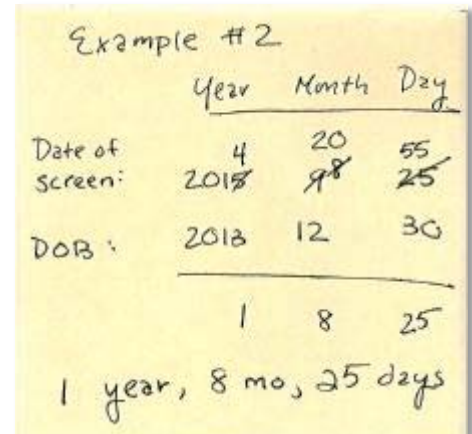
- 1) First, determine whether the child is below 2 years old. If so, ask the parent if the child was three or more weeks premature. If so, skip to example three!
- 2) If the child is 2 or older, or was not 3+ weeks premature, write the date of screening in this order: year, month, and day. Write the child's birthday below it in the same order.
- 3) Subtract. If you don't have to “carry,” this is easy.

Example #1

	Year	Mon.	Day
Date of screen:	2015	9	25
DOB:	2013	6	3
	2	3	22
2 years, 3 mo, 22 days			

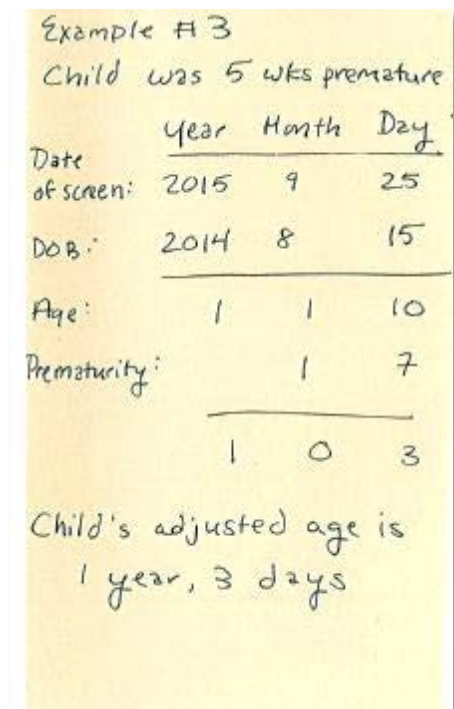
**Example Two:**

- 1) Determine whether you need to adjust for prematurity. If so, skip to example three!
- 2) Write the date of screening in this order: year, month, and day. Write the child's birthday below it in the same order.
- 3) Subtract. In this example, this math requires you to "carry." 30 days are borrowed in the month column and 12 months are borrowed in the year column.



**Example Three:**

- 1) The child in this example is below 2 years old and was more than 3 weeks premature (in this example, the child was 5 weeks premature). So, we need to adjust the child's age for prematurity before selecting a SWYC form.
- 2) Write the date of screening in this order: year, month, and day. Write the child's birthday below it in the same order. Calculate the chronological age by subtracting.
- 3) Now, convert the weeks premature into weeks and months (we are considering 4 weeks = 1 month). Write these numbers out below the chronological age that you just calculated and subtract again. Now you have a prematurity-adjusted age.



When do I need to adjust a child's age for prematurity?

You only need to adjust for prematurity if the child is under 24 months and was born at least 3 weeks prematurely.



Do I really have to do all of those calculations just to pick out the right SWYC form?

It's important to calculate a child's age exactly so that you pick the correct form. Otherwise, the child's scoring won't work correctly and the results will be impossible to interpret. But the good news is that you don't need to do all the math we described above!

Use our downloadable age calculator to work out the child's age quickly and easily. We have an Excel sheet on our website, [www.theSWYC.org](http://www.theSWYC.org), that calculates the child's age and tells you what SWYC form to use. All you have to do is type in the date, the child's birthday, and (if relevant) the number of weeks the child was premature.

Fig. 2.3

Child Age	SWYC Form	POSI Validity Range
15 mo	15 month	<i>Parent's Observations of Social Interactions (POSI)</i>
16 mo		
17 mo		
18 mo	18 month (includes POSI)	
19 mo		
20 mo		
21 mo		
22 mo		
23 mo	24 month (includes POSI)	
24 mo		
25 mo		
26 mo		
27 mo		
28 mo		
29 mo	30 month (includes POSI)	
30 mo		
31 mo		
32 mo		
33 mo		
34 mo	36 month	
35 mo		
36 mo		
37 mo		
38 mo		
39 mo		
40 mo		
41 mo		
42 mo		
43 mo		
44 mo		
45 mo		
46 mo		



Why is the POSI only on the 18-, 24-, and 30-month forms despite having evidence for its validity across a broader range?

Validity studies of the POSI have been performed on samples of children from 16-36 months. These age ranges do not correspond perfectly with the SWYC forms (see the table to the left). Thus, although the POSI would be valid for some children who fall into the age range of the 15- and 36-month forms, these forms also include children who are too young or too old for the POSI. Therefore, the POSI is included only on the 18-, 24-, and 30-month SWYC forms, where there is evidence for its validity across the entire age range.

However, you can use the POSI as a stand-alone tool for the entire range for which there is evidence of its validation: 16 to 36 months. On the other hand, if you are using the POSI as part of the age-specific SWYC forms, you will be administering it only to children 18 to 35 months.

## **2. Explain Screening and the SWYC to Parents:**

Many front-desk staff introduce the SWYC to parents with a simple request, like “your child’s physician has asked that you complete this form.” In order to increase the validity and reliability of responses, staff administering the SWYC should be prepared to explain to parents the purpose and process of developmental screening and monitoring as well as to offer instructions for completing the SWYC. Furthermore, staff members must be prepared to answer any questions that the parents may have throughout the administration process (see below).



When I hand parents the SWYC, I tell them that their child’s doctor has asked that they complete the form. Sometimes parents then ask for more information about why they need to do so. What should I say?

*We would suggest saying something like: “This questionnaire is a tool that helps your child’s pediatrician keep track of (child’s name)’s development and behavior. Don’t worry if he or she is not doing all of the things this questionnaire asks about –most children can’t do every skill described. The questions are just a way for your doctor to get a sense of what things you should talk about in more detail.”*

How about if they want to know what I will do with the information?

*We would suggest saying something like: “Your answers to this questionnaire are confidential- the only people who will see your responses are your doctor and [staff who see results at your practice]. The questionnaire will also become part of your child’s medical record.”*

### ***Purpose:***

Staff members can inform parents that the goal of the SWYC is to *maximize the amount of information about their child’s development that can be made available to their pediatric primary care provider (PPCP) before their visit.* It is possible that parents will be apprehensive about completing a screening instrument for fear that their child will be negatively labeled or stigmatized (e.g., seen as “below average”), or that they will be judged as parents. Some parents may also feel sensitive about answering family risk items. Hence, it will be important for receptionists to reassure parents that their answers will be kept confidential (unless abuse is suspected), as greater trust and comfort will help ensure higher compliance and reliability of answers. Parents should be reminded that the SWYC is not a diagnostic test – it is simply a questionnaire designed to gather information to help PPCPs determine whether their child is “on track” developmentally. Additionally, parents should be notified about how their child’s scores may be tracked longitudinally over time (e.g., stored in medical chart or EMR). As such, the results will be used by the PPCP to indicate whether further investigation or referral is

needed. Thus, despite the potential discomfort to parents, it is in the best interest of the *child's* well-being to periodically check his/her functioning.



How long does it take to complete the SWYC?

Different parents require different amounts of time to complete the SWYC. Most take under 10 minutes.

**Instructions:**

Parents should be informed that the SWYC will take on average 10-15 minutes to complete. Although the questions are generally self-explanatory, parents should follow the directions written at the top of each component. The response options for the items of the SWYC are intended to be interpreted subjectively by parents. For example, it is up to the parent to determine what the response option “very much” means to them and answer accordingly. Administrators of the SWYC should be aware of this definition when instructing parents to complete forms. Lastly, it is useful to remind parents to complete all items on the form to increase the accuracy of the results.

**Reading questions aloud to parents with low literacy:**

If a parent's literacy level is too low to read the SWYC independently, he/she will need someone to read the form aloud. If he/she is accompanied by another adult family member with a higher literacy level, he/she may wish to have that family member read him/her the form. The other option is for a member of your staff to read to the parent the SWYC and record his/her responses.

If a member of your staff is going to read the SWYC to a parent, there are a few things to bear in mind. First, remember that the parent might feel less comfortable endorsing problem behaviors or responding truthfully to the *Family Questions* when they are responding to a verbally administered screener. Second, remember that there is a risk of skewing the parent's responses by providing extra interpretation of the items or response options beyond what the parent would read if he/she were completing the SWYC form independently. It is not possible to totally control for these effects – responses collected by reading the forms aloud will always be somewhat changed by the atypical method of administration. However, there are a few things you can do to make the responses as comparable as possible to those collected from a typically-administered SWYC form:

- Take the parent to a place where his/her responses will not be overheard by other patients.
- Read the *SWYC* items and response options verbatim. Try to think of yourself as a voice recording – just reading the words on the page and deviating from the form as little as possible.
- Parents will ask you questions. If the question is about what response option to select (for example, if a parent asks “if my child cries every time he is in a new place, does that mean I should say ‘very much?’”) tell the parent something like “you should pick whatever response seems most accurate to you.” If the question is about a definition or the parent doesn’t understand the wording of an item – for example, “what does the word ‘routine’ mean?” – try to respond helpfully but as neutrally as possible. For this question, you might say something like “a routine is a schedule or daily plan.”

Presenting the form neutrally can be challenging, but it is important to standardize the reading of the items as much as possible so that you can know that responses collected verbally are comparable to responses collected on paper or electronically.

**Content:**

It may be helpful to describe the four components of the *SWYC* to parents, as well as any special considerations. For example, it may be helpful to mention that the *SWYC Milestones* items range from easier to more difficult and that children typically demonstrate some, but not all, of the ten skills. These “harder” items may serve to help parents anticipate and appreciate emerging developmental skills. Likewise, many parents can be expected to endorse at least some behavioral symptoms on the *BPSC* or *PPSC*. An outline of the *SWYC*’s overall content can be found in section 1A on “Overview of the *SWYC*.”



How many questions are on a *SWYC* form?

Parents are asked to complete a two-page, age-specific form. Depending on the child’s age, the form includes either three or four components: (1) cognitive, language, and motor development; (2) behavioral/emotional development; (3) family risk factors, including parental depression, discord, substance abuse, and hunger; and, for children between 15 months and 36 months, (4) risk for autism spectrum disorder. The length of the *SWYC* forms varies slightly by age, but there are roughly 40 questions on each age-specific form.

## D) Scoring

Once parents have completed the *Survey of Well-being of Young Children (SWYC)*, check their responses for missing values and ask them to complete any questions left blank. Next, a designated staff member may score the *SWYC*. The scoring process is designed to be easy to perform. In general, if a child's score falls outside the expected range (i.e., a positive result) then this means that the child may be at risk for having a problem in that area of well-being. Notably, a positive result on the *SWYC Milestones* occurs when a child's score is *below* the scoring threshold whereas a positive result on all other *SWYC* components occurs when a child's score *exceeds* the scoring threshold.

The scoring guide for each component of the *SWYC* is outlined on the pages that follow. Additionally, scoring charts for paper administration are included at the end of this section in order to help with longitudinal tracking. Lastly, although data to support the validation of the *SWYC* will be discussed at length in chapter 5 on "*SWYC* Research," it is important to note upfront that we cannot provide scoring thresholds for the 2- and 60-month *SWYC Milestones* at this time. The individual questions are valid and reliable and may be useful for surveillance, but our initial research did not support the validity of the overall scores for detecting developmental delays. We hope to rectify this in future revisions.



Why is a "high score" positive on some *SWYC* components but a "low score" is positive on others?

The *SWYC Milestones* measure developmental achievements. The more achievements that are reported the better. As such, a high score on the *SWYC Milestones* is good, and therefore not indicative of risk.

All other *SWYC* components measure negative attributes (i.e., symptoms). As such, a high score on these components would mean more symptoms, which would indicate risk.

### SWYC Milestones

SWYC Milestones scoring can be done electronically. Please see our Milestones Excel calculator in the “Form Selector and Milestones Calculator” link on our website:

[www.theSWYC.org](http://www.theSWYC.org). For manual scoring, see below.

- Each form includes 10 items. Score each item using these values: “Not Yet” corresponds to “0”; “Somewhat” to “1”; and “Very Much” to “2.” Missing items count as zero.
- Add up all 10 item scores to calculate the total score.
- On the SWYC Milestones scoring chart (see right), the child’s age in months is indicated in the “age” column. Check to be sure that the parent completed the correct form for the child’s age (far left column labeled “form”). If not, the score will be misleading.

**Please Note:** Cut scores are not available for the 2- and 60-month forms. The individual questions are valid and reliable and may be useful for surveillance, but our initial research did not support the validity of the overall scores for detecting developmental delays.<sup>1</sup>

- Following along the appropriate age row, determine whether the child’s total score falls into the “Needs Review” or “Appears to Meet Age Expectations” category.
- If a child scores in the “Needs Review” range, further evaluation or investigation is indicated (as with all other components, please see section 2F on “Follow-up and Referral” for more detail).

FORM	Age (m)	Needs Review	Appears to meet age expectations
2m	1 - 3	No Milestones cut scores available	
4m	4	≤13	≥14
	5	≤15	≥16
6m	6	≤11	≥12
	7	≤14	≥15
	8	≤16	≥17
9m	9	≤11	≥12
	10	≤13	≥14
	11	≤14	≥15
12m	12	≤12	≥13
	13	≤13	≥14
	14	≤14	≥15
15m	15	≤10	≥11
	16	≤12	>13
	17	≤13	≥14
18m	18	≤8	≥9
	19	≤10	≥11
	20	≤11	≥12
	21	≤13	≥14
	22	≤14	≥15
24m	23	≤10	≥11
	24	≤11	≥12
	25	≤12	≥13
	26	≤13	≥14
	27	≤14	≥15
	28	≤15	≥16
30m	29	≤9	≥10
	30	≤10	≥11
	31	≤11	≥12
	32	≤12	≥13
	33 - 34	≤13	≥14
36m	35	≤10	≥11
	36	≤11	≥12
	37	≤12	≥13
	38 - 39	≤13	≥14
	40 - 41	≤14	≥15
	42 - 43	≤15	≥16
48m	44 - 46	≤16	≥17
	47	≤12	≥13
	48 - 50	≤13	≥14
	51 - 53	≤14	≥15
	54 - 57	≤15	≥16
60m	58	≤16	≥17
	59 - 65	No Milestones cut scores available	

<sup>1</sup> We will attempt to correct this difficulty in future revisions of the SWYC Milestones. Please see section 5D on “Future Research” for more detail.



### ***Baby Pediatric Symptom Checklist (BPSC)***

1. The *BPSC* is divided into three subscales, each with 4 items. Determine the *BPSC* subscale scores by assigning a “0” for each “Not at All” response, a “1” for each “Somewhat” response, and a “2” for each “Very Much” response, and then sum the results.
  - a. In the event that parents have selected multiple responses for a single question and are unavailable for further questioning, then choose the more concerning answer (i.e. "Somewhat" or "Very Much") farthest to the right.
  - b. In the event that there is a missing response, that item counts as zero.
2. Any summed score of 3 or more on any of the three subscales indicates that a child is “at risk” and needs further evaluation or investigation.

### ***Preschool Pediatric Symptom Checklist (PPSC)***

1. Determine the *PPSC* total score by assigning a “0” for each “Not at All” response, a “1” for each “Somewhat” response, and a “2” for each “Very Much” response, and then sum the results.
  - a. In the event that parents have selected multiple responses for a single question and are unavailable for further questioning, then choose the more concerning answer (i.e. "Somewhat" or "Very Much") farthest to the right.
  - b. In the event that there is a missing response, that item counts as zero.
2. A *PPSC* total score of 9 or greater indicates that a child is "at risk" and needs further evaluation or investigation.

**Parent's Observations of Social Interactions (POSI)**

1. Score each of the seven questions. Each question is assigned either a "1" or a "0". If the parent selects one or more responses that fall in the last three columns, the question is scored as "1"; otherwise, it is scored as "0" (see image below).
2. For items where parents have selected multiple responses for a single question (i.e., multiple responses in each row):
  - c. Choose the more concerning answer (i.e., lower-functioning behavior) farthest to the right.
  - d. If the parent has selected multiple answers in the last three columns for one item, assign only one point for the item.
  - e. Missing items count as zero.
3. Since there are seven questions total, there is a maximum of seven potential points.
4. A result of three or more points in the last three columns indicates that a child is "at risk" and needs further evaluation or investigation.<sup>ii</sup>


**3 or more responses (from different items) in these 3 columns**

<b>PARENT'S OBSERVATIONS OF SOCIAL INTERACTIONS (POSI)</b>						
Does your child bring things to you to show them to you?	Many times a day	A few times a day	A few times a week	Less than once a week	Never	
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Is your child interested in playing with other children?	Always	Usually	Sometimes	Rarely	Never	
When you say a word or wave your hand, will your child try to copy you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Does your child look at you when you call his or her name?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Does your child look if you point to something across the room?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
How does your child <u>usually</u> show you something he or she wants?	Says a word for what he or she wants	Points to it with one finger	Reaches for it	Pulls me over or puts my hand on it	Grunts, cries or screams	
<i>(please check all that apply)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
What are your child's favorite play activities?	Playing with dolls or stuffed animals	Reading books with you	Climbing, running and being active	Lining up toys or other things	Watching things go round and round like fans or wheels	
<i>(please check all that apply)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

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<sup>ii</sup> Based on recent data, we are actively working to revise the POSI scoring system. Our goal is to maintain sensitivity while increasing positive predictive value.

### Example of a Positive POSI


 <b>SWYC:</b> 18 months, 0 days to 34 months, 31 days		Child's Name: Birth Date: Today's Date:				
PARENT'S OBSERVATIONS OF SOCIAL INTERACTIONS (POSI)						
Does your child bring things to you to show them to you?	Many times a day	A few times a day	A few times a week	Less than once a week	Never	0
	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Is your child interested in playing with other children?	Always	Usually	Sometimes	Rarely	Never	0
When you say a word or wave your hand, will your child try to copy you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	0
Does your child look at you when you call his or her name?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	0
Does your child look if you point to something across the room?	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	1
How does your child <u>usually</u> show you something he or she wants?	Says a word for what he or she wants	Points to it with one finger	Reaches for it	Pulls me over or puts my hand on it	Grunts, cries or screams	1
(please check all that apply)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
What are your child's favorite play activities?	Playing with dolls or stuffed animals	Reading books with you	Climbing, running and being active	Lining up toys or other things	Watching things go round and round like fans or wheels	1
(please check all that apply)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
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**Total Score: 3**

Note: Omitted questions receive a score of 0.

Note: Each question has a maximum score of 1. Even though these two "check all that apply" questions have two checks in the three right columns, they only count for one point each.

### Example of a Negative POSI

 <b>SWYC:</b> 18 months, 0 days to 34 months, 31 days		Child's Name: Birth Date: Today's Date:				
PARENT'S OBSERVATIONS OF SOCIAL INTERACTIONS (POSI)						
Does your child bring things to you to show them to you?	Many times a day	A few times a day	A few times a week	Less than once a week	Never	0
	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Is your child interested in playing with other children?	Always	Usually	Sometimes	Rarely	Never	0
When you say a word or wave your hand, will your child try to copy you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	0
Does your child look at you when you call his or her name?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	0
Does your child look if you point to something across the room?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	0
How does your child <u>usually</u> show you something he or she wants?	Says a word for what he or she wants	Points to it with one finger	Reaches for it	Pulls me over or puts my hand on it	Grunts, cries or screams	1
(please check all that apply)	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	
What are your child's favorite play activities?	Playing with dolls or stuffed animals	Reading books with you	Climbing, running and being active	Lining up toys or other things	Watching things go round and round like fans or wheels	1
(please check all that apply)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	
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**Total Score: 2**

Note: Omitted questions receive a score of 0.

Note: Each question has a maximum score of 1. Even though these two "check all that apply" questions have two checks in the three right columns, they only count for one point each.

### **Family Questions**

Positive endorsement of items on this list indicates that a child should be monitored further. *If after reviewing the Family Questions, a PPCP believes a child or family member may be at immediate risk of harm, appropriate steps should be taken to refer the child and/or family to the appropriate child protection agency for help as soon as possible.*

1. **Question 1:** We incorporated a single-item screen for tobacco use, "Does anyone smoke tobacco at home?" This "yes" or "no" response question has been found to be a valid way to screen for tobacco use among parents in pediatric practice.<sup>iii</sup>
2. **Questions 2, 3, and 4:** At least one positive response on the *Two-item Conjoint Screener (TICS)* has been found to detect substance abuse disorders with adequate sensitivity and specificity (nearly 80% or higher).<sup>6</sup> In addition, we have included an additional question: "Has a family member's drinking or drug use ever had a negative effect on your child?"
3. **Question 5:** We have incorporated one question based on Kleinman and colleagues' (2007) single-question screening tool. In a study of 1705 families, this question identified food-insecure families with 83% sensitivity and 80% specificity.<sup>7</sup>
4. **Questions 6 and 7:** Parental depression is assessed by the *Patient Health Questionnaire-2 (PHQ-2)*.<sup>8</sup> Answers are scored such that "Not at All" is given a "0", "Several Days" is given a "1", "More than Half the Days" is given a "2", and "Nearly Every Day" is given a "3." If the total score on both questions sums to 3 or greater, the remaining questions of the *Patient Health Questionnaire-9 (PHQ-9)*, a well-validated criterion-based measure for diagnosing depression and evaluating symptom severity,<sup>9</sup> could be administered where available resources exist.
5. **Questions 8 and 9:** These questions deal with domestic violence. The short version of the *Woman Abuse Screening Tool (WAST-Short)*<sup>10</sup> is considered positive if "A Lot of Tension" for question 8 or "Great Difficulty" for question 9, is endorsed on one or both of the items.
6. **Parent's Concerns:** These two questions ask whether parent(s) have any additional concerns about their child's behavior, learning, or development. These questions were adapted from *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* and have no formal recommended scoring template<sup>11</sup>. If a parent endorses being "Somewhat" or "Very Much" concerned about his or her child on either of the two *Parent's Concerns* questions, pediatricians should use this as an opportunity for additional conversation.

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<sup>iii</sup> Please see the American Academy of Pediatrics' EQIPP module, "Eliminating tobacco use and exposure to second hand smoke" at: <http://eqipp.aap.org/>

### Longitudinal Scoring Chart

We created a comprehensive scoring chart for paper administration, which is comprised of all the components of the *SWYC* on one piece of paper. This form is available on the next page and as a separate download on our website, [www.theSWYC.org](http://www.theSWYC.org).



Yikes! Those hand scoring guides look overwhelming. Isn't there another way?

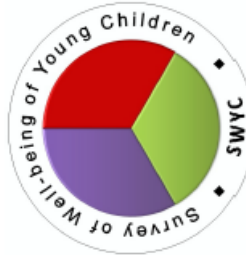
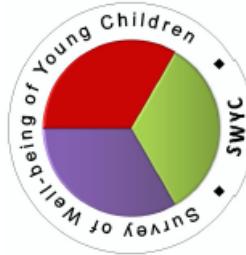
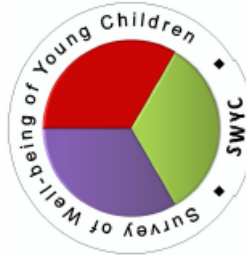
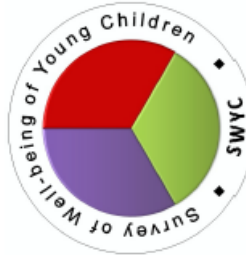
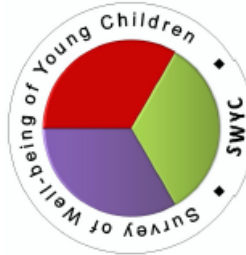
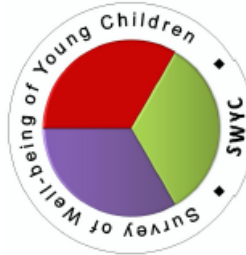
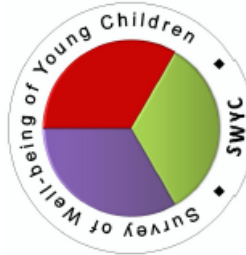
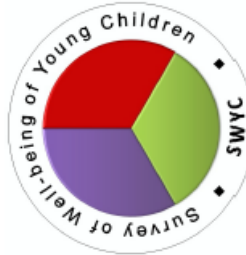
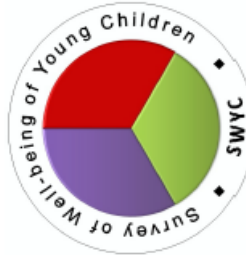
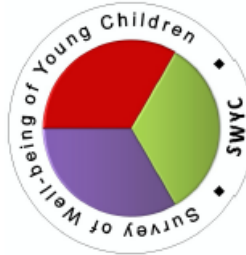
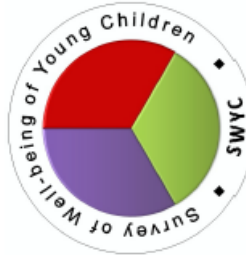
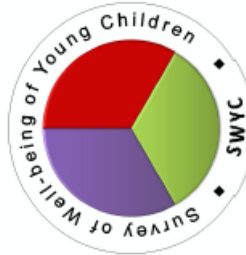
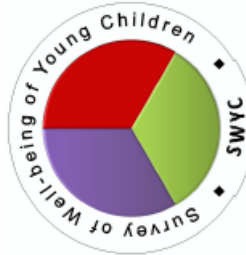
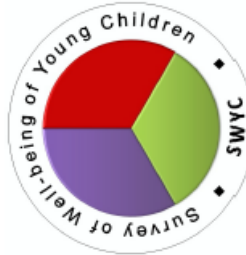
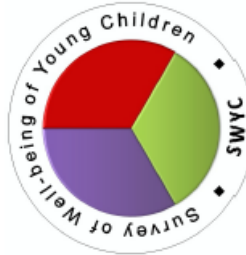
Yes, there is! When the *SWYC* is administered electronically, the scoring is done automatically. The *SWYC* may eventually become available as a standard offering from electronic medical record (EMR) providers. In the meantime, some practices have incorporated the *SWYC* into their local EMR systems on their own.

If you don't have an EMR, there is an Excel-based calculator available on our website that takes a lot of the work out of the *SWYC Milestones* scoring. You just enter the child's raw *SWYC Milestones* score, and it tells you whether that score indicates a need for review or appears to meet age expectations. Download the calculator from [www.theSWYC.org](http://www.theSWYC.org).



I just reviewed the *SWYC Milestones* forms for two of my patients. One child is 6 months old and the other is 7 months old. Both of their parents completed the 6 Month *SWYC* form. Both children got a *SWYC Milestones* score of 12, but when I checked my scoring chart I saw that the younger child's score fell in the "Appears to Meet Age Expectations" range, while the older child's score fell in the "Needs Review" range. Since they have the same score on the same age-specific *SWYC* form, I don't understand why this is.

Each *SWYC* form covers an age range. The 6 month form is for children who are 6, 7, and 8 months old. Children who are at the younger end of the age range for a particular form will tend to score lower than children that are older in the same age range. The scoring algorithm adjusts for this tendency. So despite the fact that the 6-month *SWYC Milestones* was completed for both of your patients, a score of 12 for a 6 month old child falls under the "Appears to Meet Age Expectations" range, whereas a score of 12 for a 7 month old child falls under the "Needs Review" range.

SWYC Longitudinal Hand Scoring		Milestones		Irritability		BPSC		Routines		DOB:		MR#:		Parent Concerns					
FORM	Age (m)	Needs Review	Appears to meet age expectations	Appears ok	Needs Review	Appears ok	Needs Review	Appears ok	Needs Review	Smoke tobacco	More than meant to	Needed to cut back	Had a bad effect	Hunger	Depression (2 Item Total Score)	Tension	Arguments	Dev. Behv.	Concerns
2m	1-3	No cut scores available	≥ 14	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
4m	4	≤ 13	≥ 14	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
6m	5	≤ 15	≥ 16	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
9m	6	≤ 11	≥ 12	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
12m	7	≤ 14	≥ 15	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
15m	8	≤ 16	≥ 17	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
18m	9	≤ 11	≥ 12	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
24m	10	≤ 13	≥ 14	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
30m	11	≤ 14	≥ 15	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
36m	12	≤ 12	≥ 13	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
48m	13	≤ 13	≥ 14	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
60m	14	≤ 14	≥ 15	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
	15	≤ 10	≥ 11	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
	16	≤ 12	≥ 13	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
	17	≤ 13	≥ 14	< 3	≥ 3	< 3	≥ 3	< 3	≥ 3	N	Y	N	Y	N	Y	-	+	N	Y
	18	≤ 8	≥ 9	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	19	≤ 10	≥ 11	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	20	≤ 11	≥ 12	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	21	≤ 13	≥ 14	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	22	≤ 14	≥ 15	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	23	≤ 10	≥ 11	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	24	≤ 11	≥ 12	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	25	≤ 12	≥ 13	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	26	≤ 13	≥ 14	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	27	≤ 14	≥ 15	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	28	≤ 15	≥ 16	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	29	≤ 9	≥ 10	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	30	≤ 10	≥ 11	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	31	≤ 11	≥ 12	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	32	≤ 12	≥ 13	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	33-34	≤ 13	≥ 14	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	35	≤ 10	≥ 11	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	36	≤ 11	≥ 12	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	37	≤ 12	≥ 13	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	38-39	≤ 13	≥ 14	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	40-41	≤ 14	≥ 15	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	42-43	≤ 15	≥ 16	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	44-46	≤ 16	≥ 17	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	47	≤ 12	≥ 13	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	48-50	≤ 13	≥ 14	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	51-53	≤ 14	≥ 15	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	54-57	≤ 15	≥ 16	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	58	≤ 16	≥ 17	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+
	59-65	No cut scores available	≥ 17	< 9	≥ 9	< 3	≥ 3	 www.TheSWYC.org		N	Y	N	Y	N	Y	-	+	N	Y
	60m	No cut scores available	≥ 17	< 9	≥ 9	< 3	≥ 3			N	Y	N	Y	N	Y	N	Y	-	+

## **E) Interpretation**

Universally, the interpretation of any screening instrument requires an understanding of: (1) setting screening thresholds and the corresponding tradeoff between a screener's sensitivity and positive predictive value (PPV); and (2) the uncertainty inherent in screening results. We present a brief summary of both topics below; however, please see chapter 8 on "Decision Thresholds: A Deeper Look" for more detail. At the end of this section, we present concrete guidelines for interpreting the *Survey of Well-being of Young Children (SWYC)* scores.

### **1. Understanding Screener Thresholds:**

Every screening instrument needs a defined cut-score or threshold score at which it is considered "positive" or the child is considered at risk. Defining this threshold is a complex matter, based on several assumptions. Setting a lower threshold means that more children will score positive. This means that:

- Most children who *should* be detected will score positive (more true positives).
- Many children who do *not* have a real problem will also be detected (more false positives).
- Fewer children will score negative unless they really should (fewer false negatives).
- Most children who screen negative will really be negative (more true negatives).
- Setting a higher threshold would have the opposite effect.

For the *SWYC*, we have chosen a lower threshold to be sure we miss as few children who really should be detected as possible (i.e., we prioritize sensitivity). Given that the *SWYC* is a first-level screening instrument, we believe that it is imperative to minimize the number of false negatives (i.e., children who are at risk but not identified) at the expense of identifying more false positives (i.e., children who are healthy but identified as at risk). Thus, fewer children who need services will be missed and more children will receive further evaluation.

For clinicians, the most important indicator of the usefulness of a screening instrument is the Positive Predictive Value (PPV). This is the proportion of those children whose test score is in the "Needs Review" range who actually have the condition in question – i.e. what is the chance that a child with a positive score on any component of the *SWYC* actually has a delay or disorder. The PPV is affected by the sensitivity and specificity of the test, but even more by the prevalence of the condition.

It seems like the *SWYC* detects a lot of false positives. Why can't it just tell me which children have a real problem and which children don't?



**A screening instrument can't give a diagnosis – it can only indicate risk.** So, when we were creating the *SWYC*, we had to decide how to set our scoring thresholds. If we made it relatively hard to score positive, that would mean that the only children who score positive would have very concerning scores and almost certainly have a real problem. However, it would also mean that the *SWYC* would miss lots of children with less extreme scores who also really did have a problem that needed addressing.

If we made it relatively easy to score positive, the *SWYC* would probably not miss many children with real issues. However, this would also mean that it would detect more false positives – children who score positive, but are really doing fine.

**As a first-level screener, we decided to prioritize missing as few children as possible with real cause for concern. This does mean that the *SWYC* will pick up some false positives, but it also means that children with real issues are less likely to be missed.**

## **2. Uncertainty Inherent in Screening Results:**

It is also important while interpreting scores to recognize that the meaning of screening results is often uncertain. The results of a screening test that depend on parents' reports may be inaccurate or misleading for any number of reasons. For example, the parent may have not understood one or more questions correctly, or the parent's response style might have tended toward noting more or fewer behaviors than is typical. Furthermore, parents with limited literacy and/or who speak a language not available for the *SWYC* might be particularly likely to interpret and answer questions differently. Also, the degree of trust between parent and provider can influence a parent's willingness to report on behavioral, developmental, or familial concerns. Lastly, in instances where multiple reporters complete separate *SWYC*s for a child (e.g., both parents of the child), there is the possibility that the *SWYC* scores will be quite different despite being about the same child. These are some of the many reasons it is crucial to properly train program personnel about using the *SWYC*.

Another source of uncertainty derives from the influence of prevalence on the positive predictive value (PPV). If you use a screener in a population of children among whom a particular condition is very common (i.e., highly prevalent), then PPV will be higher; whereas if prevalence is lower, PPV will be lower. However, unless you know the prevalence of a particular problem in the population of children you serve (which you rarely do), you cannot know with certainty the probability that a positive screening result will be correct. For the purposes of the *SWYC*, prevalence rates for all developmental-behavioral disorders (combined) is estimated to



be *at least* 15-20%; whereas for individual conditions, prevalence is typically much lower (e.g., around 1-5%).

### **3. Concrete Guidelines for Assessment and Surveillance after Using the SWYC:**

The uncertainty inherent in screening and assessment can be daunting. Fortunately, we have received numerous endorsements from pediatricians who report that their practice has been enriched by using the *SWYC*. Physicians who value screening should not rely solely on screening results to make clinical decisions. Instead, they should think of screening as the beginning of a process that involves a conversation with the parent(s) and observation of the child.

Here's what we can say definitively: for the *SWYC*, children who score positive are at much higher risk for having developmental-behavioral problems than children who score negative. And, if a child scores above the threshold on more than one component of the *SWYC*, this implies that he or she is at greater risk for having a developmental-behavioral problem than is a child who scored above the threshold on only one component.

So what should a pediatric primary care provider (PPCP) make of *SWYC* scores? First, it is important to understand that the *SWYC* is a first-level screener designed to monitor risk – not to diagnose disorders or disabilities. Furthermore, a positive score on a given portion of the *SWYC* **can indicate risk for any number of disorders**. For example, it is not unreasonable that a parent may report oppositionality in a child with clinical levels of anxiety. A child with language delays may present as frustrated or withdrawn. Impairment associated with significant behavior problems may limit opportunities for learning and growth, perhaps resulting in delays in development.

Thus, in our view, the PPCP's first step is to determine *why* the parent reported as he or she did, and then decide what that report signifies. Careful discussion with parents (paying particular attention to parents' concerns and/or potential cultural viewpoints), close observation of the child, reports from other adults who know the child, and/or administration of another validated developmental or behavioral assessment may all be helpful in determining the meaning of *SWYC* scores. Because children who score positive are at significantly higher risk, it makes sense for clinicians to put their greatest efforts into assessing this group to determine which ones need further help. However, they should also attend to risk factors and warning signs among children who score negative, because some will have problems despite their low screening score.

The following are some concrete guidelines to further aid in interpreting the SWYC:

**If a child scored within the “needs review” range,** consider the following questions to determine how the positive score was achieved:

- *Parent comprehension:* Can the parent read and understand the SWYC well enough to provide valid answers? Is there a language barrier? Was s/he paying attention, or did s/he rush to complete the SWYC?
- *Know the questions:* Which ones did the parent endorse at the highest level? Consider asking the parent for examples. After listening, do you agree with the rating or are you less concerned than the score might suggest?
- *Understand the parent's response style:* Many SWYC questions include response options like “Not at All,” “Somewhat,” and “Very Much.” What do these mean to the parent? Some parents will choose “Somewhat” for any behavior that ever occurs, even rarely. Others will choose “Somewhat” only for behaviors that occur with at least moderate frequency. Neither style is right or wrong, but it will influence the scores. Consider asking the parent about a few questions s/he endorsed at the same level – do you agree with the rating? Are you more or less concerned than the score might at first suggest?
- *Consider the culture and context of the parent and child:* Some questions on the SWYC may be understood differently by parents across different cultures. For example, a parent in a culture that strongly disapproves of displays of aggression may respond “Very Much” to the item “Is your child aggressive?” while a parent in a culture more tolerant of aggressive displays may respond “Somewhat,” even when the children exhibit very similar behaviors. In fact, in some Native American languages there is no word for “aggression.” Context matters as well: A parent in a community where there are no stairs (e.g., some rural areas) may respond “Not at all” to an item about the child climbing stairs, reflecting a lack of opportunity rather than a developmental delay.
- *Assess impairment:* For example, is there anything that the parent avoids because of how the child might react? Remember, however, that some problems experienced by young children will not be experienced as impairing but may nevertheless lead to future impairment. Consider a family with a young child who has autism spectrum disorder (ASD). Many young children with ASD are quite content – yet we consider ASD to be a problem because we believe that it will lead to impairment in the future when demands are greater (e.g., when the child enters school and/or tries to make friendships).

If a child scored in the “appears to meet expectations” range, consider asking a few questions anyway to assure yourself that there are no developmental-behavioral problems present.

Possible questions include:

- What is the parent’s greatest concern?
- Is there anything that the parent avoids because of how the child might react?
- Ask the parent to describe a recent time with the child that was most difficult. If the behaviors described are mild, the clinician can gain confidence in the negative score.
- As above: *know the questions*. No questionnaire includes every possible question, and all screeners have gaps. For example, the *SWYC Milestones* include more questions about expressive language at some ages than others. Some of the *SWYC* forms include more questions about motor development. Is the child experiencing problems in an area not assessed by the *SWYC*?



How do I use the *SWYC* longitudinally?

Keep a *SWYC* Longitudinal Scoring Chart (see section 2D on “Scoring”) in each patient’s file. At each visit, circle your patient’s score in each domain on the same chart you used in previous visits. This will allow you to track your patient’s development over time.

## **F) Follow-up and Referral**

After the pediatric primary care physician (PPCP) or other qualified person has used his or her clinical judgment to interpret the *Survey of Well-being of Young Children (SWYC)* results, the next steps are to: (1) explain the findings to the parents; (2) consider appropriate courses of action for the child based on the findings; and (3) communicate findings to other appropriate providers.

### **1. Follow-Up with Parents:**

It should be noted that the conversation with the parents is the first step of intervention. As such, PPCPs and others should be mindful of the manner in which they present the results to the parents, given the preliminary nature of screening scores and the potential sensitivity of the topics to be discussed. Although the following may already be familiar to many PPCPs, we provide some general advice for added guidance:

1. Be mindful that children's development and behavior are likely to be sensitive subjects to parents. Therefore it is important to discuss screening results confidentially, in a positive and empathetic tone, and with sensitivity to the parents' concerns and cultural viewpoints.
2. Explain what the findings mean (and what they don't mean), including the uncertainty inherent in any screening procedure. Reiterate that the purpose of screening is to identify concerns, not to diagnose.
3. Ask parents about the strengths of the child, so as to be able to talk about his or her strengths in addition to any weaknesses found on the *SWYC*.
4. Provide empathy to parents about how hard but important their jobs as parents are.
5. Congratulate parents for being good observers of their child and for their efforts to support his/her development and well-being.
6. Ask whether the parent finds any particular behaviors to be difficult or impairing, and ask what the parent would like to change the most. If indicated, discuss how intervention might influence these behaviors and help the parents meet their goals for their child.

#### **How to start the conversation:**

If a child scores in the "needs review" range on:

- The *SWYC Milestones*, you might say...Based on your responses to this form, it seems like it might be worth us taking a closer look at your child's development. Could you tell me more about...

- Or, you might note the particular skills s/he hasn't mastered and investigate further, e.g. something like "I see she isn't pulling herself up to standing yet. Is she getting to a sitting position OK? Does she crawl?" If the child is not saying words you might ask "how does he let you know what he wants?"
- The *BPSC* or *PPSC*, you might say...compared to other parents with kids the same age, you are reporting more difficulties with behavior or emotions. It's important that we understand that better. Can you give me more examples?
  - Or, you might highlight the items the parent noted to be of concern and discuss them further, e.g. if the child is noted to have a hard time being with new people you could ask if there are others in the family with anxiety, or ways the parent has found to comfort the child.
- The *POSI*, you might say...compared to other parents with kids the same age, you are reporting more limited social interactions. It's important that we understand that better to determine if s/he needs any special attention.
  - Or you could ask for details, e.g. "tell me how he plays with his trains" or "what kinds of things does she try to imitate?"
- If one or more of the *Family Questions* items is indicated, the specific circumstances should be explored further, and resources offered. For example, "it seems that you have been sad or stressed recently; can you tell me what's going on? Would you like to talk to a counselor about how you can feel better?"

## **2. Determine Need for Referral or Further Investigation:**


After a clinical judgment is made, the type of result on the *SWYC* should suggest the appropriate course of follow-up. A suspected true negative result should indicate no necessary action except to re-administer the *SWYC* at the next visit and continue to monitor the child's progress. A suspected false negative or false positive may warrant further screening, heightened monitoring of progress, and/or re-administering the *SWYC* at the next visit. If a true positive is suspected, PPCPs should provide either immediate counseling and/or referral for in-office or external assessment and intervention. Some options for immediate counseling include: (1) providing psycho-education about the child's risk and/or reading materials for parents; and (2) offering ways to stimulate the child's development in weaker areas and/or encourage parental strategies for emotional development (e.g., reading to a child with marginally delayed language skills or suggesting a parenting education class for parents of an oppositional toddler).

Many useful online resources exist to assist parents with monitoring and stimulating their young child's development, and provide guidance for parenting skill building.<sup>i</sup>

If more intensive evaluation or treatment is indicated, formal referrals should be facilitated by providing the parents with support and encouragement to intervene early in their child's development in order to maximize the benefits of consultation and treatment. If a pediatric office or other program includes a mental health and/or developmental clinician, an appropriate referral might be to such a colleague for further evaluation and/or intervention. If not, a referral should be made to a local Early Intervention Program, the public school system, and/or to a community mental health center or other local resource. It is important that a list of local resources with contact information be created (and periodically updated) to help facilitate referrals, as indicated. If there is a state referral source or program, such as Help Me Grow,<sup>ii</sup> this should be included on such a resource guide.

### **3. Communicate with Other Providers:**

When feasible and with parents' permission, we encourage all professionals involved in a child's and family's care to communicate with one another about their patients' screening results, needs and referrals.



What should we do when a child screens positive on the SWYC? We can't possibly refer every child.

When a child screens positive on the SWYC, this indicates that a conversation with the parent is needed. **Often, a conversation is all the intervention that is required.**

A positive score on the SWYC indicates concern, not diagnosis. Some children who screen positive on the SWYC will, upon further conversation with the parent, actually turn out to be doing just fine. Some will be struggling with behaviors or skills that the parent could use some guidance on managing. For others, you may want to wait and see if particular behaviors have improved by their next visit.

Some children who score positive on the SWYC will require a referral, but not most. You should use your clinical judgment to determine when this is the best next step.

<sup>i</sup> For example: the American Academy of Pediatrics website: [www.healthychildren.org](http://www.healthychildren.org); Please see Center for Disease Control and Prevention (CDC) at: <http://www.cdc.gov/parents/essentials/index.html>; the American Academy of Pediatrics (AAP) at: [www.aap.org](http://www.aap.org); and the American Academy of Child and Adolescent Psychiatry (AACAP) at: [https://www.aacap.org/aacap/Families\\_and\\_Youth/Family\\_Resources/Home.aspx](https://www.aacap.org/aacap/Families_and_Youth/Family_Resources/Home.aspx).

<sup>ii</sup> Please see: <http://www.helpmegrwnational.org/>

## Feedback from SWYC Users

*"The most profound impact I have found using SWYC has been my increased awareness regarding families' struggles with depression and tension between the parents. I just left an exam with a beautiful, healthy, 6 month old boy. Mom is white, middle class, always looks well groomed, adjusted, and relaxed. The baby appears to be thriving. But here is her SWYC data:*

- *Family Questions PHQ-2 Score: 6 (Positive)*
- *Family Questions Domestic Violence Score: 2 (Positive)*

*I did my usual review, exam, talking all about the baby and then commented on mom's questionnaire. Tears began to flow immediately. We spent the next 15 minutes talking. About her autistic 2 year old, her husband's inability to cope so he is working more, her finally admitting she was depressed today, being afraid to say so before, how she knows it's not good for her baby, etc. If I hadn't used the SWYC for this routine visit I would have never known. I would never have asked. If it hadn't been done electronically I wonder if mom would have decided to be honest. This is not the first time I have found the family risk questions have led me to ask about how things are going in ways I never have in the past." - A Minnesota pediatrician*



*"In January of 2014, we began to use the SWYC for every well child visit from 2 months through 5 years. It has changed everything. Now it is what we use to start our conversation with the family when we enter the room. We know before we go in, that the mom is depressed or under stress or that her child's behavior is worrisome to her. We have a way to ask about domestic violence that is non-threatening, as we follow up on those questions.*

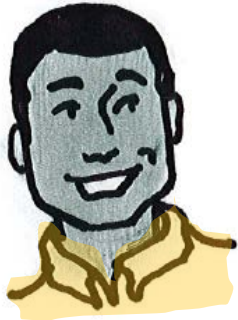
*We knew that if we screened for behavioral and developmental issues and toxic stress, we would need to have services available to deal with the positives, so we started at the same time collaborating with our local behavioral health agency.*

*Because of the SWYC, we can now engage in a meaningful conversation with families about where they see their stress as well as worries that they may have about their children. We can explain how the services we have available for them can help their children to thrive and succeed and also help them with their own problems and help them enjoy being parents." -A Massachusetts pediatrician*



*"A' was a 4 month old baby girl with a Spanish speaking mom who was here for the first visit with her Spanish and English speaking boyfriend. The SWYC was all fine except for the 2 questions about the relationship with her boyfriend. She answered (1) for each of them. When we met with the mother alone, she talked about feeling overwhelmed. She said that her boyfriend did not hit her and she felt physically safe, but that she did feel emotionally abused. She also said that she had seen her own father get shot and killed when she was a child and she was having a hard time with this since her baby was born. She was very grateful for our referral to a therapist." - a Massachusetts nurse practitioner*





*“J” was an adorable, active 3 year old here for well child check. His SWYC was normal for everything except for the PPSC. A score of 9 or more is positive, and he had a score of 15. His development on the SWYC Milestones was perfect. There were no positive responses on the Family Questions. His mother said she had no questions or concerns, but when I went over the PPSC, she got tearful, saying that she had a hard time and he was out of control. She said she thought that this may be normal 3 year old behavior but still she was quite stressed by it. He was at home with just her and her new 6 month old baby. She said she did not have time to read him stories but he watched a lot of educational TV and he was very smart.*

*He was very engaging and talkative and eager to play with the building toys in the office. He was quite excited to listen to the book I gave him. Mom was very happy to get some parenting advice to help manage these ‘normal, but challenging’ behaviors. We helped her find out how to get him into Head Start. When I saw them again in 2 months, things were going much better and he was enrolled in Head Start. Mom was delighted!” – a Massachusetts nurse practitioner*



*“At the 2 month visit for ‘B’ her mother disclosed via the Family Questions that she was depressed. I referred her to a therapist as well as EI to help her with parenting in the house, as she was high risk. At the 2 year check-up, the SWYC was completely negative. The mother denied depression, she still had a therapist, and also EI was still in the home. The baby was developing very well and she said that was no longer depressed.” – a Massachusetts nurse practitioner*



*“Sponsored by the Cherokee Nation, we set up a booth where parents could complete the SWYC and discuss the results. We were approached by a mother with two foster children and one biological child. Staff explained that the SWYC measures developmental, social and emotional milestones for children up to 5 years old. She was very interested in completing the SWYC for her two foster children, who were displaying some aggressive behaviors. However, she did not think her biological child needed to be screened. After speaking to staff, she was persuaded to complete the SWYC for all three children. Her responses on the SWYC indicated that her biological daughter was having some difficulty with change and social withdrawal. This was a great surprise to the mother, who had noted the externalizing behaviors her foster children were displaying but had not been concerned about her biological daughter’s internalizing behaviors. By detecting her daughter’s withdrawing behavior, the SWYC provided this mother an opportunity to learn how she could alter her parenting style to better address all three children’s needs.”- an Oklahoma social worker*



# **Chapter 3**

## **Electronic *SWYC***

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Electronic versions of the *Survey of Well-being of Young Children (SWYC)* have the potential to allow for more efficient and accessible implementation than the paper version at each stage of the process. For example, electronic applications would make it possible for parents to complete the SWYC at home prior to their scheduled visit. They would make the process of choosing the correct form for a child's age much easier, even if the SWYC were filled out in the office waiting room. Also, electronic administration would expedite the administrative and scoring process, as forms do not have to be printed and stored, and scores can be computed automatically by electronic software. In the future, electronic versions could deliver the questions by speech rather than writing to reach parents with limited literacy.

Electronic versions also have the potential for presenting data in unique and more easily interpretable ways (please see Figure 3.1 and 3.2 on page 59-60 for example templates). In addition, electronic administration could allow for norming the SWYC's components across local populations. Additionally, electronic formats could provide clinical decision support [e.g., delivering to pediatric primary care providers (PPCPs) appropriate follow-up questions based on findings] or follow-up resources (e.g., providing handouts and/or lists of local resources for referral).

Given the many advantages of electronic administration, we designed the SWYC without the need for any images or testing materials and asked questions that could be answered reliably from memory. By designing it in this way the SWYC allows for flexible administration (e.g., via paper, computer, tablet, smartphone, and/or telephone). In general, there are two possible approaches to incorporating electronic versions into a screening program: (1) freestanding eSWYC; and (2) integration into electronic medical record (EMR) templates.

### **1. Freestanding eSWYC:**

Several commercial companies, such as The Child Health and Developmental Interactive System (CHADIS; [www.CHADIS.com](http://www.CHADIS.com)) and PatientTools ([www.PatientTools.com](http://www.PatientTools.com)), offer freestanding software to administer parent questionnaires in medical settings. Such systems offer the flexibility to administer screening instruments and present results in different formats. Many physicians have found these systems to be useful.

Nevertheless, we are often asked whether we intend to develop our own freestanding system for the SWYC. We have put a great deal of thought into this possibility, but we are not currently pursuing it. Here's why:

- **Developing a full system is expensive.** It is complicated to design a system with all the features we would want. For example, offering easy access for parents and PPCPs while maintaining strict security is not a trivial design task. Storing and presenting data longitudinally complicates this task further. Making it work on the myriad devices and operating systems in use today, as well as in settings that have Wi-Fi and those that lack Wi-Fi, only adds further complications.

- Maintaining a full system is expensive. All software has bugs that need to be fixed. This requires ongoing work from computer specialists. Moreover, software must be updated as new operating systems are launched, and security features should be updated to meet new threats. Finally, users often have questions and require support to install and use complex software.
- We are not computer experts – but others are. We look to computer developers to develop low cost options to administer the SWYC. Below we offer design suggestions for anyone thinking of doing so (see “Creation of new electronic platforms for the SWYC”). We also offer further detail on other ways to access electronic versions of the SWYC.

## **2. Integration into EMR Templates and other computer systems:**

Several commercial companies, such as CHADIS ([www.CHADIS.com](http://www.CHADIS.com)) and Patient Tools ([www.PatientTools.com](http://www.PatientTools.com)), offer the potential to administer the SWYC to parents in medical settings.

The SWYC can easily be integrated into the patient portals of many EMR systems. Once templates are created, they can be offered to PPCPs at no additional cost (beyond the expense of the EMR itself). Results are automatically stored in the medical record, allowing for a longitudinal record and requiring little effort on the part of the PPCP.

Many pediatric practices around the country have created versions of the SWYC in the local versions of their EMR systems (EPIC Systems Corporation and eClinicalWorks). In addition, we are currently in discussion with several EMR companies to add the SWYC to their core offerings so that PPCPs can access and use the SWYC without the need for local programmers.

Work is underway to incorporate the SWYC into other systems, including:

- Computer systems used by the Children’s Services Council (CSC) of Palm Beach County, Florida ([www.cscpb.org](http://www.cscpb.org)).
- Computer systems used at New York University (NYU) Langone Medical Center.
- The TriVox System created at Boston Children’s Hospital
- Local EPIC EMR systems.

### **Creation of new electronic platforms for the SWYC:**

We have been supportive of outside efforts to create other electronic formats of the SWYC, with the following stipulations:

- 1) There must be no cost to end users of the SWYC.
- 2) The SWYC has undergone initial validation, but much more research is necessary and ongoing. As revisions are posted on our website, [www.theSWYC.org](http://www.theSWYC.org), electronic forms should be updated accordingly.
- 3) Thus, we have requested contact information for anyone creating electronic forms of the SWYC so that we can notify you about important revisions and additions.

- 4) The version number and date should be noted on each form and should be apparent to the user. This will ensure that updates are transparent to users.

A number of software packages like SurveyMonkey and Qualtrix make creating online surveys simple. Many offer appropriate security as well. The downside of these systems is that they do not present or store information where most child health providers need it – i.e., in office charts or EMR systems. As a result, SWYC forms completed in these systems would need to be printed and scanned into the EMR – requiring a separate step.

Designers of systems like CHADIS have chosen the flexibility of independent software to design full-featured systems, and some are working toward integration with EMR systems to incorporate results with other patient data. In contrast, several groups have chosen to work with some EMR systems' survey capabilities to provide such integration up front.

### **Primary design considerations for the eSWYC:**

Many features are important in designing an electronic version of the SWYC. The most critical components are:

1. Appropriate data security and encryption is a necessity.
2. The system must be able to provide the correct SWYC form based on the child's age.
3. The system must include identifiers to allow for a longitudinal record of the child.
4. Parents must be able to complete SWYC forms electronically (e.g. on a tablet, smartphone, or computer) at home or in a pediatric, child care, or preschool setting.
5. The electronic system must be programmed to score all components of the SWYC accurately.
6. Child health providers must be able to view and save results.
7. There should be a mechanism for results to be printed or delivered electronically to a permanent record.
8. In settings that serve families with low-literacy levels, features that allow questions to be read aloud via computer may be useful (and can be adapted to varied linguistic needs).
9. Not all settings have reliable Wi-Fi access. Thus, it is desirable for devices to be able to save data internally until they are connected at a later time.
10. An additional benefit would accrue if there were a secure way for the results to be stored for later access for research.
11. Creation of appealing visual displays, for parents and for pediatricians, will facilitate efficient use of these systems

In creating an electronic version of the SWYC, we have recommended engaging specialists trained to create visual displays that facilitate understanding of complex information at a glance (see Figure 3.1 and 3.2 on page 59-60). This area of specialty is often known as “human factors research” or “user experience design (UX)” and it has been used successfully in many industries,

such as the design of cockpits to ensure airline safety. In her work on the *eSWYC*, Chelsea Stevens – then a student in human factors engineering – developed a design concept that includes appealing and clear visual presentation of *SWYC* questions for parents and results for pediatricians. The design was developed, tested, and approved through interviews with pediatricians.

The interface that presents questions to parents must be user-friendly and simple to understand. Similarly, the screen on which results are displayed must be simple, appealing, and straightforward. Feedback from pediatricians suggests that a simple pass/fail score is helpful at the initial glance, but the ability to access responses to individual items is important as well. For example, being able to quickly review current screening results and to compare them not only to local and national norms but also to past screening results for an individual child or practice may be useful for interpretation. See following pages for examples.

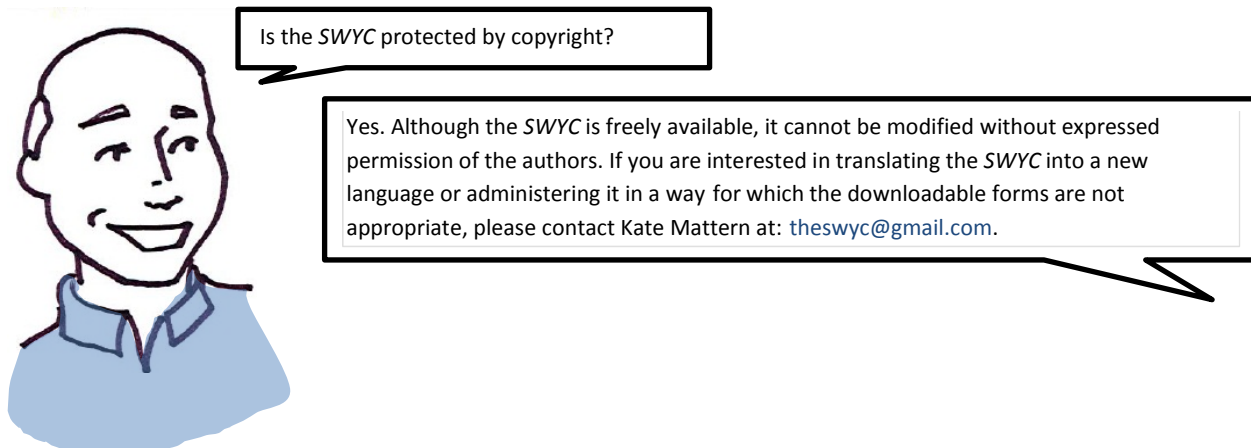



Figure 3.1 – eSWYC Design Concept, Patient Portal


Welcome, JANE DOE  
settings | logout

▼ Children

- Doe, Charlotte R.
- Doe, Samuel J.
- Doe, Alexis P.
- Learn more
- Help

## Charlotte R. Doe: 36 Month SWYC

DOB: 3-18-10

Wednesday, 3-20-14

### Parents Pediatric Symptoms Checklist

These questions are about your child's development. Please tell us how much your child is doing each of these things. If your child doesn't do something any more, choose the answer that describes how much he or she used to do it. Please be sure to answer ALL the questions.

	Not at all	Sometimes	Very Much
Does your child... Seem nervous or afraid?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seem sad or unhappy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get upset if things are not done a certain way?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have a hard time with change?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have trouble playing with other children?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Break things on purpose?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fight with other children?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have trouble paying attention?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have a hard time calming down?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have trouble staying with one activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all	Sometimes	Very Much
Is your child... Aggressive?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fidgety or unable to sit still?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Angry?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Not at all	Sometimes	Very Much
Does your child... Seem nervous or afraid?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Seem sad or unhappy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get upset if things are not done a certain way?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have a hard time with change?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have trouble playing with other children?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

1

2

3

4

Next »

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**Figure 3.2 – eSWYC Design Concept, Output for Provider**

*Visual presentation of results*

**Patient Profile: SULLIVAN, Josephine** Close

DOB: 3-18-2010 (37 months)

▶ **Latest SWYC**

SWYC trends

Previous SWYCs

- 30 months
- 24 months
- 18 months
- 15 months
- 12 months
- 9 months
- 6 months
- 4 months
- 2 months

Add / view notes

**Latest SWYC: 36 months** Completed 3-22-2013 | 37 months

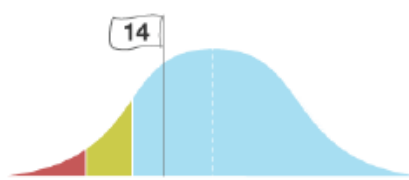
Concerns: Milestones, PPSC, Parent Concerns, Family Questions Responses Summary

---

**Milestones** + Add note

Screen: Negative


Score: 14



**PPSC** + Add note

Screen: WARNING

Score: 8



**Parent Concerns** + Add note

Concerned about child's development? Not at all

Concerned about child's behavior? Somewhat

**Family Questions** + Add note

Tobacco
Substance abuse
Nutrition

Parental depression
Domestic violence

*Access to responses to individual questions*

**Latest SWYC** Responses Summary

DOB: 3-18-2010 (37 months)

▶ **Latest SWYC**

SWYC trends

Previous SWYCs

- 30 months
- 24 months
- 18 months
- 15 months
- 12 months
- 9 months
- 6 months
- 4 months
- 2 months

Add / view notes

**Latest SWYC: 36 months** Completed 3-22-2013 | 37 months

Concerns: Milestones, PPSC, Parent Concerns, Family Questions

---

**Milestones** Responses

Screen: Negative

Score: 14

Talks so other people can understand him or her most of the time.	Very much
Washes and dries hands without help (even if you turn on the water).	<span style="background-color: #ffc107; padding: 2px;">Somewhat</span>
Asks questions beginning with "why" or "how" like "Why no cookie?"	<span style="background-color: #dc3545; color: white; padding: 2px;">Not yet</span>
Explains the reasons for things, like needing a sweater when it's cold.	<span style="background-color: #ffc107; padding: 2px;">Somewhat</span>
Compares things using words like "bigger" and "shorter."	Very much
Answers questions like "what do you do when you're cold?"	Very much
Tells you a story from a book or tv show.	<span style="background-color: #ffc107; padding: 2px;">Somewhat</span>
Says words like "feet" for more than one foot, and "men" for more than one man.	<span style="background-color: #ffc107; padding: 2px;">Somewhat</span>
Uses words like "yesterday" and "tomorrow" correctly.	Very much
Draws simple shapes, like a circle or a square	Very much

Version 1.01, 3/4/16

www.TheSWYC.org

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# **Chapter 4**

# **Translations and Cultural Adaptations**

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<b><u>B) Guidelines for Translation Process into New Language or Cultural Context</u></b>	Page 65
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## **A) Translations and Cultural Adaptations**

### **1. Availability in languages other than English**

Many indicators suggest the need for developmental-behavioral screening in languages other than English. Census data show that ethnic minorities account for 44% of children in the US, and nearly 1 in 5 US citizens speaks a language other than English at home,<sup>12</sup> with the vast majority indicating Spanish as their primary language. This number reflects a more than 100% increase over the past thirty years,<sup>13</sup> and further increases are projected. Children living in the United States (US) whose parents are not fluent and/or literate in English experience significant disparities in the identification of developmental delays and disorders and are thus less likely to receive diagnoses that may qualify them for services.<sup>14</sup> While Hispanic children from English-speaking families are diagnosed with developmental delays and disorders at a rate comparable with their non-Hispanic counterparts, Hispanic children from Spanish speaking families are much less likely to be diagnosed with disorders such as intellectual disabilities, developmental delays, and autism spectrum disorder, suggesting that language may be a primary barrier.<sup>15</sup>

In addition, developmental screening is increasingly advocated as being critical in deciding issues of resource allocation across the globe. Unfortunately, a recent systematic review documents that few developmental screening instruments are accessible in the full range of languages encountered in primary care and child care settings in the US and abroad<sup>16</sup>. Moreover, the published evidence to support those translations that do exist is often inadequate to fully assess their validity. We will do all we can to make the SWYC available in multiple languages that are valid across cultures. We are committed to making clear the level of evidence that exists to support SWYC translations at any given time (see section 4D on “Current and Future SWYC Translations” for more detail). Available translations can be found on the SWYC website ([www.TheSWYC.org](http://www.TheSWYC.org)).

It is worth noting that these translations are unlikely to fully address the clinical challenges of working with families whose native language is not English. Shortages of translations suitable for families who speak languages that are rare in the US are likely to continue. Even high quality translations may fail to account for regional differences in dialect and cultural variation. Wide variations in vocabulary exist, for example, in the type of Spanish spoken in Spain versus in various Latin American countries. Finally, children who are raised in bilingual environments may be difficult to assess using instruments and milestones developed for and normed among their monolingual peers. We strongly recommend careful attention to the linguistic background of the child and its implications for the validity of screening in non-English-speaking families.

## **2. Cultural sensitivity and adaptations**

In addition to translation of the SWYC into languages other than English, cultural sensitivity and adaptations are critical in any language. Even among people who share a language, there exist multiple subcultures, which have different experiences, linguistic conventions, and shared understandings. The same basic language spoken in various subcultures may vary in both linguistic details and cultural mores and assumptions.

Differences may be as simple as differing idioms and accents (e.g. in the Southern vs. Northeastern US), or as complex as the meaning of certain behaviors (e.g. pointing and/or direct eye gaze are expected in some cultures but seen as disrespectful in others). Beliefs about appropriate childrearing often differ across subcultures within the same language groups. For example, children's assertiveness is rewarded in some middle class US families but may be seen as aggressive in some Asian and American Indian cultures.

It is important to recognize that for some populations, language translation may not be necessary but cultural adaptation may be needed. For instance, most American Indians and Alaska Natives (AIAN) speak English, but children in these communities may be exposed to different contexts and cultural norms that impact their development. Differential opportunities exist for children raised in different contexts to accomplish certain tasks. In some rural AIAN communities where stairs are not commonly used, some motor items may not function as they do in other populations. Similarly, in communities where an oral tradition is more typical than reading books aloud to children, items about reading may not be as relevant.

Interpretation of response options may vary by culture. Many of the response options available for portions of the SWYC use indefinite language; e.g. "somewhat", or "very much." This reflects a choice we made intentionally, as we explicitly want parents to make their own judgments rather than report on a defined frequency or intensity of a particular behavior. We recognize that the item "does your child cry a lot?" may be answered by a parent from one culture as "somewhat" and a parent from another culture as "very much," even if their children cry with the same frequency and intensity. What we are interested in is the interpretation of the infant's crying for this particular parent. Parents' responses are likely to be influenced by both individual and cultural expectations of child behavior.

## **B) Guidelines for Translation Process into New Language or Cultural Context**

The goal of the translation process is to create a screener in a new language or cultural context that offers a valid way to detect developmental-behavioral disorders among young children who speak and understand that language and are growing up in that culture. Ideally, scores and questions would have the same meaning across forms – but as described above, this is rarely or never fully possible. The more important goal is to ensure that a translated screening instrument is valid in its own right, whether or not its questions precisely correspond to the original.

Considerable time and effort are necessary to produce a valid translation of a screening instrument. Simply translating the content of a screening instrument is necessary but not sufficient to ensure that the instrument will have the same meaning and/or be valid in another language. We encourage anyone considering translation of the *Survey of Well-being of Young Children (SWYC)* to review expert guidelines in this area.<sup>17 - 21</sup>

Below, we provide a brief description of each of these steps in the translation process. Note that translation is an iterative process. If cognitive interviewing reveals that certain items from the original translation are misunderstood or confusing, or if analyses of a sample of normative data reveal that questions are unreliable, the process must be revisited.



What is cognitive interviewing?

Cognitive interviewing is a form of qualitative research by which a professional interviews participants who have been administered a new translation of an instrument for the purposes of understanding how questions and response options are perceived and understood.

### **1. Translation and Adaptation Procedures:**

#### ***a. Translation into a New Language***

1. **Forward Translation.** The first step is to translate the text of each component, with an emphasis on conceptual rather than literal translations as well as natural, simple, and concise language to accommodate the broadest audience possible. In order to increase the reliability of the forward translation, we encourage using two or more translators,

preferably individuals with a health professional and/or child development background (i.e., well versed in the terminology of the instrument) whose primary language is that of the target culture. It is helpful if these translators include people from various subcultures of the specific language group (e.g. various countries of central and south America). We also recommend that such translators consult with an expert in the screener during the translation process in order to better capture the meaning and intent of the original questions in the new language. In addition, clear documentation about choices made and alternative wordings can be helpful at later stages if the translated text requires editing.

- 2. Back-translation.** Using the same approach as outlined in the first step, the next step is for independent translators to translate the instrument back into English. Such translators should be fluent English-speakers and preferably have no knowledge of the instrument or reference to the original translation. The back-translation should then be compared to the original translation for accuracy. Comparison can be conducted by any investigators who speak English, but these investigators should be independent of those who conducted the forward or back-translations. During these two initial steps of the translation process, variations in cultural expectations and opportunities, and proposed adaptations, should be noted.
- 3. Cognitive Interviewing.** An additional step is to pilot test the translated version with parents who represent several subcultures within the target population. During or after the instrument is administered, an experienced professional should interview participants in order to understand parents' perceptions of the meaning of each question (e.g., determine words or expressions that they did not understand and confer as to what words or expressions would be more appropriate). In some cases, a focus group may serve as an alternative or adjunct to cognitive interviewing.
- 4. Expert panel review.** Throughout the process outlined above, questions are likely to arise that require resolution. An expert panel is useful in this regard. Such a panel may consist of the translators and bilingual experts (i.e., experience with the instrument and translations in various subcultures), as well as individuals with content expertise in the design and use of the *SWYC*. To maintain the intent of the *SWYC*, we also recommend careful review of the *SWYC*'s "design principles" as described in chapter 1. This panel may also be used to compare forward and back-translations for accuracy.

It is important to ensure that the translated instrument is easily interpretable by all or most parents who speak the language of interest, and that the meaning of the translated text of each component of the *SWYC* closely approximates the meaning of

the original version. Therefore it is not enough for a single bilingual individual to translate a form. Judgment on the part of the translation team is critical, as allowances must often be made to accommodate cultural and linguistic differences among countries and regions in which the base language is the same. For example, Spanish spoken in Spain and in various countries of Latin America includes different idioms and word definitions that may not be understood across national boundaries.

### ***b. Cultural adaptation.***

If you are considering a cultural adaptation— i.e., modifying a version of the *SWYC* that already exists in the predominant language of a particular region in order to better fit the customs and expectations of a sub-group that speaks the same language—then the same initial process of forward and back translation is not applicable. We encourage those considering such a cultural adaptation to consult an extensive qualitative study carried out by the Tribal Early Childhood Research Center, which provides a model of the value of interviewing and focus groups among parents, community groups, and professionals<sup>22</sup>. After assessing cultural variations and how they may influence parents' response to the *SWYC*, consider whether changes in scoring and interpretation are sufficient to address cultural differences. Changes to the instrument itself should be considered only as a last resort. Steps 2 and 3 below are best practice for both language and cultural adaptations.



How can I access translated versions of the SWYC?

Thanks to teams who have generously shared their translation work with us, you can download several translations for free from our website, [www.theSWYC.org](http://www.theSWYC.org).

## **2. Collection of Normative Data:**

Once translations or cultural adaptations have been created and carefully reviewed, a large sample of data should be collected across the entire age range of the *SWYC*. Such data are essential for creating scoring guidelines. Until normative data have been collected and scoring procedures have been revised for the new translation, *SWYC* scores generated using any language or cultural adaptation of the *SWYC* should be interpreted with extreme caution.

Collection of normative data provides the opportunity to conduct additional research on the quality of the translation. For example, confirmatory factor analyses (CFA) can be conducted to determine whether the translated questions function together in a similar way to the original. Given a diverse sample, analyses of differential item functioning (DIF) may be conducted to determine whether questions function similarly across different patient populations.

Note that unless analyses of differential item functioning (DIF) or measurement invariance are conducted to compare translated items to original items in an English-language sample, it is not possible to say that the questions and scale-scores have the same meaning across forms. However, forms with slightly different meaning can each be independently valid in their own languages. For example, a translated item might be altered to account for regional and cultural differences – for example, using “black bean” instead of “cheerio” in the question about fine motor skills on the Portuguese *SWYC*. It is possible that the meaning of the two items will differ, for example if these foods are typically offered to children at different stages of development, or if one is more difficult to grasp than the other. However, each item may still be uniquely valid as an indicator of fine motor development.

## **3. Validation:**

The final step of the translation process is to demonstrate empirically the validity and reliability of the new translation and compare those results with the psychometric characteristics of the original language. Ideally, diagnostic accuracy is assessed in comparison to a “gold standard” criterion using appropriate research methods.<sup>23,24</sup> However, such validation studies are expensive, and the cost of repeating them over multiple translations is likely to be prohibitive. Probably for this reason, we found that few quality diagnostic accuracy studies have been conducted for developmental screening instruments.<sup>16</sup> Nevertheless, careful research on diagnostic accuracy should be conducted when resources allow. Standards for evaluating diagnostic accuracy are available.<sup>23</sup>



### **C. How to Proceed Without a Fully Validated Translation or Cultural Adaptation**

When normative and validation studies are not available or possible, clinicians are left with four options: (1) identify another screening instrument that is fully validated in the language or setting of interest; (2) use a translated version of the *SWYC* that has not been fully validated, or (3) use a version of the *SWYC* that is in the correct language but is not perfectly suited for the target population (for instance, the standard English-language *SWYC* in an English-speaking AIAN population, without modification to account for cultural differences); or (4) do not use any screening instrument at all.

As we stated above, we know of few developmental screeners that are fully validated in other languages (and even fewer that take into account cultural variations that may significantly affect scores), but our systematic review offers a guide to the existing evidence.<sup>16</sup> If using a fully-validated screener is not an option, we expect that many clinicians will choose option (2) or (3) above.

When you modify an instrument or the context in which it is used in any way--be that by translating it into a new language, modifying questions to better match cultural context, or even keeping the instrument exactly the same but using it in a new setting or new population--the instrument would ideally be re-normed in order for the scoring to be reliable. Even in the absence of reliable scoring, however, imperfect language translations or cultural adaptations may well prove to be more useful than no screening instrument at all.

Should you choose to proceed with a language or cultural adaptation that has not been re-normed or is not fully appropriate for the group in which you are using it, you may be faced with decisions about how to best administer and interpret the screening. For example, if administering the standard English *SWYC* in an AIAN population in which storytelling is more typical than reading, a pediatrician may choose to a) advise parents to skip an item about reading; b) ask parents to substitute a similar observation of their child's responsiveness to hearing stories; or c) use the item as is, while understanding that it does not carry the same meaning as for the general population. The pediatrician should understand that choosing *any* of these options means that the measure has been substantively changed. If parents skip the item, scoring is affected by the missing response. If parents are advised to substitute an observation about the child's responsiveness to hearing stories, then the parent has essentially completed an ad-hoc cultural adaptation, and in changing the item has also changed the validity of the scoring. If the parent completes the item as is, the scoring is also affected because it is not appropriate for the cultural context in which it is being used.

No matter what option the pediatrician were to select in the hypothetical situation above, he or she would need to interpret results with caution and engage parents in follow-up discussions

about their responses. The pediatrician should be curious about and respectful of many possible differences in children's experiences and the variety of individual and cultural interpretations of their behaviors.

In the absence of re-norming, we recommend interpreting scores with caution, engaging parents in conversation about the meaning of their responses, and simultaneously conducting research on the validity of the *SWYC* using available data. For example, research that documents associations with known risk factors may offer support for the *SWYC*'s construct validity. While not a replacement for studies of diagnostic accuracy, such evidence would still offer support for the validity of a screening instrument.

## **D) Current and Future SWYC Translations**

The *Survey of Well-being of Young Children (SWYC)* is in need of further translation and validation efforts to meet the needs of many underserved populations and diverse cultures around the globe. We strongly encourage researchers and organizations to translate the *SWYC* into any language and cultural context as long as proper guidelines are followed. Any changes to the *SWYC*, whether a translation or any other adaptation, should be consistent with the *SWYC*'s design principles. Given that translation includes rewording of all items and response scales in a new language as well as adapting items to match local context and culture, the result of a translation process is in many respects a different instrument from the original one.<sup>16</sup> Hence, we can't stress enough the importance of adhering to the translation process guidelines.

Multiple translations of the *SWYC* are underway, but the process of re-norming and validating translations is resource-intensive. Below, we list the languages into which the *SWYC* has been translated, along with a brief description of planned and ongoing research activities (please check [www.theSWYC.org](http://www.theSWYC.org) for up-to-date versions and information on translations). We are committed to supporting high quality translation research and providing clear, transparent summaries of the evidence that exists for translations into different languages. However, clinical judgment will always be required to address differences in dialect and culture.

**Spanish:** All *SWYC* forms have been translated into Spanish and are available on our website, [www.theSWYC.org](http://www.theSWYC.org), with a detailed description of the translation process. Data to support norming and validation are being collected by investigators at the Children's Hospital of Philadelphia (CHOP) and in several communities collaborating in the EC-Linc project.<sup>i</sup>

**Burmese and Nepali:** The 9-, 18-, and 24-month forms of the *SWYC* have been translated into Burmese and Nepali. Standardization and validation research are still needed.

**Brazilian Portuguese:** All *SWYC* forms have been translated by a research team from Brazil. The team is conducting further research to standardize and validate this translation of the *SWYC*.

**Yoruba:** All *SWYC* forms are currently being translated by a research team from Nigeria. The team plans to conduct further research to standardize and validate this translation of the *SWYC*.

**Haitian Creole:** A team from the Children's Services Council of Palm Beach County Florida has plans to translate the *SWYC* into Haitian Creole. A timetable for this translation process has not yet been formulated.

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<sup>i</sup> For more detail, please see: <http://www.cssp.org/reform/early-childhood/early-childhood-linc>

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# **Chapter 5**

# **SWYC Research**

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## **A) History of the Development of the SWYC**

The *Survey of Well-being of Young Children (SWYC)* began with a small planning grant from the Commonwealth Fund in 2008. With further help from the Commonwealth Fund, the primary authors, Ellen Perrin, MD and Chris Sheldrick, PhD, worked over the next several years to conceptualize, design, refine, test, and publish each portion of the SWYC. The following describes the series of steps by which we created the initial versions of each of the four components of the SWYC.

### **1. Cognitive, Language, and Motor Development:**

Items for the *SWYC Milestones* were designed to capture observable aspects of communication, cognitive, and motor development. We aimed to create items that had clinical importance and meaning in terms of children's developmental progress, but also would be easily understood by parents from a range of educational and cultural backgrounds. Each item is intended to address accomplishments that parents can remember reliably. Like all other components of the SWYC, the *SWYC Milestones* questions were written to be short, easy to read, salient to parents, and assess types of risk that are most readily amenable to intervention. Furthermore, no components include images or prompts, allowing the SWYC to be easily amendable to electronic formats or implemented over the phone.

#### ***Sidebar: Item Response Theory (IRT) Basics:***

*For most questionnaires, responses for each question are assigned a number, and the numbers are summed to calculate the total score of the test. IRT works differently in that each question is designed to offer unique information about the construct being assessed.*

*Here is an example. Imagine playing a game where you need to guess a child's age. You ask, "Can the child walk?" and the parent says "Yes." You then ask "Does the child speak any words?" and the parent says "No." Based on these answers, how old do you think the child is? Somewhere between 12 and 18 months would be a reasonable guess, and you could probably make an even better guess if you could ask more questions.*

*IRT uses a similar process to combine answers from different questions and make an estimate of a continuous variable, such as age or ability. The scoring system for the *SWYC Milestones* questionnaire uses IRT to estimate children's developmental ages based on their parents' answers to specific questions.*

*Comparing the "developmental age" of the child to the actual chronological age of the child offers an estimate of risk for developmental delay.*

*Another great thing about IRT is that it allows each question to be validated individually. Therefore if electronic scoring is used, it allows forms to be scored despite missing data.*

We reviewed several validated instruments that assess children's developmental progress, including the *Preschool Language Scale (PLS)-2*, *Denver Developmental Screening Test (Denver II)*, *Infant-Toddler Developmental Assessment (IDA)*, *Battelle Developmental Inventory*, *Ages and Stages Questionnaire (ASQ)*, *Parent's Evaluation of Developmental Status-Developmental Milestones (PEDS-DM)*, *Clinical Adaptive Test/Clinical Linguistic and Auditory Milestone Scale (CAT/CLAMS)*, and the *Communication and Symbolic Behavior Scales (CSBS)*, from which we generated a lengthy list of behaviors that we thought parents would be able to remember and report about their children. We asked a panel of parents and professionals to review the initial list of questions, and thus created 174 items reflecting cognitive, language and motor functioning. We then recruited large samples of parents from primary care and referral settings to complete these items. Response options for all questions were: "Very Much," "Somewhat," and "Not Yet." Like other components of the SWYC, response options were designed such that parents should answer them according to their own point of view (e.g., a parent should interpret the response option "Very Much" as whatever they view as "very much"). Latent variable modeling was used to identify and remove unreliable items; it also supported scoring by quantifying age-based expectations for each individual question. Scoring was based on a graded item response theory (IRT) model, which is used to estimate each child's "developmental age" based on how their parents answer each question (see sidebar on previous page).

Ten items were chosen for each age-level *SWYC Milestones* form, including indicators of fine and gross motor, language, and cognitive development. These 10 questions are of varying difficulty, and therefore it is not expected that children will be able to do all items for their respective age form. Some harder and some easier items are included in order to reflect the wide range of children's developmental skills at every age. The "harder" items may also be useful to help parents anticipate and appreciate emerging developmental skills. "Easier" items were included in order to increase the odds of detecting children with developmental delays. Children who are not yet able to perform these "easier" items are at risk for delay.



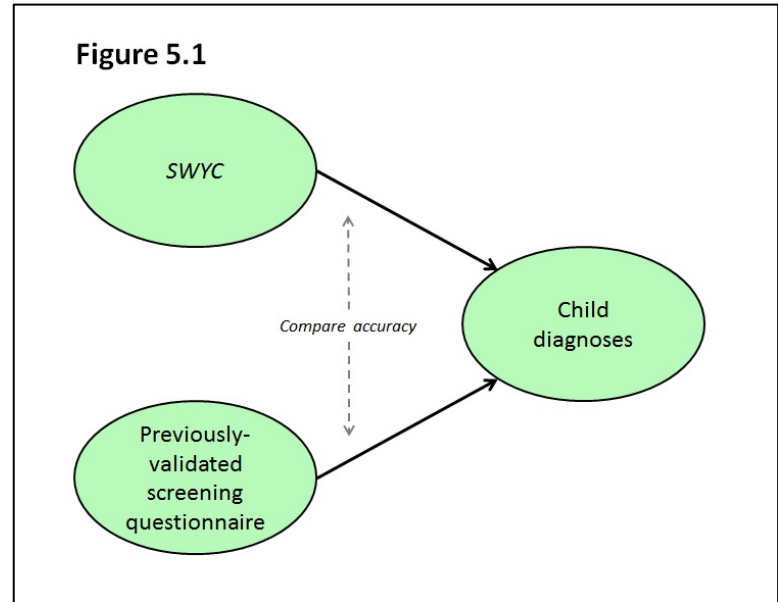
The last couple questions on each age-specific form's *SWYC Milestones* questions seem advanced. Most children won't be able to do those skills yet. Why are the *Milestones* written like that?

There are 10 *SWYC Milestones* items on each age-specific *SWYC* form. The first few items on each form are "easier" skills that most children will be doing. As the list goes on, the skills become more challenging. Most children will not be able to do all ten skills listed at any particular age.

We designed the forms in this way to provide continuity between the age-specific forms (so that the "harder" items at 12 months, for instance, become the "easier" items at 15 months) and to provide parents with some idea of what skills they may see their children doing next.



After the ten items were chosen for each age-level form, we recruited an independent replication sample of parents from different primary care practices. We utilized a “comparative accuracy” approach with the original and replication samples (see Figure 5.1). That is, we determined the accuracy with which the *SWYC* detected a criterion (e.g., parents’ reports of diagnoses). Next, we determined the accuracy with which another evidence-based screening instrument detected the same criterion in order to give us a head-to-head comparison of the accuracy of the *SWYC* compared to other screeners.



Specifically, we tested the *SWYC Milestones* forms’ concurrent validity relative to the *Ages & States Questionnaire, 3<sup>rd</sup> Edition (ASQ-3)*<sup>25</sup> and parents’ reports of developmental diagnoses. With the exception of the 2-month form, the *SWYC Milestones* scores correlated well with the *ASQ-3*, with correlations ranging from moderate to large (i.e., Pearson correlations between 0.40 to 0.70). Furthermore, *SWYC Milestones* scores detected parents’ reports of developmental delays and disorders with a level of accuracy that is comparable to other evidence-based screening instruments. The overall sensitivity was 76% and specificity was 77%.

The 2- and 60-month forms were somewhat less reliable in predicting parents’ reports of diagnoses and ASQ scores. For the 2-month form, this is most likely because developmental progress is happening so fast and with such variability during this period that measuring these changes over monthly increments rather than over days is not precise enough. For the 60-month form, we suspect that we created too few items appropriate for older children; this weakness will be corrected with further research. Please see our publication on the *SWYC Milestones* for more detail.<sup>26</sup>

## **2. Social/Emotional Functioning:**

The *Baby Pediatric Symptom Checklist (BPSC)* and the *Preschool Pediatric Symptom Checklist (PPSC)* were modeled after the widely used *Pediatric Symptom Checklist (PSC)*.<sup>27-29</sup> The *BPSC* and *PPSC* were created in consultation with the *PSC*’s co-developers, Michael Jellinek, MD and Michael Murphy, EdD. We used a similar format to the *PSC*, including items focusing on internalizing, externalizing, and attentional problems. For the youngest children, we added

items that described the transactional nature of children's behavioral and emotional development, including items about the experience of parents in caring for their child.

## 2a) BPSC

For the *BPSC*, we began by identifying common questions and constructs across several parent-report measures designed for children under 18 months, including the *Infant-Toddler Social and Emotional Assessment (ITSEA)*,<sup>30</sup> the *Ages & Stages Questionnaire: Social/Emotional (ASQ:SE)*,<sup>31</sup> the *Greenspan Social-Emotional Growth Chart*,<sup>32</sup> the *Behavioral Assessment of Baby's Emotional and Social Style*,<sup>33</sup> and the *Temperament and Atypical Behavior Scale*.<sup>34</sup> In addition, we reviewed relevant literature on temperament and infant behavior and generated items based on our clinical experience. All items were designed to reflect observable features of children's behavior and temperament as well as parents' experience of their children's behavior.

The initial list of *BPSC* items was reviewed by a panel of parents of young children and child development experts, which led to a list of 25 draft questions. Then we recruited an original sample of parents from primary care practices and referral clinics in Eastern Massachusetts. Parents were asked to respond to the 25 draft questions. For each item (e.g., "Does your child have a hard time calming down?" or "Is your child fussy or irritable?"), response options included: "Not at All," "Somewhat," and "Very Much." After we had conducted analyses on the original samples, we sought to replicate those analyses in an independent sample from other primary care practices.

Because there is no parent-report criterion measure of infant behavior that is valid for children from birth through 18 months, we decided to administer several measures of constructs similar to what the *BPSC* is intended to assess. We chose 3 comparison instruments: (1) the *ASQ:SE*, a screening instrument intended to reflect social-emotional status among children starting at 3 months of age; (2) the 2-item *Patient Health Questionnaire (PHQ-2)*,<sup>8</sup> a well-validated brief screening tool used to identify risk for depression among adults; and (3) the *Parenting Stress Index-Short Form (PSI-SF)*,<sup>35</sup> which consists of 3 subscales labeled "Parental Distress," "Dysfunctional Interactions," and "Difficult Child." Notably, the *PSI-SF* was only compared to the *BPSC* in the replication sample.

Factor analysis was used to identify the presence of 3 subscales in the *BPSC*, entitled: "Irritability," "Inflexibility," and "Difficulty with Routines." The three subscales reflect different but related dimensions of the child's behavior. Cronbach's alpha was adequate across subscales, with the exception that the internal reliability of the "Irritability" subscale fell below 0.70 in the replication sample. Retest reliability was also adequate across

subscales (0.70 for “Irritability,” 0.81 for “Inflexibility,” and 0.78 for “Difficulty with Routines”). The “Irritability” and “Difficulty with Routines” subscales displayed moderate correlation with the *ASQ:SE* and *PHQ-2* in the original sample and moderate correlation with the *ASQ:SE* and *PSI-SF* in the replication sample. The “Inflexibility” subscale had only mild correlation with the *PSI-SF*'s “Parental Distress” and “Difficult Child” subscales in the replication sample. It is not unexpected that there were no other significant correlations, given that certain subscales or sections of these comparison instruments do not directly assess constructs targeted by the *BPSC* (e.g., the *PSI-SF*'s “Dysfunctional Interaction” scale, which mostly includes items that assess the child's effect on the parent). Please see our publication on the *BPSC* for more detail.<sup>36</sup>

## 2b) *PPSC*

We used a similar approach in creating the *PPSC*: we began by identifying constructs common across several parent-report measures that had previously been validated for children under 5 years, including the *PSC*, the *Child Behavior Checklist 1.5–5 years (CBCL)*,<sup>37</sup> the *ITSEA*, the *Children's Depression Inventory (CDI)*, and the *ASQ:SE*. In addition, we reviewed relevant literature and generated items based on our clinical experience. Items were developed to encompass four domains of interest, including three that are included in the *PSC* (i.e., “Internalizing,” “Externalizing,” and “Attention Problems”)<sup>38</sup> and one new domain, “Parenting Challenges.”

The initial list of items was reviewed by a group of parents of young children and experts in child development who provided feedback regarding clarity, reading level, and relevance of items. This process resulted in a list of 73 new questions. For each item (e.g., “Does your child have a hard time calming down?” or “Does your child fight with other children?”), response options were: “Not at All,” “Somewhat” and “Very Much.” After we had conducted analyses on the original samples, we sought to replicate those analyses in an independent sample from other primary care practices.

Factor analysis was used to identify a bifactor model, supporting the creation of a single total score for the *PPSC*. Cronbach's alpha for this scale was adequate across samples (i.e., between 0.86 and 0.92). Retest reliability was also adequate (i.e., intraclass correlation coefficient was equal to 0.75). The *PPSC* was compared to the *CBCL* and the *ASQ:SE* in the initial sample, but the *ASQ:SE* was removed from the replication sample to reduce participant burden. Sensitivity and specificity estimates with respect to *CBCL* scores for the *PPSC* fell consistently above 80%; furthermore, *PPSC* sensitivity was significantly higher than the *ASQ:SE* for the original clinic referral sample (88% vs. 70%, respectively). The *PPSC*'s sensitivity and specificity, with respect to parents' reports of child diagnoses of attention-deficit hyperactivity disorder (ADHD), anxiety, depression, conduct problems, and other

diagnoses, consistently fell above 70%, with the exception of anxiety disorders in the replication sample for which sensitivity was 33%. The confidence interval for this estimate was greatly affected by a low sample size (i.e., only 3 children were reported to have anxiety disorders). The *PPSC*'s and *ASQ:SE*'s sensitivity and specificity did not differ with respect to parents' reports of diagnoses. Please see our publication on the *PPSC* for more detail.<sup>39</sup>

### **3. Autism Symptoms:**

The *Parent's Observations of Social Interactions (POSI)* was designed using a different process. A group of clinicians and researchers, supported by a small grant from the Boston Autism Consortium, collaborated over several months to write, format, and pilot test the questions that eventually became the seven-item *POSI*. The group was generated and led by Alice Carter, PhD, and consisted of: Marilyn Augustyn, MD, Elizabeth Caronna, MD, Ellen Perrin, MD, Alison Schonwald, MD, and Chris Sheldrick, PhD. Scoring was refined through subsequent research. Three studies have been conducted: (1) 132 parents of children 16 to 30 months recruited from primary care practices; (2) 100 parents of children 16 to 30 months recruited from a developmental referral clinic; and (3) 485 parents of children 16 to 48 months recruited from a developmental referral clinic.

In the primary care sample, a positive score based on parents' responses to the *POSI* questions was compared with the parents' reports of a diagnosis of an ASD. In the referral clinic sample, parents were asked to complete the *M-CHAT* and the *POSI* checklists prior to the clinical evaluation. Because these clinics serve populations of children with developmental delays and disorders that often include some problems with social interactions and language, we anticipated that the specificity of both the *M-CHAT* and the *POSI* would be relatively low in the referral clinic samples. In these samples, the criterion measure was a clinical diagnosis of an ASD made by a Board-certified developmental-behavioral pediatrician.

Findings from these studies demonstrated adequate internal reliability for the *POSI* (Cronbach's alpha = 0.83 and 0.86, respectively) as well as comparative accuracy with the *M-CHAT* among children 16 to 30 months (the age for which the *M-CHAT* has been validated). Specifically, in the primary care sample, the *POSI*'s sensitivity (89%) was significantly higher than the *M-CHAT*'s (71%), whereas their specificities were not significantly different (*POSI*: 54% and *M-CHAT*: 62%). In the referral clinic samples, the *POSI*'s sensitivities (83% and 94%) were somewhat higher than the *M-CHAT*'s (50% and 77%) however, its specificity was significantly lower (*POSI*: 42% and *M-CHAT*: 55%).

For children 31 to 48 months referred to a regional developmental-behavioral evaluation program, the sensitivities of the *POSI* and the *M-CHAT* were not significantly different, but

notably both were adequate (75% and 69% respectively). The Table 5.1 below is based on the referral clinic sample.

**Table 5.1**

**Sensitivity and specificity of MCHAT and POSI in two age groups**

	Sensitivity	Specificity
<b>Ages 16-30 months (n=271; 63.8% were diagnosed with ASD)</b>		
POSI	93.6% (95% CI: 88.9%-96.8%)	40.8% (95% CI: 31%-51.2%)
MCHAT	77.5% (95% CI: 70.5%-83.5%)	54.1% (95% CI: 43.7%-64.2%)
p value (McNemar Test)	0.0001	0.02
	Sensitivity	Specificity
<b>Ages 31-48 months (n=214; 57.9% were diagnosed with ASD)</b>		
POSI	75% (95% CI: 66.4%-82.3%)	47.8% (95% CI: 37.1%-58.6%)
MCHAT	69.4% (95% CI: 60.4%-77.3%)	58.9% (95% CI: 48%-69.2%)
p value (McNemar Test)	0.34	0.13

Future research with larger, more diverse samples is needed to re-evaluate and revise scoring algorithms and develop an appropriate follow-up protocol for the *POSI* (see section 5D on “Future Research”).<sup>i</sup> Please see our publication on the *POSI* for more detail.<sup>40</sup>

#### **4. Family Stress:**

Items assessing family stress that appear in the *Family Questions* were drawn from the research literature and are available in the public domain. We sought to identify questions that assessed types of risk that are most readily amenable to intervention through pediatrics. For example, rather than assessing poverty (which is difficult to address directly), we chose items that assess food insecurity (which can be addressed with referrals to food pantries or programs). Other items on the *Family Questions* assess parental depression, family discord (which is effective for detecting domestic violence), and substance abuse. All questions have evidence for validity published in previous studies.<sup>6-10</sup> **These questions were not separately validated as part of the SWYC.** Validated screening questions assessing other family risks can be added based on particular needs and contexts.

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<sup>i</sup> The *POSI* appears to be valid up to 48 months, but a lot more research has to be done to verify this. If so, future versions of the *SWYC* will extend the age range of the *POSI*.

## **5. Additional Validation Research:**

In addition to the procedures described above for the *SWYC Milestones*, *BPSC/PPSC*, and *POSI* (but not the *Family Questions*, as its items weren't separately validated), we also used latent variable modeling to look for "differential item functioning," or DIF. DIF occurs when parents' responses vary despite having children with the same score on a particular item. For example, if children from two countries display the same level of gross motor skills, but parents from one country are more likely to report "kicks a ball" than parents from another country, then the question about kicking a ball is said to display DIF. This may occur for a number of reasons. Perhaps there are cultural differences (e.g., soccer is more popular in one country than in another), perhaps there are educational difference (e.g., parents in one country have lower levels of literacy and don't understand the item), or perhaps an item is simply interpreted differently across contexts (e.g., perhaps "kicks a ball" is only endorsed if the child scores a goal). We looked for evidence of DIF with respect to parents' education, family income, and race/ethnicity, and whenever possible we excluded items that displayed significant DIF. Widespread clinical use of the *SWYC* may offer the opportunity to analyze large samples of data from different patient populations. Such data would allow for a more detailed examination of DIF than was possible in our initial validation studies.

From the early stages of its development, we also received inquiries about the *SWYC* from interested parties around the nation and world. We were invited to speak and give webinars at numerous institutions and agencies (please see [www.theSWYC.org](http://www.theSWYC.org) for a periodically updated list), and we engaged in frequent telephone conferences. As described in the "Acknowledgements" section, multiple independent investigators and practitioners began to research and pilot the *SWYC*. For example, Marsha Gerdes, PhD and colleagues from the Children's Hospital of Philadelphia (CHOP) undertook a study to investigate the accuracy of Spanish translations of the *SWYC*. Nancy Whitesell, PhD, Michelle Sarche, PhD, Caitlin Trucksess, MPH, and their colleagues from the Tribal Early Childhood Research Center conducted an extensive study of the acceptability of the *SWYC* in United States (US) American Indian and Alaskan Native populations.<sup>22</sup> Investigators from Brazil and Nigeria obtained funding from the Bill and Melinda Gates Foundation to use the *SWYC* as an outcome measure in their intervention research. To do this they created new translations. Meanwhile, groups of researchers and pediatricians around the country began to pilot the *SWYC* in practice, including groups in Massachusetts, Connecticut, Rhode Island, Minnesota, Pennsylvania, California, and Oklahoma.

We also received a grant from the National Institute of Child Health and Development (NICHD) to conduct a study in which the accuracy of the *SWYC* and other prominent developmental-behavioral screening instruments are assessed in relation to criterion tests. At the time of this writing [February 2016], the NICHD study is ongoing (please see section 5B on "Ongoing Research" for more information).

As we write the initial draft of this manual, interest in the *SWYC* continues to grow rapidly. We are currently seeking external funding to harness this growing energy by developing a governance plan. Such a plan would allow for shared decision making about the future of the *SWYC*.



If an instrument's specificity and sensitivity are over 70%, does that mean it's good for my practice?

Maybe yes, maybe no. There are at least two things to understand about sensitivity and specificity:

1. **Sensitivity and specificity are not inherent traits of a screening instrument.** Instead, a screener displays a certain level of sensitivity and specificity in a particular study with respect to a particular outcome, in a particular sample population, and using a specific study design. If you are using the screening instrument in a different setting, with a different population, or in a different way than the study from the measure's validity studies, your sensitivity and specificity will be different as well.
2. **Sensitivity and specificity are just a start—you should also consider whether a screener adds unique information that improves detection in the overall system.** It is worthwhile to ask, "Does this screening test offer new information at the point in the care process when it is used?"

## **B) Ongoing Research**

Screening instruments are often described as either being “validated” or not. In reality, there is a continuum of validity that depends not only on the instrument itself, but also the purpose for which it is used and the particular children it is meant to help. As a result, continuous, high-quality, up-to-date research, ideally published in peer-reviewed journals, is necessary to determine whether a screening instrument is accurate enough for its intended use. This validation research may include independent replication among groups that may differ from the original population with which the instrument was developed and normed, direct comparisons to existing screening instruments, accuracy studies in which the screener is compared to an independent assessment, and/or referral outcome studies in which the impact on actual patient care is investigated.

If a screener has been changed in any way, whether translated into a new language or used in a new setting or with a new population, new research is necessary to demonstrate its continued accuracy despite these changes. As a result, further research into the validity and reliability of the *Survey of Well-being of Young Children (SWYC)* is essential in conjunction with its dissemination. We provide greater detail regarding contemplated further SWYC validation research and description of QI projects below.

As detailed in the earlier section of this chapter entitled: “History of the Development of the SWYC,” initial validity studies of the SWYC were performed by comparing parents’ responses on the SWYC with: (1) their reports of developmental-behavioral disorders; and (2) their responses on other, previously validated parent report measures. With funding from the National Institute of Child Health and Development (NICHD), we are currently in the process of a more robust test of the diagnostic accuracy of the SWYC, the ASQ-3 and the PEDS, comparing each to children’s performance on a clinical assessment. This assessment includes standardized developmental tests [i.e., *Bayley Scales of Infant and Toddler Development, 3<sup>rd</sup> Edition (Bayley-3)*<sup>41</sup> or *Differential Ability Scales, 2<sup>nd</sup> Edition (DAS-2)*<sup>42</sup>, and *Battelle Developmental Inventory, 2<sup>nd</sup> Edition (BDI-2)*<sup>43</sup>] and parents’ responses to extensive standardized clinical interviews [e.g. the *Preschool Age Psychiatric Assessment (PAPA)*<sup>44</sup>]. All of these assessments are carried out in English or Spanish, based on families’ preference. A similar independent diagnostic accuracy study is being carried out at the Children’s Hospital of Philadelphia (CHOP) among Hispanic and African immigrants.



## **C) Quality Improvement Research**

Continuous high-quality research is needed to maximize the impact of the *Survey of Well-being of Young Children (SWYC)* and other screening instruments on child health. Below, we discuss opportunities for quality improvement (QI) projects and more formal research studies.

Ongoing evaluation is essential to achieve high-quality clinical care. Hence, we present a discussion on QI projects designed for localized settings, such as in pediatric primary care settings or preschool, child care, or home visiting programs, as well as those designed to create generalizable knowledge across a broader range of settings.

QI projects unique to each setting can provide feedback on the implementation of a planned screening procedure, avoid wasting resources and time, and increase the participation of as many parents as possible. Though seemingly straightforward, implementation of the *SWYC* should be done carefully and the success of its administration should be evaluated.

Monitoring of (and regular efforts to improve) indicators of quality in pediatric care have become routine in many settings. They are advised and/or required by Medicaid, insurance companies, the American Academy of Pediatrics (AAP), the American Board of Pediatrics (ABP), the Centers for Disease Control and Prevention (CDC), the National Institute for Children's Health Quality (NICHQ), and many other administrative entities. Specifically, Bright Futures recommends using QI to integrate screening and surveillance of developmental-behavioral problems into primary care. There are many excellent sources of information about how to conduct quality improvement (QI) projects, and we do not attempt to review them here. Instead, we focus on possible targets of QI programs that may be considered to improve screening programs. Similar efforts are taking hold in related settings, such as child care and educational programs.

QI efforts often follow a "Plan-Do-Study-Act" or PDSA cycle.<sup>1,45</sup> The first step is identifying an aspect of practice that participants would like to improve (e.g., increasing the proportion of parents who are asked to complete a screening questionnaire). The next step is making a plan for the change to be tested or implemented, which involves defining the target outcomes of a QI project and defining measurable thresholds to determine success and change.

There are many possible foci for PDSA cycles. For example, a practice might consider monitoring and improving: (1) how many children under 5 years of age are scheduled for a well-child visit in a given week; (2) how many of those arrive for the visit; (3) how many are given a

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<sup>1</sup> Please see for more detail:

[http://www.institute.nhs.uk/quality\\_and\\_service\\_improvement\\_tools/quality\\_and\\_service\\_improvement\\_tools/planning\\_do\\_study\\_act.html](http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/planning_do_study_act.html)

SWYC form to fill out; (4) how many complete the form; and (5) how many of the PPCPs receive the scored form at the beginning of the visit. A practice might have as goals that parents attend at least 80% of their visits before the age of 5 years, that 85% of those who arrive are asked to complete the SWYC, and that 75% of those are made available to their PPCP. At baseline those targets may be much lower, and the goal of the QI project would be to discover and create systems within the practice to increase those proportions.

Other potential targets of QI projects for the SWYC include:

- a) *Assess satisfaction*: Obtain feedback from users (i.e., parents and professionals) via short questionnaires to help improve delivery systems.
- b) *Referral completion*: Monitor the number of children identified on the SWYC as needing further assessment and the outcomes of their subsequent assessments.
- c) *Practice variation*: Assess variations among PPCPs or others administering the SWYC to identify clues to efficiency and successful identification of developmental-behavioral disorders and appropriate referrals.
- d) *Broader QI and Implementation Science*: Screening is a complex process, and any part of the process may be a good candidate for further research and QI. To understand the complexity of screening, we find that a model of effectiveness outlined in a now classic paper published in the journal *Medical Decision Making* offers a helpful guide.<sup>46</sup> The authors argue that to establish clinical effectiveness, six levels of evidence are required (see Table 5.1). Initial levels (1-2) focus on how screening instruments are used (technical effectiveness and diagnostic accuracy) and how they affect case conceptualization among physicians (Level 3, diagnostic thinking). Support at these levels must be followed by evidence that treatment plans are influenced (Level 4, therapeutic), that patient outcomes improve (Level 5) and that on balance, society benefits from the program (Level 6).

**Table 5.1 - Clinical Effectiveness of Screening**

<i>Level</i>	<i>Effectiveness</i>	<i>Questions with regard to developmental-behavioral screening</i>
1	Technical	Who is screened? Was screening instrument scored properly (or at all)? Are the results available to the care provider at the time of examination?
2	Diagnostic Accuracy	Is accuracy sufficient as used in practice and with the specific patient population? Are the rates of false positives or negatives acceptable?
3	Diagnostic Thinking	Are screening results credible to physicians? Do results confirm or alter their opinions regarding children's developmental status?
4	Therapeutic	Do screening results alter treatment plans or generate more referrals? Are enough treatment resources available if identification increases?
5	Patient Outcome	Do families follow through with referrals? Are available treatments effective in producing positive outcomes?
6	Societal	Are these positive outcomes detectable on a societal level? If so, do they justify the cost?

Any level of effectiveness described in Table 5.1 may offer an opportunity for improvement. For example, (1) *technical effectiveness* refers to whether screening procedures are followed appropriately. Are all eligible parents receiving screening questionnaires? Are they scored appropriately and made ready for the care provider? Does the EMR offer the most up-to-date version of the SWYC? Do all providers understand and “buy in” to the screening procedures? Do the procedures work even when the clinic is busy? Are the procedures followed correctly?

(2) *Diagnostic accuracy* offers another target for understanding and possible improvement. What data are available that can be used to compare children who score within the expected range to those who score outside? Do risk factors vary in expected ways? Do children who are referred qualify for services? While a true diagnostic accuracy study requires a large, methodologically rigorous study<sup>23</sup>, collecting local data may be useful in understanding diagnostic accuracy in a local patient population.

Although the SWYC itself (like any validated instrument) cannot be informally changed for each setting, it is possible to alter its predictive validity by changing the threshold. As discussed previously (see section 2E on “Interpretation”), we recommend doing so with extreme care. Raising a threshold increases positive predictive value (PPV), but it also reduces sensitivity. As a first stage screener, we strongly believe that sensitivity should be maximized (i.e., maximizing

the number of affected children that are identified). However, in certain settings – especially those with extremely high prevalence rates – it is possible that too high a proportion of children will score positive on the *SWYC* for those scores to be clinically useful in triaging available treatment resources. In such cases, *SWYC* thresholds might be changed. If changing thresholds is under consideration, we recommend conducting a rigorous QI project to collect a sufficiently large sample of local data in order to understand the distribution of *SWYC* scores with accuracy. We also recommend involving a large group of stakeholders in the decision-making process to ensure that the choice of threshold is informed by a range of views and perspectives on how best to maximize the effectiveness of screening. For example, a large statewide QI project designed to improve screening [e.g., the Assuring Better Child Health and Development (ABCD) project in North Carolina]<sup>47</sup> may provide an appropriate context to reconsider screening thresholds.

In our experience, (3) *diagnostic thinking* and (4) *therapeutic efficacy* are often overlooked in the published literature on screening, and we believe that these areas offer an excellent avenue for QI. Perspectives on the appropriate balance between clinical judgment and reliance on “objective” measures like evidence-based screening instruments varies considerably across fields,<sup>48</sup> but in pediatrics, clinicians clearly have an active role in conceptualizing cases and formulating dispositions. We should not assume that simply having parents complete questionnaires will improve children’s health (please see publications for contrasting findings)<sup>49,50</sup> – instead, changes in the *diagnostic thinking* of healthcare providers are also necessary.

Healthcare providers vary greatly in how they provide care,<sup>51</sup> including how they think about and use screening instruments. While research can document these variations, research is seldom able to determine which strategy is best. For example, if one pediatrician refers 30% of children who score positive on the *SWYC*, while another refers 15%, then which pediatrician is right? Although it is impossible to answer this question, we believe that these two hypothetical pediatricians may have a lot to learn from one another. For example, perhaps one knows of a useful referral source that the other does not, or perhaps one has received advanced training in detecting early signs of autism spectrum disorder (ASD) that can be disseminated to other physicians. On the other hand, perhaps one physician is referring too many children for problems that can be better handled in the practice. A QI program that examines practice variation, involves healthcare providers as key stakeholders, and allows for in-depth discussion of practice patterns promises to yield useful insights into care.

(5) *Patient outcomes* and behavior may also be worth examining. Do patients follow through with referrals (and do rates vary for different healthcare providers)? Anecdotally, one practice has reported to us that, as a result of implementing the *SWYC*, they realized the need for more

referral sources and therefore hired a mental health professional who is now co-located in their practice. QI projects involving co-located and collaborative care models may be extremely useful in improving the impact of screening on children's health.

Finally, screening effectiveness at the (6) *societal* level may be considered. For example, following a court mandate for behavioral screening in Massachusetts, statewide assessments have been conducted to better understand population level effects.<sup>52,53</sup> Simulation modeling may also allow for estimates of societal effects of screening, based on existing evidence.<sup>54</sup>

In summary, QI projects can be directed at improving the logistics of screening itself, or at improving the role of screening within the systems of care in which they are embedded. Clinicians are in a unique position to observe healthcare delivery systems and to hypothesize on their flaws and potential improvements. We support innovations in QI to address a wide range of factors that have the potential to improve the developmental and behavioral health of young children and their families.

## **D) Future Research**

Initial research in pediatric settings about all components of the *Survey of Well-being of Young Children (SWYC)* supports their validity in identifying children at risk for cognitive, language, motor, and/or emotional disorders.<sup>26,36,39,40</sup> Much research remains to be done in order to affirm the value of the *SWYC* for the larger goal of early identification and intervention to treat these conditions and reduce their impact on a broad scale. We expect that further research will yield a revised *SWYC (2.0)* incorporating new research. We plan to constitute an advisory group that will collaborate with researchers who wish to do further research with the *SWYC* and will ensure that future research will be consistent with the design principles outlined in section 1B. We encourage outside, impartial evaluators interested in conducting further research on the *SWYC* to contact the authors so that we can learn from one another's work.<sup>i</sup>

Many opportunities exist for further research on the *Survey of Well-being of Young Children (SWYC)*, including studies of more diverse populations and settings, studies in languages other than English, studies of alternate administration media (e.g., via phone, computer/tablet), improvements to specific components of the *SWYC*, and/or a large-scale, comprehensive revision of the entire *SWYC*. The following is a description of some of these topics of research that have recently been proposed or are currently underway.

### **1. Development of National Norms in English and Other Languages:**

The initial validation of the *SWYC* was carried out in two independent samples of parents of diverse ethnic, racial, and socioeconomic status (SES) backgrounds. However, it included parents residing in only one state, and only in English. A high priority for further research is to collect data from parents from across the United States (US), with diverse racial, ethnic, and SES backgrounds.

All components and age forms of the *SWYC* have now been translated into Spanish and Brazilian Portuguese, and selected forms are available in Burmese, Nepali, and Yoruba. The process of translation into other languages has been discussed in section 4D on "Current and Future *SWYC* Translations." Re-standardization and revision of scoring algorithms has begun for Spanish, Portuguese, and Yoruba forms. For any individual translation, additional research and transparent reporting regarding the extent of research conducted is essential.

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<sup>i</sup> Questions or concerns about the *SWYC* or interest in conducting further research on the *SWYC* should be addressed to Kate Mattern at: [theswyc@gmail.com](mailto:theswyc@gmail.com).

## **2. Improvements in Individual Components of the SWYC:**

Evidence for the validity of various components of the *SWYC* varies. Many developmental tests for young children demonstrate weaker validity at the younger ages of their range. This is in large part due to the fast pace of change in developmental accomplishments in the first 6 months of life. The *SWYC* is no exception, with the 2-month *SWYC Milestones* and the *BPSC* showing weaker correlations with other screening tests than those administered to older children. In this regard, it is important to note that very few screening tests exist against which the *SWYC* components for these young ages can be tested, and few developmental disorders are formally diagnosed at these young ages. Therefore, validation research is more difficult and less reliable at younger ages than for older children.

In addition, the *SWYC Milestones* form for older children (60-month) also demonstrates lower correlations with parents' reports of disorders and with comparison tests than at other ages. We believe that this is due to a 'ceiling effect' by which fewer items were tested that challenge the most advanced children at these ages; thus, new items should be created, tested, and added to these forms.

The scoring algorithm for the *POSI* was created to maximize sensitivity. Used in this way the *POSI* has shown sensitivities similar to or better than the *M-CHAT*, but the relatively low prevalence of autism has made criterion testing difficult to accomplish. One or two of the 7 items may be confusing and benefit from rewording. Further work is in progress to revise the wording of the questions and to re-evaluate the scoring algorithm.

In the future, we plan to pursue two methods to improve the *SWYC*. First, we would like to develop promising candidate questions to consider adding to the *SWYC*. After collecting data from a large sample of parents and validating these questions, they can be considered for use in the *SWYC*, either replacing or in addition to existing questions. To ensure that changes to the *SWYC* do not compromise its use in existing settings, we intend to make any decision about revisions with the involvement of a range of stakeholders who currently work with the *SWYC*. This strategy is particularly important for the *SWYC Milestones* in order to achieve a greater number of validated questions across the age range.

In addition, independent researchers have proposed and are piloting enhancements to the *SWYC* that may be incorporated into future versions. For example, the Massachusetts Child Psychiatry Access Project (MCPAP) has added a more extensive post-partum depression screen (based largely on the *Edinburgh Postpartum Depression Screen*) to respond to a state-level initiative to address this problem. Another group of investigators is piloting the use of a short set of school readiness questions as part of the *SWYC* at 48 and 60 months. Depending on the results of these pilots, the adaptations described will be considered for future revisions of the

SWYC. Other investigators have suggested additional questions about articulation, and about social determinants of health to the *Family Questions* component of the SWYC.

### **3. Studies of the Validity of the SWYC in Diverse Populations (e.g., different cultural groups and different states, regions, and countries):**

An in-depth analysis was carried out by the Tribal Early Childhood Research Center, to understand the acceptability and validity of the SWYC among American Indian and Alaska Native (AIAN) populations.<sup>22</sup> Extensive interviews in diverse AIAN communities affirmed that the SWYC would be acceptable in these populations, but that some modifications in the wording of specific items and translation into local languages would be necessary. The Tribal Early Childhood Research Center is hoping to identify a funding source to study these potential revisions. As described above, further study of differential item functioning (DIF) among diverse populations also promises to enhance scoring and interpretation.

We are committed to ensuring that the SWYC is appropriate for use with diverse populations of children. We recognize that this will sometimes require adaptations to existing forms. At the same time, use of standardized questions across different populations offers some advantages. Together with stakeholders who are working to ensure the SWYC's validity in diverse populations, we intend to develop a process designed to achieve the appropriate balance between standardization and adaptations for particular populations.

### **4. Studies of the SWYC as Administered in Settings other than Pediatrics (e.g., child care, preschool, home visiting):**

Consistent with a "system of care" approach to identifying risk and optimizing children's development, we support the development of protocols by which the SWYC is administered to parents by home visiting, child care, preschool, and other child-serving providers. Interpretation and follow-up should be provided by professionals who are qualified to provide further clarification of the results of SWYC scores and to ensure that parents are directed to appropriate resources for intervention, if needed. In addition, a variation of the SWYC could be developed that would be intended for completion by home visitors, child care providers, and preschool teachers. This could help to expand screening efforts in communities where pediatric providers are scarce (e.g., rural communities, AIAN communities). It goes without saying that, if such a variation were created, it would require independent validation.



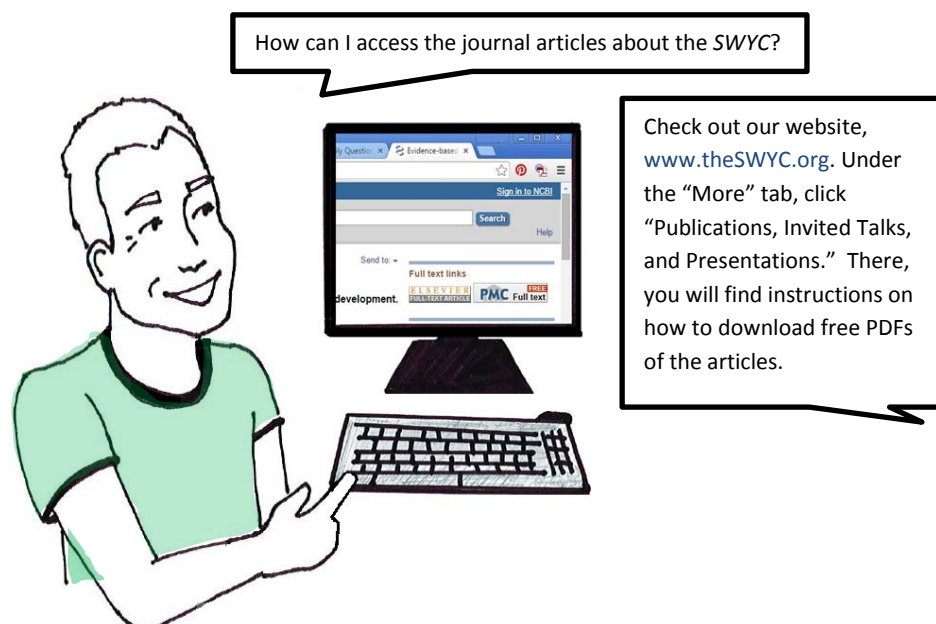
## **5. Studies of the Validity of the SWYC as Administered via Different Modalities [e.g., phone, computer/tablet, electronic medical record (EMR) portal]:**

To maximize feasibility of the regular use of the SWYC, the creation and dissemination of various electronic formats will be critical. Research comparing responses in different modalities should be done to confirm their consistency.

## **6. Comprehensive Revision:**

In addition to the modifications described above, a more comprehensive revision may be advisable at some point in the future. Any future revisions should be conducted in the appropriate way:

- Using as much available data as possible – pulling together datasets where the SWYC has been used clinically.
- Including strong engagement from key stakeholders (i.e., those who have used and/or researched the SWYC).
- Making use of the results of *local experiments* with the SWYC, such as those piloting of new sections such as expanded assessment of post-partum depression, a literacy screen for 4 and 5 year-olds, and additional questions regarding adverse childhood experiences, following the design and development principles of the SWYC (e.g., maintaining brevity and comprehensiveness, ensuring that items are statistically reliable and relatively free of DIF). To achieve these goals, we are working to develop a governance structure to guide the future use and development of the SWYC.



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## **Chapter 6**

# **When to Screen: A Deeper Look**

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How often and when parents should be asked to report on their children's developmental progress through formal screening is a subject of considerable interest and controversy. In its 2006 Policy Statement about developmental screening, the American Academy of Pediatrics (AAP) asserted that formal developmental screening should occur when children are 9, 18, and 30 months old (or at 24 months if the child will not be seen at 30 months).<sup>2</sup> This has become the accepted routine for most state guidelines and many Medicaid and private insurance companies pay for screening at these (and only these) ages. These ages were identified because they appear to be times when certain recognizable patterns of developmental disabilities will typically have become manifest. Additionally, these young ages have the advantage of allowing for timely referral to Early Intervention (EI) services (i.e., before three years old). Subsequently, these three ages for formal screening have become codified in the minds of pediatricians, parents, payers and policy-makers. However, given new scientific evidence and policy developments over the past decade, we wonder if these guidelines continue to make sense.

In order to maximize the integration of developmental-behavioral screening with regular pediatric care, we designed the *Survey of Well-being of Young Children (SWYC)* to have the potential to be used at every well-child visit in the first 5 ½ years of life. There are several arguments supporting our recommendation for screening at every visit:

1. Screening at every visit enhances feasibility of systematic screening.
2. Screening at every visit changes expectations.
3. Screening at every visit enhances the opportunity for screening to reach every child.
4. Difficulties and disorders become evident at various times across the age spectrum.
5. Frequent screening enhances collaboration with other community-based child-serving professionals, for whom windows of opportunity differ.
6. Early identification is a pathway to early intervention.

### **1. Screening at Every Visit Enhances Feasibility:**

The reports we have received from pediatric primary care providers (PPCPs) suggest that screening at every visit helps feasibility by increasing predictability: (1) administrative staff expect to distribute forms to every patient; (2) parents expect to complete forms at every visit; and (3) PPCPs expect screening results for every patient. These reports are consistent with the experience of pediatric screening in Massachusetts, where a court mandate required behavioral screening for all children on Medicaid at every visit. Several years after implementation, more than 70% of pediatric visits billed to Medicaid include the use of an approved screening instrument,<sup>55</sup> and gains in service use have been documented.<sup>52</sup> All other major payers have developed similar policies.

## **2. Screening as part of every well child visit changes expectations.**

If comprehensive screening is included as part of every health supervision visit, parents will come to expect their observations and concerns about their child's cognitive, language, motor, and social-emotional development to be discussed at each visit. This expectation will enhance parents' observations, and improve both efficiency and depth of discussions about these issues with pediatricians. These recurrent conversations may also serve to increase parents' trust in sharing sensitive concerns.

## **3. Screening at every visit Increases the opportunity for screening to reach every child:**

Note that the benefits of screening at any one visit are reduced by a number of factors. To be detected on a screening instrument and receive services, a child with a developmental-behavioral problem must: (1) attend the pediatric visit at which screening is offered; (2) receive a screener at that visit; (3) be detected by that screener; and then (4) follow through with the follow-up plans recommended by the PPCP. Thus, in order to maximize the impact of developmental screening, administration at multiple visits is indicated.

Because on average children attend only 65% of recommended well child visits in the first 5 years of life, a system should be put in place in the office such that a child who misses a screening visit is notified and the recommended screening procedure is administered at the next available opportunity. Such a reminder system is easier to institute when the office has an electronic medical record in place. If screening is routinely administered at every visit, the need for a secondary system to reach children who miss appointments is less critical.

## **4. Difficulties and Disorders Become Evident at Various Ages Across the Age Spectrum:**

The wide range of developmental-behavioral problems may develop and become evident at different ages. Very early manifestations of regulatory disorders may be evident within the first 6 months and impair developing relationships. Early symptoms of anxiety disorders, attention disorders, and aggressive/oppositional disorders may be detectable as early as 2 years of age, but often not until the preschool period or even later. Irritability in the preschool period has been shown to predict various later mental health diagnoses. A recent study demonstrates that a substantial number of children with autism spectrum disorder (ASD) may not meet diagnostic criteria until at least their third birthday.<sup>56</sup> This is one of the reasons that we advocate for consideration of a more extensive window for systematic screening for developmental-behavioral difficulties and disorders.

## **5. Collaboration with Providers of Varying Needs and Schedules:**

PPCPs collaborate with a range of other providers who increasingly perform developmental screening that goes beyond the AAP recommendations. The SWYC was developed for PPCPs,

but information about children's well-being may be helpful for home visitors, child care providers, preschool teachers, and others who monitor children's development. All involved individuals should collaborate on approaches to give children and parents what they need to succeed. The same is true for many other screening instruments.

For all of these reasons we suggest that our recommendation to systematically screen at every well-child visit is supported by the current understanding of the prevalence, emergence, and multifaceted manifestations of developmental-behavioral difficulties and disorders, and by the realities of the practical applications of screening in pediatric and community settings.

### **6. Early Identification is a Pathway to Early Intervention:**

Early identification creates opportunities for supportive guidance and early interventions. If mild concerns about developmental-behavioral concerns are identified by parents, pediatricians and others can provide suggestions and refer parents to helpful resources.<sup>i</sup> Frequent screening encourages parents to report concerns before symptoms become severe.

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<sup>i</sup> For example: the American Academy of Pediatrics website: [www.healthychildren.org](http://www.healthychildren.org); Please see Center for Disease Control and Prevention (CDC) at: <http://www.cdc.gov/parents/essentials/index.html>; the American Academy of Pediatrics (AAP) at: [www.aap.org](http://www.aap.org); and the American Academy of Child and Adolescent Psychiatry (AACAP) at: [https://www.aacap.org/aacap/Families\\_and\\_Youth/Family\\_Resources/Home.aspx](https://www.aacap.org/aacap/Families_and_Youth/Family_Resources/Home.aspx).

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# **Chapter 7**

## **Evaluating a Screening Instrument: A Deeper Look**

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To have an impact on children's health, screening instruments should be feasible to use in a variety of settings, accurate, and contribute meaningfully to the decision-making process of pediatricians and other professionals caring for the child. Many professional guidelines recommend that screening instruments be chosen that display sensitivity and specificity over 70%. But the reported sensitivity and specificity of a screening instrument are not enough to make a good choice.

**Sensitivity and specificity are not properties of a screening instrument—they only indicate performance in past studies.** A screener does not *have* a sensitivity and a specificity of a specific value. Instead, a screener *displays* a certain level of sensitivity and specificity in a *particular* study with respect to a *particular* outcome, in a *particular* sample population, and using a *specific* study design. Therefore, a statement like, "Screener X has 80% sensitivity and 80% specificity," is not meaningful in itself—you will need to know more to understand it. 80% sensitivity and specificity with respect to what outcome? Measured how? Among children of what backgrounds and of what ages?

Evaluating the evidence for the sensitivity and specificity displayed by a particular screener is complicated. Frequently an average value across several studies is reported. However, because many studies on a given screener report sensitivity and specificity using different methodologies, we strongly recommend a systematic review of all the available evidence (and, if appropriate, meta-analysis). Such reviews should consider study quality following the two expert consensus statements on how to conduct diagnostic accuracy studies (STARD and QUADAS-2). Such independent reviews of screener accuracy are important to inform decisions about which screeners are best to use. Unfortunately, systematic reviews require significant research support and few exist for developmental-behavioral screening of young children (see Drotar et al., 2008 for an important exception).<sup>57</sup>

Comparisons of screening instruments should consider all the factors that influence their sensitivity and specificity, including how outcomes were defined, what populations were included, and what study design was employed. If two studies of different screening instruments use different criterion measures and/or were conducted with different designs or on different populations, they are not directly comparable. Because of all this complexity, head-to-head comparisons -- in which two instruments are compared in the same study with the same outcomes measured -- are the best way to determine the relative benefits of a particular screening test.

**Accuracy is not the only property of a screening instrument—also consider feasibility and influence on clinical decision making.** Obviously, screening instruments only work if they are *actually completed*. Therefore, ease of use for parents, office staff, and pediatricians, along with

overall feasibility in the intended setting are essential, as is availability in appropriate languages.

Moreover, it is important to remember that in many settings (including pediatric offices in particular), the final decisions regarding follow-up to screening test results and outside referrals is made by a human being (often a pediatrician). In study after study, practicing pediatricians refer only a proportion of children who screen positive.<sup>49,58-61</sup> Clearly, they are making decisions on a case-by-case basis, based on many factors in addition to the screener. Screeners will be maximally effective if decision-makers trust their results and find them useful in guiding their decisions.

Along these lines, it is also important to consider whether a screener offers new information that improves detection in the context of an overall system. As explained by Dr. Bonnie Camp across a series of articles, “High sensitivity and specificity do not insure that the test will be clinically useful...”<sup>62</sup> What is at least as important is that “each procedure contributes something unique...”<sup>63</sup> This statement draws from the study of evidence-based medicine, which often advocates the use of a statistic known as “likelihood ratios” to combine results across multiple tests.<sup>64,65</sup> While the details of using likelihood ratios are better explained elsewhere, a central point is the information a screener offers is reflected not only by its sensitivity and specificity (which reflect how accurate the screener is on its own), but also on how independent the results are from other tests and information (i.e., low correlation).

In summary, it is important to choose an informative, accurate screening test that is feasible to use at the appropriate point in the care process. Many qualities involved should be evaluated—including accuracy, feasibility, and impact on clinical decision making.

Is the SWYC validated?



This is a complex question for any screening instrument, and there is seldom (if ever) a simple “yes” or “no” answer. The question is whether one can have confidence that a screening instrument is accurate enough for its intended use. High-quality, up-to-date research, ideally published in peer-reviewed journals, should increase one’s confidence. We also look for independent replication and direct comparisons to existing screening instruments. If a screener has been changed in any way, whether translated into a new language or used in a new setting or with a new population, we look for research demonstrating its accuracy despite the changes.

Research on the SWYC is described in this manual and our publications. Three of the SWYC’s four components have been compared statistically to a well-respected screening instrument (*ASQ-3* and *ASQ-SE*), and to parents’ reports of developmental-behavioral diagnoses. One has also been compared to the *CBCL*, a frequently used parent report of symptoms of behavioral/emotional disorders. The items that comprise the fourth component of the SWYC, called *Family Questions*, were assembled from previously-validated tests and have not been separately evaluated. Detailed descriptions of the methods of study and the statistical techniques used to validate the SWYC are described in our manuscripts. Ongoing research conducted by us and by independent investigators will compare the SWYC to “gold standard” clinical assessments (see section 5B on “Ongoing Research”)

# **Chapter 8**

## **Decision Thresholds: A Deeper Look**

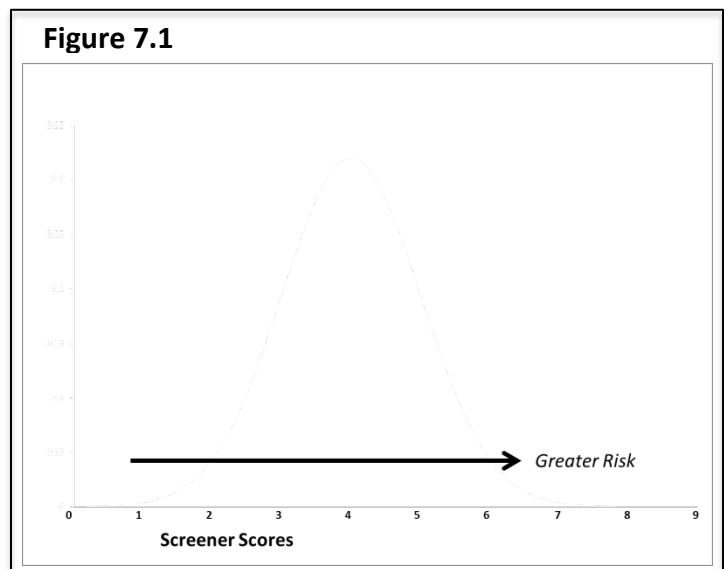
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In section 2E on “Interpretation” we discuss the tradeoffs and uncertainty in screening that are important to understand in order to properly interpret the *Survey of Well-being of Young Children (SWYC)*. Given the importance - yet complexity - of these topics, we provide greater detail here in order to further understanding. For an even more in-depth discussion of these topics, we refer readers to our article in the *Journal of Child Psychology and Psychiatry*.<sup>66</sup>

### **1. Understanding the Tradeoffs in Screening:**

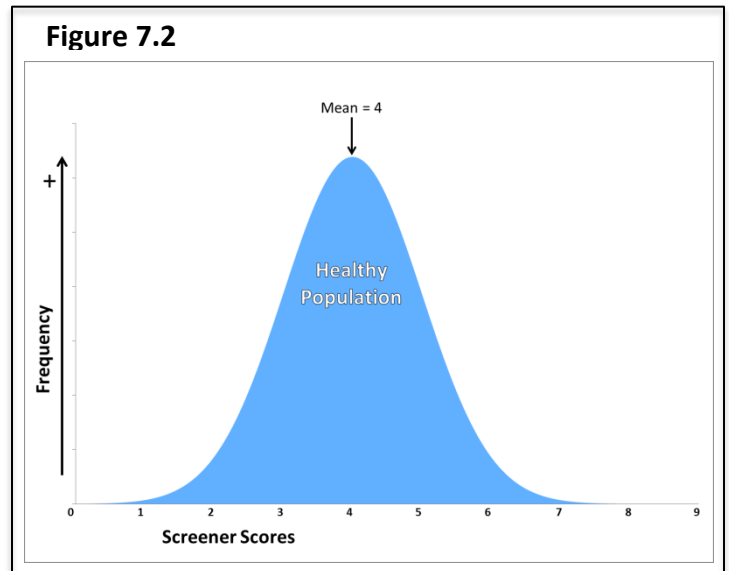
Interpretation of scores from the *SWYC* (or any other screening instrument) requires an understanding of how screening thresholds (also known as cut scores) are set. All screeners result in some errors – either when “healthy children”<sup>i</sup> screen positive (i.e., false positive) or when children with problems screen negative (i.e., false negative) – and all thresholds strike a balance between the two. It is the relationships among the proportions of false positives and false negatives that we will describe below. In the following pages, we review the logic of setting thresholds using a series of figures. We did our best to make the examples realistic. All figures below depict the accuracy of a hypothetical screener (capable of achieving sensitivity of 77% and specificity of 77%) in detecting developmental-behavioral problems, which are assumed to affect 20% of the population (i.e., prevalence = 20%). Although the language of the hypothetical scenario is written about developmental-behavioral problems, it should be noted that the following applies to screening and assessment instruments in general.

Imagine a screening questionnaire with scores that range from 0 to 9. Higher scores indicate greater risk. Note that in some screening tests (e.g., the *SWYC Milestones*) it is lower scores that indicate more risk. The same principles apply.



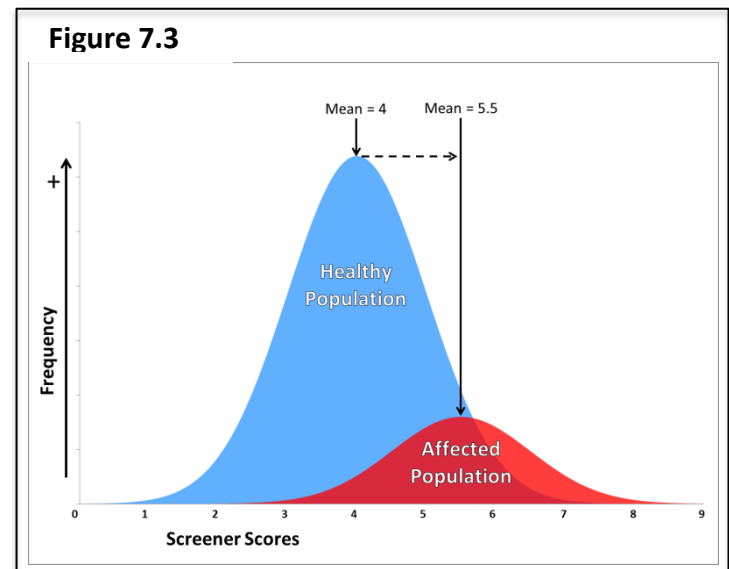
<sup>i</sup> By “healthy children”, we are referring to children who do not have any developmental-behavioral disorder.

When parents of healthy children complete this screener, they get a wide range of scores. Imagine that the scores are normally distributed in a “bell shaped” pattern. In this case, the average score is 4 with a standard deviation of 1. This means that more than 95% of screening scores fall between 2 and 6 (that is, the average score of  $4 \pm 2$  standard deviations).



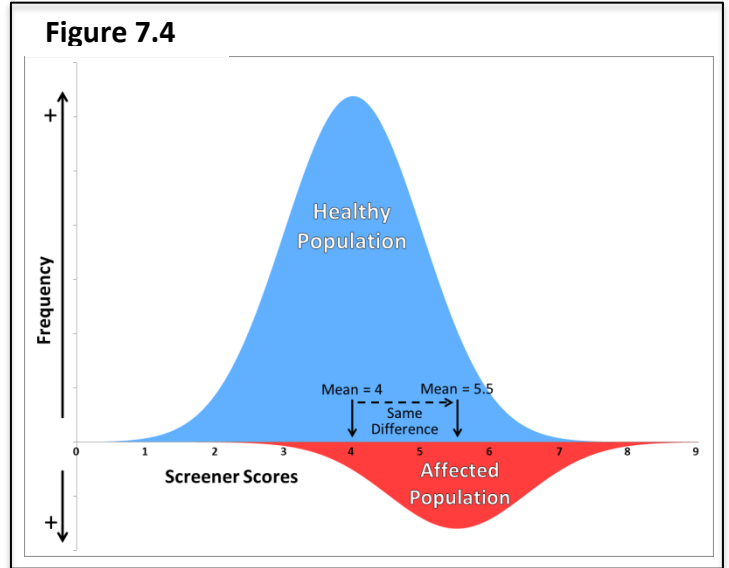
When parents of children who are affected by developmental-behavioral problems complete the screener, their scores will be higher, indicating greater risk. In our hypothetical example, their average score is 5.5.

Since we are assuming 20% prevalence, 20% of children are in the “affected” population, while 80% are in the “healthy” population. Note that these differences in prevalence are reflected by the diverse proportions of the two bell curves.

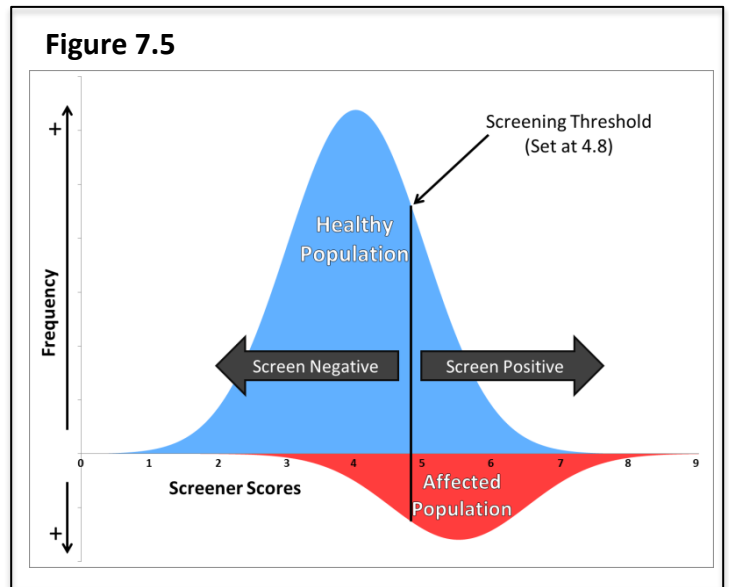




To make things easier to see, we flipped the scores for the affected population below the x-axis (with frequencies increasing away from the x-axis positively in both directions). Everything else is exactly the same, except now the two population distributions don't visually overlap.



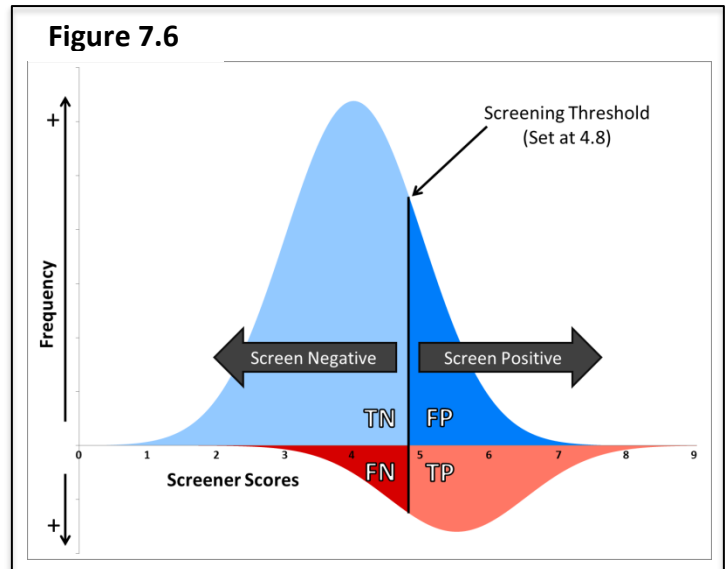
Traditionally, we expect a screener to result in a “positive” or “negative” score. Therefore, every screener needs a “cut score” or “threshold,” and our hypothetical screener is no exception.<sup>ii</sup> Let's set this screening threshold at 4.8. This means that everyone who scores a 4.8 or higher will screen positive and everyone who scores lower than a 4.8 will screen negative.



<sup>ii</sup> A negative score below the threshold falls in the “healthy” range whereas a positive score above the threshold falls into the “at-risk” range”.

As you can see in Figure 7.6, the screener has four possible results:

1. **True Positive:** A child who scores positive might be a member of the “affected” population, in which case the positive screening result is correct. We call this a “**true positive**” or **TP** (as depicted in light red in the lower right).
2. **False Positive:** A child who scores positive might also be a member of the “healthy” population, in which case the positive screening result is NOT correct. We call this a “**false positive**” or **FP** (as depicted in dark blue in the upper right).
3. **True Negative:** A child who scores negative might be a member of the “healthy” population, in which case the negative screening result is correct. We call this a “**true negative**” or **TN** (as depicted in light blue in the upper left).
4. **False Negative:** A child who scores negative might also be a member of the “affected” population, in which case the negative screening results is NOT correct. We call this a “**false negative**” or **FN** (as depicted in dark red in the lower left).



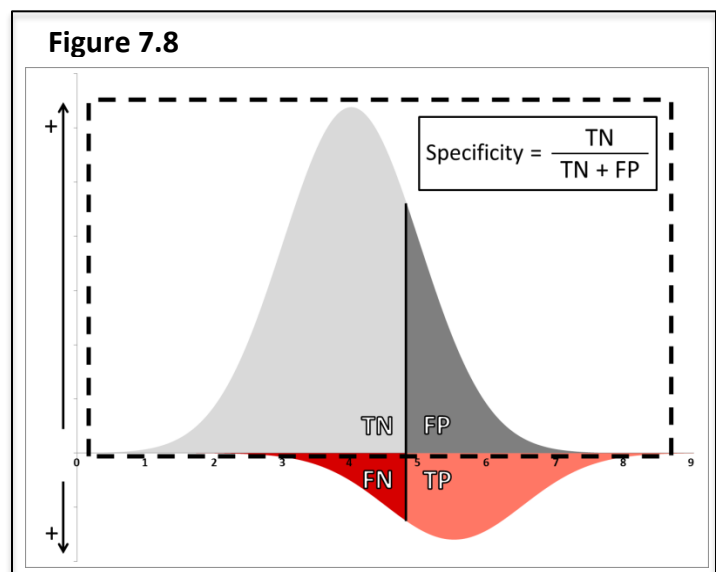
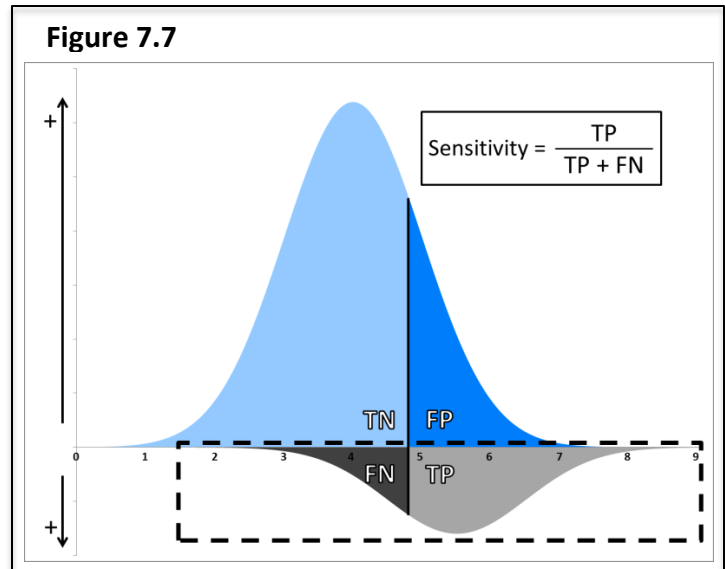
Thus, there are two ways for a screening result to be correct (TP and TN) and two ways for a screening result to be incorrect (FP and FN).

In a perfect world, a screening test would detect all children who are affected with developmental-behavioral problems (i.e., no FN's). "Sensitivity" tells us how close we come to that ideal. Specifically, sensitivity refers to the *proportion of children in the affected population who are correctly classified by the screener*.

Look at Figure 7.7. We drew a box around the affected population. The *sensitivity* of the test is the proportion of the affected population that scored above the threshold, in this case **77%**.<sup>iii</sup>

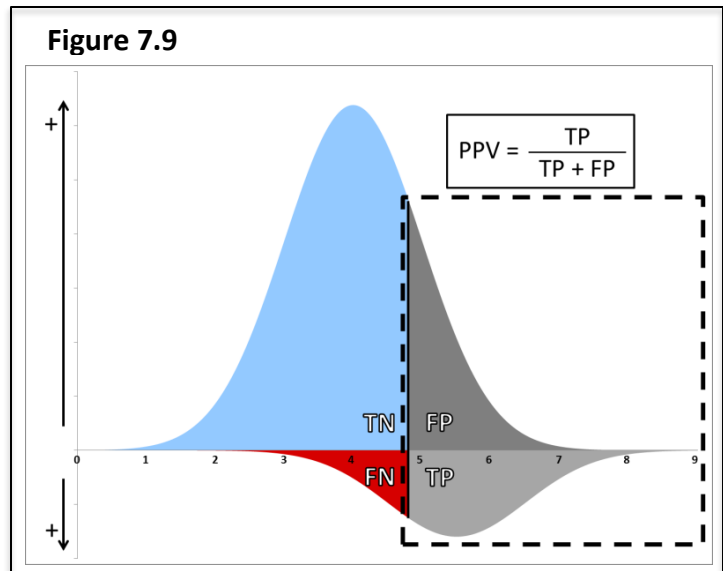
The opposite of sensitivity is *specificity*. In an ideal world, all healthy children would score *negative* on the screener (i.e., no FP's). "Specificity" tells us how close we come to this ideal. Specifically, specificity refers to the *proportion of children in the healthy population who are correctly classified by the screening test*.

Look at Figure 7.8. We drew a box around the healthy population. The screener's *specificity* is the proportion of the healthy population who scored below the threshold. In this case, **specificity is also 77%**. Thus, sensitivity and specificity are balanced, as is true for many screening instruments.



<sup>iii</sup> Please see appendix i on "Mathematical Calculations from Chapter 8" for those interested in understanding how this value (and all other statistical numbers hereafter) was calculated.

There is another way of understanding the accuracy of a screening test. Imagine that you're a clinician and you are evaluating a child. The child scores positive. You know that this positive result might be accurate or inaccurate. In order to know how to interpret the score, you will want to know how likely it is to be accurate. The answer for which you are looking is *positive predictive value* or *PPV*. Specifically, PPV refers to the *proportion of children who score positive on the screening test who are correctly classified by the screening test*.



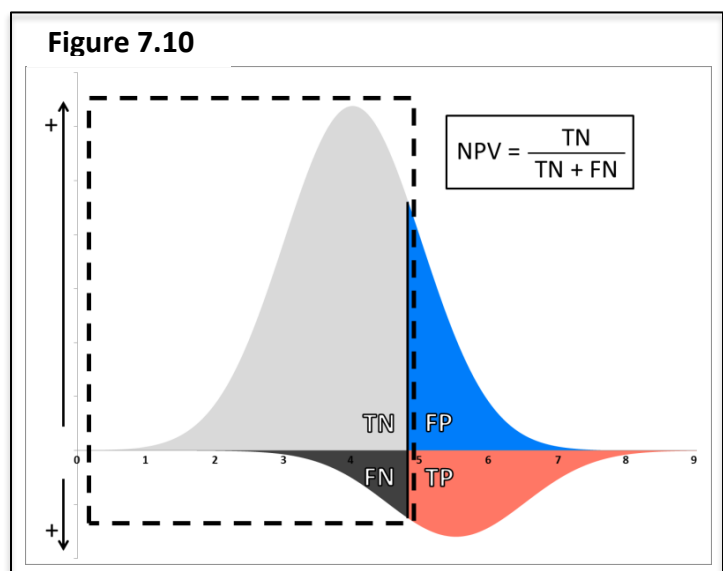
Look at Figure 7.9. We drew a box around the children who score positive on the screening test. The positive predictive value is the proportion of this group of children who actually have a developmental-behavioral condition (the section of the curve labeled TP). In this case, using a screening test with 77% sensitivity and 77% specificity, in a population with 20% prevalence of the condition you are screening for, the **PPV is 46%**.

In contrast, imagine that you want to know how likely it is that a negative score is accurate. The answer for which you are looking is *negative predictive value* or *NPV*.

Specifically, NPV refers to the *proportion of negative results that are true negatives*. The higher the negative predictive value of a screener, the more accurately the screener identifies negative results.

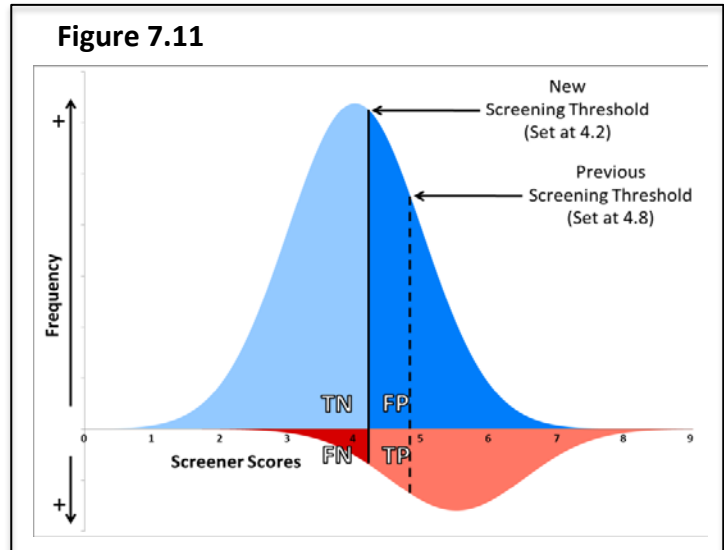
Look at Figure 7.10. We drew a box around the children who score negative on the screening test. The screener's *NPV* is the proportion of those children who do not have any developmental-behavioral condition (the portion of the curve labeled FN).

In this case, assuming the same sensitivity and specificity of the screening test and the same prevalence of the condition in your population, the **NPV is 93%**. More practically, imagine

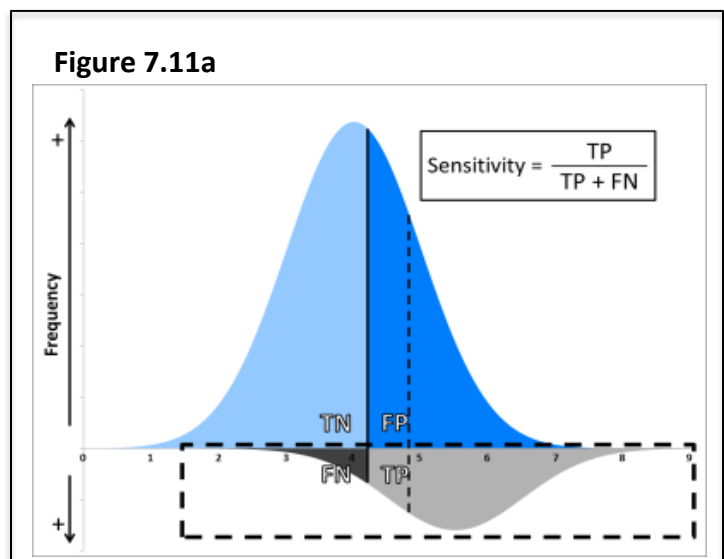


you want to know the likelihood that a negative score is inaccurate. In this case, the answer is **1 – NPV, which is 7%**.

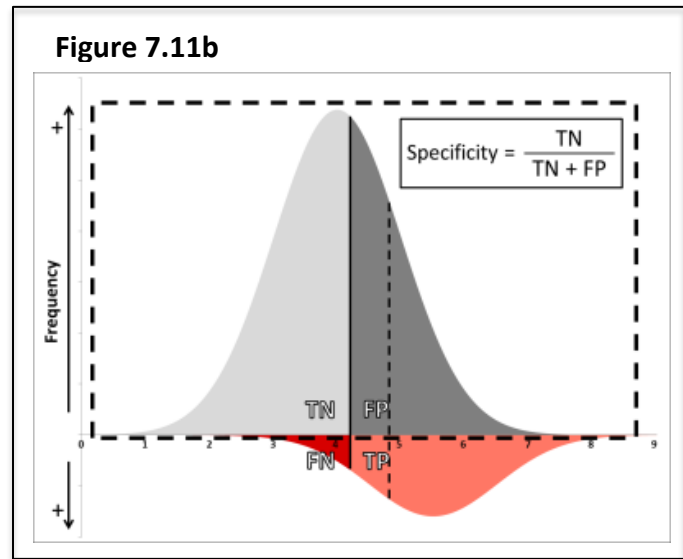
Now, what happens if we change where the screener's threshold is set? First, imagine that it is decreased from 4.8 to 4.2, as depicted in Figure 7.11. Hence, everyone who scores a 4.2 or higher will screen positive and everyone who scores lower than a 4.2 will screen negative.



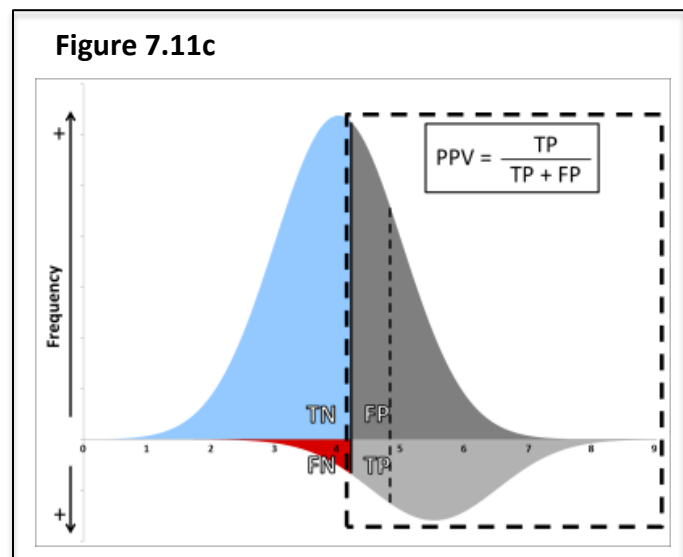
- What is the effect on sensitivity? Among affected children, do more children or fewer children screen positive? Looking at Figure 7.11a, you can see that *more affected children score positive when we lower the threshold*. Thus, **sensitivity goes up from 77% to 91%** (which is great).



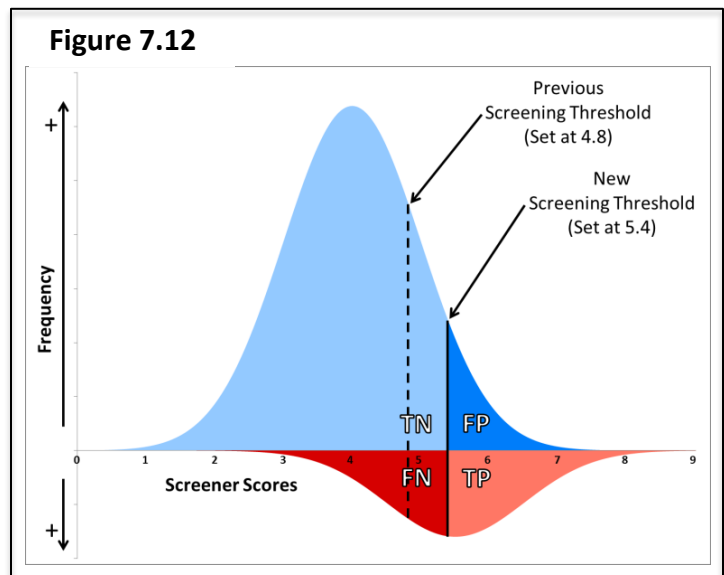
- What is the effect on specificity? Among healthy children, do more children or fewer children screen negative as we would hope? Looking at Figure 7.11b, you can see that *fewer healthy children score negative when we lower the threshold*. Thus, **specificity goes down from 77% to 56%** (which is unfortunate).



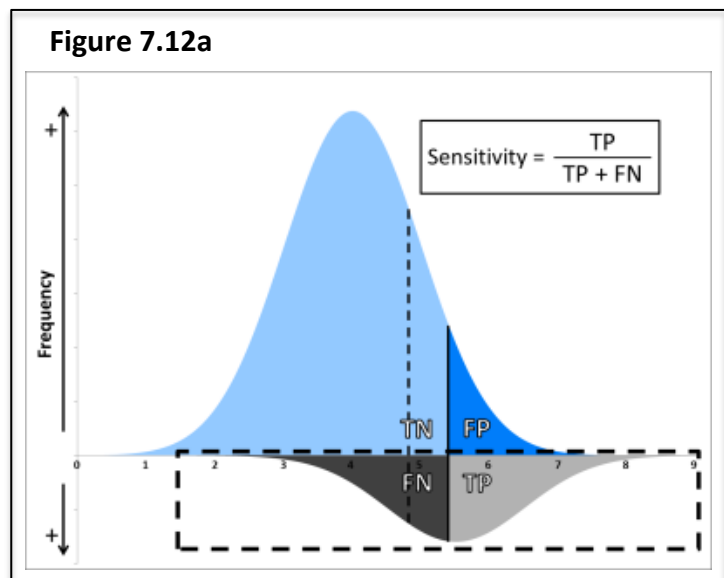
- What is the effect on PPV? Among children who score positive, are more children or fewer children in the affected population? This one is a bit tougher to see – look carefully at the areas to the right of the new threshold on Figure 7.11c. *A smaller proportion of children who score positive are in the affected population when we lower the threshold*. Thus, **PPV goes down from 46% to 34%** (which is also unfortunate).



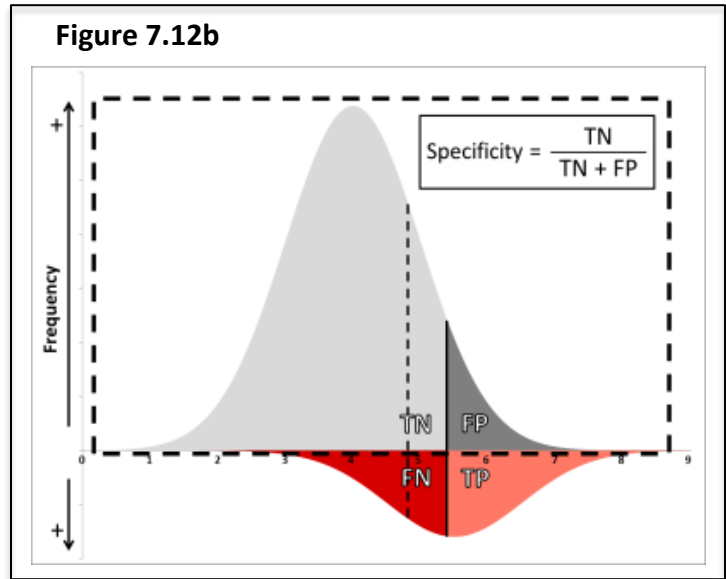
What if we change the threshold the same size distance but in the opposite direction, so that we increase it from 4.8 to 5.4?



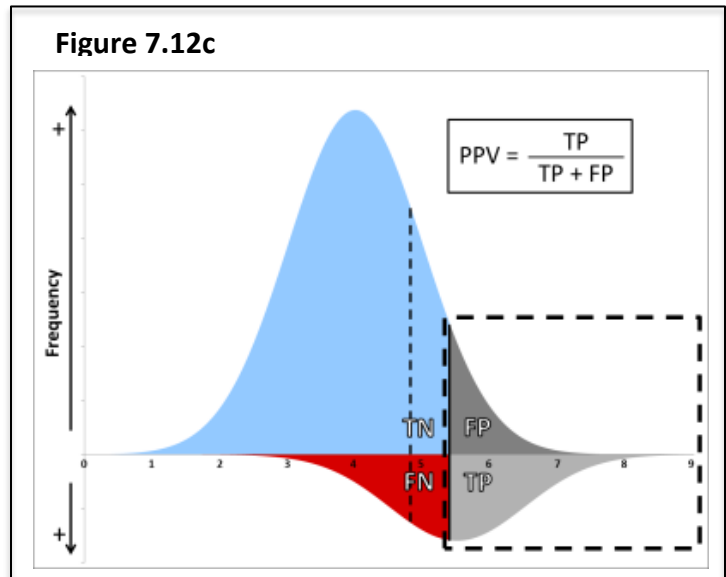
- What is the effect on sensitivity? Among affected children, do more children or fewer children screen positive as we would hope? Looking at Figure 7.12a, you can see that *fewer affected children score positive when we raise the threshold*. Thus, **sensitivity goes down from 77% to 56%** (which is unfortunate).



- What is the effect on specificity? Among healthy children, do more children or fewer children screen negative, as we would hope? Looking at Figure 7.12b, you can see that *more healthy children score negative when we raise the threshold*. Thus, **specificity goes up from 77% to 91%** (which is great).



- What is the effect on PPV? Among children who score positive, are more children or fewer children in the affected population? Again, this one is a bit tougher to see – look carefully at the areas to the right of the new threshold on Figure 7.12c. *A larger proportion of children who score positive are in the affected population when we raise the threshold*. Thus, **PPV goes up from 46% to 61%** (which is also great).





**CONCLUSION:** There are tradeoffs in choosing a threshold for any screening instrument:

- Choose a higher threshold, and positive scores are more likely to be correct (higher PPV), but you are likely to miss more children who might benefit from treatment – i.e., more false negatives (lower sensitivity).
- Choose a lower threshold (for example, a threshold that balances sensitivity and specificity), and positive scores are less likely to be correct (lower PPV), but you will detect more children who are likely to benefit from treatment – i.e., more true positives (higher sensitivity).
- The effect of prevalence on PPV is discussed in more detail on page 1112.

As was outlined in section 1B on “Design Principles,” it is important to note that in creating the scoring guidelines for the SWYC, we have chosen a lower threshold to favor sensitivity over specificity. Given that the SWYC is a first-level screening instrument, we believe that it is imperative to minimize the number of false negatives (i.e., children who are at risk but not identified) at the expense of identifying more false positives (i.e., children who healthy but identified as at risk). Thus, fewer children who need services will be missed and more children will receive further evaluation.



I think too many children score positive on screening instruments, so I only really trust positive results that are several points above the stated threshold. Is that OK?

The effect is the same as if you had raised the threshold. Positive results will be more likely to be correct (higher PPV ☺), but you will miss more children who might benefit from treatment (lower sensitivity ☹). Be aware of the tradeoff in this approach.

## **2. Uncertainty in Healthcare (...and in Screening Results):**

### **Systemic uncertainty:**

Uncertainty is endemic to many areas of healthcare. In an excellent review that offers a taxonomy of the types of uncertainty common in healthcare, Han and colleagues (2011)<sup>67</sup> quote David Eddy's (1984)<sup>61</sup> perspective:

Uncertainty creeps into medical practice through every pore. Whether a physician is defining a disease, making a diagnosis, selecting a procedure, observing outcomes, assessing probabilities, assigning preferences, or putting it all together, [he or she] is walking on very slippery terrain. It is difficult for non-physicians, and for many physicians, to appreciate how complex these tasks are, how poorly we understand them, and how easy it is for honest people to come to different conclusions. (p. 828).

Screening is no exception. Ideally, if a child scores positive on a screener, a clinician would like to know the probability that the child has a problem. Unfortunately, there is considerable uncertainty in estimates of positive predictive value (PPV).

One source of uncertainty is intrinsic to the research itself. Few studies evaluate screeners by comparing them to "gold standard" evaluations. Those studies that do so are likely to have chosen different "gold standard" tests and interviews, leading to somewhat different results. Variations in the size and heterogeneity of the populations studied, methods of administering screening tests, and even random variations among studies add to the uncertainty in research evidence.

### **Uncertainty created by differences in prevalence:**

There is a second type of uncertainty that we will discuss in detail. This type of uncertainty stems from the fact that the **PPV of a screener is dependent on prevalence**.<sup>iv</sup> As prevalence varies among populations or over time, PPV will also vary. Thus, unless prevalence is known with precision (which is seldom the case), clinicians will not be able to estimate PPV with certainty. In general, prevalence rates for all developmental-behavioral disorders (combined) is estimated to be *at least* 15-20%; whereas for individual conditions, prevalence is typically much lower (e.g., around 1-5%).

Prevalence influences PPV in a particular way, and it is very useful to understand how this happens. For example, if the specificity and sensitivity of a screening test are held constant, and the screener is used with a group of children who are rarely affected by developmental-behavioral disorders, PPV will be much lower than if the same screener is used in a group of

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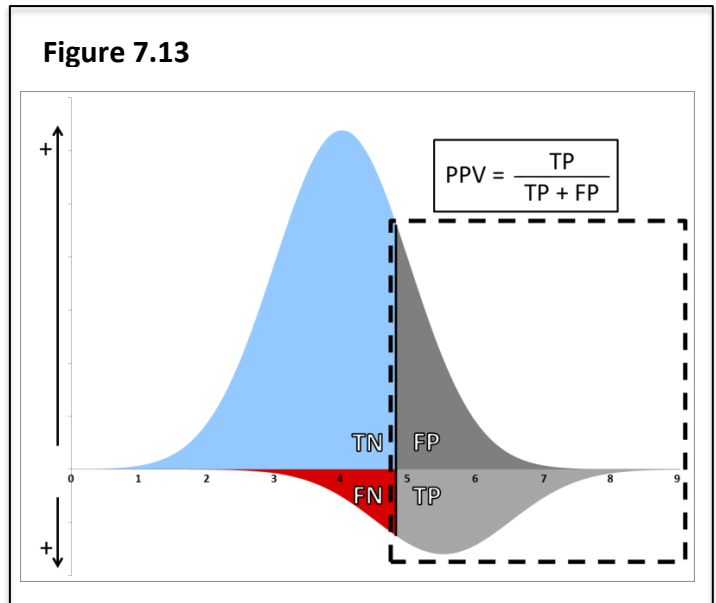
<sup>iv</sup> By "prevalence", we are referring to the true proportion of children in a population who have a condition (in our case, developmental-behavioral problems).

children of whom many are affected. We will demonstrate this fact by walking you through a series of figures. As above, we did our best to make the examples realistic: (1) the prevalence of developmental-behavioral problems is first assumed to be 20% and is then varied; and (2) the screener depicted is capable of achieving sensitivity of 77% and specificity of 77%.

### *Prevalence = 20%*

Here is the same figure on PPV that we showed you above (see Figure 7.9 on page 112), but now labeled Figure 7.13. 20% of children are affected by developmental-behavioral problems.

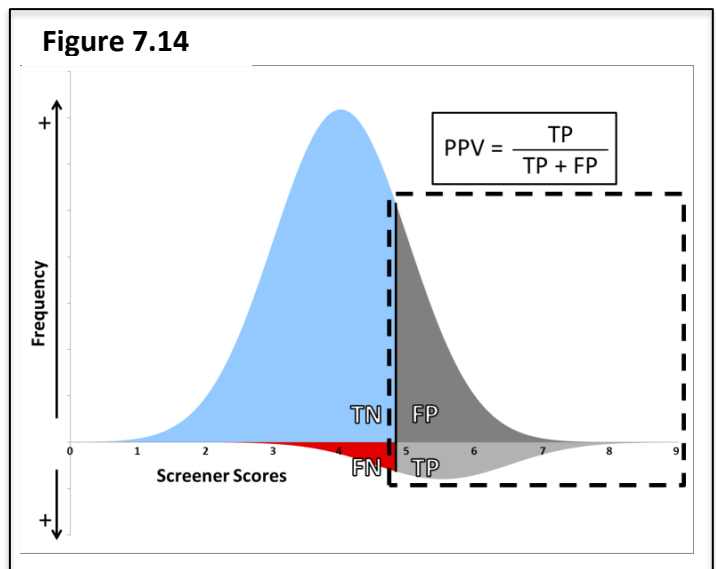
Look at the proportion of children who score positive who are correctly classified (the segment of the curve labeled TP) – the **PPV is 46%**.<sup>v</sup>



### *Prevalence = 10%*

In this picture, now only 10% of children are affected by developmental-behavioral problems. You can see in Figure 7.14 that the bell curve on top (depicting the healthy population) is now larger in comparison to the curve on the bottom (depicting the affected population).

Look at the proportion of children who score positive who are correctly classified (the segment of the curve labeled TP). True positives (TP) now represent a much smaller portion of the total. **PPV has decreased and is now 28%.**

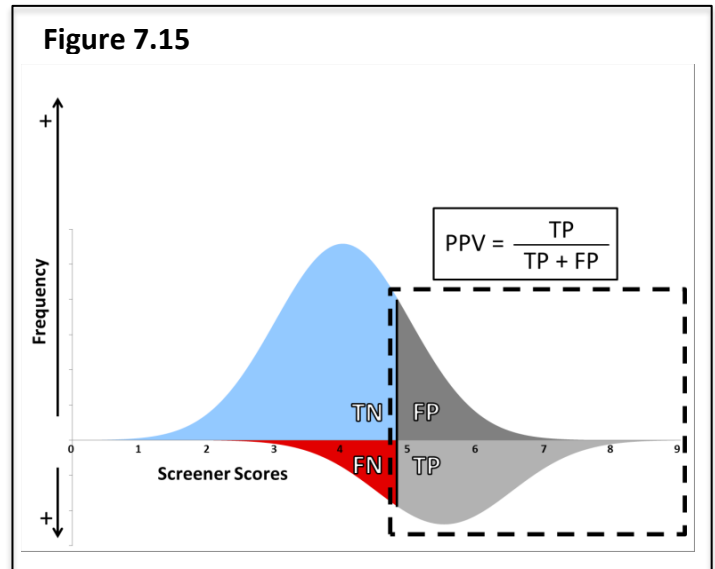


<sup>v</sup> As in the scenario on screening thresholds, please see appendix i on “Mathematical Calculations from Chapter 8” for those interested in understanding how this value (and all other statistical numbers hereafter) was calculated.

*Prevalence = 30%*

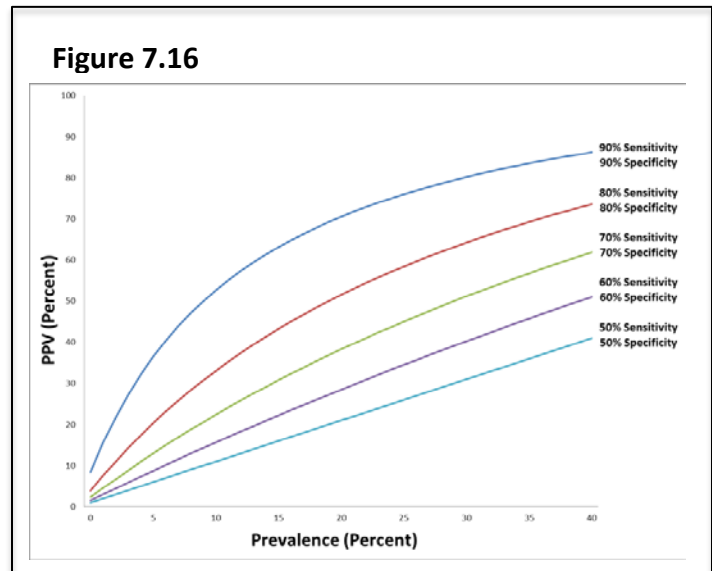
In this picture, 30% of children are affected by developmental-behavioral problems. You can see in Figure 7.15 that the bell curve on top is smaller and that the one on the bottom is bigger.

Look at the proportion of children who score positive who are correctly classified (the segment of the curve labeled TP). More than half are true positives! **PPV has increased and is now 59%.**



### Uncertainty based on accuracy of a screening test:

If we know sensitivity, specificity, and prevalence, then we can calculate PPV. That's what we did in Figure 7.16. Figure 7.16 shows the PPV for five hypothetical screeners with different sensitivities and specificities (each depicted by a different line), where the prevalence of the affected population ranges from 1% to 40% (as shown on the horizontal axis).



Note that:

- The higher the prevalence, the higher the PPV (i.e., lines get higher from left to right).
- The more accurate the screener (i.e., if sensitivity and specificity are higher), the higher the PPV.
- Using a typical screener (with 70% sensitivity and 70% specificity) and a plausible prevalence (15%), PPV is well below 50%. This is a surprising and unwelcome phenomenon for a clinician using any screening test. We would like to assume that a positive result means that the child has the condition for which we are screening – but in fact it is more likely that a child with a positive result is a false positive. For this reason any screening test result must be followed by further evaluation: observation of the child, discussion with the parent and perhaps another adult who knows the child, and/or further screening by the clinician.
- Using a screening test with a given level of accuracy (sensitivity and specificity), the chance that a positive screening result is correct (i.e., PPV) depends on the proportion of children being screened who have the problem for which you are screening. If a lot of them have such problems, PPV will be higher; if not, PPV will be lower.
- Clinicians will seldom (if ever) know the prevalence of the condition for which they are screening, in the population they are screening; therefore they cannot know the PPV of a screener with great accuracy.

**Clinical dilemma:**

1) It is natural for clinicians to want higher PPV. After all, the higher the PPV, the more you can trust positive screening results! When you are talking with a parent whose child has screened positive on a screening test, you naturally want to be as definitive as possible about whether the child truly has a problem that needs follow-up evaluation and/or treatment.

What should you do if you are using a screener with a threshold that is too low, that is, one that yields too many false positives? As a clinician, one option is that you can always raise the PPV by treating scores that are positive but close to the threshold as if they were negative. If you do so, you are effectively raising the threshold. Consider our discussion above – what is the effect of raising a threshold?

- Raising a threshold increases PPV (as intended), but it also lowers sensitivity, meaning that you will miss a higher proportion of children who truly have a problem.

2) It is sometimes suggested that all children with a positive screening test result should be referred – to Early Intervention, to a mental health clinician, or for in-depth testing. We suggest that because the PPV is almost always lower than any clinician would prefer, there are some steps that should be taken in between screening and referral. The opinions and concerns of the child's parent(s), observations of other people who know the child (e.g. another parent, a grandparent, a child care provider or teacher), and the clinical judgment of the pediatrician should all be taken into account in decision-making with regard to a positive screening test.

The appropriate next step in the face of a positive screening test result is not referral, but further conversation, observation, and sometimes administration of a different screening test.

# **Chapter 9**

## **Revisions and Licensed Works**

**A) Revisions**

Page [125](#)

**B) Licensed Works**

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## **A) Revisions**

When revisions are made to the *SWYC* forms, the forms are marked with a new version number and date and the change made is added to the revision history available on our website, [www.theSWYC.org](http://www.theSWYC.org). Please periodically check in with our website to make sure you are using the most up-to-date version of the forms.

We ask that all users of the *SWYC* include the full version number on all forms. This will allow users to know whether their version of the *SWYC* requires updating.

## **B) Licensed Works**

The following comprise LICENSED WORKS:

Survey of Well-being of Young Children (SWYC) and its component questionnaires (comprising Survey of Well-being of Young Children Milestones, Baby Pediatric Symptoms Checklist, Preschool Pediatric Symptom Checklist, the Parent Observation of Social Interaction questionnaire and the Survey of Well-being of Young Children Family Questions with the exclusion of the questions stated below.

List of questions in the Survey of Well-being of Young Children Family Questions not created by Tufts Medical Center:

1. In the last year, have you ever drunk alcohol or used drugs more often than you meant to?
2. Have you felt you wanted to or needed to cut down on your drinking or drug use in the past year?
3. In the past month was there any day when you or anyone in your family went hungry because you did not have enough money for food?
4. Over the past two weeks, how often have you been bothered by any of the following problems?
  - a. having little interest or pleasure in doing things?
  - b. Feeling down, depressed, or hopeless?
5. In general how would you describe your relationship with your spouse/partner?
6. Do you and your partner work out arguments with....no difficulty/some difficulty/great difficulty/NA
7. Do you have any concerns about your child's learning or development?
8. Do you have any concerns about your child's behavior?

# Appendices

<b><u>i) Mathematical Calculations from Chapter 8</u></b>	Page <a href="#">129</a>
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### **i) Mathematical Calculations from Chapter 8**

Here we provide examples for readers interested in how to calculate sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV), as discussed in chapter 8 on “Decision Thresholds: A Deeper Look.” We use 2 x 2 tables to guide the calculations, and provide multiple examples to showcase how prevalence (of the condition) affects the values of these statistics.

**Example 1 – Prevalence 20%:**

Let’s imagine that there are 10,000 individuals in the total population and the prevalence of the condition for which a child is being screened is 20%. These individuals complete a screening instrument, and the frequencies of individuals for each scoring possibility [i.e., true positive (TP), false positive (FP), false negative (FN), and true negative (TN)] are shown below in Figure A.1. Using the formulas provided, we see that the PPV is 46% and the NPV is 93% (note, all numbers are rounded to the nearest whole).

		Condition (Prevalence 20%)			
		Present	Absent		
Screening Score	Positive	TP 1,547	FP 1,812	TP+FP 3,359	<u>PPV</u> $TP/(TP+FP) = 1,547/3,359 = 46\%$
	Negative	FN 454	TN 6,187	TN+FN 6,641	<u>NPV</u> $TN/(TN+FN) = 6,187/6,641 = 93\%$
		TP+FN 2,001	TN+FP 7,999	Total 10,000	<u>Sensitivity</u> $TP/(TP+FN) = 1,547/2,001 = 77\%$
					<u>Specificity</u> $TN/(TN+FP) = 6,187/7,999 = 77\%$

**Example 2 – Prevalence 10%:**

Now, let’s change the prevalence of the condition to 10%. We will still use the same screening test, so the sensitivity and specificity will remain the same (each are 77%). Looking at Figure A.2, you can see that the PPV is much smaller (i.e., the chances of a person with a positive screening result actually having a diagnosis is smaller). PPV is now 27%. Furthermore, you can

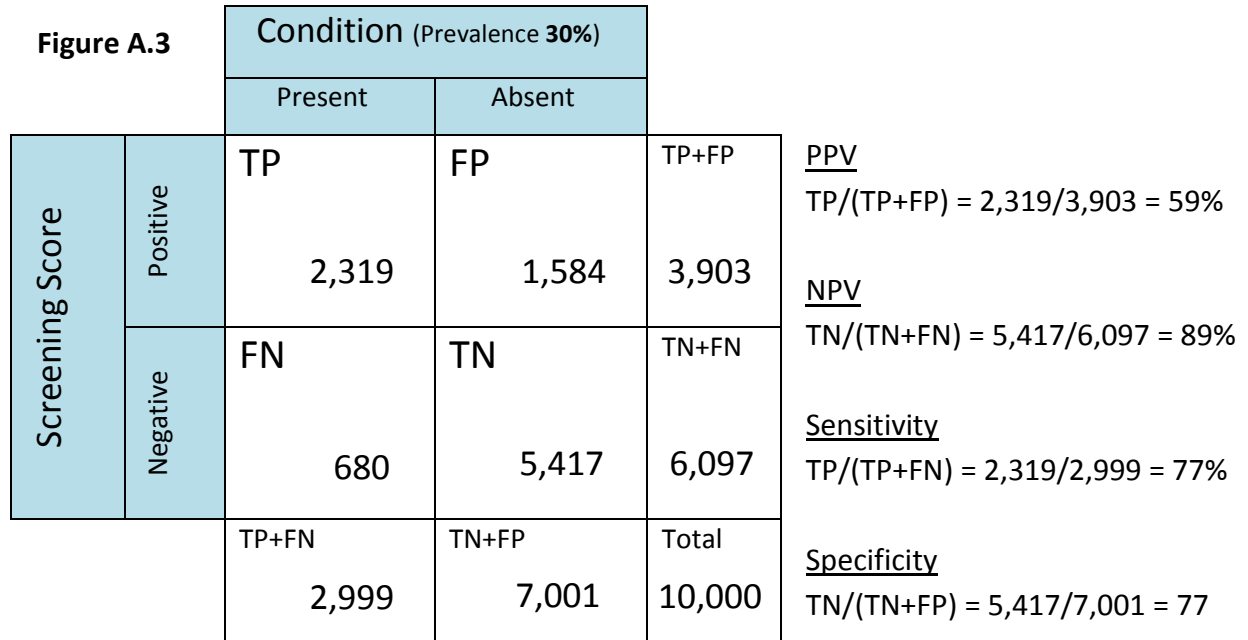
see that the NPV is larger (i.e., the chances of a person with a negative screening result not actually having a diagnosis is larger). NPV is now 97%.

**Figure A.2**

		Condition (Prevalence 10%)			
		Present	Absent		
Screening Score	Positive	TP 773	FP 2,038	TP+FP 2,811	<u>PPV</u> $TP/(TP+FP) = 773/2,811 = 27\%$
	Negative	FN 228	TN 6,961	TN+FN 7,189	<u>NPV</u> $TN/(TN+FN) = 6,961/7,189 = 97\%$
		TP+FN 1,001	TN+FP 8,999	Total 10,000	<u>Sensitivity</u> $TP/(TP+FN) = 773/1,001 = 77\%$
					<u>Specificity</u> $TN/(TN+FP) = 6,961/8,999 = 77\%$

**Example 3 – Prevalence 30%:**

Finally, let's change the prevalence of the condition once more, now up to 30%. Again, the screening instrument is the same, so sensitivity and specificity are still both 77%. Looking at Figure A.3, you can see that PPV is now much bigger (i.e., the chances of a person with a positive screening result actually having a diagnosis is larger). PPV is now 59%. NPV is now smaller (i.e., the chances of a person with a negative screening result not actually having a diagnosis is smaller). NPV is now 89%.



## **ii) Frequently Asked Questions (FAQs)**

### **1. *Where do I buy the SWYC?***

No purchase is required. All of the age-specific *SWYC* forms are freely available on our website: [www.theSWYC.org](http://www.theSWYC.org). You can find them by clicking on "Age-Specific Forms" in the navigation bar.

### **2. *Who should be asked to complete the SWYC?***

The *SWYC* can be completed by any caregiver, including parents and grandparents, who have enough knowledge about the child to be able to answer the *SWYC* questions reliably.

### **3. *What makes someone qualified to interpret the SWYC?***

By "qualified," we mean someone who:

- has the skills and experience to understand what a positive screen does and does not mean
- possesses the ability to explain results to parents in a way that enhances trust and benefits the child
- maintains patient confidentiality

Whether or not someone is qualified is not necessarily based on specific degrees or training. Ultimately, the criteria that determine whether or not someone is qualified to interpret *SWYC* scores are up to your team.



#### 4. **How do I know which age-specific SWYC form to use?**

There are two ways to pick the right age-specific SWYC form to use.

- a. Calculate the child's age by hand (see page 29). Then, use the chart below to select the appropriate form or consult the age ranges listed on the forms themselves.

Form	Minimum Age	Maximum Age
2	1 month, 0 days	3 months, 31 days
4	4 months, 0 days	5 months, 31 days
6	6 months, 0 days	8 months, 31 days
9	9 months, 0 days	11 months, 31 days
12	12 months, 0 days	14 months, 31 days
15	15 months, 0 days	17 months, 31 days
18	18 months, 0 days	22 months, 31 days
24	23 months, 0 days	28 months, 31 days
30	29 months, 0 days	34 months, 31 days
36	35 months, 0 days	46 months, 31 days
48	47 months, 0 days	58 months, 31 days
60	59 months, 0 days	65 months, 31 days

- b. Use the Excel-based Form Selector and *Milestones* calculator that is available for download on our website, [www.theSWYC.org](http://www.theSWYC.org). You just need to enter the date of administration and the child's birthday, and the calculator will tell you which form to use.

#### 5. **Can I use only the behavioral/emotional screener, or only the SWYC Milestones, or do all 4 components of the SWYC have to be used together?**

The SWYC is designed to be a comprehensive, first-level screening instrument for routine use in regular well-child care. It combines what is traditionally "developmental" with traditionally "behavioral" screening, and adds screening for autism and for parental depression and other family risk factors. As such, it is designed to be used as a single package, and to be used regularly over the course of health supervision. However, it is also acceptable to use individual parts of the SWYC separately to meet particular needs.

#### 6. **When do I need to adjust a child's age for prematurity?**

You only need to adjust for prematurity if the child is under 24 months and was born at least 3 weeks prematurely.

**7. Do I really have to do mathematical calculations by hand just to pick out the right SWYC form?**

It's important to calculate a child's age exactly so that you pick the correct form. Otherwise, the child's scoring won't work correctly and the results will be impossible to interpret. But the good news is that you don't need to do all of the math we described on page 29!

Use our downloadable age calculator to work out the child's age quickly and easily. We have an Excel sheet on our website, [www.theSWYC.org](http://www.theSWYC.org), that calculates the child's age and tells you what SWYC form to use. All you have to do is type in the date, the child's birthday, and (if relevant) the number of weeks the child was premature.

**8. Why is the POSI only on the 18-, 24-, and 30-month forms despite having evidence for its validity across a broader range?**

Validity studies of the *POSI* have been performed on samples of children from 16-36 months. These age ranges do not correspond perfectly with the *SWYC* forms (see the table to the left). Thus, although the *POSI* would be valid for some children who fall into the age range of the 15- and 36-month forms, these forms also include children who are too young or too old for the *POSI*. Therefore, the *POSI* is included only on the 18-, 24-, and 30-month *SWYC* forms, where there is evidence for its validity across the entire age range. However, you can use the *POSI* as a stand-alone tool for the entire range for which there is evidence of its validation: 16 to 36 months. On the other hand, if you are using the *POSI* as part of the age-specific *SWYC* forms, you will be administering it only to children 18 to 35 months.

Child Age	SWYC Form	POSI Validity Range
15 mo	15 month	<i>Parent's Observations of Social Interactions (POSI)</i>
16 mo		
17 mo		
18 mo	18 month (includes <i>POSI</i> )	
19 mo		
20 mo		
21 mo		
22 mo		
23 mo		
24 mo	24 month (includes <i>POSI</i> )	
25 mo		
26 mo		
27 mo		
28 mo		
29 mo		
30 mo	30 month (includes <i>POSI</i> )	
31 mo		
32 mo		
33 mo		
34 mo		
35 mo		
36 mo	36 month	
37 mo		
38 mo		
39 mo		
40 mo		
41 mo		
42 mo		
43 mo		
44 mo		
45 mo		
46 mo		

**9. *When I hand parents the SWYC, I tell them that their child's doctor has asked that they complete the form. Sometimes parents then ask for more information about why they need to do so. What should I say?***

We would suggest saying something like: "This questionnaire is a tool that helps your child's pediatrician monitor (child's name)'s development and behavior. Don't worry if he or she is not doing all of the things this questionnaire asks about –most children can't do every skill described. The questions are just a way for your doctor to get a sense of what things you should talk about in more detail."

If the parent would like more information about what you will do with the information, we would suggest saying something like: "Your answers to this questionnaire are confidential- the only people who will see your responses are your doctor and [staff who see results at your practice]. The questionnaire will also become part of your child's medical record."

**10. *How long does it take to complete the SWYC?***

Different parents require different amounts of time to complete the SWYC. Most take under 10 minutes.

**11. *How many questions are on a SWYC form?***

Parents are asked to complete a two-page, age-specific form. Depending on the child's age, the form includes either three or four components: (1) cognitive, language, and motor development; (2) behavioral/emotional development; (3) family risk factors, including parental depression, discord, substance abuse, and hunger; and, for children between 15 months and 36 months, (4) ASD. The length of the SWYC forms varies slightly by age, but there are roughly 40 questions on each age-specific form.

**12. *Why is a "high score" positive on some SWYC components but a "low score" is positive on others?***

The SWYC *Milestones* measure developmental achievements. The more achievements that are reported the better. As such, a high score on the SWYC *Milestones* is good, and therefore not indicative of risk. All other SWYC components measure negative attributes (i.e., symptoms). As such, a high score on these components would mean more symptoms, which would indicate risk.

**13. Is there an alternative to hand-scoring the forms?**

Yes, there is! When the SWYC is administered electronically, the scoring is done automatically. The SWYC may eventually become available as a standard offering from electronic medical record (EMR) providers.

There is also an Excel-based calculator available on our website that takes a lot of the work out of the SWYC Milestones scoring. You just enter the child's raw SWYC Milestones score, and it tells you whether that score indicates a need for review or appears to meet age expectations. Download the calculator at [www.theSWYC.org](http://www.theSWYC.org).

**14. I just reviewed the Milestones forms for two of my patients. One child is 6 months old and the other is 7 months old. Both of their parents completed the 6 Month SWYC form. Both children got a SWYC Milestones score of 12, but when I checked my scoring chart I saw that the younger child's score fell in the "Appears to Meet Age Expectations" range, while the older child's score fell in the "Needs Review" range. Since they have the same score on the same age-specific SWYC form, I don't understand why this is.**

Each SWYC form covers an age range. The 6 month form is for children who are 6, 7, and 8 months old. Children who are at the younger end of the age range for a particular form will tend to score lower than children that are older in the same age range. The scoring algorithm adjusts for this tendency. So despite the fact that the 6-month SWYC Milestones was completed for both of your patients, a score of 12 for a 6 month old child falls under the "Appears to Meet Age Expectations" range, whereas a score of 12 for a 7 month old child falls under the "Needs Review" range.

**15. It seems like the SWYC detects a lot of false positives. Why can't it just tell me which children have a real problem and which children don't?**

A screening instrument can't give a diagnosis – it can only indicate risk. So, when we were creating the SWYC, we had to decide how to set our scoring thresholds. If we made it relatively hard to score positive, that would mean that the only children who score positive would have very concerning scores and almost certainly have a real problem. However, it would also mean that the SWYC would miss lots of children with less extreme scores who also really did have a problem that needed addressing.

If we made it relatively easy to score positive, the *SWYC* would probably not miss many children with real issues. However, this would also mean that it would detect more false positives – children who score positive, but are really doing fine.

As a first-level screener, we decided to prioritize missing as few children as possible with real cause for concern. This does mean that the *SWYC* will pick up some false positives, but it also means that children with real issues are less likely to be missed. For more extensive discussion of these issues, see chapter 8.

**16. How do I use the *SWYC* longitudinally?**

Keep a *SWYC* Longitudinal scoring chart (see section 2D on “Scoring” or the “Choose a Form and Score the *SWYC*” tab on [www.theSWYC.org](http://www.theSWYC.org)) in a patient’s file. At each visit, circle your patient’s score on the same chart as used in previous visits. This will allow you to track your patient’s development over time.

**17. What should we do when a child screens positive on the *SWYC*? We can’t possibly refer every child.**

When a child screens positive on the *SWYC*, this indicates that a conversation with the parent is needed. Often, a conversation is all the intervention that is required. A positive score on the *SWYC* indicates concern, not diagnosis. Some children who screen positive on the *SWYC* will, upon further conversation with the parent, actually turn out to be doing just fine. Some will be struggling with behaviors or skills that the parent could use some guidance on managing. For others, you may want to wait and see if particular behaviors have improved by their next visit. Children who score positive on the *SWYC* will sometimes require a referral, but not most. You should use your clinical judgment to determine when this is the best next step.

**18. Is the *SWYC* protected by copyright?**

Yes. Although the *SWYC* is freely available, it cannot be modified without expressed permission of the authors. If you are interested in translating the *SWYC* into a new language or administering it in a way for which the downloadable forms are not appropriate, please contact Kate Mattern at: [theswyc@gmail.com](mailto:theswyc@gmail.com).

**19. What is cognitive interviewing?**

Cognitive interviewing is a form of qualitative research by which a professional interviews participants who have been administered a new translation of an instrument for the purposes of understanding how questions and response options are perceived and understood.

**20. How can I access translated versions of the SWYC?**

Thanks to teams who have generously shared their translation work with us, you can download several translations for free from our website, [www.theSWYC.org](http://www.theSWYC.org).

**21. The last couple questions on each age-specific form's SWYC Milestones questions seem advanced. Most children won't be able to do those skills yet. Why are the SWYC Milestones written like that?**

There are 10 *SWYC Milestones* items on each age-specific SWYC form. The first few items on each form are "easier" skills that most children will be doing. As the list goes on, the skills become more challenging. Most children will not be able to do all ten skills listed at any particular age.

We designed the forms in this way to provide continuity between the age-specific forms (so that the "harder" items at 12 months, for instance, become the "easier" items at 15 months) and to provide parents with some idea of what skills they may see their children doing next.

**22. If an instrument's specificity and sensitivity are over 70%, does that mean it's good for my practice?**

Maybe yes, maybe no. There are at least two things to understand about sensitivity and specificity:

- 1. Sensitivity and specificity are not inherent traits of a screening instrument.** Instead, a screener displays a certain level of sensitivity and specificity in a *particular* study with respect to a *particular* outcome, in a *particular* sample population, and using a *specific* study design. If you are using screening instrument in a different setting, with a different population, or in a different way than the study from the measure's validity studies, your sensitivity and specificity will be different as well.

2. **Sensitivity and specificity are just a start—you should also consider whether a screener adds unique information that improves detection in the overall system.** It is worthwhile to ask, “Does this screening test offer new information at the point in the care process when it is used?”

### **23. How can I access journal articles about the SWYC?**

Check out our website, [www.theSWYC.org](http://www.theSWYC.org). Under the “More” tab on the navigation bar, click on “Publications, Invited Talks, and Presentations.” There, you will find instructions on how to download free PDFs of the articles.

### **24. Is the SWYC validated?**

This is a complex question for any screening instrument, and there is seldom (if ever) a simple “yes” or “no” answer. The question is whether one can have confidence that a screening instrument is accurate enough for its intended use. High-quality, up-to-date research, ideally published in peer-reviewed journals, should increase one’s confidence. We also look for independent replication and direct comparisons to existing screening instruments. If a screener has been changed in any way, whether translated into a new language or used in a new setting or with a new population, we look for research demonstrating its accuracy despite the changes.

Research on the SWYC is described in this manual and our publications. As of 2013, three of the SWYC’s four components have been compared statistically to a well-respected screening instrument (*ASQ-3* and *ASQ-SE*), and to parents’ reports of developmental-behavioral diagnoses. One has also been compared to the *CBCL*, a frequently used parent report of symptoms of behavioral/emotional disorders. The items that comprise the fourth component of the SWYC, called *Family Questions*, were assembled from previously-validated tests and have not been evaluated in their current form. Detailed descriptions of the methods of study and the statistical techniques used to validate the SWYC are described in our manuscripts. Ongoing research conducted by us and by independent investigators will compare the SWYC to “gold standard” clinical assessments (see section 5B on “Ongoing Research”)

**25. I think too many children score positive on screening instruments, so I only really trust positive results that are several points above the stated threshold. What is the effect of that decision?**

The effect is the same as if you had raised the threshold. Positive results will be more likely to be correct (higher PPV ☺), but you will miss more children who might benefit from treatment (lower sensitivity ☹). Be aware of the tradeoff in this approach.

**26. There are lots of screening instruments; what is unique about the Survey of Well-being of Young Children (SWYC)?**

The SWYC was created in order to provide a screening instrument that includes questions addressing a broad array of areas of development in preschool children. It was also designed to be free of cost and easily accessed by parents, pediatric primary care providers (PPCPs), home visit providers, preschool teachers, nurses, and other professionals involved in child care and early education. It includes items that assess cognitive, language, motor, and social-emotional development, as well as family risk factors (e.g., parental depression, conflict, substance abuse, and hunger) and behaviors suggestive of autism spectrum disorder (ASD). It is short and easy to score. It is amenable to electronic administration.



### **iii) Glossary**

**Attention Deficit Hyperactivity Disorder (ADHD):** A developmental disorder characterized by inattention and distractibility and/or hyperactivity and impulsivity.

**Autism Spectrum Disorder (ASD):** A continuum of developmental disorders characterized by impairments in communication/social interaction and stereotyped/repetitive patterns of behavior or interests.

**Back-Translation:** Translating an instrument back into its original language from another language (without referencing the original translation).

**Cognitive Interviewing:** In the translation process, cognitive interviewing refers to a form of qualitative research by which a professional individually interviews participants who have been administered a new translation of an instrument for the purposes of gaining feedback.

**Concurrent Validity:** A subtype of criterion validity that is demonstrated when a test correlates well with a measure that has been previously validated.

**Differential Item Functioning (DIF):** DIF is an indicator in latent variable modeling (see below) used to detect when individuals responses vary despite having the same score on a particular item (e.g., if children from two countries display the same level of gross motor skills, but parents from one country are more likely to report “kicks a ball” than parents from another country, then the question about kicking a ball is said to display DIF).

**Expert Panel:** In the translation process, an expert panel is group of experts convened to provide qualitative feedback about a new translation.

**Factor Analysis:** Factor analysis is a process in which the values of observed data are expressed as functions of a number of possible causes or “latent factors” in order to determine which are the most important. For example, factor analysis was used to determine that the questions in the *BPSC* were best explained by three underlying factors. If investigators have no prior hypotheses about underlying factors (as is typical at the beginning of instrument development), exploratory factor analysis (EFA) is appropriate. Thereafter, confirmatory factor analysis (CFA) can be used to determine how well previous factor structures are replicated in new sets of data.

**First Level Screening Instruments:** First level screening instruments such as the *SWYC* are designed to be the initial step in detecting issues. As a first-level instrument, the *SWYC* is intended to be administered to all children, not just a subset for which there is particular concern. First-level instruments generally favor sensitivity over specificity (meaning that it is

relatively easy to screen positive). While this decision increases the number of false positives, it also minimizes the number of children with real issues (true positives) who are missed.

**Focus Group:** In the translation process, a focus group refers to a form of qualitative research in which a group of people is asked about their perceptions, opinions, and attitudes towards a newly translated instrument.

**Forward Translation:** Translating an instrument from its original language into another (emphasizing conceptual translations over literal).

**Gold Standard:** Also known as “criterion standard”, is the highest validated measure in a given sector that serves as a benchmark to diagnostically compare other less validated measures.

**Latent Variable Model:** A latent variable is one that is not observed directly, but can be inferred from specific observations. For example, intelligence is a latent variable that can be inferred from the responses to IQ tests. Latent variable models refer to a host of methods for analyzing latent variables, including factor analysis, latent class analysis, and item response models.

**Item Response Theory (IRT):** In classical test theory, a test is first scored and then the reliability and validity of that score are investigated. In IRT, the relationship of individual questions (or items) to a latent variable are investigated to create a measurement model. IRT allows for unique combinations of questions to measure a concept, making adaptive computer testing, which is now used for many standardized tests, possible. For further information, see the sidebar in section 5A on “History of the Development of the SWYC” on page 75.

**Medical Home:** A model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective to all patients. Furthermore, a medical home is a family-centered partnership within a community-based system that provides uninterrupted, integrated, and interdisciplinary care with appropriate payment to support and sustain optimal health outcomes.

**Negative Predictive Value (NPV):** Statistically measures the proportion of negative results that are true negatives.

**Pediatric Periodicity Schedule:** Refers to the schedule of screening and assessments recommended by the American Academy of Pediatrics at each well-child visit from infancy through adolescence. Please see appendix ii on “Frequently Asked Questions (FAQs)” for a chart listing the specific intervals on the pediatric periodicity schedule (this chart is also located in the “SWYC FAQs” link on our website: [www.theSWYC.org](http://www.theSWYC.org)).

**Pediatric Primary Care Provider (PPCP):** Throughout this manual and the rest of the SWYC system, the umbrella term “PPCP” refers to any and all types of child care professionals,

including, but not limited to: pediatricians, family physicians, nurse practitioners, and physicians' assistants.

Pediatric Symptom Checklist (PSC): A brief screening questionnaire that is used by pediatricians and other healthcare professionals to improve the recognition and treatment of psychosocial problems in children.

Patient Health Questionnaire 9 (PHQ-9): A multipurpose instrument for screening, diagnosing, monitoring, and measuring the severity of depression.

Positive Predictive Value (PPV): Statistically measures the proportion of positive results that are true positives.

Predictive Value: A subtype of criterion validity that assesses the extent to which a score on an instrument predicts scores on some criterion measure (e.g., how accurately positive scores on the SWYC predict disorders as measured by diagnostic second-level instruments).

Reliability: In psychometrics, reliability refers to the overall consistency of a measure (i.e., producing similar results under consistent conditions).

Receiver Operating Characteristic (ROC) Curve: The receiver operating characteristic (ROC) curve is aptly named because it is a comparison of two operating characteristics, true positive rate (TPR) and false positive rate (FPR), at various threshold settings. TPR is synonymous with sensitivity (see below) whereas FPR, or "fall-out," is equal to  $1 - \text{specificity}$  (see below). ROC analyses provide cost/benefit information for diagnostic decision making. As such, ROC curves can help determine optimal thresholds.

Sensitivity: Statistically measures the proportion of actual positives that are correctly identified as such (i.e., the percentage of affected individuals who are correctly identified as having the condition). In combination with a psychometric instrument's specificity, an instrument's sensitivity is an indication of its statistical (diagnostic) power.

Specificity: Statistically measures the proportion of actual negatives that are correctly identified as such (i.e., the percentage of healthy individuals who are correctly identified as being healthy). In combination with a psychometric instrument's sensitivity, an instrument's specificity is an indication of its statistical (diagnostic) power.

Standard Deviation: A statistical measure that is used to quantify the amount of variation or dispersion of a set of data values. For a dataset that is normally distributed, approximately 68% of the data falls between one standard deviation of the mean, 95% falls between two standard deviations of the mean, and 99% falls between three standard deviations of the mean.

**Standardization:** Standardization, also known as normalization, is the process of adjusting raw data measured on different scales to a notionally common (standard) scale. Hence, this process allows for accurate comparison of data between previously disparate scales.

**Threshold:** A threshold, also known as a “cut score”, is a value that is chosen to distinguish a range of values from one another. Specifically, on a screener, individuals who score above the threshold are denoted as positive whereas those who score below are denoted as negative.

**Toxic Stress:** Toxic family stress refers to frequent, sustained, and uncontrollable stress without protective influences.

**True Positive:** Correctly detecting an effect when one is truly present (i.e., a child was identified as being at risk for autism spectrum disorder when they truly do have the condition).

**True Negative:** Correctly detecting no effect when there isn't one truly present (i.e., a child was not identified as being at risk for autism spectrum disorder when they truly don't have the condition).

**False Positive:** Detecting an effect when one is not truly present, also known as a “type 1 error” (e.g., a child was mistakenly identified as being at risk on a screener for autism spectrum disorder, when in reality they did not have the condition).

**False Negative:** Failing to detect an effect when one is truly present, also known as a “type 2 error” (e.g., a child was mistakenly not identified as being at risk on a screener for autism spectrum disorder, when in reality they had the condition).

**Validity:** In psychometrics, validity refers to the accuracy of a measure (i.e., the degree to which an instrument measures what it claims to measure).

**Well-Child Visit:** A preventative care visit to a pediatrician in order to check a child's development and well-being, including a full physical examination and possible immunizations.

## **iv) About the Authors**

**Ellen C. Perrin, MD**, Professor, Division of Developmental-Behavioral Pediatrics, Floating Hospital for Children, Tufts University School of Medicine, Boston, MA.

Dr. Perrin's career has blended her background and interest in developmental psychology with her passion to improve the lives of children and their parents. As President of the Society for Developmental-Behavioral Pediatrics, she was instrumental in gaining formal subspecialty status for Developmental-Behavioral Pediatrics through the American Board of Medical Specialties and was the first Chair of the American Board of Pediatrics' sub-board on Developmental-Behavioral Pediatrics. She is committed to helping primary care pediatricians to address children's optimal development and behavior most effectively. In her clinical work and research, she has worked with pediatricians in the care of children with chronic physical health conditions and a wide range of developmental-behavioral difficulties. In addition, she has been committed to advocacy for teens and parents who are gay or lesbian, and gender nonconforming young children. Recognizing the importance of early identification and intervention in developmental-behavioral problems and a need for a different kind of screening strategy, she worked with Dr. Chris Sheldrick (see below) to develop the *Survey of Well-being of Young Children (SWYC)*.

**Chris Sheldrick, PhD**, Associate Professor, Division of Developmental-Behavioral Pediatrics, Floating Hospital for Children, Tufts University School of Medicine, Boston, MA.

Dr. Sheldrick is a research psychologist and an Associate Professor of Pediatrics at the Tufts University School of Medicine. He received his BA from Brown University and his PhD in Clinical Psychology from Temple University, and has received further training through a Career Development Award (KM1) fellowship on comparative effectiveness. Dr. Sheldrick's research focuses on the science and practice of screening, spanning from instrument development to implementation and evaluation. Recognizing the importance of early identification and intervention for developmental-behavioral problems and a need for a different kind of screening strategy, he worked with Dr. Ellen Perrin (see above) to develop the *SWYC*.

**Zach Visco, BA**, Clinical Research Coordinator in Department of Psychiatry and Research Assistant in the Division of Developmental-Behavioral Pediatrics, Floating Hospital for Children, Tufts Medical Center, Boston, MA

Beyond his work on the *SWYC: User's Manual*, Mr. Visco participates in the research endeavors of the Autism Behavioral Consultation Program, an interdisciplinary clinic that provides comprehensive therapeutic and consultative services to families of children with autism spectrum disorder (ASD), at Tufts Medical Center. Mr. Visco is also a research assistant for the

NICHHD-funded Screen Early, Screen Accurately for child Well-being (SESAW) study. Previously, Mr. Visco worked as a Mental Health Specialist at McLean Hospital, providing counseling to inpatients with a variety of psychiatric disorders, and as a pediatric neuropsychology intern at Tufts Medical Center's Floating Hospital for Children.

**Kathryn Mattern, BA**, SWYC Coordinator, Division of Developmental-Behavioral Pediatrics, Floating Hospital for Children, Boston, MA

Ms. Mattern has worked with the Division of Developmental-Behavioral Pediatrics at the Floating Hospital for Children since 2010 and was involved with data collection for the SWYC validation studies. She served as the project coordinator for the SESA W study from 2013-2015 before beginning full-time work with the SWYC. Ms. Mattern is responsible for creating/maintaining the SWYC website: [www.theSWYC.org](http://www.theSWYC.org). She also created the illustrations in this manual.

## **v) Acknowledgments**

The Survey of Well-being of Children (SWYC) owes its inception and development to a great many thoughtful colleagues and friends who have all contributed generously to the thought and work that went into its creation. In particular, we have relied on many friends and advisers – from our initial conceptualization of its goals and principles to its dissemination and current use. We are also grateful for the financial support from the Commonwealth Fund, the J. F. Maddox Foundation, the Children's Services Council of Palm Beach County, and the JPB Foundation. Unfortunately, we cannot possibly list everyone who has contributed by name, but we hope you will see in the product some evidence of your time, care, and effort.

Some people and institutions deserve specific recognition here, because they have been so central to the creation and development of the SWYC. Ed Schor, MD, at the time the Vice President at the Commonwealth Fund and now the Senior Vice President for Programs and Partnerships at the Lucile Packard Foundation for Children's Health, was immediately receptive to our original idea of creating a freely available screening tool for pediatrics. He provided encouragement, funding, and a wealth of ideas to initiate the process and has continued to advise us wisely as we encounter new dilemmas and challenges.

We are grateful to Brandi Henson, PsyD, a dedicated and committed colleague who participated actively in the early discussions and efforts that led to the development of the SWYC. In particular, she contributed her deep understanding of infant and preschool development and her sensitivity to parents' concerns to the conceptualization of the SWYC and the writing of items.

Michael Jellinek, MD, Professor of Psychiatry and Pediatrics at Harvard Medical School, and Michael Murphy, EdD, Associate Professor of Psychology at Harvard Medical School and the Department of Psychiatry at Massachusetts General Hospital, were enthusiastic about the opportunity to use their experience in developing and testing the Pediatric Symptom Checklist (PSC) to help us create symptom checklists to identify risk for mental health difficulties among younger children.<sup>27-29</sup> The behavioral/emotional components of the SWYC are modeled and named after the PSC.

Camille Smith, EdS, MS, CPD, Behavioral Scientist for the National Center on Birth Defects and Developmental Disabilities at the Centers for Disease and Control and Prevention, Katherine Beckmann, PhD, MPH, Senior Policy Advisor for Early Childhood Health and Development at the Administration for Children and Families, United States Department of Health and Human Services, and Amy Fine, MPH, a Senior Policy Fellow at the Center for the Study of Social Policy were enthusiastic from early in the development of the SWYC about the possibilities inherent in it. They gave us many excellent ideas and the courage to make it a reality.

We thank Erin Gallagher, BA, Michelle Gross, PhD, and Lisa Williams-Taylor, PhD of the Children's Services Council of Palm Beach County, Florida for their advice. We are particularly grateful for the ongoing support of Tana Ebbole, MA, with whom we originally connected through her leadership of the Children's Services Council of Palm Beach County, Florida, and who continues to provide us valuable counsel in her new role at the JPB Foundation. She is masterful in perceiving the needs of children and implementing creative ways to move towards meeting those needs.

We appreciate the many other colleagues who advised and encouraged us as we conceived and created the *SWYC*. We can never list all of them here, and we apologize for any inadvertent omissions. They include Ben Siegel, MD, Michael Yogman, MD, John Straus, MD, David Keller, MD, Pamela High, MD, Paul Dworkin, MD and Robert Sege, MD. Their enthusiasm and wise advice have provided courage and direction.

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Some "early adopters" of the *SWYC* in pediatric practices across the US have contributed invaluable feedback about the strengths and challenges that they have encountered in using the *SWYC*. We are very grateful to the following practice leaders and their teams: Anne Stephen, MD, Carol Gibson-Miller, B.A.S, Stephanie Carlin, DO, Ailis Clyne, MD, Michael Tang, MD, Steven Boos, MD, Natalie Golova, MD, and Lucy Garbus, PNP. We appreciate the extensive work of Barbara Howard, MD and Ray Sturner, MD, who encouraged us to make the *SWYC* available to participating pediatricians through their innovative CHADIS system. In addition, we greatly value the support and advice of Joseph Hagan, MD, FAAP and Judith Shaw, EdD, MPH, RN, whose dedication and hard work in successive revisions of *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* has provided education and guidance for generations of pediatricians. We thank Vera Frances "Fan" Tait, MD, Associate Executive Director of Community and Specialty Pediatrics at the American Academy of Pediatrics for her encouragement and guidance.

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From the beginning, we have been interested in the use of this instrument among culturally and linguistically diverse populations. Marsha Gerdes, PhD and her colleagues at the Children's Hospital of Philadelphia (CHOP) have been especially instrumental in helping us to create and in validating the Spanish *SWYC* and to develop translations of some *SWYC* forms into Nepali and Burmese. Nancy Rumbaugh Whitesell, PhD, Michelle Sarche, PhD, and Caitlin Trucksess, MPH, at the Centers for American Indian and Alaska Native Health at the University of Colorado School of Public Health, initiated an extensive evaluation of the acceptability of the *SWYC* in diverse American Indian and Alaska Native communities and recommended adaptations to improve its use in those contexts. Claudia Regina Lindgren Alves, MD, PhD and Livia C. Magalhães, PhD, OTR led the translation of the *SWYC* into Portuguese. A. Olupelumi Adebisi, MBChB, MPH, FMCPH translated the *SWYC* into Yoruba. Drs. Lindgren-Alves, Magalhães and Adebisi are making use of the *SWYC* to document the benefits of innovations in early childhood programs in Brazil and Nigeria.

Throughout the *SWYC*'s development, we have been fortunate to work with devoted research staff who have dedicated their time, effort, and creativity to everything from the collection of data, to the design of *SWYC* materials, and to our understanding of how to explain the *SWYC* to participants and patients. We would particularly like to thank Emily Neger and Shela Merchant, who were instrumental in the original development of the *SWYC*.

We appreciate the many committed clinicians, researchers, and policy-makers from around the world who are working hard to translate, implement, and/or improve the *SWYC*. Moreover, we acknowledge the considerable challenge for clinicians of identifying and treating children with developmental-behavioral problems. The *SWYC* screening forms are available without cost, but the process of evaluating children and ensuring that they receive appropriate services is far from free. We appreciate your work and hope that this manual helps you help the children for whom you provide support and care.

Lastly, we are extremely appreciative to all those who reviewed drafts of this manual and provided invaluable feedback. This first edition of the *SWYC* manual is much improved as a result of the suggestions we received from many colleagues. We take full responsibility for whatever shortcomings it still has, and are eager to hear feedback from users so we can make the second edition even better.

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