

## ABSTRACT

Durling, Jesslyn M. A Quasi-Experimental Evaluation of the SPIRIT Toolkit for Facilitating Autism Diagnostic Feedback with Caregivers. (Under the direction of Dr. John C. Begeny).

Providing information to clients (e.g., adults, parents, caregivers) is common practice used in various fields to communicate the results of assessments, deliver diagnoses, and disseminate recommendations for services or additional resources. Providing such information is a complex interpersonal practice between the clinician and client, influenced by emotional and cultural factors that affect a client's engagement, satisfaction, and utilization of recommended services. Although there are some structural, content, and interpersonal level recommendations in the literature for delivering certain types of information to parents or caregivers as clients, there is almost no research evaluating structured information-sharing (i.e., feedback) models. This study evaluated the SPIRIT toolkit, a structured toolkit designed to (a) support clinicians' individualization of autism spectrum disorder (ASD) evaluation feedback to families; and (b) enhance caregivers' follow through on recommended services. Using a within-subject, pre-post group quasi-experimental design, this study evaluated clinicians' fidelity of using the SPIRIT toolkit and evaluated clinicians' social validity of SPIRIT. Findings showed that each clinician used more of the SPIRIT steps and strategies following training and increases between pre- and post-training were statistically significant. Furthermore, clinicians found the toolkit to be socially valid but also provided suggestions for improving the toolkit.

© Copyright 2025 by Jesslyn M. Durling

All Rights Reserved

A Quasi-Experimental Evaluation of the SPIRIT Toolkit for Facilitating Autism Diagnostic  
Feedback with Caregivers

by  
Jesslyn Mariah Durling

A dissertation submitted to the Graduate Faculty of  
North Carolina State University  
in partial fulfillment of the  
requirements for the degree of  
Doctor of Philosophy

Psychology

Raleigh, North Carolina  
2025

APPROVED BY:

---

Dr. John C. Begeny  
Committee Chair

---

Dr. Christina Corsello

---

Dr. Jaime Pearson

---

Dr. Kelly Lynn Mulvey

## DEDICATION

I would like to dedicate this dissertation to my family and friends. As the first in my family to graduate from college—let alone to complete graduate school—each of you has contributed to my success and well-being. I am proud to share this achievement with all of you. To my mom, Kelli—no matter what life throws your way, you have shown incredible strength and taught me how to persevere in the face of challenges. To my dad, Jeremy— thank you for reminding me that even in adulthood, it is ok to have fun, laugh, and play. To my siblings, Karson and Madison—It has been an immense privilege to watch you grow and thrive, even in the face of adversity. You inspire me more than you know. To my grandparents, Bill and Polly—you taught me the value of education and instilled in me a lifelong love of learning. I hope to one day embody a fraction of your leadership and kindness. To my in-laws, Marianne and Mark— thank you for welcoming me into your family with open arms and for going the extra mile to support my research. To my friends—thank you for your comradery and encouragement. You helped me stay connected, hopeful, and human throughout this process. Last, but certainly not least, to my husband, Matthew—thank you for walking beside me from the very beginning of my graduate school journey. You’ve witnessed every high and every low, and in moments where I doubted myself you were my biggest cheerleader. Thank you for reminding me that it’s okay to be fully myself. Your love, patience, and unwavering support have been my anchor. I am endlessly grateful for all of you.

## **BIOGRAPHY**

Jesslyn Durling is a school psychology PhD student at North Carolina State University. She completed her undergraduate training at the University of North Carolina at Chapel Hill where she studied psychology, neuroscience, and education. Before attending graduate school, she worked for the Carolina Institute for Developmental Disabilities at the Autism Research Registry where she connected individuals with a confirmed diagnosis of autism spectrum disorder with research studies. From this experience, she learned more about the inequities individuals with disabilities often face in the U.S. public educational system, which drove her to pursue her PhD in school psychology. Jesslyn is involved in the Educational Research and Partnerships for Academic Success (ERPAS) team, which is a community engaged scholarship team that partners with the community to advance educational equity by improving academic outcomes for children. She is currently completing her APPIC internship at the University of Tennessee Professional Psychology Internship Consortium, and she has accepted a postdoctoral fellowship at the University of North Carolina at Chapel Hill TEACCH Autism Program.

## ACKNOWLEDGMENTS

This dissertation would not have been possible without the support and guidance of several mentors along the way. First and foremost, I would like to express my deepest gratitude to my chair, Dr. John Begeny. Your thoughtful feedback and high standards consistently challenged me to grow as both a scholar and a writer. I am especially thankful to Dr. Christina Corsello—not only for allowing me to work on this project, but also for your invaluable mentorship throughout this process. To the rest of my committee, Dr. Kelly Lynn Mulvey and Dr. Jamie Pearson, thank you for your insightful feedback and expertise. Your contributions greatly enhanced the quality and depth of this work, and I am sincerely grateful for your time and support.

# TABLE OF CONTENTS

LIST OF TABLES .....	vii
LIST OF FIGURES .....	viii
<b>Chapter 1: Introduction</b> .....	1
Role of Emotions in Feedback Satisfaction and Service Initiation.....	1
Cultural Considerations for Feedback .....	3
Research-Based Practices in Delivering Feedback.....	6
Feedback Structure.....	6
Content of the Feedback Session .....	7
Emotionally and Culturally Sensitive Feedback.....	8
Scope of the Study .....	10
Training for Clinicians to Provide Feedback .....	11
The SPIRIT Toolkit .....	12
Study Purpose and Research Questions .....	14
<b>Chapter 2: Method</b> .....	16
Participants and Settings .....	16
Materials .....	16
SPIRIT Toolkit .....	16
The SPIRIT Strategies Overview.....	17
The Service Path Tool.....	17
Post-Evaluation Handouts.....	17
The Parent Profile Guidelines and Cheat Sheet.....	18
The SPIRIT Fidelity Checklist.....	19
The SPIRIT Strategies Reminder Card.....	20
Survey Measures.....	20
Procedures.....	21
Iterative Design.....	21
Training Clinicians to Use the SPIRIT Toolkit .....	21
Assessing Fidelity of Using the SPIRIT Toolkit .....	22
Feedback Surveys .....	23
Study Design.....	23
Inter-observer Agreement .....	23
Data Analysis .....	23
<b>Chapter 3: Results</b> .....	26
Fidelity Data.....	26
Agreements in Reporting Fidelity (Direct Observation Versus Clinician Self-Report).....	28
Social Validity for the SPIRIT Toolkit.....	29
<b>Chapter 4: Discussion</b> .....	32
Limitations .....	36
Directions for Future Research .....	38
Implications for Research .....	41

Implications for Practice .....	42
<b>Chapter 5: Conclusion</b> .....	<b>44</b>
<b>APPENDICES</b> .....	<b>60</b>
Appendix A: SPIRIT Sample Strategies Overview .....	61
Appendix B: SPIRIT Service Path Tool .....	62
Appendix C: Sample Post-Evaluation Handout.....	63
Appendix D: Sample Additional Resource Handout .....	64
Appendix E: Sample SPIRIT Parent Profile Guidelines.....	65
Appendix F: SPIRIT Parent Profile Cheat Sheet.....	66
Appendix G: Sample SPIRIT Fidelity Checklist.....	67
Appendix H: SPIRIT Strategies Reminder Card .....	68
Appendix I: Clinician Perceptions of SPIRIT Survey .....	69

## LIST OF TABLES

Table 1.1	Clinicians' fidelity to the SPIRIT toolkit pre- and post-training.....	56
Table 1.2	Percentage agreement of secondary observer and clinician self-report Measures of fidelity to the SPIRIT toolkit .....	57
Table 2.1	Social validity of the SPIRIT toolkit using the AIM-IAM-FIM by item and subscale.....	58
Table 3.1	Participant responses to open-ended social validity questions.....	59

# CHAPTER 1

## INTRODUCTION

Clinicians' sharing of professional information (henceforth referred to as delivering feedback) is a commonly used practice in education, psychology, and medicine to communicate the results of assessments, deliver diagnoses (if applicable), and disseminate recommendations for services or additional resources. Individuals delivering feedback (hereinafter referred to as clinicians for brevity) often include (but are not limited to) educational professionals, social workers, medical doctors, and psychologists. Feedback is most frequently conducted with the individual for whom the assessment, diagnosis, and recommendations are for, and they can also include caregivers (particularly if the feedback pertains to a minor) or other professionals. Delivering feedback is a complex interpersonal practice influenced by emotional and cultural factors that affect caregiver engagement, satisfaction, and follow through with recommended services (Abbott et al., 2013; Hayes et al., 2023; Nelson Gott et al., 2013; Postal & Armstrong, 2013; Suurmond & Seeleman, 2006).

### **Role of Emotions in Feedback Satisfaction and Service Initiation**

Several studies from educational, psychological, and medical research have shown the important and interrelated role that emotional states and reactions have on one's ability to engage in and process feedback, particularly for caregivers involved in feedback. Caregivers report experiencing a range of strong emotions such as relief or vindication, distress or sadness, anxiety or worry, guilt, grief or loss, shock and confusion, denial, and anger or frustration. For example, many caregivers report a sense of relief and validation after feedback because they have answers and explanations for their child's difficulties (Abbot et al., 2013; Hayes et al., 2023). On the other hand, families may also be faced with changing perceptions of their child and uncertainty

about the future of their child or family, evoking feelings of grief or loss related to altered hopes and expectations (Fernández-Ávalos et al., 2021; Graungaard & Skov, 2006; Hayes et al., 2023). Caregivers may also report feelings of guilt related to a sense of responsibility for passing down the disorder to the child (Abbott et al., 2013; Fernández-Ávalos et al., 2021) or not getting a diagnosis sooner.

It is also often the case that caregivers experience many of these emotions at once and their emotions often change over time (Nelson Gott et al., 2013), which can contribute to additional feelings of confusion and ongoing challenges with processing emotions. Many of these emotions are often amplified by the long waitlist and complicated process of receiving an evaluation (Hayes et al., 2023; Connolly & Gersch, 2013). Studies also suggest that caregivers continue to experience and cope with these strong emotions after the feedback, ranging from weeks to years after diagnosis (Boshoff et al., 2018; Fernández-Ávalos et al., 2021); Nelson Goff et al., 2013).

Caregivers' emotional states at the time of feedback have also been shown to impact the ability to process information delivered during feedback, overall satisfaction with the feedback or assessment process, and the likelihood that they will utilize recommended services. For example, many caregivers report difficulty with understanding and consolidating information during feedback due to both the overwhelming emotions after receiving a diagnosis and the quantity of information shared during the feedback (Abbott et al., 2013). In fact, caregivers who report feeling overwhelmed during feedback indicate that they are unable to recall recommendations given during feedback (Hayes et al., 2023). Research in the medical field similarly show the role of caregiver affect in treatment initiation and engagement. For example,

Ozkaya and colleagues (2010) found that high levels of maternal anxiety were associated with an increased risk of incomplete vaccination status for their children.

The field of psychology provides some explanation as to how caregivers' emotions may impact their overall satisfaction and perceptions of the feedback process. For example, research has shown that high levels of anxiety can negatively impact working memory (the ability to hold and manipulate small amounts of information in memory; Hayes et al., 2008) and memory consolidation (the ability to convert short-term memory to long-term memory for later retrieval; McGaugh, 2000). Moran (2016) similarly found that anxiety was broadly associated with deficits in fluid cognition (i.e., general reasoning, abstract thinking, and problem-solving abilities). For many individuals and families, this may present as difficulties with attending to feedback and recommendations, remembering important details, or being an active participant in the feedback (e.g., asking questions) (Jashar et al., 2019). As such, it is highly relevant that clinicians are aware of and attentive to the role of caregivers' emotional experiences during feedback.

### **Cultural Considerations for Feedback**

Feedback is heavily reliant on language, which in and of itself is cultural. Linguistically diverse families often report that clinicians do not effectively communicate during feedback (Boshoff et al., 2019). For example, when clients and clinicians are culturally similar, clinicians can more easily interpret "cues" given by the family to indicate levels of mutual understanding. However, clinicians may misinterpret or overlook "cues" from ethnically or culturally diverse clients, leading to incorrect assumptions of mutual understanding, which can result in clinicians making minimal attempts to optimize mutual understanding (Meeuwesen et al., 2007). Even with translators, it may be difficult to convey the correct meaning of findings due to differences in translations (Postal & Armstrong, 2013). Similarly, clinicians often overuse medical language

(Boshoff et al., 2019) which leads to difficulties with understanding aspects of the evaluation and recommendations (Abbott et al., 2013). Language barriers might also result in an inability to share vital information, prevent the exchange of relevant treatment options, or result in clinicians making decisions for the family or client with limited family input (Suurmond & Seeleman, 2006).

Feedback sessions are a highly interpersonal process that is heavily impacted by rapport, which is influenced by the culture of the clinician and individual or family. For example, families may have their own cultural norms and expectations about what is permissible to say, what their status is in the interactions with the clinician (i.e., passive receiver of information or partner in collaboration), and their goals for the feedback. Shared decision-making is a common approach to feedback in the United States. This collaborative approach emphasizes that clinicians and clients work together to share information and make decisions (Elwyn et al., 2012). However, Suurmond and Seeleman (2006) revealed that there are several cultural factors, such as varying ideas about health and illness, or different role expectation, that can impact the shared decision-making process. In a collaborative or shared decision-making model, it is expected that the clients disclose relevant information, ask questions, and evaluate treatment options. However, several studies note that families often feel uncertain or de-skilled, and therefore are unsure of which questions to ask, how to ask questions, or when to ask questions (Abbott et al., 2013), which can be further exacerbated by cultural differences. For example, in a study observing differences in communication with immigrant parents, Meeuwesen and colleagues (2006) found that clients identifying as ethnic minorities tended to agree with doctors more and argued less, while clients who had similar cultural identities to the doctor were more assertive in their communication and expressed more disagreement.

Biases, stereotypes, and mismatches in values are also commonly present during the feedback process and can influence what information is shared, how information is shared, and how family concerns are acknowledged (Suurmond and Seeleman, 2006). Specifically, bias and stereotyping may result in concerns being ignored or the client's contribution to the shared decision making not being taken seriously (Suurmond & Seeleman, 2006). For example, families have reported that they experienced delays in diagnosis due to concerns being ignored or dismissed (Stoner et al., 2005) and Black families often report that their concerns are not taken seriously or that clinicians may lack knowledge on cultural diversity, which results in delayed diagnoses and therefore a loss of early intervention services (Pearson & Meadan, 2018). Marginalized racial/ethnic groups' negative experiences and discrimination in healthcare negatively impacts their trust in providers (Brown et al., 2024; Hausmann et al., 2013) and overall ratings of quality of care (Sorkin et al., 2010), which can reduce their medical adherence or utilization of preventative healthcare or other services (Casagrande et al., 2007; Musa et al., 2009). For Black families in particular, satisfaction with the diagnostic process has been shown to impact service utilization (Fisher & Lynch, 2024). Caregivers have also reported a mismatch between information they indicate as important to them and the type of information and recommendations they receive from clinicians (Hennel et al., 2016). Families and clinicians may also share different values about health, illness, and the concept or role of the family and the community in their care (Ravindran & Myers, 2012). Finally, caregivers sometimes report being suspicious, wary, and concerned about how people with more power perceive them and therefore may be more hesitant to engage in discussions around various diagnoses (Postal & Armstrong, 2013).

## **Research-Based Practices in Delivering Feedback**

It is paramount for clinicians to be aware of and responsive to caregivers' emotional states during diagnostic feedback while also attending to cultural considerations. While there is no "gold standard," or universal method of delivering feedback, some books/chapters (e.g., Holliday et al., 2016; Postal & Armstrong, 2013), systematic meta- and literature reviews (Pattinson et al., 2021; Tharinger et al., 2008), and individual studies across different fields (e.g., medicine, education, psychology), suggest that several steps can be implemented to increase the effectiveness of delivering feedback to caregivers that is mindful of caregivers' affective needs while attending to cultural considerations. Recommendations for guiding effective feedback sessions can be categorized into structural, content, and interpersonal level recommendations.

### ***Feedback Structure***

Regarding structure of the feedback, consideration should be given to the promptness of delivering feedback, time allotment, environmental structure, and individuals in attendance. Regarding timing of the feedback, the literature widely recommends delivering feedback as soon as possible after the evaluation (Hennel et al., 2016; Holliday et al., 2016; Pattinson et al., 2021). Feedback should also be conducted in a private and comfortable setting to allow caregivers to experience and express their emotional reactions (Graungaard & Skov, 2006). For example, environmental cues such as having tissues nearby and seating arranged in a way that promotes conversation (i.e., in a circle) can indicate a supportive environment, promote conversation, and enhance the collaborative nature of the feedback (Holliday et al., 2016). Sessions should be long enough to allow ample time to address family concerns, provide assessment feedback, and discuss appropriate recommendations. Generally, families report higher satisfaction with longer feedback (Smith et al., 2007), most commonly ranging from an hour to an hour and a half

(Abbott et al., 2013; Holliday et al., 2016), with many families also appreciating additional appointments for discussion if needed (Abbott et al., 2013). Follow-up appointments may be helpful for caregivers to ask questions they were unable to ask during the initial meeting (Jashar et al., 2019). Reviewing the evaluation process and providing an outline for feedback discussion also aids in clarifying caregivers' understanding of the evaluation and expectations for feedback (Holliday et al., 2016). Clinicians should also ask the family who they want in attendance at the feedback. Specifically, many caregivers note the importance of having a support person such as a spouse or partner, family member, or friend present to provide comfort and support (Holliday et al., 2016). Special attention should also be placed on whether it is culturally or developmentally appropriate to include the child present at feedback, as many families report being satisfied when clinicians explain the results to their child (Holliday et al., 2016).

### ***Content of the Feedback Session***

There are also recommendations regarding the content discussed during the feedback that addresses emotional, cultural, and developmental concerns. At the start of the evaluation process, it is important to ask families about their goals for the evaluation and any relevant cultural considerations (e.g., perspectives on relevant diagnoses and preference for communication) (Armstrong et al., 2024). The literature largely supports the use of specific and individualized feedback (Pattinson et al., 2021) that is focused on the individual's strengths (Abbott et al., 2013). In many cases where a given diagnosis is unexpected for the family, it may also be appropriate to provide caregivers with specific details about the criteria of the diagnoses given and which criterion or symptoms are present in the child (Holliday et al., 2016; Osborne & Reed, 2008; Pattinson et al., 2021). When delivering feedback, it is also recommended to use written and verbal information such as completed reports or parent-friendly fact sheets (Abbott et al.,

2013; Hennel et al., 2016; Holliday et al., 2016; Pattinson et al., 2021), as this helps to address concerns that caregivers may struggle to recall information discussed during feedback (Armstrong et al., 2024). Written materials such as reports not only help strengthen caregivers' understanding of their child, but also help caregivers communicate their child's strengths and needs with other professionals (Hayes et al., 2023).

When delivering recommendations, it is important to tailor recommendations to individual and family characteristics (Pattinson et al., 2021) such as socioeconomic status, education level, geographic location, cultural compatibility, and language. Recommendations clinicians provide should be practical (Armstrong et al., 2024). Clinicians may want to ask themselves if the recommendations they are providing are relevant to the individual or family's activities of daily living (Postal & Armstrong, 2013), or match with the goals of the evaluation indicated by the individual or family. In cases where families are more resistant or upset with a diagnosis, research also suggests that families are more likely to accept diagnoses if feedback is ordered in terms of its similarity to the family's narratives. For example, findings that verify the parents' conceptualization of the child are presented first, and findings that are novel or discrepant from the parent's conceptualization of their child are presented last (Tharinger et al., 2008). Successfully communicating findings to address family concerns of everyday life promotes engagement in feedback and increases the likelihood of caregivers using clinician recommendations (Tharinger et al., 2008).

### ***Emotionally and Culturally Sensitive Feedback***

The literature also provides some guidance for clinicians on how to develop feedback that is supportive of families' emotional states and fosters collaboration while acknowledging and respecting families' cultural differences. Simply exploring caregivers' emotional states and

inquiring about past service use and experience with those providing feedback can significantly increase engagement (Girio, 2010). For example, one study found positive correlations between clinician attentiveness and empathy and client self-efficacy and engagement (Zachariae et al., 2003). Families also report feeling more at ease with the feedback process when clinicians are positive, supportive, and are aware of their emotions, and make efforts to get to know their child as an individual (Abbott et al., 2013). For example, one study on caregivers' reactions to diagnosis disclosures showed that clinicians' warmth and positivity were associated with positive emotional reaction and reduced confusion during feedback (Anderberg & South, 2021). In fact, when feedback is provided in a constructive and affirming manner, it can even work to increase positive emotions (Holm-Denoma et al., 2008). Clinicians should also aim to instill realistic hope when communicating diagnoses (Armstrong et al., 2024).

It is also paramount to ask families about their cultural values, perspectives on the diagnoses in question, and their current understanding of relevant diagnoses. Although it is important to confirm the family's primary language at the onset of the evaluation, it is also important to ask families for their preferred language for feedback. For example, even if the assessment is conducted in English, individuals and families may wish to have others present at the feedback session who may not speak English. The use of visual materials beyond the written assessment report may also be beneficial when families are linguistically diverse (Postal & Armstrong, 2013). It is important that any written materials are provided in the family's primary language and at a reading level commensurate with their educational level (Armstrong et al., 2024). Efforts should also be made to ensure that the feedback session is collaborative (Tharinger et al., 2008). Specifically, professionals should describe the collaborative nature of the feedback session explicitly from the beginning and emphasize the value of the caregivers'

expertise in their child (Stoner et al., 2005) and clarify roles (Suurmond & Seeleman, 2006). To aid in collaboration, clinicians should also make conscious efforts to allow the family multiple opportunities to ask questions throughout (Holliday et al., 2016). For several reasons such as difficulty emotionally processing feedback, language barriers, or cultural differences, families may not know what questions to ask or how to ask them. As such, clinicians can ask caregivers what areas they were most confused by or least clear about (Postal & Armstrong, 2013) and answer anticipated questions throughout feedback.

### **Scope of the Study**

According to the Centers for Disease Control and Prevention, approximately one in six children are diagnosed with a developmental disability, and one in 36 children are diagnosed with autism spectrum disorder (ASD) (Center for Disease Control and Prevention, 2023), making it the third most diagnosed developmental disability. One of the major roles of delivering feedback is to disseminate service recommendations and resources. For children diagnosed with ASD, the literature indicates the short- and long-term benefits of early intervention across multiple domains, such as language, communication, socialization, cognitive abilities, and adaptive behavior (Dawson & Burner, 2011; Estes et al., 2015; Schertz et al., 2013; Wergeland et al., 2022).

However, studies show that children diagnosed with ASD are at higher risk for having unmet specialty and therapy care needs (Chiri & Warfield, 2012) and do not utilize recommended services (Shivers et al., 2019). Caregivers of children with ASD report many challenges with accessing recommended services such as receiving limited information about services (Smith-Young et al., 2019), not understanding services that are recommended (Rouse et al., 2008), and feeling dismissed by or a lack of trust with professionals (Jackson et al., 2020).

Difficulties in engaging in services for children with ASD are also further exacerbated by increased levels of stress and negative emotional responses to receiving an ASD diagnosis (Ooi et al., 2016). Given the prevalence of ASD, the noted importance of receiving intervention as soon as possible, and the noted difficulty many caregivers have with connecting with recommended services, this study looked to investigate the feedback practices of psychologists providing feedback regarding ASD evaluations in a clinical setting.

### ***Training for Clinicians to Provide Feedback***

Research on clinicians training to provide diagnostic feedback is limited, however, research that does exist suggests that many psychologists are not specifically trained in how to provide feedback (Merker et al., 2010). For example, a recent study of Brazilian neurology trainees found that students were not formally trained (i.e., through lectures, practice, or feedback) on how to deliver bad news (Lima et al., 2023). Similarly, another study of fifth and sixth year Polish medical students revealed most students (75.1%) felt inadequately prepared to deliver bad news (Lenkiewicz et al., 2022). Other studies show that upwards of 35.6% of clinicians found their coursework and practica training to be “very little” or “not at all” helpful for preparing them to provide feedback in practice (Curry and Hanson, 2010).

Furthermore, one important gap in the research on delivering feedback is that almost no studies have evaluated the impact of structured feedback models or tools. While some papers have developed guidelines for feedback (Armstrong et al., 2024) and other studies suggest delivering feedback using a specific (i.e., collaborative) approach (Tharinger et al., 2008), little to no studies on feedback follow or evaluate a structured feedback model based on research that gives explicit steps or materials to facilitate feedback systematically. For example, in a literature review of the best practices regarding psychological assessment, it is recommended that

feedback, “be deliberate in thinking about issues related to what and how feedback will be delivered, including topics and ways of delivering,” but does not provide specific strategies for such differentiation (Wright et al., 2022). Although Autism Speaks had developed a clinician’s guide to delivering feedback (Autism Speaks, 2012), it does not appear this toolkit has been evaluated in research. One structured feedback tool that has been developed with explicit steps, strategies, and tools to provide differentiated feedback is the SPIRIT toolkit (Haine-Schlagel et al., 2022).

### ***The SPIRIT Toolkit***

The SPIRIT toolkit was developed specifically for supporting families in processing an ASD diagnosis. Specifically, it was designed to increase caregiver satisfaction and improve utilization of recommended services by promoting parent engagement and efficacy in the evaluation. The SPIRIT toolkit, named for each step in the process, outlines six-steps for clinicians to deliver ASD evaluation feedback: 1) Start off on the right foot, 2) Pause to plan, 3) Individualize diagnostic communication, 4) Readjust plan, 5) Individualize recommendations, and 6) Thank the parent. SPIRIT incorporates research-based practices in the toolkit through various tools (discussed later) and feedback strategies. For example, it prompts clinicians to consider cultural responsiveness, promote clinicians to encourage caregiver engagement and participation, and attends to the emotional readiness and needs of the family through differentiated feedback practices. The toolkit also provides recommendations for how to individualize the delivery of feedback by emphasizing the child’s strengths, revisiting caregivers’ evaluation goals, prioritizing recommendations, and providing visuals.

The initial SPIRIT pilot study (Haine-Schlagel et al., 2022) was a Quality Assurance Performance Improvement (QAPI) style research study that systematically incorporated

community feedback and data into the toolkit development. Across two phases, this study aimed to (a) identify needs and challenges during ASD evaluation and collaboratively develop a tool to address them, and (b) pilot the training and delivery of the SPIRIT toolkit and assess clinician and caregiver social validity. During the first phase, 11 psychologists from a hospital that provides developmental and ASD evaluations participated in three 60-minute focus groups. The focus groups assessed providers' perspectives on the challenges families faced with following through on clinicians' recommendations. The clinicians also provided their perspectives on initial drafts and proposed toolkit elements. This phase identified several themes regarding the challenges families often experience, including grief or inability to process recommendations following the delivery of an ASD diagnosis, difficulty navigating the ASD service system, lack of caregivers' knowledge about ASD and related services, and limited resources. Barriers included rushed feedback due to limited clinician time or insurance restraints, limited resources to facilitate initiation of recommended services, challenges in accessing the report, and variable skills among providers' ability to communicate recommendations. Feedback from this phase resulted in the development of several resources in the toolkit (discussed in greater detail later): (a) the Parent Profile Cheat Sheet, (b) a Service Path Tool, (c) post-evaluation handouts, and (d) a SPIRIT fidelity checklist.

After development, seven clinicians were trained to use the toolkit in a one-time (two-hour) training. Clinicians completed a feedback survey two months after training and participated in a 15–20-minute phone interview ten months after training to assess their perceived social validity. Clinicians also regularly submitted self-rated fidelity checklists following ASD evaluations. 16 Caregivers completed a 15-minute phone interview one to three months following their evaluation before ( $n = 10$ ) and after ( $n = 6$ ) providers received SPIRIT

training. The percentage of service initiation was also calculated as a proportion of services initiated to total services recommended. Clinicians rated SPIRIT as having moderate-to-high feasibility, acceptability, appropriateness, and utility. Specifically, they found the Parent Profile Cheat Sheet to be the most useful. There were mixed results with the recommendations portion of the SPIRIT toolkit. For example, clinicians found the Service Path Tool and Enhanced Patient Instructions useful as clinician resources but indicated they needed major revisions to be more appropriate for parents. Service Path Tool and Enhanced Patient Instructions were also the strategies utilized the least by the sample of clinicians. The Service Path Tool was used the least with the lowest fidelity as it was found to be too long and complex. Most clinicians indicated they planned to use SPIRIT in the future. Caregivers reported greater prioritization of recommendations, clarity of communication, and high evaluation satisfaction when providers had SPIRIT training.

### **Study Purpose and Research Questions**

The initial study of the SPIRIT toolkit by Haine-Schlagel and colleagues (2022) showed that the toolkit may be feasible to implement in a community setting to increase caregiver satisfaction with ASD feedback, but it also revealed some key areas for refining the toolkit. It is important to revise the toolkit such that it is feasible, acceptable, and appropriate for the user-population it is designed for (i.e., clinicians). If the toolkit is not considered socially valid by clinicians, it may not be used with fidelity or not used at all. Additionally, the initial SPIRIT pilot study measured clinicians' fidelity through self-report alone. While some research indicates that self-report measures can be reliable and concurrent with observer-rated fidelity (Khoury et al., 2019; Hogue et al., 2021), other research suggests self-report measures may not be reliable or accurately reflect clinician use (Fiske, 2008; Lillehoj et al., 2004; McLeod et al., 2022), or that it

may vary by intervention (Hogue et al., 2015). As such, it is crucial to evaluate fidelity of SPIRIT implementation using multiple measurements of fidelity, including direct observations in addition to self-report measures. To further research around delivering feedback to caregivers more broadly, as well as to further examine the SPIRIT toolkit more specifically, one goal of this project was to use past research and an iterative design process to refine the SPIRIT toolkit.

After making such refinements, this study aimed to investigate the following research questions:

1. Compared to practice as usual, are the steps of the refined SPIRIT toolkit implemented more frequently by clinicians after receiving training on how to use the toolkit?
2. As measured by a direct observation, are clinicians able to implement the refined SPIRIT toolkit with appropriate fidelity after training, as defined by correctly using at least 80% of the 50 steps in the toolkit?
3. When comparing direct observation and clinician self-report of fidelity in using the SPIRIT toolkit, what is the percentage agreement in the two measures of fidelity?
4. To what extent do clinicians utilize and find the refined SPIRIT toolkit socially valid as measured with a provider feedback survey?

## CHAPTER 2

### METHODS

#### Participants and Settings

Participants for this study included 10 ASD specialist clinicians from four university-based regional centers that specialize in ASD in the south-eastern United States. At these centers, evaluations and feedback sessions typically adhere to the following structure: (a) a one-day, 3-4 hour evaluation of cognitive skills (or developmental ability for younger children) and ASD symptomology; (b) a short break (typically an hour) for clinicians to score evaluation measures, determine a possible diagnoses, and develop an initial list of appropriate recommendations; and (c) a feedback session with the family lasting 1-1.5 hours. During feedback, families are typically provided with handouts with recommendations and additional resources. Families are typically contacted two-weeks after the evaluation by the resource and referral specialist at the clinic to answer questions the family might have after the evaluation and feedback are completed. A full report is sent to families 1-2 weeks after the evaluation and feedback. Further details about the families will not be provided as they are not the subject of the study. Each clinician participant in this study was assigned a randomized identification number. An IRB was obtained prior to study recruitment, data collection, and clinician training. There was no attrition of participants in this study. When clinicians were directly observed during pre- and post-training to address the first three research questions in the study, verbal consent was obtained from the caregivers receiving clinician feedback in those sessions.

#### Materials

**SPIRIT toolkit.** The original SPIRIT toolkit (Haine-Schlagel et al., 2022) included six steps, strategies within each step, and tools to help facilitate and individualize the delivery of

feedback. These tools include: the SPIRIT Strategies Overview, the Service Path tool, post-evaluation handouts, the Parent Profiles Guidelines, a Parent Profile Cheat sheet, and a fidelity checklist. As noted previously, one goal of this project was to refine some of these materials. All descriptions of materials refer to the refined (i.e., version 2) SPIRIT toolkit that were created as a result of an iterative design process employed as part of this study (discussed later).

***The SPIRIT Strategies Overview.*** The SPIRIT Strategies Overview is a multi-page document outlining the six steps of the SPIRIT toolkit (i.e., start off on the right foot, pause to plan, individualize diagnostic communication, readjust plan, individualize recommendations, and thank the parent) (Haine-Schlagel et al., 2022). The document provides the explanation for each step, specifies when each step is implemented, and gives several actionable strategies for the clinician to ensure the step is completed (see Appendix A for a sample).

***The Service Path Tool.*** The Service Path Tool (see Appendix B) is a visual path provided to caregivers by the clinician that includes the separate health plan and public or community services and systems that the family can access (Haine-Schlagel et al., 2022). Clinicians use the Service Path Tool to prioritize recommendations for the family to consider. Specifically, clinicians indicate what recommended services families should keep doing, do now, or consider for later using a “K,” “N,” or “L,” respectively. This tool was developed specifically to address challenges related to a lack of parental knowledge of services, difficulty with processing recommendation, and a need for care coordination (Haine-Schlagel et al., 2022).

***Post-Evaluation Handouts.*** In the pilot study by Haine-Schlagel et al., the SPIRIT toolkit included Enhanced Patient Instructions, which were developed to be used during the recommendations portion of the feedback session to highlight next steps for families. The Enhanced Patient Instructions were designed to match the Service Path Tool, provide more

information on how to access the evaluation report, and include detailed information about the recommended services. In the pilot study, this tool was found to be too lengthy and complex to use with families. Furthermore, the clinicians found it difficult to use with families because of the inability to edit or tailor them to the family. For the present study, significant changes to this tool were made as part of an iterative design process (discussed later) to address this feedback. The Enhanced Patient Instructions were modified to become two distinct sets of Post Evaluation Handouts that include (a) detailed descriptions of prioritized recommendations, and (b) a separate document listing additional resources. The descriptions of recommended services (see Appendix C for a sample) are concise snapshots of the Service Path tool divided by service type (e.g., autism-specific, school-based, developmental) that provides detailed descriptions and instructions on how to access recommended services. When providing this handout to families, clinicians select the most relevant post-evaluation handouts for the services recommended for a more tailored experience for the family and indicate which services are a priority. The additional resource handout (see Appendix D for a sample) is a one-page front-and-back document with general resources that may be valuable to the family. Both documents include checkboxes for clinicians to signal to families with services or resources are most appropriate for them. As indicated by the SPIRIT toolkit and fidelity checklist, clinicians provide this document in its entirety for families to reference as needed. This revised tool is henceforth referred to as the Post Evaluation Handouts.

***The Parent Profile Guidelines and Cheat Sheet.*** The Parent Profile Guidelines is a document for clinicians to use to help create an individualized plan for how to reach the evaluation goal based on a caregiver's emotional readiness. SPIRIT provides six emotional profiles (i.e., sad, overwhelmed, reluctant, distrustful, zealous or inquisitive, or relieved and

ready) that include the characteristics of each profile to help clinicians identify the appropriate emotional profile of the family (Haine-Schlagel et al., 2022). For instance, clinicians may be able to identify caregivers as sad if they are crying or share negative thoughts or worries. The goal of the feedback session in this case would be to provide understanding of the diagnosis and hope. The Profile Guidelines also include specific tips for individualizing feedback with each different emotional profile regarding the structure of the feedback session, how the diagnosis is delivered, and recommendation guidelines. For example, clinicians may need to provide feedback at a slower pace, clarify misconceptions about ASD, and emphasize services that promote hope for caregivers identified as sad. This tool is used as a reference for clinicians and is not provided to families. This tool was also developed to specifically address challenges with diagnosis feedback such as parent grief and the inability to process information given after a diagnosis (see Appendix E for a sample). The Parent Profile Cheat Sheet is a one-page simplified version of the Parent Profile Guidelines, used as a visual aid and reference for clinicians (see Appendix F).

***The SPIRIT Fidelity Checklist.*** The original SPIRIT fidelity checklist includes a set of 22 strategies organized within the six steps of the SPIRIT process to ensure accurate and consistent implementation adherence across families and clinicians (Haine-Schlagel et al., 2022). The fidelity checklist was revised for this study in collaboration with one of the lead developers of SPIRIT to include more specific, objective indicators of successful implementation of each step and strategy—which should help to ensure more accurate fidelity measurements across observers (see Appendix G). For example, the original item “*consider cultural responsiveness of the evaluation*” was modified by splitting it into four observable items: *addressed the language of the evaluation prior to start; asked caregivers who they want to attend during the feedback session; acknowledged or asking about cultural perspectives for communication, behavior, and*

*play*; and *clinician used culturally appropriate testing items*. After revising the fidelity checklist for the purpose of this study, the revised checklist included a set of 50 items.

***The SPIRIT Strategies Reminder Card.*** The SPIRIT Strategies Reminder Card is a one-page tool with the 6 major steps of the SPIRIT toolkit on the left and blank space for clinicians to write on the right (see Appendix H). This was used as a tool during trainings for clinicians to write examples of how they could apply the SPIRIT strategies in their practice, or for clinicians to write other reminders or helpful items during training. The SPIRIT Strategies reminder card was made available to clinicians after training to use during feedback sessions.

**Survey Measures.** A 14-item survey was used to collect clinician perceptions of acceptability, usability, and feasibility (i.e., social validity) of the revised SPIRIT toolkit. Twelve items from the survey were adapted from Weiner et al. (2017) and evaluated clinicians' perceptions of the acceptability of intervention (AIM;  $\alpha = 0.85$ ), intervention appropriateness (IAM;  $\alpha = 0.91$ ) and intervention feasibility (FIM;  $\alpha = 0.89$ ) (Weiner et al., 2017) to create three subscales with four questions each. Acceptability measured the perception among stakeholders that a treatment is satisfactory (e.g., "The SPIRIT toolkit meets my approval"), appropriateness measured the perceived compatibility of a practice to address a particular issue (e.g., "The SPIRIT toolkit seems suitable"), and feasibility measured the extent to which a treatment can be successfully used in setting (e.g., "The SPIRIT toolkit seems feasible to implement"). Survey items will be rated on a Likert scale from strongly disagree (1) to strongly agree (5). Two open-ended questions were provided for additional clinician feedback not captured by the Likert items to provide insight on items needing further refinement (i.e., "What would you change about the SPIRIT tools?" and "What would you make sure to keep in terms of the SPIRIT tools themselves?") (see Appendix I).

## **Procedures**

**Iterative Design.** Prior to training clinicians on the SPIRIT toolkit, and as part of this project, an iterative design process was used to revise the Enhanced Patient Instructions of the original SPIRIT toolkit, as that was the part of the toolkit not found to be acceptable to clinicians in the pilot study of SPIRIT (Haine-Schlagel et al., 2022). The iterative design process included a call with the participants of the original SPIRIT study in a group setting for approximately 30-minutes during a regular staff meeting. The iterative design process also included resource and referral specialists and interventionists (i.e., autism specialist clinicians who do not provide assessments) in the setting of participants in the present study with brief 10–15-minute individual meetings to ensure modifications to the toolkit met the needs of the families in study population. Feedback from 3 families were obtained. Clinicians participating in the present study were not included in the iterative design process. The iterative design process utilized a card sort task where clinicians, resource specialists, interventionists, and families who participated in the iterative design process were asked to indicate their preference for the post-evaluation handouts among 3 prefabricated options. Additional feedback including what they liked, what they would add, or what they would change was also. The revised documents with the most positive feedback and votes were used in the SPIRIT training and given to clinicians (i.e., participants of this study) to use for delivering feedback, as outlined above.

**Training Clinicians to Use the SPIRIT toolkit.** Clinicians were trained to implement the SPIRIT toolkit in a one-time, two-hour virtual training facilitated by one of the lead developers of the SPIRIT toolkit. Four separate trainings were held for clinicians given their varying schedules, availabilities, and locations. The training materials were the same for each group. Training included an overview of the toolkit and detailed descriptions of key steps and

strategies. Clinicians were shown all the SPIRIT handouts and were instructed on how to utilize them. Training also used case vignettes, interactive practice, and discussion. Following the training, clinicians were provided with the SPIRIT manual, revised toolkit handouts, and fidelity checklist. Clinicians were instructed to utilize the SPIRIT toolkit for delivering all feedback to families following the training. As discussed in the following section, each clinician's use of SPIRIT strategies was evaluated pre- and post-training using the SPIRIT fidelity checklist.

**Assessing Fidelity of Using the SPIRIT toolkit.** Clinician fidelity in using the toolkit was evaluated by the lead researcher of this study and another member of the research team using live in-vivo direct observations. Observations were conducted using a two-way mirror or live video feed, such that the observer was not in the room with the family or clinician. Prior to conducting the observations, the families were notified another person would be watching the clinician's feedback practices, and verbal consent was obtained. In each fidelity assessment, the observer directly watched the clinicians' feedback sessions while rating the clinician's fidelity by using a fidelity checklist evaluating the steps and strategies of the SPIRIT toolkit (see Appendix G for a sample). The observers were trained directly by the lead developer of the SPIRIT toolkit to use the toolkit and monitor its fidelity. Each clinician was observed once at pre-training and once at post-training. All efforts were made to conduct post-training observations at with approximately equivalent time between their training and post-training observation for all clinicians. However, due to time constraints, limited numbers of research personnel able to conduct observations, scheduling difficulties, and a disruption in data collection due to a natural disaster, the time between the training and post-training observations varied between clinicians. Although clinicians had conducted a median number of 11 evaluations ( $M = 14.5$ ) prior to post-

training observations, weeks between training and post-training observation ranged between 3 and 32 weeks.

**Feedback Surveys.** Clinicians were given a survey following their post-training observation to provide anonymous feedback regarding their usage and perceived social validity of the SPIRIT toolkit.

### **Study Design**

This study used a quasi-experimental, within-subject, pre-post group design. Specifically, measures of clinicians' fidelity to the SPIRIT toolkit were measured once pre-training and once post-training. Clinicians' pre- and post-training fidelity were collected using in-vivo direct observation of clinicians' feedback sessions while observers used the SPIRIT fidelity checklist. Pre-training observations using the same fidelity checklist indicated what elements of SPIRIT were already used by the clinicians (i.e., practice-as-usual).

### **Inter-observer Agreement**

Either the lead researcher or another member of the research team conducted fidelity observations of the clinicians. During 15% of the sessions (all of which were conducted during pre-training observations), both individuals independently observed the clinician to evaluate inter-rater reliability among the two observers.

### **Data Analysis**

To analyze research question one, descriptive statistics (range, mean, and standard deviation) were used to summarize fidelity across all participants pre- and post-training. Given the relatively small sample size for this study, the Wilcoxon signed rank test was used to assess statistically significant differences in fidelity between pre- and post-training. Percentage

agreement between observers showed high inter-observer agreement, ranging from 90% - 98%, with an average inter-rater agreement of 94%.

To analyze research question two, descriptive analyses (e.g., range, mean, and standard deviation) were used to analyze clinicians' fidelity post-training and determine the degree to which each clinician used SPIRIT with fidelity. Mean and mode were also used to describe the steps and strategies utilized with the most and least frequency. Although there is no gold-standard for fidelity (Wilczynski, 2017), and levels of adequate fidelity vary by intervention (Durlak & DuPre, 2008), 80% has been conventionally used as a threshold for good fidelity (Bond & Drake, 2020). Based on fidelity data collected from the pilot study (Haine-Schlagel et al., 2022) and discussions with one of the lead developers of the SPIRIT toolkit, 80% adherence to the fidelity checklist was the minimum for fidelity to be considered adequate—and this criterion was determined prior to beginning data collection.

To compare direct observation and clinician self-report of fidelity in using the SPIRIT toolkit, percentage agreement was calculated for all post-training feedback sessions. Percentage agreement was calculated item-by-item by dividing the number of items of the fidelity checklist agreed upon by the total number of possible items ( $n = 50$  items). According to What Works Clearinghouse (2022), acceptable levels of inter-rater agreement are 80% or higher. Therefore, 80% was used as the threshold for adequate inter-rater agreement for this study.

Data regarding social validity of SPIRIT was collected using an anonymous Qualtrics survey. Given the small number of the participants, and the possibility participants could be identified by their feedback, participants anonymously completed the social validity survey. To analyze research question four, Likert responses for each subscale were averaged by item and subscale, with higher subscale scores indicating greater social validity. Sub-scale scores above

4.0 correspond with “Agree” were interpreted to reflect adequate social validity. Descriptive analyses (e.g., mean and standard deviation) were also used to describe each clinician’s usage and social validity of the SPIRIT toolkit on the survey measures. Specifically, mean was used to summarize clinician ratings on survey measure to indicate overall perceptions of social validity. Items on the survey indicated as the highest or lowest acceptability were also be reported. Inductive thematic analysis was used to evaluate clinician responses to the two open-ended questions. All open-ended responses were categorized by theme, and frequency of similar response themes were reported. Some answers included more than one theme. Given the small sample size of the study, quotes from all responses in each theme were reported.

## CHAPTER 3

### RESULTS

#### Fidelity Data

Pre-training, fidelity to the SPIRIT toolkit ranged from 56.5% - 74.5%, with an average baseline fidelity across participants of 62.7% (see Table 1). After receiving training, levels of fidelity increased for every participant. Increases in overall fidelity from pre-training to post-training observation for each participant ranged from 17.6% - 36.4%, with an average increase of 24.0% across all participants. Post-training fidelity to the SPIRIT toolkit ranged from 77.6% - 100%, with an average fidelity across participants of 86.7%. A Wilcoxon signed-rank test indicated that clinician's use of SPIRIT strategies, as measured by the revised SPIRIT fidelity checklist, was significantly higher after they received SPIRIT training ( $Z = -2.80, p = .005$ ). When measured by direct observation, 9 out of 10 clinicians implemented the SPIRIT toolkit with at least 80% fidelity. In fact, two clinicians were able to demonstrate fidelity with at least 90%, and one clinician implemented with 100% fidelity (see Table 1). The one clinician (Participant 4) who did not meet adequate levels of fidelity was close to this threshold (77.6%). Table 1.1 also shows the number of weeks that took place between training and the post-training observation. As stated previously, there were several factors (e.g., limited number of observers, natural disaster, scheduling) that made it challenging to ensure the number of weeks until the post-training observation were consistent among all clinicians (range of weeks = 3-32;  $Mdn = 11$ ). However, the data in Table 1.1 show that the number of weeks did not seem to influence clinicians' improvement in using the SPIRIT Toolkit with fidelity. A Spearman's correlation between the number of weeks between training and the post-training observation revealed the relationship was not significant ( $r_s = -0.41, p = 0.24$ ).

Prior to training, on average across clinicians, some of the most frequently implemented steps of the SPIRIT toolkit included: *addressed language of evaluation prior to start* (100%), *provided expectations for the evaluation* (100%), *asked caregiver(s) if child's performance was typical* (100%), and *provided behavioral observations of child during assessment* (100%). Prior to training, the following items were implemented with the least frequency: *asked caregiver(s) who they want at the feedback meeting* (10%), *acknowledged or asked about cultural perspectives for communication, behavior, or play* (20%), *acknowledged caregiver(s)' effort to schedule/attend* (10%), and *stated caregiver(s)' role as a crucial participant of the evaluation team* (10%). After training, 29 items were implemented with 100% frequency across all participants. Notably, one of the items implemented with the least frequency at pre-training, *acknowledged caregiver(s)' effort to schedule/attend*, was implemented with 100% frequency at post-training. After training, the following items were implemented with the least frequency: *asked caregiver(s) who they want at the feedback meeting* (40%), *acknowledged or asked about cultural perspectives for communication, behavior or play* (50%), *clinician used culturally appropriate testing items* (56%), *stated caregiver(s)' role as a crucial participant of the evaluation team* (60%), and *restated caregiver(s)' goal(s) for the evaluation* (60%). Several items implemented with the lowest fidelity at pre-training were also some of the items implemented with the lowest fidelity at post-training.

Seven items from the revised fidelity checklist assessed clinicians' use of SPIRIT specific tools (e.g., Service Path Tool, Post Evaluation Handouts, Parent Profiles). Prior to training, clinicians were unable to implement these tools because they had not yet received the training. At the post-training observation, 100% of participants identified a Parent Profile before delivering the diagnosis, identified a parent profile before communicating recommendations, and

referred to the Parent Profile Cheat Sheet. Additionally, 100% of participants individualized the delivery of the diagnosis and recommendation communication using the Parent Profile Guidelines when applicable. Seventy percent of participants gave the Service Path Tool to caregivers and emphasized the purpose of the Service Path Tool. Only 20% of clinicians used the SPIRIT Strategies Reminder Card. Although participants could use their own handouts at pre-training and post-training, it is notable that 100% utilized the revised SPIRIT Post-Evaluation Handouts at post-training.

### ***Agreements in Reporting Fidelity (Direct Observation Versus Clinician Self-report)***

All clinicians were asked to complete self-rater fidelity checklists at the post-training observations. These inter-rater agreements ranged from 78% - 100% with an average of 90.8% agreement (see Table 2.1 ). Over half of the items on the checklist ( $n = 29$ ) had 100% agreement between direct observation and self-report. Most other items ( $n = 15$ ) had 80% - 90% agreement between direct observation and self-report. However, some items appeared more difficult for clinicians to self-monitor. Specifically, three items from the “Start Off on the Right Foot” step of the SPIRIT toolkit only had 60% agreement between direct observation and self-report. These items included: *discusses concerns caregiver(s) raised (if applicable)*, *stated how this evaluation is different from previous evaluations (if applicable)*, and *stated caregiver(s)’ role as a crucial participant of the evaluation team (e.g., the evaluation is collaborative)*. One other item from the “Start Off on the Right Foot” step, *acknowledged or asked about cultural perspectives for communication, behavior, or play*, of the SPIRIT toolkit had 70% agreement. Two items from the “Individualize Recommendation Communication” step of the SPIRIT toolkit also had lower agreement between direct observation and self-report. Specifically, the item, *reiterating importance of getting report as step 1 to getting services (e.g., verbally or by circle/highlight)*

had 60% agreement, while *recommendations were considerate of cultural considerations or values raised by caregiver(s) (if applicable)* had 50% agreement between direct observation and self-report.

### **Social Validity for the SPIRIT Toolkit**

Seven of the 10 social validity surveys were returned, reflecting a 70% response rate. On average, clinicians had positive perceptions of the acceptability, appropriateness, and feasibility of the SPIRIT toolkit (see Table 3.1 ). Most respondents had positive responses (Strongly Agree or Agree) on all questions. Average ratings per subscale ranged from 4.25 - 4.43. Clinicians found the toolkit to be acceptable ( $M = 4.29$ ). Six out of seven clinicians indicated that they liked the toolkit, found it appealing, and indicated it met their approval, giving an average subscale rating ranging between 4 - 5. One participant had more neutral ratings of acceptability ( $M = 3$ ). Similarly, clinicians on average found the toolkit to be appropriate ( $M = 4.43$ ). Six out of seven clinicians indicated that the toolkit was fitting, suitable, and a good match for their practice, giving average subscale ratings ranging from 4 - 5. One clinician had more neutral ratings of appropriateness ( $M = 3.50$ ). Notably, this is the same clinician who gave moderate ratings of acceptability. Lastly, clinicians found the toolkit to be feasible ( $M = 4.25$ ). Five out of seven clinicians had more favorable perceptions of the feasibility of the toolkit, with average subscale ratings of 4 - 5. Two out of seven clinicians had more neutral perceptions of the feasibility, with average subscale ratings ranging from 3.25 - 3.75. Although all questions had an average response of 4.14 or above, the questions with the least overall positive ratings included clinicians' perceptions that the toolkit was implementable and easy to use.

Qualitatively, clinicians also responded to the two open-ended questions regarding their perceptions of the toolkit, "What would you change about the SPIRIT tools?" and "What would

you make sure to keep in terms of the SPIRIT tools?” Of the seven returned surveys, six contained responses to the open-ended questions (see Table 4.1). When asked what clinicians would change about the SPIRIT tools, two comments were made about reducing the amount of paper required to implement the tools, two comments were made suggesting the Service Pathway be editable, one comment suggested reducing items on the fidelity checklist, and one comment suggested translating the toolkit or creating other versions of the toolkit for other populations. Regarding reducing the amount of paper, two clinicians reported the amount of paper required to implement the tools (e.g., the Service Path Tool, Post Evaluation Handouts) were too much. For example, one clinician noted that, “when it comes to paperwork it is a lot to manage with all the other assessment processes.” Similarly, two clinicians indicated that they wanted the Service Path Tool to be more editable. Specifically, although clinicians could indicate which service paths they recommended to families, two clinicians noted that not being able to remove services not recommended might be overwhelming to caregivers. One clinician wrote “I think it’s a bit overstimulating, even though we are only drawing attention to the services they need.”

When asked what clinicians would make sure to keep about the tools, four comments were made regarding the Parent Profiles, two comments were made about the Service Path Tool, and two comments were made about the usability of the toolkit for training purposes. The part of the toolkit that received the most positive feedback was the use of the Parent Profiles for helping clinicians individualize their delivery of an autism diagnosis and recommendation communication. One clinician noted that the Parent Profiles helped them to, “Focus on parent's emotional needs when providing feedback; focusing recommendations on targeted steps to reduce confusion and not overwhelm parents.” Notably, although some clinicians reported they would change the layout or the editability of the Service Path Tool, other clinicians reported that

they liked the utility of the Service Path Tool for communicating recommendations to the family. For example, one clinician reported that “it reinforces things the parents have achieved and where they can go next.” Four of the six clinicians also found the Parent Profiles helpful in structuring their overall feedback process. One clinician commented that “the information about the dimension the parent is in is very helpful in structuring an approach to the interpretive session.” Lastly, some clinicians noted the utility of the SPIRIT toolkit for trainees. One clinician wrote, “I also find this to be a particularly helpful tool to use with trainees.”

## CHAPTER 4

### DISCUSSION

Delivering feedback is a complex emotional (Boshoff et al., 2018; Hayes et al., 2023; Fernández-Ávalos et al., 2021) and cultural (Boshoff et al., 2019; Stoner et al., 2005; Suurmond & Seeleman, 2006) process. These factors can impact clients' satisfaction and engagement with feedback, which can ultimately affect their utilization of recommended services (Brown et al., 2024; Meeuwesen et al., 2007; Musa et al., 2009; Pearson & Meadan, 2018). Caregivers of autistic children report experiencing emotional and cultural barriers during feedback (Abbot et al., 2013; Anderberg & South, 2021; Fisher & Lynch, 2024; Hennel et al., 2016). Many children with ASD have unmet service needs (Chiri & Warfield, 2012; Shivers et al., 2019), and their caregivers frequently express having difficulties with processing recommendations, navigating the complex service system, understanding ASD, and having limited resources (Haine-Schlagel et al., 2022). Therefore, it is indicated that clinicians tailor ASD feedback to the client (Zuckerman et al., 2016) and attend to recommendations regarding the structure, content, and process in which feedback is given (Armstrong et al., 2024; Holliday et al., 2016; Pattinson et al., 2021; Postal & Armstrong, 2013; Tharinger et al., 2008; Wright, 2020) to ensure families are satisfied and engaged in feedback.

Studies examining clinicians' preparedness to deliver feedback is sparse, however research that does exist shows that clinicians reportedly receive little if any explicit training in how to deliver feedback (Lenkiewicz et al., 2022; Lima et al., 2023; Merker et al., 2010). For those who do receive training or exposure to providing feedback in their training programs, some literature suggests that clinicians do not find the training helpful in practice (Curry and Hanson, 2010). While some researchers have proposed guidelines for delivering feedback (Armstrong et

al., 2024), no experimental research examining the use of structured models (or toolkits) for delivering ASD feedback were found at the time of this study. This is an important gap in the literature given that many clinicians report a lack of explicit training on how to deliver feedback (Lenkiewicz et al., 2022; Lima et al., 2023; Merker et al., 2010), and the ways in which clinicians deliver feedback can impact caregivers' engagement and satisfaction with feedback (Anderberg & South, 2021; Holm-Denoma et al., 2008; Zachariae et al., 2003). The SPIRIT toolkit (Haine-Schlagel et al., 2022) is one structured toolkit that contains steps and strategies to help clinicians tailor ASD evaluations to caregivers' needs.

In the present study, clinicians' feedback practices were observed before and after training to implement the SPIRIT toolkit. Results of this study showed that after training, all but one participant was able to implement the SPIRIT toolkit with adequate levels of fidelity, defined as 80% or more steps within the respective fidelity checklist. Furthermore, all participants' fidelity scores increased from pre-training to post-training. This suggests that the 2-hour training was generally sufficient for helping clinicians use the SPIRIT toolkit with appropriate or high fidelity. Most items on the revised fidelity checklist ( $n = 43$ ) pertained to clinical interpersonal skills (e.g., promoting caregiver efficacy, promoting bi-directional communication) compared to evaluating clinicians' use of SPIRIT specific tools. Although all clinicians implemented some of the SPIRIT strategies at pre-training (e.g., providing expectations for the evaluation, noting consistencies between what caregivers reported and what was observed, asking caregivers if their child's performance was typical), their use of the SPIRIT strategies increased significantly post-training. Furthermore, clinicians in this study implemented specific SPIRIT tools with greater frequency than clinicians in the pilot study. Specifically, in the pilot study (Haine-Schlagel et al., 2022), clinicians used the Service Path Tool 58% of the time

and the Enhanced Patient Instructions 63% of the time. In the present study, clinicians' use of the Service Path Tool increased to 70%. The Enhanced Patient Instructions were revised significantly during the iterative design process and renamed Post Evaluation Handouts, and clinicians used these handouts 100% of the time at post-training in the present study. These data may suggest that refinements made as part of the iterative design addressed concerns raised by participants of the pilot study—and this aligns with past scholarship highlighting the importance of iterative design processes in developing interventions or other clinical tools (Doolittle & Buckley, 2024; Kwasnicka et al., 2021, & Koerner, 2016). It is also possible the clinicians in this study readily adopted SPIRIT steps and strategies post-training to a high degree given their level of training and experience.

The utility of self-report measures in research as a methodology is mixed in the literature. While some studies suggest that self-report can be commensurate with direct observation (Khoury et al., 2019; Hogue et al., 2021), others contend that self-report fidelity may not be reliable or accurate (Fiske, 2008; Lillehoj et al., 2004; McLeod et al., 2022), or that it may vary by intervention (Hogue et al., 2015). Therefore, it is important for any study utilizing self-report fidelity measures to also obtain direct observation and examine reliability between the two types of measurement. Self-rater and direct observation in this study showed high levels of inter-rater agreement on average (94%) at post-training observations. This is notable given that inter-rater reliability between self-rater and direct observation has not been evaluated for the SPIRIT toolkit. These data may suggest that revisions made to the SPIRIT fidelity checklist strengthened the objectivity of each item and in turn increased the probability of clinicians being able to reliably monitor their own fidelity. Most items with lower levels of agreement (70% or less) were strategies under the “Start Off on the Right Foot” step of the SPIRIT toolkit. This may

suggest that further refinements may be needed to this portion of the fidelity checklist to ensure these items are able to be reliably rated between self-report and direct observation.

Social validity is important to consider for any intervention because interventions are not likely to be used or have long-term effects if they are not deemed to be socially valid (i.e., feasible, acceptable, appropriate) (Klaic et al., 2022; Proctor et al., 2011). The pilot SPIRIT study (Haine-Schlagel et al., 2022) showed that clinicians had overall moderate to high ratings of social validity. Specifically, clinicians found the original toolkit to be acceptable ( $M = 4.36$ ), appropriate in their setting ( $M = 4.5$ ), and feasible to use in practice ( $M = 4.21$ ). The Parent Profiles were indicated to be the most useful elements of the toolkit. Participants also indicated that the length or complexity—and the inability to edit or tailor the Enhanced Patient Instructions—made it challenging to use with families. In the present study, clinicians who completed the social validity scale generally found the SPIRIT toolkit (with the revised tools) to be socially valid. Although the social validity measures in both studies were different, this study found similarly positive ratings of the toolkit's acceptability ( $M = 4.29$ ), appropriateness ( $M = 4.43$ ), and feasibility ( $M = 4.25$ ). When asked what clinicians would keep about the SPIRIT toolkit, most participants responded favorably to the Parent Profiles and noted their usefulness for helping clinicians tailor their feedback based on caregivers' emotional needs. This is consistent with the pilot study, which found the Parent Profiles to be the most useful of the SPIRIT toolkit materials. In the current study, participants noted they would reduce the number of papers necessary for the toolkit and increase the editability of the Service Path Tool. This finding is also consistent with participant responses in the pilot study. One clinician also suggested that the fidelity checklist could be reduced to a few essential items and another clinician stated they would like a version in Spanish and a version to use for adults who are the

receiver of their own feedback (rather caregivers receiving feedback about their child). These comments may suggest the need for further refinements or adaptations of the toolkit to use with other populations.

### **Limitations**

Despite promising findings, additional research is needed to address key limitations of the present study as well as an overall sparse literature-base in the area of supporting clinicians with providing feedback to clients. There are several limitations pertaining to the fidelity data. The participants of the present study are autism specialist level clinicians. Given their advanced training, it may be possible that the clinicians in this study adopted the SPIRIT strategies more readily or to a level higher than might be expected for other clinicians with less specialized training. Furthermore, the clinicians in the present study are employed at an academic medical center that frequently conducts research and emphasizes the implementation of evidence-based interventions. As a result, it is possible the participants of this study may be more accustomed to adhering to fidelity protocols.

Regarding the collection of fidelity data, only one fidelity observation was conducted pre- and post-training. Clinicians' practice and implementation varies, and the use of a single rating pre- and post- training may over or under-estimate clinician's use of the SPIRIT toolkit. The one participant who did not implement the toolkit with 80% fidelity at the post-training observation was close to this threshold (77.6%), and three participants implemented with fidelity just above cutoff with fidelity ranging from 80%-82.2%. It is possible that these clinicians could have implemented with adequate or inadequate levels of fidelity in a different session.

Additionally, the timing of post-observation data collection varied for every participant due to

several mitigating factors (e.g., time constraints, scheduling issues, a natural disaster, limited observers).

The limited number of research team members trained in the SPIRIT fidelity checklist also limited the number of inter-rater reliability data collected between the two research team members who conducted SPIRIT fidelity observations. Relatedly, agreement between these observers was only collected for pre-training observations. Although the agreement between research team members was high (94%), the percentage of inter-rater reliability data points is less than what is sometimes recommended in related scholarship. According to What Works Clearinghouse (2022), inter-rater reliability should be collected for at least 20% of the data points. The present study only collected inter-rater for 15% of the data points.

Due to the small sample size and the fact one of the developers of the SPIRIT toolkit was the trainer and clinical director of the participants, demographic information was not collected to protect participant confidentiality. Therefore, this study was unable to investigate whether demographic variables (such as clinicians' years of experience) contributed to changes in implementation of the SPIRIT strategies pre-training and post-training. Relatedly, participant IDs were not collected on social validity surveys to protect participant anonymity and elicit honest feedback. Consequently, clinicians' responses to the social validity survey were not able to be linked to their fidelity data. For this reason, this study was unable to investigate whether clinician ratings of social validity related to changes in their use of the SPIRIT steps and strategies pre-training and post-training. Another limitation with the social validity survey is that only 70% of participants responded. It is unknown, but possible, that the participants who did not respond may have had less favorable perspectives of the SPIRIT toolkit but may not have been comfortable with sharing that feedback. For this reason, and because surveys are inherently

subject to social desirability bias, clinicians may have responded in a way they believed would be more favorable to the researchers.

### **Directions for Future Research**

This was the first quasi-experimental study of the SPIRIT toolkit. Future research would benefit from a more robust methodology to strengthen the research base of the SPIRIT toolkit. For example, the study design could include the use of a control group (i.e., a group of clinicians who are not trained in the SPIRIT toolkit) to strengthen the internal validity of the findings. Future research should also aim to collect at least two data points pre- and post-training to even better assess clinicians' use of the SPIRIT toolkit. Furthermore, future studies may wish to collect demographic information from clinicians (e.g., years of education, licensure/credentials, years of experience, age), as this would allow for the investigation of potential differentiated baseline levels or differences in the change of clinician practices after receiving SPIRIT training.

Participants for this study were clinicians at an academic medical center specializing in autism evaluations and interventions and are therefore not representative of the field at large. Feedback is delivered in many fields (e.g., education, mental health, healthcare) by various types of professionals (e.g., educators, social workers, speech language pathologists, medical doctors). Future studies should recruit larger and more diverse samples of participants (clinicians in general outpatient clinics, in community-based mental health clinics, hospitals, etc.) to increase the generalizability of the findings. For example, future research could explore whether the toolkit could be useful for providing feedback regarding special education eligibility in schools, diagnosing internalizing/externalizing disorders in outpatient settings, or providing medical feedback in hospital settings. Additionally, assessments can be conducted by teams and feedback may be given by more than one individual in other settings (i.e., schools, multi-disciplinary

clinics). It is worth exploring in future studies whether the SPIRIT toolkit can be used when feedback is provided by a group or team of providers.

One of the major goals of the SPIRIT toolkit is to increase caregiver satisfaction and engagement in feedback to increase utilization of recommended services following a diagnosis of autism (Haine-Schlagel et al., 2022). The scope of this study was limited to exploring whether the SPIRIT training was sufficient in increasing clinician practices, the reliability of self-report fidelity, and clinician perceptions of the toolkit. Therefore, it is unknown from this study whether use of the toolkit is socially valid for caregivers, or whether it increases service utilization. Future studies should look to examine whether implementation of the SPIRIT toolkit increases caregiver satisfaction, engagement, and utilization of recommended to services. The SPIRIT toolkit guides clinicians to identify a Parent Profile based on various observable parent characteristics. For example, the SPIRIT toolkit identifies a “sad” profile for caregivers who may be crying or sharing negative thoughts or worries. However, the literature on SPIRIT has not explored whether clinicians’ identification of a Parent Profile matches what a caregiver would self-identify as their emotional state during the delivery of the diagnosis or recommendations. Given that the SPIRIT toolkit provides differentiated strategies for tailoring the delivery of the diagnosis and communication of recommendations by the Parent Profile, it may be worth exploring whether caregivers’ self-reported profile is consistent with clinicians’ identified Parent Profile.

Future research may also benefit from exploring the adaptability of the SPIRIT toolkit. Although information about the families were not collected for this study, the observations were restricted to English-speaking families because the SPIRIT materials were only available in English, which is one limitation that was even noted by a clinician in the survey. It would be

beneficial for future research with SPIRIT to translate SPIRIT materials and evaluate whether the SPIRIT toolkit can be feasibly implemented in languages other than English, or whether it can be implemented when clients and clinicians who do not speak the same language. This is particularly important given the research that shows that linguistically diverse families experience difficulties with communication during feedback. For example, linguistically diverse parents report that clinician's do not effectively communicate the need for diagnosis or services (Boshoff et al., 2019) and may incorrectly assume mutual understanding (Meeuwesen et al., 2007). The SPIRIT toolkit was also specifically designed for delivering feedback regarding an ASD diagnosis for young children. However, it is unexplored whether the SPIRIT toolkit could be adapted for use with adult clients as the receiver of feedback (rather than to use when providing feedback to caregivers of a child client), or when ASD is not a diagnostic question (e.g., for diagnosing an internalizing disorder or other neurodevelopmental disorders such as attention-deficit hyperactivity disorder).

Lastly, the literature would benefit from investigating the training practices for the SPIRIT toolkit. Clinicians in this study were trained to use the toolkit with a one-time, two-hour training. One participant who did not meet the threshold for adequate fidelity (80%) implemented with 77.6% fidelity to the toolkit, and three participants implemented with fidelity ranging from 80% - 82.2%. Some research suggests that short, one-day training or professional development may not be sufficient (or less impactful) at increasing intervention fidelity (Darling-Hammond et al., 2017). The use of coaching can be effectively used to improve the fidelity of evidence-based interventions (Durling et al., in press; Kretlow & Bartholomew, 2010). Studies could be conducted to evaluate whether additional coaching or support sessions are beneficial to increase levels of implementation of SPIRIT following training, or whether other methods of

training (e.g., self-study) are effective for achieving adequate fidelity. This may be especially worth investigating given that, in this study, the items implemented with the lowest frequency at pre-training were also implemented with the lowest frequency post-training.

### **Implications for Research**

Despite methodological limitations, the results of the present study may offer valuable implications for research. The current study showed that after a one-time training, most participants could be trained to achieve adequate levels of fidelity ( $\geq 80\%$ ). This is important given that little to no research exists examining structured feedback models, and to date there is only one other study of the SPIRIT toolkit. The SPIRIT toolkit was designed to address concerns that children with ASD may not be receiving recommended services following feedback (Chiri & Warfield, 2012; Shivers et al., 2019) by training clinicians to tailor their feedback. This study adds to the growing literature about individualized feedback practices, which sets the foundation for exploring the effects of such practices on client satisfaction, engagement, and utilization of recommended services.

The current study is also important because it explores whether self-report fidelity to the SPIRIT toolkit is reliable with direct observation. Findings of the present study showed high levels of agreement between self-report and direct observation. The high level of agreement between self-report and direct observation fidelity measurements may suggest that the fidelity checklist was refined to reduced subjectivity in such a way that a clinician and observer could reliably agree on whether a step was implemented. This may also mean that the use of self-report fidelity may be a viable tool to measure fidelity (or add additional data points) to the SPIRIT toolkit in future research.

Although the use of SPIRIT specific tools increased from the pilot study, the use of specific SPIRIT tools was not unanimous at post-training, and some comments were given about improvements that could be made to these tools. Themes from open-ended questions on the survey indicate targeted areas of improvement for future research, such as reducing the amount of paper required, increasing editability of the Service Pathway, reducing items on the fidelity checklist, and translating the toolkit or creating other versions. Clinician feedback from the present study suggest that while social validity of the toolkit was overall positive, and tools refined through the iterative process showed increased frequency of implementation from the pilot study, further refinement of the tools may be helpful.

### **Implications for Practice**

The findings of the present study may also have relevant implications for clinical practice. Despite already using some of the strategies in the SPIRIT toolkit at the pre-training observation, the clinicians' increase in these strategies were significant following SPIRIT training. This suggests that SPIRIT training may be value-added to clinicians' feedback practices, even if they implement some strategies pre-training. This study also addresses gaps in practice that clinicians do not receive training in their graduate programs or don't find the training they receive helpful (Curry and Hanson, 2010; Lenkiewicz et al., 2022; Lima et al., 2023; Merker et al., 2010). In fact, two participants made comments on the social validity questionnaire that the toolkit would be useful for training students or new clinicians.

The increased implementation of the specific SPIRIT tools (i.e., the Post Evaluation Handouts) may suggest that the revisions made as part of the iterative design process were beneficial in addressing some of the suggestions from the pilot study. Even though the Service Path Tool was not revised as part of the iterative design, participants in the current study

implemented it more frequently at post-training than clinicians in the pilot study. The high levels of inter-rater reliability between clinician self-report and direct observation fidelity may also suggest that the revised fidelity checklist could be used as a tool for clinicians to monitor their fidelity to the SPIRIT toolkit in practice.

Social validity is especially important when investigating the practices of clinicians who are tasked with many roles and responsibilities during evaluations and feedback sessions. For clinicians like those in this study, they must often complete evaluations and deliver feedback in the same day, with approximately an hour break in between the assessment and feedback to score assessments, make diagnoses, pull together resources for families, and to decide the best approach to delivering feedback to families, social validity is ever more important. This study is important because it suggests that using the SPIRIT toolkit, even in these types of conditions, may be socially valid during clinical practice.

## **CHAPTER 5**

### **CONCLUSION**

Delivering feedback is an emotionally, culturally, and interpersonally complex process. The SPIRIT toolkit is one structured toolkit to help clinicians tailor ASD feedback to increase caregiver engagement and satisfaction with feedback, with the goal of increasing caregiver utilization of recommended services. The pilot SPIRIT study showed that, overall, clinicians had positive perceptions of the toolkit, but felt some tools may need revisions to be useful for families. The present study evaluated clinicians' use of the toolkit with the revised tools. This study showed that autism specialist level clinicians can be trained to deliver the SPIRIT toolkit with adequate fidelity. Clinicians also demonstrated strong inter-rater reliability between self-rater and observer-rater fidelity. Findings for this study show some initial evidence for the social validity of the toolkit. More research is needed to investigate the use of the SPIRIT toolkit and evaluate its social validity.

## REFERENCES

- Abbott, M., Bernard, P., & Forge, J. (2013). Communicating a diagnosis of autism spectrum disorder – A qualitative study of parents’ experiences. *Clinical Child Psychology and Psychiatry, 18*(3), 370–382. <https://doi.org/f4865v>
- Anderberg, E. & South, M. (2021). Predicting parent reactions at diagnostic disclosure sessions for autism. *Journal of Autism and Developmental Disorders, 51*, 3533-3546. <https://doi.org/10.1007/s10803-020-04817-5>
- Armstrong, M. J., Bedenfield, N., Rosselli, M., Curiel Cid, R. E., Kitaigorodsky, M., Galvin, J. E., ... & Bylund, C. L. (2024). Best practices for communicating a diagnosis of dementia: results of a multi-stakeholder modified delphi consensus process. *Neurology: Clinical Practice, 14*(1), 1-10. <https://doi.org/n96p>
- Autism Speaks (2012, September). *Providers guide to effective communication with families affected by autism*. Autism Speaks. <https://www.autismspeaks.org/tool-kit/providing-feedback-families-affected-autism>
- Bond, G. R., & Drake, R. E. (2020). Assessing the fidelity of evidence-based practices: History and current status of a standardized measurement methodology. *Administration and Policy in Mental Health and Mental Health Services Research, 47*(6), 874-884. <https://doi.org/gk4pxx>
- Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2018). A meta-synthesis of how parents of children with autism describe their experience of advocating for their children during the process of diagnosis. *Health & Social Care in the Community, 27*(4). <https://doi.org/gnf9mz>

- Brown, J. A., Taffe, B. D., Richmond, J. A., & Roberson, M. L. (2024). Racial discrimination and health-care system trust among American adults with and without cancer. *Journal of the National Cancer Institute*, 116(11), 1845-1855. <https://doi.org/n7pq>
- Casagrande, S. S., Gary, T. L., LaVeist, T. A., Gaskin, D. J., & Cooper, L. A. (2007). Perceived discrimination and adherence to medical care in a racially integrated community. *Journal of General Internal Medicine*, 22, 389-395. <https://doi.org/bfm3gd>
- Center for Disease Control and Prevention (2023). *Data and statistics on ASD*. <https://www.cdc.gov/ncbddd/autism/data.html>
- Chiri, G. & Warfield, M. E. (2012). Unmet need and problems accessing core health services for children with autism spectrum disorder. *Maternal and Child Health Journal*, 16, 1081-1091. <https://doi.org/d86bxs>
- Connolly, M. & Gersch, I. (2013). A support group for parents of children on a waitlist for an assessment for autism spectrum disorder. *Educational Psychology in Practice*, 29(3), 293-308. <https://doi.org/gpczt5>
- Curry, K. T. & Hanson, W.E. (2010). National survey of psychologists' test feedback training, supervision, and practice: A mixed methods study. *Journal of Personality Assessment*, 92(4), 327-336. <https://doi.org/bcbqff>
- Darling-Hammond, L., Hyler, M. E., Gardner, M., & Espinoza, D. (2017). *Effective teacher professional development*. Learning Policy Institute. <https://learningpolicyinstitute.org/product/teacher-prof-dev>
- Dawson, G. & Burner, K. (2011). Behavioral interventions in children and adolescents with autism spectrum disorder: A review of recent findings. *Current Opinion in Pediatrics*, 23(6), 616-620. <https://doi.org/b3w844>

- Doolittle, E. J., & Buckley, J. A. (2024). Supporting Innovative Scalable Approaches to School-Based Mental Health: Development and Innovation Research at the US Department of Education's Institute of Education Sciences (IES). *School Mental Health, 16*(3), 913-918. <https://doi.org/pdhh>
- Durlak, J. A., & DuPre, E. P. (2008). Implementation matters: A review of research on the influence of implementation on program outcomes and the factors affecting implementation. *American Journal of Community Psychology, 41*, 327-350. <https://doi.org/gqg>
- Durling, J. M., Begeny, J. C., Wang, J., O'Neal, C.S., & Musti, S. (in press). Effects of V-COACH, a virtual coaching model in supporting pre-service teachers' implementation of a virtual evidence-based reading intervention. *Journal of School Psychology*.
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., ... & Barry, M. (2012). Shared decision making: a model for clinical practice. *Journal of General Internal Medicine, 27*, 1361-1367. <https://doi.org/f393r9>
- Estes, A., Munson, J., Rogers, S. J., Greenson, J., Winter, J., Dawson, G. (2015). Long-term outcomes of early intervention in 6-year-old children with autism spectrum disorder. *Journal of the American Academy of Child & Adolescent Psychiatry, 54*(7), 580-587. <https://doi.org/f3g6mw>
- Fisher, A. P., & Lynch, J. D. (2024). Differences between Black and White caregivers in the association between autism diagnostic process satisfaction and service use. *Journal of Autism and Developmental Disorders, 1-13*. <https://doi.org/g5w3c7>
- Fiske, K. E. (2008). Treatment integrity of school-based behavior analytic interventions: A review of the research. *Behavior Analysis in Practice, 1*(2), 19-25.

- Fernández-Ávalos, M. I., Pérez-Marfil, M. N., Ferrer-Cascales, R., Cruz-Quintana, F., & Fernández-Alcántara, M. (2021). Feeling of grief and loss in parental caregivers of adults diagnosed with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 34(3), 712-723. <https://doi.org/n96k>
- Graungaard, A. H. & Skov, L. (2006). Why do we need a diagnosis? A qualitative study of parents' experiences, coping and needs, when the newborn child is severely disabled. *Child: Care, Health, and Development*, 33(3), 296-307. <https://doi.org/d5cq9>
- Girio, E. L. (2010). *Kindergarten screening and parent engagement to enhance mental health service utilization* [Doctoral dissertation, Ohio University]. Ohio University Thesis and Dissertation Services.  
[https://etd.ohiolink.edu/apexprod/rws\\_etd/send\\_file/send?accession=ohiou1283178607&disposition=inline](https://etd.ohiolink.edu/apexprod/rws_etd/send_file/send?accession=ohiou1283178607&disposition=inline)
- Haine-Schlagel R., Corsello, C., Caplan, B., Gould, H., & Brookman-Frazee, L. (2022). Setting families up for success: A pilot study of a toolkit to Enhance the autism spectrum disorder diagnostic evaluation process. *Journal of Autism and Developmental Disabilities*, 1-10. <https://doi.org/h7vc>
- Hausmann, L. R. M., Kwoh, C. K., Hannon, M. J., & Ibrahim, S. A. (2013). Perceived racial discrimination in health care and race differences in physician trust. *Race and Social Problems*, 5(2), 113-120. <https://doi.org/n7pk>
- Hayes, N., Bagley, K., Hewlett, N., Elliott, E. J., Pestell, C. F., Gullo, M. J., ... & Reid, N. (2023). Lived experiences of the diagnostic assessment process for fetal alcohol spectrum disorder: A systematic review of qualitative evidence. *Alcohol: Clinical and Experimental Research*, 47(7), 1209-1223. <https://doi.org/n96m>

- Hayes, S., Hirsch, C., & Mathews, A. (2008). Restriction of working memory capacity during worry. *Journal of Abnormal Psychology, 117*, 712–717. <https://doi.org/c77992>
- Hennel, S., Coates, C., Symeonides, C., Gulenc, A., Smith, L., Price, A. MH., and Hiscock H. (2016). Diagnosing autism: Contemporaneous surveys of parent needs and paediatric practice. *Journal of Paediatrics and Child Health, 52*, 506–511. <https://doi.org/10.1111/jpc.13157>
- Hogue, A., Bobek, M., Porter, N., MacLean, A., Bruynesteyn, L., Jensen-Doss, A., & Henderson, C. E. (2021). Therapist self-report of fidelity to core elements of family therapy for adolescent behavior problems: Psychometrics of a pragmatic quality indicator tool. *Administration and Policy in Mental Health and Mental Health Services Research, 49*, 298-311. <https://doi.org/gpg3c2>
- Hogue, A., Dauber, S., Lichvar, E., Bobek, M., & Henderson, C. E. (2015). Validity of therapist self-report ratings of fidelity to evidence-based practices for adolescent behavior problems: Correspondence between therapists and observers. *Administration and Policy in Mental Health and Mental Health Services Research, 42*(2), 229-243. <https://doi.org/f64btr>
- Holliday, E. L., Stanley, H. C., Fodstad, J. C., & Minshawi, N. F. (2016). Stress and Satisfaction in the Diagnostic Process. In *Handbook of Assessment and Diagnosis of Autism Spectrum Disorder* (pp. 137-155). Springer, Cham.
- Holm-Denoma, J. M., Gordon, K. H. Donohue, K. F., Waesche, M. C., Castro, Y., Brown, J. S., Jakobsons, L. J., Merrill, K. A., Buckner, J. D., & Joiner, T. E. (2008). Patients' affective reactions to receiving diagnostic feedback. *Journal of Social and Clinical Psychology, 27*(2), 555-575.

- Jackson, L., Keville, S., & Ludlow, A. K. (2020). Mothers' experiences of accessing mental health care for their child with an autism spectrum disorder. *Journal of Child and Family Studies, 29*, 534-54. <https://doi.org/10.1007/s10826-019-01662-8>
- Jashar, D. T., Fein, D., Berry L. N., Burke, J. D., Miller, L. E., Barton, M. L., & Dumont-Mathieu, T. (2019). Parental perceptions of a comprehensive diagnostic evaluation for toddlers at risk for autism spectrum disorder. *Journal of Autism and Developmental Disorders, 49*, 1763-1777. <https://doi.org/10.1007/s10803-018-3851-z>
- Klaic, M., Kapp, S., Hudson, P., Chapman, W., Denehy, L., Story, D., & Francis, J. J. (2022). Implementability of healthcare interventions: an overview of reviews and development of a conceptual framework. *Implementation Science, 17*(1), 10. <https://doi.org/gtfk5x>
- Khoury, C. R., McIntosh, K., & Hoselton, R. (2019). An investigation of concurrent validity of fidelity of implementation measures at initial years of implementation. *Remedial and Special Education, 40*(1), 25-31. <https://doi.org/ktvb>
- Kretlow, A. G., & Bartholomew, C. C. (2010). Using coaching to improve the fidelity of evidence-based practices: A review of studies. *Teacher Education and Special Education, 33*(4), 279-299. <http://doi.org/fqhxgs>
- Kwasnicka, D., Ten Hoor, G. A., Hekler, E., Hagger, M. S., & Kok, G. (2021). Proposing a new approach to funding behavioural interventions using iterative methods. *Psychology & Health, 36*(7), 787-791. <https://doi.org/pddn>
- Lenkiewicz, J., Lenkiewicz, O., Trzcíński, M., Sobczak, K., Plenikowski, J., Przeniosło, J., & Kotłowska, A. (2022). Delivering bad news: Self-assessment and educational preferences of medical students. *International Journal of Environmental Research and Public Health, 19*(5), 2622. <https://doi.org/gsjqhh>

- Lillehoj, C. J., Griffin, K. W., & Spoth, R. (2004). Program provider and observer ratings of school-based prevention intervention implementation: Agreement and relation to youth outcomes. *Health Education & Behavior, 31*(2), 242-257. <https://doi.org/bbkjsp>
- Lima, T. A. C. D., Bruno, F. P., Gushken, F., Degani-Costa, L. H., & Novaes, N. P. (2023). Breaking bad news in neurology: Assessing training, perceptions, and preparedness among residency programs in Brazil. *Einstein (São Paulo), 21*. <https://doi.org/n966>
- Lyon, A. R., & Koerner, K. (2016). User-centered design for psychosocial intervention development and implementation. *Clinical Psychology: Science and Practice, 23*(2), 180. <https://doi.org/gjksk2>
- Meeuwesen, L., Harmsen, J. A. M., Bernsen, R. M. D., & Bruijnzeels, M. A. (2006). Do Dutch doctors communicate differently with immigrant patients than with Dutch patients. *Social Sciences & Medicine, 63*, 2407-2417. <https://doi.org/dfqgh>
- Meeuwesen, L., Tromp, F., Schouten, B. C., & Harmsen, J.A.M. (2007). Cultural differences in managing information during medication interaction: How does the physician get a clue? *Patient Education and Counseling, 67*, 183-190. <https://doi.org/b26nhr>
- Merker, B., Hanson, W. E., & Poston, J. M. (2010). National survey of psychologists' training and practice in breaking bad news: A mixed methods study of the MUM effect. *Journal of Clinical Psychology in Medical Settings, 17*, 211-219. <https://doi.org/df64hp>
- McGough, J., L. (2000). Memory – A century of consolidation. *Science, 287*(5451), 248-251. <https://www.jstor.org/stable/3074478>
- McLeod, B. D., Sutherland, K. S., Broda, M., Granger, K. L., Cecilione, J., Cook, C. R., Conroy, M. A., Snyder, P. A., & Southam-Geriw M. A. (2022). Examining the correspondence

- between teacher- and observer-report treatment integrity measures. *School Mental Health, 14*, 20-34. <https://doi.org/ks6z>
- Moran, T., P. (2016). Anxiety and working memory: A meta-analysis and narrative review. *Psychological Bulletin, 142*(8), 831-864. <https://doi.org/f8xcjw>
- Mulligan, J., Macculloch, R., Good, B., & Nicholas, D. B. (2012). Transparency, hope, and empowerment: A model for partnering with parents of a child with autism spectrum disorder at diagnosis and beyond. *Social Work in Mental Health, 10*, 311–330. <https://doi.org/10.1080/15332985.2012.664487>
- Musa, D., Schulz, R., Harris, R., Silverman, M., & Thomas, S. B. (2009). Trust in the health care system and the use of preventative health services by older black and white adults. *American Journal of Public Health, 99*(7), 1293-1299.
- Nelson Goff, B. S., Springer, N., Foote, L. C., Frantz, C., Peak, M., Tracy, C., Veh, T., Bentley, G. E., & Cross, K. A. (2013). Receiving the initial Down Syndrome diagnosis: A comparison of prenatal and postnatal parent group experiences. *Intellectual and Developmental Disabilities, 51*(6), 446-457. <https://doi.org/f5pwsn>
- Ooi, K. L., Ong, Y. S., Jacob, S. A., & Khan, T. M. (2016). A meta-synthesis on parenting a child with autism. *Neuropsychiatric Disease and Treatment, 12*, 745-762. <https://doi.org/10.2147/NDT.S100634>
- Osborne, L. A., & Reed, P. (2008). Parents' perceptions of communication with professionals during the diagnosis of autism. *Autism, 12*(3), 309–324.
- Ozkaya, E., Eker, H. H., & Aycan, N. (2010). Impact of maternal anxiety level on the childhood vaccination coverage. *European Journal of Pediatrics, 169*, 1397-1401. <https://doi.org/bwtsz3>

- Pattinson, E., Ure, A., Mattiga, S. R., Williams, K., and Freeman, N. C. (2021). The feedback session of an autism assessment: A scoping review of clinical practice guideline recommendations. *Journal of Autism and Developmental Disorders*, 52, 1821-2840. <https://doi.org/10.1007/s10803-021-05067-9>
- Pearson, J. N. & Meadan, H. (2018). African American parents' perceptions of diagnosis and services for children with autism. *Education and Training in Autism and Developmental Disabilities*, 53(1), 17-32.
- Postal, K. & Armstrong, K. (2013). *Feedback that sticks: The art of communicating neuropsychological assessment results*. Oxford University Press.
- Proctor, E., Silmere, H., Raghavan, R., Hovmand, P., Aarons, G., Bunger, A., Griffey, R., & Hensley, M. (2011). Outcomes for implementation research: Conceptual distinctions, measurement challenges, and research agenda. *Administration and Policy in Mental Health Services Research*, 36, 65-76. <https://doi.org/d5tnwq>
- Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies*, 21, 311-319. <https://doi.org/dntjx7>
- Schertz, H. H., Odom, S. L., Baggett, K. M., & Sideris, J. H. (2013). Effects of joint attention mediated learning for toddlers with autism spectrum disorders: An initial randomized controlled study. *Early Childhood Research Quarterly*, 28, 249-258. <https://doi.org/f4vx7t>
- Shivers, C. M., Sonnier-Netto, L., & Lee, G. K. (2019). Needs and experiences of family caregivers of individuals with autism spectrum disorders across the lifespan. *Journal of*

*Policy and Practice in Intellectual Disabilities*, 16(1), 21–29. <https://doi.org/10.1111/jppi.12272>

Smith, S. R., Wiggins, C. M., & Gorske, T. T. (2007). A survey of psychological assessment feedback practices. *Assessment*, 14(3), 310-319. <https://doi.org/bx2h83>

Smith-Young, A., Chafe, R., & Audas, R. (2019). “Managing the wait”: Parents’ experiences in accessing diagnostic and treatment services for children and adolescents diagnosed with autism spectrum disorder. *Health Services Insights*, 13, 1-10. <https://doi.org/kb2t>

Sorkin, D. H., Ngo-Metzger, Q., & De Alba, I. (2010). Racial/ethnic discrimination in health care: Impact on perceived quality of care. *Journal of General Internal Medicine*, 25(5), 390-396. <https://doi.org/d6cbqw>

Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, P. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities*, 20(1), 39-51.

Suurmond, J. & Seeleman, C. (2006). Shared decision-making in an intercultural context: Barriers in the interaction between physicians and immigrant patients. *Patient Education and Counseling*, 60, 253-259. <https://doi.org/cqps44>

Tharinger, D. J., Finn, S. E., Hersh, B., Wilkinson A., Christopher, G. B., & Tran, A. (2008). Assessment feedback with parents and preadolescent children: A collaborative approach. *Professional Psychology: Research and Practice*, 39(6), 600-609. <https://doi.org/fk69gd>

Weiner, B. J., Lewis, C. C., Stanick, C., Powell, B. J., Dorsey, C. N., Clary, A., Boynton, M. H., & Halko, H. (2017). Psychometric assessment of three newly developed implementation outcome measures. *Implementation Science*, 12(108), 1-12. <https://doi.org/ggds32>

- Wergeland, G. J. J., Posserud, M.B., Fjermestad, K., Njardvik, U., Ost, L. G. (2022). Early behavioral interventions for children and adolescents with autism spectrum disorder in routine clinical care: A systematic review and meta-analysis. *Clinical Psychology: Science and Practice*, 29(4), 400-414. <https://doi.org/10.1037/cps0000106>
- What Works Clearinghouse. (2022). What Works Clearinghouse procedures and standards handbook, Version 5.0. U.S. Department of Education, Institute of Education Sciences, National Center for Education Evaluation and Regional Assistance (NCEE). [https://ies.ed.gov/ncee/wwc/Docs/referenceresources/Final\\_WWC-HandbookVer5.0-0-508.pdf](https://ies.ed.gov/ncee/wwc/Docs/referenceresources/Final_WWC-HandbookVer5.0-0-508.pdf)
- Wilczynski, S. M. (2017). *A practical guide to finding treatments that work for people with autism*. Academic Press.
- Wright, A. J. (2020). *Conducting psychological assessment: A guide for practitioners* (2<sup>nd</sup> ed.). John Wiley & Sons.
- Zuckerman, K. E., Lindly, O. J., & Sinche, B. (2016). Parent beliefs about the causes of learning and developmental problems among children with autism spectrum disorder: Results from a national survey. *American Journal on Intellectual and Developmental Disabilities*, 121(5), 432-447.

**Table 1.1***Clinicians' Fidelity to the SPIRIT Toolkit Pre- and Post-Training*

Participant	Pre-Training Observation <sup>1</sup>	Post-Training Observation <sup>1</sup>	Weeks Between Training and Post Observation	Change Between Pre- and Post- Training			
1	56.5%	81.3%	9	24.7%			
2	57.5%	82.2%	18	24.8%			
3	60.9%	88.9%	11	28.0%			
4	60.0%	77.6%	32	17.6%			
5	74.5%	93.4%	3	19.0%			
6	72.3%	91.5%	16	19.2%			
7	56.5%	85.1%	6	28.6%			
8	60.0%	80.0%	31	20.0%			
9	65.2%	87.2%	11	22.0%			
10	63.6%	100.0%	8	36.4%			
<b>Across All Participants</b>							
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>Mdn</i>	<i>M</i>	<i>SD</i>
	62.7%	6.3%	86.7%	6.9%	11	24.0%	5.8%

<sup>1</sup> Percentages reflect the percentage of steps implemented correctly on the SPIRIT Toolkit fidelity checklist

**Table 2.1**

*Percentage Agreement of Secondary Observer and Clinician Self-Report Measures of Fidelity to SPIRIT Toolkit*

Participant	Direct Observation	Clinician Self-Report	Percentage Agreement			
1	81.3%	78.3%	94.0%			
2	82.2%	93.5%	78.0%			
3	88.9%	87.0%	88.0%			
4	77.6%	89.6%	88.0%			
5	93.4%	95.7%	90.0%			
6	91.5%	93.6%	86.0%			
7	85.1%	86.7%	96.0%			
8	80.0%	82.2%	98.0%			
9	87.2%	85.4%	90.0%			
10	100.0%	100.0%	100.0%			
<b>Across All Participants</b>						
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
	86.7%	6.9%	89.2%	6.6%	90.8%	6.5%

**Table 3.1***Social Validity of The SPIRIT Toolkit using the AIM-IAM-FIM by Item and Subscale*

<i>Subscale/Question</i>	<i>M</i>	<i>SD</i>
<b><i>Acceptability</i></b>	<b>4.29</b>	<b>0.76</b>
1. The SPIRIT toolkit meets my approval.	4.29	0.76
2. The SPIRIT toolkit is appealing to me.	4.29	0.76
3. I like the SPIRIT toolkit.	4.29	0.76
4. I welcome the SPIRIT toolkit.	4.29	0.76
<b><i>Appropriateness</i></b>	<b>4.43</b>	<b>0.61</b>
1. The SPIRIT toolkit seems fitting.	4.43	0.53
2. The SPIRIT toolkit seems suitable.	4.43	0.53
3. The SPIRIT toolkit seems applicable.	4.43	0.79
4. The SPIRIT toolkit seems like a good match.	4.43	0.79
<b><i>Feasibility</i></b>	<b>4.25</b>	<b>0.67</b>
1. The SPIRIT toolkit seems implementable.	4.14	0.69
2. The SPIRIT toolkit seems possible.	4.43	0.53
3. The SPIRIT Toolkit seems doable.	4.29	0.76
4. The SPIRIT toolkit seems easy to use.	4.14	0.90

*Note:* Measure is coded on a scale of 1 (Strongly Disagree) to 5 (Strongly Agree).

7 Survey responses were returned.

**Table 4.1***Participant Responses to Open-Ended Social Validity Questions*

Change about the SPIRIT Tools	
Theme ( <i>n</i> )	Quote(s)
Reduce paper required (2)	“When it comes to paperwork it is a lot to manage with all the other assessment processes”
	“Perhaps less papers to go through”
Editability and format of the Pathway (2)	“Wish the map was more editable”
	“The current format [of the Pathway] looks a bit busy to me”
Fidelity checklist (1)	“The fidelity checklist could be reduced to a few essential items to complete”
Other versions or translations (1)	“Translation to Spanish, and would be nice to have a different version for adolescents/ adults”
Keep for the SPIRIT Tools	
Theme ( <i>n</i> )	Quote(s)
Parent Profiles (4)	“Love the parent profiles and how to tailor feedback to what might best fit a parents' needs/where they are in thinking about the diagnosis”
	“The information about the dimension the parent is in is very helpful in structuring an approach to the interpretive session”
	“Focus on parent's emotional needs when providing feedback”
	“I would make sure to keep the part of conceptualizing parenting profile and considerations for the feedback session”
The Pathway (2)	“I love the pathways as it reinforces things the parents have achieved and where they can go next”
	“[I would make sure to keep] your path to services handout”
Usability as a training tool (2)	“I also find this to be a particularly helpful tool to use with trainees”
	“I would keep the parts related to starting off on the right foot as I think these are really important strategies for trainees to consider. Overall, it is a great training resource and a great resource for clinicians”

*Note.* 7 Survey responses were returned 6 provided written responses.

## APPENDICES

## Appendix A

### SPIRIT Sample Strategies Overview

#### **Start Off on the Right Foot**

- Set up the evaluation to maximize parent engagement
  - Always follow the *SPIRIT Start Off on the Right Foot Strategies*

#### **Pause to Plan**

- Before providing feedback, consider the parent profile of the parent(s) and evaluation goal(s) for each parent profile to create a feedback plan
  - Follow the *SPIRIT Pause to Plan Strategies*
  - Refer to the *SPIRIT Parent Profile Cheat Sheet* and *SPIRIT Parent Profile Guidelines* handout for information on parent profiles

#### **Individualize Diagnosis Communication**

- Use core strategies and individualize communication about the diagnosis if needed
  - Follow the *SPIRIT Communication about Diagnosis Core Strategies*
  - Refer to the *SPIRIT Parent Profile Cheat Sheet* and *SPIRIT Parent Profile Guidelines* handout for strategies to individualize communication about the diagnosis for different parent profiles

#### **Readjust Plan**

- Before communicating your recommendations, re-evaluate your feedback plan and adjust as needed
  - Follow the *SPIRIT Re-Adjust Plan for Communicating Recommendations Strategies*

#### **Individualize Recommendations Communication**

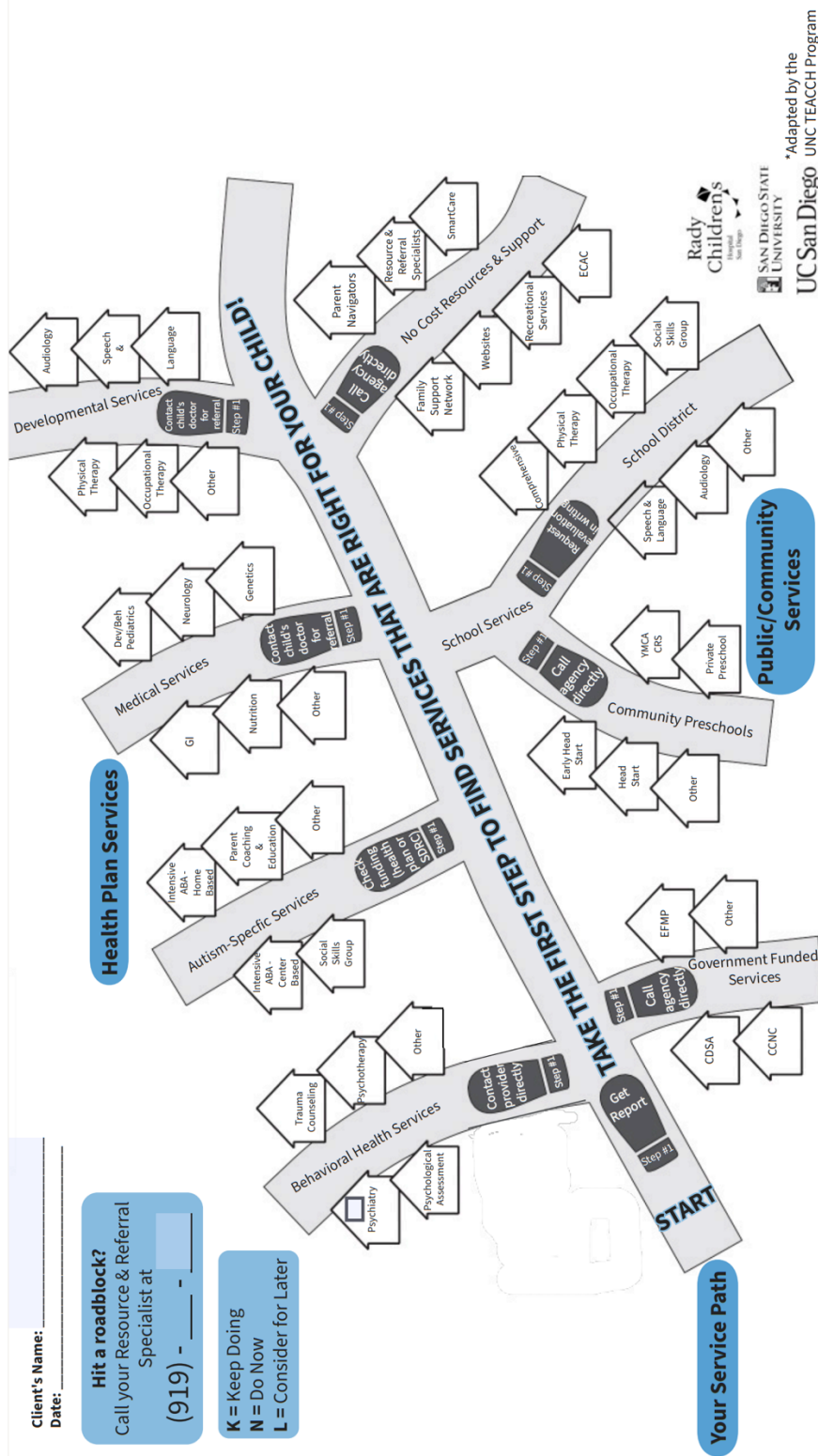
- Use core strategies and individualize communication about recommendations if needed
  - Follow the *SPIRIT Communication about Recommendations Core Strategies*
  - Refer to the *SPIRIT Parent Profile Cheat Sheet* and *SPIRIT Parent Profile Guidelines* handout for strategies to individualize communication about the recommendations for different parent profiles

#### **Thank the Parent**

- Thank the parent for being a valuable partner in the evaluation process.

# Appendix B

## SPiRiT Service Path Tool



# Appendix C

## Sample Post-Evaluation Handout

# Autism Specific Services



These services are often covered under your health plan. Some of these services may be covered under the mental health plan, but more often they are covered under the Autism Specific Benefit often referred to as ABA or ABT. This is designed to cover more intensive level of evidence-based intervention designed for children with an autism spectrum disorder. **When contacting your health plan, ask if you have specific autism benefits. You may need a copy of the comprehensive report from this evaluation as part of demonstrating eligibility for these services.**



### Social Skills Group

Your child may benefit from a social skills group designed to help children with autism spectrum disorder and other social communication challenges learn and use social and communication skills in complex social interactions. One such group is the GORILLA group which is a group run at many of the regional TEACCH Centers. Another option is:

Agency: \_\_\_\_\_  
Website: \_\_\_\_\_  
Phone: \_\_\_\_\_



### Individual Intensive Services

Your child may benefit from individual (one-on-one) intensive services to help children with autism spectrum disorder develop their social communication skills. One option is:

Agency: \_\_\_\_\_  
Website: \_\_\_\_\_  
Phone: \_\_\_\_\_



### Other Autism-Specific Service

Agency: \_\_\_\_\_  
Website: \_\_\_\_\_  
Phone: \_\_\_\_\_



### Group Intensive Services

Your child may benefit from group intensive services to help children with autism spectrum disorder develop their social communication skills. One such service is TEACCH for Toddlers. This program is designed to provide parent coaching, in home support as well as group clinic services for young children. Another option is:

Agency: \_\_\_\_\_  
Website: \_\_\_\_\_  
Phone: \_\_\_\_\_



### Parent Coaching and Education

Your child may benefit from your participation in parent coaching and education services to help you learn how to support your child's development of social communication skills. One such program is Structured TEACCHing sessions currently offered through our Regional TEACCH Centers. Another option is:

Agency: \_\_\_\_\_  
Website: \_\_\_\_\_  
Phone: \_\_\_\_\_

The TEACCH Autism Program is a comprehensive autism diagnostic and intervention program based out of The University of North Carolina in Chapel Hill that provides many of the services described below. The TEACCH program has 7 Regional Centers (<https://teacch.com/regional-centers/>) and accepts many health plans and offers services through private pay as well. Visit the webpage above to find your local center.

## Appendix D

### Sample Additional Resources Handout

# ADDITIONAL RESOURCES

## AUTISM SPECIFIC

### Autism Society of North Carolina (ASNC)

Provides advocacy, information and referral services and a wide variety of individualized, community-based programs.

1-800-442-2762

[www.autismsociety-nc.org/find-help/](http://www.autismsociety-nc.org/find-help/)



### UNC TEACCH Autism Program

Provides clinical services such as initial referral and consultation, diagnostic evaluations, family consultation sessions, parent support groups, social play and recreation groups, individual counseling, and employment services.

919-966-2174

[www.teacch.com/regional-centers/](http://www.teacch.com/regional-centers/)



### Autism Speaks

Promotes and advocates for best practices in treatment, education, and all services, from early intervention to adult care.

<https://www.autismspeaks.org/>



## FAMILY SUPPORT

### Family Support Network of North Carolina (FSN-NC)

Provides support to families of children birth to age 22 and encourages collaboration between families and service providers in the design and administration of services.



1-800-852-0042

[www.fsnn.org/](http://www.fsnn.org/)

### NC START

In home services for children, therapeutic coaching to assist family communication, improve dynamics, etc.

[www.ncdhhs.gov/divisions/mental-health-developmental-disabilities-and-substance-abuse/nc-start](http://www.ncdhhs.gov/divisions/mental-health-developmental-disabilities-and-substance-abuse/nc-start)



### First in Families of North Carolina

Helps people with disabilities and their families to achieve their current goals and plan for the future, acquire the necessary goods and services. This includes computers, furniture, child care, vehicle repairs.

252-373-7041



## DEVELOPMENTAL/DISABILITY

### NC Department of Health and Human Services

#### Vocational Rehab

Provides counseling, training, education, transportation, job placement, assistive technology, and other services. These services are provided to people with physical, psychiatric, or intellectual disabilities to assist them with living independently and with finding a job and staying on the job.

1-800-689-9090

[www.ncdhhs.gov/divisions/dvrs/vr-local-offices](http://www.ncdhhs.gov/divisions/dvrs/vr-local-offices)

#### Helpline for Children with Special Care Needs

For caregivers and professionals working with children at risk for chronic conditions that require specialized treatment and care.

1-800-737-3028

[CYSHCN.Helpline@dhhs.nc.gov](mailto:CYSHCN.Helpline@dhhs.nc.gov)



### The Children's Developmental Service Agency (CDSA)

Coordinates services, therapies, support, and more for infants and toddlers (up to age 3).

1-800-737-3082

[www.ncdhhs.gov/itp-bearable](http://www.ncdhhs.gov/itp-bearable)



### Easterseals UCP

Helps children, adults, and families living with intellectual and/or developmental disabilities (IDDs) and mental health challenges live their best possible lives.

800-662-7119

[www.eastersealsucp.com](http://www.eastersealsucp.com)



## GOVERNMENT



### Social Security Assistance

Disability Benefits (SSI, SSDI)

1-877-803-6311

[www.ssa.gov](http://www.ssa.gov)

### Department of Social Services (DSS)

919-527-6335

<https://www.ncdhhs.gov/localDSS>



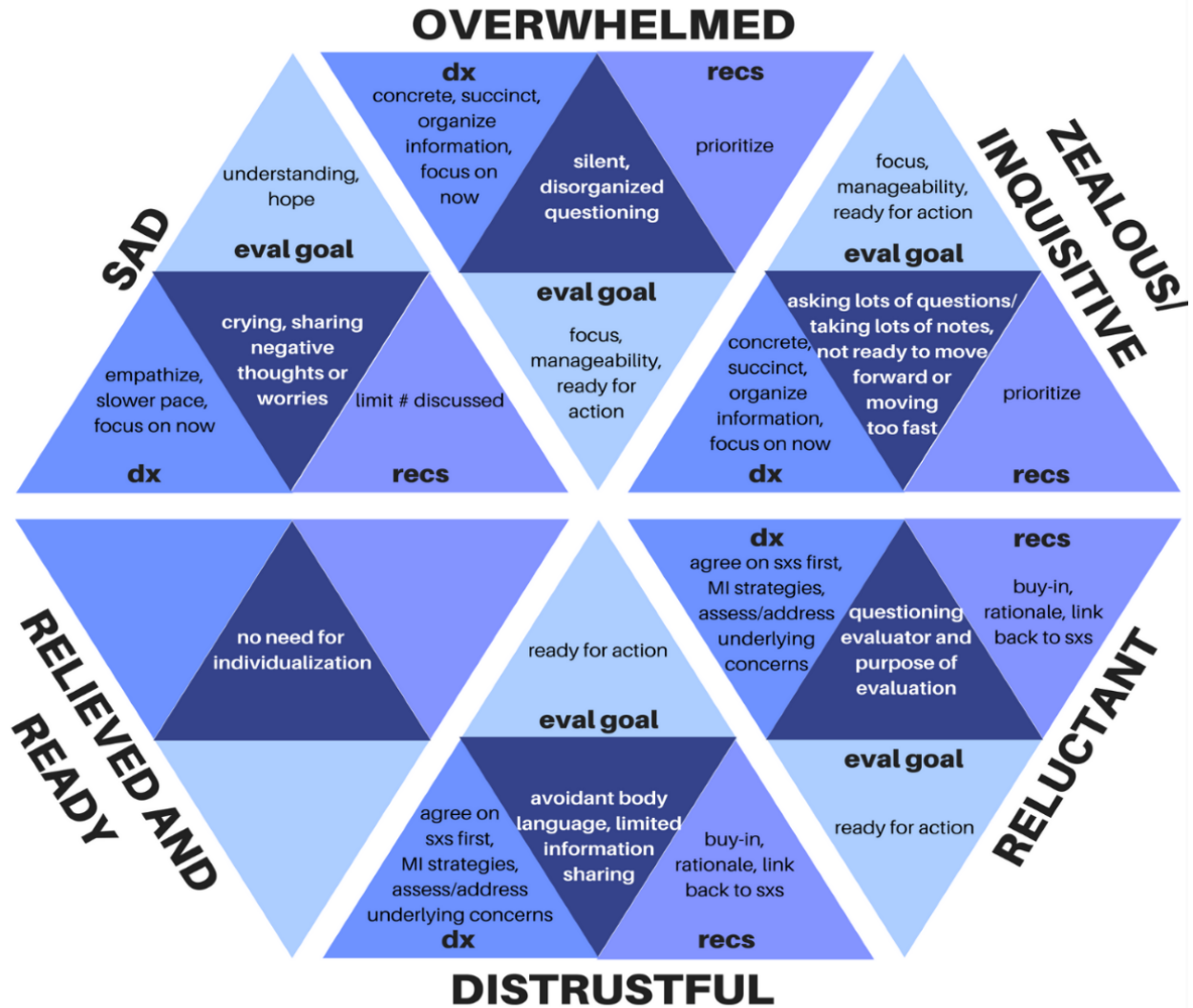
## Appendix E

### Sample SPIRIT Parent Profile Guidelines

Parent Profile	Guidelines for Individualizing the Evaluation			Recommendation Guidelines	
	Clinician Goals	Parent Characteristics <i>(the parent may present with only some of these)</i>	Dx Structure		Dx Content
Sad	<ul style="list-style-type: none"> <li>▪ Understanding</li> <li>▪ Hope</li> </ul>	<ul style="list-style-type: none"> <li>▪ Crying</li> <li>▪ Sharing negative thoughts and worries</li> </ul>	<ul style="list-style-type: none"> <li>▪ Time divided between diagnosis and recommendations</li> <li>▪ Pace is slower to allow time to empathize</li> <li>▪ Consider separate feedback session</li> </ul>	<p><b>Core Strategies</b></p> <ul style="list-style-type: none"> <li>▪ Enlist input - ask for parent's perspective on child's performance</li> <li>▪ Strengths – review child strengths</li> <li>▪ Review – child's current functioning</li> <li>▪ Discussion - Use open-ended prompt for questions (<i>What questions do you have right now?</i>)</li> </ul> <p><b>Individualizing Strategies</b></p> <ul style="list-style-type: none"> <li>▪ Empathize – understand where parent is (It can be difficult to hear news like this. This is a lot to take in.)</li> <li>▪ Provide a quiet space for parent to grieve</li> <li>▪ Normalize parent's reaction</li> <li>▪ Ask the parent what he/she thinks ASD is and clarify misconceptions</li> <li>▪ Help parent focus on right now rather than on future (<i>There are so many different possible outcomes. Focusing on the worst case scenario is not helpful.</i>)</li> <li>▪ Help parent leave with some hope (<i>A lot can happen in a year. Let's think about the next year and how we can encourage progress based on his strengths. He's too young to predict the future.</i>)</li> </ul>	<p><b>Core Strategies</b></p> <ul style="list-style-type: none"> <li>▪ Emphasize obtaining report</li> <li>▪ Incorporate parent's primary concerns into selection and prioritization of recommendations</li> <li>▪ Review Service Path Tool</li> <li>▪ Provide completed Enhanced Patient Instructions handout</li> </ul> <p><b>Individualizing Strategies</b></p> <ul style="list-style-type: none"> <li>▪ Referral to service coordinator to review recommendations</li> <li>▪ To promote hope, emphasize services can help</li> <li>▪ Incorporate at least one parent strength you perceived during eval (e.g., patience, coping with adversity, tenaciousness, advocacy skills, caring about child, commitment to parenting/child)</li> </ul>

# Appendix F

## SPIRIT Parent Profile Cheat Sheet



## Appendix G

### Sample SPIRIT Fidelity Checklist

#### SPIRIT Fidelity Checklist

Please use this checklist at any time you are discussing diagnosis or feedback with caregivers.

<b>START OFF ON THE RIGHT FOOT</b>				
Consider cultural responsiveness of evaluation	1. Addressed language of evaluation prior to start (e.g., translator provided, correct language for forms).	Y	N	
	2. Asked caregiver(s) who they want at the feedback meeting at beginning of evaluation or feedback.	Y	N	
	3. Acknowledged or asked about cultural perspectives for communication, behavior, or play (e.g., norms for communication or eye contact, importance of play).	Y	N	
	4. Clinician used culturally appropriate testing items (e.g., skin tone of ADOS-2 materials matched client).	Y	N	NA
Assessed caregiver(s) purpose for evaluation	5. Asked caregiver(s) about their main concerns for the child or goals for the evaluation.	Y	N	
	6. Asked caregiver(s) what they would like clinician to focus on in feedback or what they need to support their child.	Y	N	
	7. Provided expectations for the evaluation (e.g., sequence of testing, difficulty of items, caregiver(s) role in assessment).	Y	N	
Assessed the potential that caregiver(s) had previous negative experiences providers	8. Asked caregiver(s) about their prior evaluation or service experience.	Y	N	
	9. Discusses concerns caregiver(s) raised (if applicable).	Y	N	NA
	10. Stated how this evaluation is different from previous evaluations (if applicable).	Y	N	NA
Promoted caregiver efficacy	11. Acknowledged caregiver(s)' effort to schedule/attend.	Y	N	
	12. Emphasized caregiver(s)' knowledge (e.g., expert of child, as an advocate, understanding child's strengths/needs).	Y	N	
	13. Stated caregiver(s)' role as a crucial participant of the evaluation team (e.g., the evaluation is collaborative).	Y	N	
Promoted bidirectional communication	14. Asked caregiver(s)' if they had questions.	Y	N	
	15. Validated questions or comments (e.g., nodded head while caregiver(s) talked, thanked caregivers for information or questions, stated question was good) (if applicable).	Y	N	NA
	16. Provided response to caregiver(s)' question(s) or comments (if applicable).	Y	N	NA
<b>PAUSE TO PLAN</b>				
Considered parent profile(s) and evaluation goal(s)	17. Took a break between evaluation and feedback.	Y	N	
	18. Identified a parent profile: _____.	Y	N	
Created a plan to reach evaluation goal(s).	19. Referred to SPIRIT Parent Profile/Cheat Sheet.	Y	N	
	20. Completed SPIRIT strategies reminder card.	Y	N	
<b>INDIVIDUALIZE DIAGNOSIS COMMUNICATION</b>				
Enlisted caregiver(s) input	21. Asked caregiver(s) if child's performance was typical.	Y	N	
	22. Asked if there was anything that was not observed that should be considered.	Y	N	
	23. Asked caregiver(s) about their knowledge, understanding, and/or perspectives on ASD or relevant diagnoses.	Y	N	
Reviewed child's strengths	24. Identified relative and/or absolute strengths of child.	Y	N	
	25. Strengths were discussed before areas of difficulty.	Y	N	
Reviewed child's current functioning	26. Provided results of assessments (e.g., diagnoses, data).	Y	N	
	27. Provided behavioral observations of child during assessment.	Y	N	
	28. Noted consistencies between what caregiver(s) reported	Y	N	

Appendix H

SPIRIT Strategies Reminder Card

# SPIRIT Strategies



## Appendix I

### Clinician Perceptions of SPIRIT Survey

Please note, for all questions, “parent” refers to any primary caregiver.

*The following set of questions asks about the SPIRIT tools. Please answer honestly. Your answers will help us improve future SPIRIT tools and the fit of the SPIRIT tools within ASD evaluations.*

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. The SPIRIT toolkit meets my approval.	1	2	3	4	5
2. The SPIRIT toolkit is appealing to me.	1	2	3	4	5
3. I like the SPIRIT toolkit.	1	2	3	4	5
4. I welcome the SPIRIT toolkit.	1	2	3	4	5
5. The SPIRIT toolkit seems fitting.	1	2	3	4	5
6. The SPIRIT toolkit seems suitable.	1	2	3	4	5
7. The SPIRIT toolkit seems applicable.	1	2	3	4	5
8. The SPIRIT toolkit seems like a good match.	1	2	3	4	5
9. The SPIRIT toolkit seems implementable.	1	2	3	4	5
10. The SPIRIT toolkit seems possible.	1	2	3	4	5
11. The SPIRIT Toolkit seems doable.	1	2	3	4	5
12. The SPIRIT toolkit seems easy to use.	1	2	3	4	5

13. What would you change about the SPIRIT tools?

14. What would you make sure to keep in terms of the SPIRIT tools?