A mixed-methods approach to mapping caregiver-reported paths of service delivery following early ASD concerns

Catherine Dick

A dissertation

submitted in partial fulfillment of the

requirements for the degree of

Doctor of Philosophy

University of Washington

2023

Reading Committee:

Wendy Stone, Chair

Shannon Dorsey

Katherine Foster

Program Authorized to Offer Degree:

Department of Psychology

University of Washington

Abstract

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Catherine Dick

Chair of the Supervisory Committee:

Wendy Stone

Department of Psychology

Families with early concerns about autism spectrum disorder (ASD) for their children often experience a delay between first concerns and diagnosis (2 years on average; Sansosti et al., 2012), and many caregivers describe frustration with the system navigation involved in the process of accessing an ASD diagnostic evaluation and services. There are well-documented barriers to care that can arise at many different points along this service delivery pathway (e.g., low adherence to ASD screening guidelines in primary care; low rates of evaluation referrals; insufficient capacity for diagnostic evaluations which often results in long wait times). Despite the proliferation of research aimed at improving service delivery for early ASD identification, a number of challenges remain; in particular, the difficulty of assessing and intervening on a complex, cross-system service delivery pathway, and difficulties with family engagement and

satisfaction with the ASD diagnostic process. With the aforementioned challenges in mind, the current study employed a mixed-method approach to examine the utility of two innovative strategies for characterizing families' paths through service delivery following initial ASD concerns. Data were collected through semi-structured phone interviews with caregivers who reported early ASD concerns for their children to assess the timing and nature of initial ASD concerns, and if applicable, what their process was like to pursue an ASD diagnostic evaluation and services for their child. A quantitative approach (*cascade analysis)* was selected to characterize families' paths through service delivery at a group level across the diagnostic pathway, prioritizing breadth of understanding, while a qualitative approach (*patient journey mapping)* was selected to capture the potential complexity of a subset of families' experiences (prioritizing depth of understanding and family perspective). Results revealed a number of considerations for potential future use of these methods, while highlighting an innovative and integrative approach to mapping paths of service delivery following early ASD concerns.

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that is characterized by the presence of differences in two core domains: social communication and interaction, and restricted and repetitive behaviors and interests (APA, 2013). In the social domain, individuals with ASD demonstrate difficulty with social reciprocity, receptive and/or expressive social communication (e.g., understanding and using gestures and/or facial expressions), and in developing and maintaining social relationships. Restricted and repetitive behaviors may include stereotyped motor movements, repetitive or idiosyncratic use of speech, rigidity in thinking or behavior, and differences in responsiveness to sensory input. The presentation of ASD is highly heterogenous, and level of support needed by individuals with ASD varies widely (Johnson & Myers, 2007). Additionally, ASD frequently co-occurs with other neurodevelopmental disorders (e.g., intellectual disability, language delay, attention-deficit hyperactivity disorder), genetic syndromes, mental health/behavioral conditions (e.g., externalizing problems, self-injury, anxiety, mood disorders), and medical problems (e.g., sleep disorders, gastrointestinal problems, feeding problems; Hyman, Levy, & Myers, 2020). As a result, children with ASD and their families have a high need for behavioral, medical, and educational services and supports, ideally from providers who have proficiency caring for the unique needs of children with ASD and their families. ASD is increasingly prevalent in the United States, with the most recent estimates indicating that 1 in 36 children has an ASD diagnosis (Maenner et al., 2023).

Impact of delayed diagnosis on children and families

Despite the fact that identification of ASD has increased substantially over several decades – attributable, at least in part, to more widespread public and professional knowledge of ASD (Johnson & Myers, 2007) – accessing a diagnostic evaluation for ASD remains challenging. The typical onset of caregiver concern about their child's development or behavior,

around 18 months of age (Coonrod & Stone, 2004), coincides with the approximate age at which an accurate ASD diagnosis can be conferred (18-24 months of age; Chawarska et al., 2009; Lord et al., 2006; Turner et al., 2006; Zwaigenbaum et al., 2015). In practice, the median age of diagnosis in the United States is 49 months (Maenner et al., 2023), and on average, this interval from first concerns to ASD diagnosis is 2 years (Sansosti et al., 2012). In other words, while ASD has the potential to be diagnosed promptly following the emergence of early signs, this is not a reality for many families who have early ASD concerns for their toddler.

This delay in diagnosis impacts both children and their caregivers. It is well documented that early ASD-specialized intervention improves developmental and behavioral outcomes for children (e.g., Dawson et al., 2010; Ingersoll, 2010; Kasari et al., 2015; Landa et al., 2011; Wetherby et al., 2014), and receipt of these therapies is especially impactful during toddlerhood, given sensitive periods of development that occur in the first few years of life (Dawson, 2008). However, a formal ASD diagnosis is often a pre-requisite for accessing these therapies; thus, by the time a child receives an ASD diagnosis, they may have missed an opportunity to benefit from a variety of evidence-based early interventions during a critical developmental window.

Obtaining a diagnostic evaluation also has a subjective significance for families. For caregivers, the period that follows the emergence of their concerns for their child can be incredibly difficult. They are left with unresolved questions about their child's development and how best to support them, and report feelings of uncertainty and helplessness during this time (Moh & Magiati, 2012). A recent prospective, longitudinal analysis of caregiving-related stress during the pre-diagnostic period indicated that families with concerns about ASD reported higher levels of caregiving stress relative to families with other types of developmental concerns and families with no concerns for their toddler (DesChamps et al., 2020). Likely related to this

emotional experience prior to an ASD diagnosis, caregivers also report frustration and difficulty with the system navigation required to obtain a diagnostic evaluation. The diagnostic delay is often due to barriers that arise within and between service delivery systems, which will be described in detail in a later section, and caregivers describe needing to be quite persistent to advance the diagnostic process (Lappé et al., 2018). In one study, caregivers of children with ASD reported having seen four to five clinicians on average prior to receipt of a diagnosis, though responses ranged from 1-29 clinicians (Goin-Kochel, Mackintosh & Myers, 2006).

Service delivery systems along the diagnostic pathway

The specific process required to obtain a formal diagnosis of ASD can be conceptualized as stages or steps, including: identification of signs of ASD, referral to a diagnostic evaluation, receipt of diagnostic evaluation, and the provision of an ASD diagnosis if appropriate. Several systems have the potential to be involved in early identification of ASD at these different stages. The system most directly tasked with the initial steps in this diagnostic process (e.g., identifying ASD risk, referring to a diagnostic evaluation) is pediatric primary care. Families are likely to have frequent contact with their child's primary care provider (PCP) in early childhood. Professional guidelines from the American Academy of Pediatrics (AAP) outline timing of well-child visits and clinical activities that are recommended for preventative care, including those involved in the early identification of developmental disorders such as ASD (AAP, 2006; Adams et al., 2013; Hyman et al., 2020; Johnson & Myers, 2007). Well-child visits are recommended at specified intervals (e.g., every 1-3 months until 12 months; every 3-6 months from 12 months until age 3; and yearly thereafter; AAP, 2021). Across all primary care visits, AAP guidelines recommend developmental surveillance, including informal observation of the child, and eliciting caregiver report about development and behavior. Formal screening is also

recommended at specified well-child visits using standardized, validated measures (developmental screening at 9, 18, and 30-month well-child visits, and ASD screening at 18 and 24-month well-child visits; AAP, 2021). Providers are also recommended to take appropriate action, including formal screening, at any visit when caregivers raise concerns about development or behavior. Specific standardized ASD screening tools – most often brief caregiver-report questionnaires – are recommended for use in primary care settings, and for specific age ranges (see Hyman et al., 2020; Levy et al., 2020). If likelihood of ASD is identified through surveillance and/or screening, PCPs are responsible for: documenting results; communicating results to caregivers; scheduling follow-up visits; and making referrals (specifically, for a formal diagnostic evaluation, for developmental/early education services, and for an audiology evaluation; AAP, 2006). To further emphasize this central care coordination role of the PCP, the "medical home" model of primary care, advocated for by the AAP, considers the PCP to be the "hub" of a child's care who recommends and coordinates with other specialties and service systems, or the "spokes," as needed (AAP, 2002).

While professional guidelines for pediatric primary care explicitly recommend surveillance and screening for ASD, other systems have the potential to play a role in early identification of ASD (i.e., early signs of ASD may be identified in other community settings). For example, families who have identified developmental concerns for their young children are likely to interact with early intervention (EI) services. Children with developmental delays or disabilities are often eligible for free or low-cost EI through Part C of the Individuals with Disabilities Education Act (IDEA) until 36 months (IDEA, 2004). As developmental delays or disabilities must be present to be eligible for these services, children who will go on to have ASD diagnoses are likely to be enrolled in these services. In one study assessing earlier participation

in EI services among children who were given ASD diagnoses at a regional diagnostic clinic, 89% were already receiving EI services (Monteiro et al., 2016). However, guidance about systematically screening for ASD in these settings, and/or making referrals for clinical evaluations for ASD if concerns are present, is not well defined. For example, IDEA does not provide guidance at a federal level about systematically screening for ASD, as the primary clinical duty of this service delivery system is to provide individualized, developmentally-appropriate (but perhaps not diagnosis-specific) therapeutic or educational services. While the current guidance about ASD identification across these settings is ambiguous or absent, some studies have examined ASD screening practices in EI, which have yielded mixed findings. A study by Tomlin et al. (2013) reported that roughly two-thirds of EI providers surveyed do not conduct ASD screening in their role, and those who did report screening for ASD rarely used a formal screening tool. In a qualitative study examining ASD knowledge and self-efficacy among a small group of EI providers, a majority of providers indicated that they had shared information about community resources, including where to go for a diagnostic evaluation, with parents who report having concerns about ASD (Stone et al., 2021). Despite no large-scale investigations of EI providers' perceptions of their role and participation in screening and referral for ASD, these settings have the potential to complement primary care as a first entry point for navigating the diagnostic process.

Diagnostic evaluations for ASD typically occur in specialty-care settings by professionals such as developmental-behavioral pediatricians, psychologists, psychiatrists, or neurologists (though guidelines about professionals who are able to confer ASD diagnoses may vary by state). A comprehensive evaluation for ASD often incorporates assessment of multiple domains of development and behavior through the use of clinician-administered ASD diagnostic tools,

caregiver report, and measures of cognitive and adaptive functioning (Huerta & Lord, 2012). While this model is time and resource intensive, many argue that the diagnosis of ASD can be complex and careful diagnosis requires adequate time, information gathering, and provider expertise. Some best practice recommendations also consider a multidisciplinary team evaluation to be ideal (Penner et al., 2018). Subsequently, an ASD diagnosis often enables access to ASD-specialized interventions, which may require additional system navigation.

Known vulnerabilities in the diagnostic pathway

Along this path to a diagnostic evaluation, and potentially to ASD-specialized services if a diagnosis is conferred, there are several potential opportunities for discontinuity (i.e., drop-off), and for delays to occur. Given difficulties and delays accessing diagnostic evaluations for ASD, a great deal of research has focused on identifying and describing barriers, or common vulnerabilities in this complex cross-system process. These vulnerabilities are situated at many different points along the path to an ASD diagnostic evaluation. For instance, in the early steps of this process, despite professional guidelines, screening in primary care may not be regularly implemented, tools may be administered improperly or incompletely (i.e., lacking fidelity to recommended use of a tool), and/or providers do not take recommended actions (e.g., make referrals) following a positive screen. In a recent survey of PCPs across 13 states enrolled in an autism training program, only 51% of PCPs reported performing ASD screening at all 18-month well-child visits, and 41% reported performing ASD screening at all 24-month well-child visits (Mazurek et al., 2021). In a study that reported higher screening rates (73% of toddlers screened at 18- or 24-month visits), the follow-up interview that is recommended following positive screens for the screening tool used (Robins et al., 2014) was almost always neglected (Carbone et al., 2020). Another study that reported higher screening rates (at 93% of 18-month well-child

visits, and 82% of 24-month well-child visits) found that only 31% of children who screened positive were referred for further evaluation (Monteiro et al., 2019). Once families are referred for a diagnostic evaluation, they can face exceptionally long wait times, with averages ranging from 6-18 months (Austin et al., 2016; Gordon-Lipkin et al., 2016). Longer delays also increase the likelihood of families canceling an ASD evaluation, with one study finding a 4-5% increase in likelihood for each additional month waited (Kalb et al., 2012).

Adding to the complexity of understanding the vulnerabilities in the diagnostic process, these steps are interrelated, and problems with one step of the process have the potential to impact system performance at other steps. An earlier step would be likely to impact a later step (e.g., if ASD screening is not regularly performed, children may be under-referred for evaluation), but barriers at a later step may also influence an earlier step of the process. For example, when PCPs perceive limited availability of or long waits for diagnostic evaluations, they may not be motivated to screen or refer (Jackman, May, & Crais, 2020).

Potential family-level barriers include limited understanding of early signs of ASD (Lappé et al., 2018), perceived stigma of an ASD diagnosis, particularly for families of color (Stahmer et al., 2019; Zuckerman et al., 2015), and difficulty understanding how to approach and navigate systems, while often justified given health care system complexity (Stahmer et al., 2019). Many of the system-level barriers are also amplified for families who have lower income, lack adequate health insurance, speak a language other than English, live in low resource settings (e.g., rural regions), or experience structural racism (Dababnah et al., 2018; Smith et al., 2020; Stahmer et al., 2019; Wallis et al., 2020), which contributes to documented disparities in ASD diagnosis (Maenner et al., 2020).

Existing improvement efforts along the diagnostic pathway

As a result of these well-documented difficulties and delays accessing ASD diagnostic evaluations and services, and the known complexity of this service delivery process, there has been a proliferation of research and resources devoted to increasing access and reducing the delay to a diagnosis and subsequent services. For example, studies have attempted to improve screening processes by training primary care providers in recognizing early signs of ASD and performing formal ASD screening (Zuckerman et al., 2021), and by automating screening tools and/or integrating into the electronic health record (Brooks et al., 2016; Campbell et al., 2017; Ibañez et al., 2019; Steinman et al., 2021). Studies have also attempted to facilitate the referral process between primary care and ASD evaluation settings by using "family navigation" approaches to minimize drop-off during this transition (DiGuiseppi et al., 2021). To improve accessibility and wait times at the evaluation stage, innovations have included: embedding a specialist (e.g., a psychologist) to conduct evaluations in the primary care medical home (Hine et al., 2018); increasing efficiency by assessing and intervening on delays in evaluation clinic workflow (Austin et al., 2016); and utilizing interdisciplinary team approaches to decrease time spent during diagnostic evaluations (Gerdts et al., 2018).

Remaining challenges

While it is promising that there has been a proliferation of efforts to improve service delivery on the path to an ASD diagnostic evaluation and services, a number of challenges remain. For instance, a recent study by Broder-Fingert and others (2019) examined facilitators and barriers among five research teams who implemented large-scale systems-based innovations to improve access to early screening, diagnosis and treatment for children on the autism spectrum. Despite diverse approaches between these groups (with respect to geography, service systems engaged/steps of the diagnostic process targeted, and implementation strategies used), a

number of common themes emerged regarding perceived challenges. One such challenge that investigators described was the difficulty of working to improve this complex and interdependent cross-system care pathway, or "the difficulty of working to improve current systems within the context of so many inefficiencies". They noted "…even when we improve screening rates, all the down-stream actors are still really slow, so it can be challenging," and "it feels like we plug a hole in the dam and then another one opens downstream" (Broder-Fingert et al., 2019). This emphasizes the importance of considering the whole context of this service delivery pathway in implementation efforts. Methods of assessing system performance from start to finish may highlight specific priorities for improvement before selecting where resources are invested; for example, it may be most important to improve wait time or capacity for diagnostic evaluations in a community before investing resources in screening for ASD. The ability to assess the entirety of the diagnostic pathway at once would also allow for a comparison of overall system impact before and after a targeted intervention, including effects on up- or down-stream steps.

Another common barrier observed by this research group was difficulty with family engagement in the screening, diagnosis, and treatment process (e.g., family hesitance to engage in screening, or provider concern about alienating families if ASD concerns were discussed; Broder-Fingert et al., 2019). This, combined with evidence that families who pursue an ASD evaluation and services for their children are often dissatisfied with their experience (Moh & Magiati, 2012), emphasizes that assessing family perspectives will be crucial to improving this service delivery process. For example, understanding families' point of view about their experience navigating services may generate additional possibilities for innovation.

With these challenges in mind, strategies for: (a) gaining a comprehensive understanding of system performance across the process steps involved in accessing an ASD evaluation and

services; and (b) gaining an in-depth view of the complex and often non-linear journey families experience navigating this process, will benefit the planning and evaluation of future implementation efforts.

Utility of mixed-method research approaches

Mixed methods designs have increasingly been used in implementation research (Palinkas et al., 2011). Quantitative and qualitative approaches each have advantages and disadvantages, and the integration of both can offset their respective limitations and provide added-value compared to either used alone (Creswell & Plano Clark, 2017). Quantitative methods are often used to provide breadth of understanding (e.g., to measure and monitor implementation outcomes in the aggregate, such as rates of service delivery access). They often utilize larger sample sizes, which support generalizable results, though may also sacrifice richness of information. Qualitative methods are often used to provide depth of understanding, to prioritize participant perspectives, and/or to generate new insights. These methods often provide a more detailed or personalized view using smaller sample sizes, which can sacrifice generalizability. Given the aforementioned implementation challenges on the path to an ASD evaluation and services (e.g., assessing system performance in its entirety, and incorporating family perspective to support engagement), the use of mixed-method research designs is promising.

The current study

The current study employed a mixed-method approach to examine the utility of two innovative strategies for characterizing families' paths through service delivery following initial ASD concerns and assessing areas for improvement. Given the aforementioned advantages and limitations of quantitative and qualitative methods, a quantitative approach (*cascade analysis)*

was selected to characterize families' paths through service delivery at a group level across the diagnostic pathway from initial ASD concerns through the potential outcome of an ASD diagnosis and access to ASD-specialized services (e.g., to assess where difficulties arise along this path on average, prioritizing breadth of understanding), while a qualitative approach (*patient journey mapping)* was selected to capture the potential complexity of families' experiences navigating service delivery (e.g., as an exploratory, or inductive approach, prioritizing depth of understanding and family perspective). Data were collected through semi-structured phone interviews with caregivers who, upon enrollment in a larger study, reported ASD concerns for their toddler (i.e., child under 3 years at the time of enrollment). The semi-structured interview was designed to assess the timing and nature of initial concerns about ASD, as well as detailed information about timing and outcome of subsequent actions/interactions with providers along the path to a potential diagnostic ASD evaluation and services.

Aim 1: To examine the utility of a modified *cascade analysis* approach to quantitatively describe service delivery system performance in the ASD diagnostic process. Cascade analysis, derived from Systems Engineering (SE), has emerged as an implementation strategy applied to health care service delivery (most often in global health research) to model complex systems and diagnose where problems occur in order to prioritize solutions (Wagner et al., 2019a). In other words, a "cascade of care" comprises a series of steps, or inflection points (each with a binary yes/no outcome), that if completed would lead to a desired outcome of service delivery. Cascade analysis has often been utilized to evaluate cascades of care for HIV treatment (i.e., the path from HIV screening, to diagnosis, to treatment engagement, to suppression of viral load; Sherr et al., 2014; Wagner et al., 2019b), and has since been adapted for other areas of health care (e.g., hypertension care; Gimbel et al., 2020; see Wagner et al., 2019b for additional uses and

adaptations). This approach allows for assessment of steps in a care cascade that produce drop-off and delays, with the goal of deploying more precise solutions (and thereby more efficiently using resources). In the current study, the utility of cascade analysis is examined for the purpose of characterizing and assessing families' paths through service delivery (i.e., through a care cascade) beginning with initial ASD concerns, through potentially accessing an ASD diagnostic evaluation and ASD-specialized services – with the potential to use cascade analysis in future work to precisely match solutions to specific areas needing improvement, or assess the impact of an innovation across the whole system.

Aim 2: To examine the utility of *patient journey mapping* to qualitatively assess and depict families' experiences navigating service delivery following initial ASD concerns. Given the linear and sequential nature of cascade analysis, combined with evidence that families' journeys in the ASD diagnostic process may be non-linear (i.e., perhaps involving multiple systems, and/or repeated interactions with providers), additional insight into families' experiences navigating care can be gained using this approach. Journey mapping is a concept that originated to understand customer experiences in the marketing industry, but has since been applied to healthcare to understand patient experiences (Schildmeijer et al., 2019). A recent scoping review of patient journey mapping indicated that the prevalence of patient journey mapping in healthcare literature has accelerated in recent years, with 76.5% of articles using this approach published since 2015 (Davies et al., 2022). This approach places individuals at the center of analysis and has been described as "a patient-centric activity that details a patient's progress through a healthcare system for a given service" (Curry, McGregor, & Tracy, 2007) by "documenting elements of the journey to produce a visual or descriptive map" (Davies et al., 2022). Common functions of journey mapping projects are: to develop a deeper understanding of

a person's entire journey through the health system; to understand how people navigate through health systems; to identify delays in diagnosis and treatment; to identify gaps in care and unmet needs; and to evaluate continuity of care (among others; see Davies et al., 2022). In the current study, patient journey mapping was applied to a subset of families included in the cascade analysis, sampled from specified points along the cascade for inclusion of information-rich cases, to provide complementary depth and nuance regarding families' paths through care. Ultimately, insights gained through such an approach can inform where service delivery and/or family satisfaction with service delivery could be improved.

Importantly, given the current study's sample size and makeup (described below), this dissertation is intended to show the innovative application and mixing of these methods for characterizing and assessing the ASD diagnostic pathway, rather than to generate representative or generalizable findings regarding specific areas for service delivery improvement. Ideally this will encourage future use of these methods (or other methodological innovations) to identify and/or prioritize areas for improvement in service delivery during early ASD identification, in order to select among appropriate innovations and implementation strategies.

Method

Mixed-Method Design

Mixed methods designs are often described in terms of their structure, function, and process (Palinkas, 2011; Palinkas & Rhoades Cooper, 2017). In the current study, a complementarity approach was used, with equal weight given to quantitative and qualitative methods. Data collection was concurrent (QUANdc + QUALdc) while analysis was performed sequentially (QUANda → QUALda; Palinkas & Rhoades Cooper, 2017). The function of complementarity approaches is to utilize qualitative methods to provide depth of understanding,

to complement breadth of understanding that is afforded by quantitative methods (Palinkas & Rhoades Cooper, 2017). In this study, the quantitative and qualitative threads are integrated through embedding (i.e., a qualitative method embedded within a quantitative approach, using a subset of the quantitative sample, to answer related questions simultaneously) and merging via narrative discussion (Palinkas & Rhoades Cooper, 2017). The combination of these methods is intended to provide greater insight regarding families' trajectories through service delivery following initial ASD concerns, than either method alone would provide.

Participants

Data for the current study were collected as part of a larger study, a pragmatic trial ("Screen-Refer-Treat," or SRT; Ibañez et al., 2019) aimed at increasing capacity for early ASD screening and delivery of evidence-based ASD-specialized treatment, via training and support provided to PCPs and EI providers, respectively. The trial enrolled caregivers of young children, and PCPs and EI providers from four diverse counties (Lewis, Skagit, Spokane, and Yakima county) in Washington state. Caregivers are the focus of the current study. Caregivers were eligible for the larger study if they had ASD concerns, other developmental concerns (e.g., speech or motor delays), or no concerns for their child. Two separate cohorts of families were recruited, one prior to and one following the implementation of the community-based intervention (i.e., "pre-SRT" and "post-SRT" cohorts). The current study includes families from *both* pre- and post-SRT cohorts, though analyses will not include a comparison of these groups. Rather, both were included to maximize sample sizes for the purposes of demonstrating utility of the methods used. In the larger study, families were recruited by participating PCPs and EI providers who distributed informational flyers and/or sent study recruitment emails to families of children between 16 and 33 months of age. All study materials were available in both English

and Spanish. The research team contacted families who completed a "permission-to-contact" form in participating primary care and EI settings to complete a structured telephone screening interview to determine eligibility for the study, and to categorize caregivers in one of the three caregiver concerns groups (ASD, developmental, or no concerns for their child) based on a researcher-developed algorithm. Caregivers were assigned to the "ASD Concerns" group at enrollment in the larger study if the caregiver: (a) endorsed having ASD concerns for their child; (b) indicated that one of the child's providers had expressed concerns about ASD; (c) reported that the child had screened at-risk for ASD; and/or (d) the child had an existing ASD diagnosis. Families of children with severe medical, physical, or genetic conditions (e.g., cerebral palsy, deafness) were ineligible for the larger study.

For inclusion in the current study, caregivers who were: (a) enrolled in the larger study in either the Pre-SRT or Post-SRT study cohort, and (b) in the ASD Concerns group upon initial study enrollment, were contacted to participate in an optional, semi-structured phone interview regarding the timing and nature of initial ASD concerns, and if applicable, what their process was like to pursue an ASD diagnostic evaluation and services for their child ("ASD Concerns and Services Phone Interview;" Appendix A). Of 151 eligible caregivers in the ASD Concerns group, across both SRT cohorts, 70 caregivers (n=35 Pre-SRT; n=35 Post-SRT) completed the phone interview (46% response rate). The majority of those not interviewed for the current study were not able to be reached, while a small subset (i.e., $n<10$) were reached but declined to participate in the optional phone interview. Interview data from the full sample were included in Aim 1 (cascade analysis) to examine paths through service delivery at the group level, while Aim 2 (patient journey mapping) included a subset of the sample selected to illustrate information-rich cases to serve the goal of complementarity. Selection procedures for Aim 2 will be described

further in a later section. Demographic information was collected upon entry to the larger study, including child age, sex, race, ethnicity, household income, and primary language spoken (English or Spanish). Participant demographic information for caregivers who participated in the current study (ASD Concerns, Interviewed; n=70), as well as those who did not participate in the optional semi-structured interview (ASD Concerns, Not Interviewed; n=81), is described in Table 1. Note that we did not systematically collect information about child age (in mos.) at the time of first ASD concerns during the larger study, so this is not reported for families who were not interviewed.

Table 1. Participant demographic information

	ASD Concerns, Interviewed (n=70)		ASD Concerns, Not Interviewed (n= 81)	
	M	*SD*		
Child age at first ASD concerns (months)	19.7	7.0		
Child age at phone interview (months)	46.3	9.8		
	n	%	n	%
Child sex				
Male	45	64.3	47	58.0
Female	25	35.7	26	32.1
Missing	0	0	8	9.9
Child race				
White	46	65.7	52	64.2
More than one race	9	12.9	10	12.3
Asian	3	4.3	1	1.2
Black or African American	1	1.4	0	0
American Indian or Alaskan Native	1	1.4	2	2.5
Other (not listed)/unknown	10	14.2	16	19.7
Child ethnicity				
Not Hispanic or Latino	43	61.4	46	56.8
Hispanic or Latino	24	34.3	26	32.1

Unknown	3	4.2	1	1.2
Household income				
<$20,000	17	24.3	22	27.8
$20,001-40,000	19	27.1	20	24.7
$40,001-60,000	8	11.4	11	13.6
$60,001-80,000	4	5.7	7	8.6
$80,001-100,000	5	7.1	4	4.9
>$100,000	6	8.5	1	1.2
Unknown	11	15.7	16	19.7

Procedure

All procedures were approved by the University of Washington institutional review board. All participants in the current study provided consent upon enrollment in the larger study, and later provided consent to participate in the optional ASD Concerns and Services Phone Interview, for which they were compensated with a $30 gift card. Recruitment for the larger study occurred between 2015 and 2019; optional phone interviews that collected semi-structured interview data for the current study were conducted between 2018 and 2020.

All caregivers in the ASD Concerns group (n=151) were contacted about the opportunity to participate in an optional 20-30 minute semi-structured phone interview. A short email was first sent to each caregiver indicating that they could expect to receive a phone call from someone on the research team within approximately one week of receipt of the email. Emails were sent individually to small groups of caregivers at a time, so that the research team could make initial phone contact within the specified time frame. The email message provided a brief description of the purpose of the call, as well as information about expected length of the call and compensation. Caregivers were contacted in ascending order of participant ID. All caregivers enrolled in the Pre-SRT cohort were contacted prior to families enrolled in the Post-SRT cohort. Two separate attempts were made to contact each caregiver by phone, if not reached on the first

attempt. If on either attempt there was no answer, a brief voicemail message was left that included contact information for making a return call. When a caregiver was reached, the caregiver was greeted and oriented to the purpose of the call, and oral consent was obtained and documented prior to initiating the phone interview. Current mailing addresses were confirmed at the conclusion of each phone interview so that gift cards could be sent by mail.

All phone interviews were conducted by graduate students and/or full-time research staff trained in the phone interview procedure. Seven of the 70 phone interviews (10%) were conducted in Spanish by fluent Spanish-speaking members of the research team. All calls were completed in teams of two, with one caller and one additional note-taker, who each recorded responses during the phone interview on a copy of the telephone interview guide. Immediately following a call, the interview was reviewed to reconcile the two sets of notes, and data (both closed- and open-ended responses) were entered into a REDCap database, which was reviewed by both interviewers.

Measures

ASD Concerns and Services Phone Interview

The ASD Concerns and Services semi-structured phone interview guide was developed by the principal investigator of the parent study (WS) and a graduate student (CD). The full telephone interview guide can be found in Appendix A. It was designed to capture detailed information about: timing and nature of general developmental concerns and of ASD concerns; who was first concerned; if concerns were discussed with a professional (if the caregiver or another non-professional was first to be concerned); what the response was, including any actions taken; and what the process was like for accessing an ASD diagnostic evaluation and/or specialized services (if applicable). Specifically, information gathered about the process

included: whether the caregiver ever completed a formal screening tool for ASD; if the child had ever been referred for a diagnostic evaluation (or for other services); if they were on waitlist(s); if an evaluation was completed; and if so, what the results were. For each of these markers, the caregiver was asked to report child's age in months (or approximate month and year to calculate age in months). For instances when a caregiver reported an age range for a given event (e.g., the caregiver reported first having concerns for ASD between age 2-2½ years), these ages were averaged and the age was recorded as age in months (e.g., 27 mos.).

Aim 1: Quantitative Analysis

Cascade analysis

A modified version of cascade analysis was used to visualize and quantify service delivery system performance across "inflection points" (i.e., clinical encounters or steps in the process that have a binary yes/no outcome) from initial ASD concerns through potential receipt of an ASD diagnostic evaluation, ending at receipt of ASD-specialized services. The present use of this method is considered a *modified* application of this approach, given that typically cascade analysis utilizes clinic-level data (e.g., from chart review or other clinic data sources) to evaluate a care cascade specific to a given health system or clinic (Wagner et al., 2019b). In contrast, the current study used caregiver-reported data to examine a clinical care pathway that is likely to cross several health care systems (e.g., primary care, and tertiary/specialty care settings). Additionally, cascade analysis has primarily been used to evaluate cascades of care for medical diagnoses (e.g., HIV), which makes binary outcomes of screening and diagnosis much more clear-cut. As determining the presence of ASD relies on behavioral diagnostic criteria, identifying ASD concerns and making a diagnosis can be less straightforward or conclusive, and at various stages some drop-off from the cascade may be acceptable (e.g., some drop off after a

discussion with provider may be appropriate, if it was accurately assessed that likelihood for ASD was low). While we collected some data that may help to indicate to whether drop-off was appropriate or desired (e.g., whether caregivers were still, or were no longer, concerned for ASD at the time of the phone call if their child had not received an ASD evaluation or diagnosis), it remains a limitation of this study that we were not able to validate accuracy of early ASD concerns and/or diagnosis. Implications of these modifications from most prior uses of cascade analysis will be discussed.

Design

The initial step in implementing cascade analysis was to design the cascade of care (i.e., identify a linear sequence of inflection points that represents a dominant care pathway). To do this, members of the research team met to brainstorm and generate a list of important steps along a "standard" pathway of care leading to an ASD diagnosis, and to determine how broadly or narrowly defined the steps along the cascade would be. For example, while the process of accessing appropriate evaluations and services for ASD could have included multiple parallel cascades representing involvement in different systems of care (e.g., engagement in primary care *and* simultaneous referral pathways to Part C EI services in the community, with potential branching between cascades), the team opted to prioritize a single cascade of steps involved in accessing a diagnostic evaluation and subsequent ASD-specialized services for the current study, with supplemental descriptive information about who was involved in various steps (i.e., "actors") including providers from different systems of care. An initial set of inflection points was agreed upon by the research team: initial ASD concerns; a discussion with a provider about ASD concerns (i.e., a caregiver and provider discussing ASD concerns as an entry point to care); referral for an ASD evaluation (i.e., whether a referral was made based on a discussion with a

provider); ASD evaluation accessed (i.e., whether an ASD evaluation took place); received ASD diagnosis (i.e., whether an ASD diagnosis was given at the evaluation); recommendation for ASD-specialized services (i.e., ASD services were recommended); and ASD services accessed (i.e., receipt of ASD-specialized services).

The research team engaged in an iterative process of testing the fit of the cascade with available data, using a small subset of randomly selected participants, and modifying inflection points in the cascade as appropriate. Through this iterative process, the cascade was modified in the following ways. First, given that several participants indicated that their first discussion regarding ASD concerns with a professional did not result in an evaluation referral, and that they indicated they were later referred for an evaluation by the same or another provider, a branching "indirect" path to evaluation referral was created to reflect this common deviation from the team's originally defined cascade. Second, the team considered including 'formal screening for ASD', and 'screening results indicating ASD risk', as important inflection points along the cascade prior to being referred for an evaluation. We considered including these steps given professional recommendations for ASD screening in primary care, making it a salient step in an assumed care cascade, and given that this information could provide some metric of likelihood for ASD (i.e., this inflection point could help contextualize appropriate drop-off if a screening tool did not indicate ASD probability). However, we found that we were unable to include this inflection point using the available data, as caregivers frequently responded that they were not aware of whether a screening tool had been administered, or they recalled completing questionnaires about development but did not recall the results. Third, while "drop-off" (i.e., attrition from the care pathway) is an important outcome of cascade analysis, we discovered that, for our sample, it was also important to represent the outcome of remaining on a waitlist between

certain inflection points, such as being on a waitlist for a diagnostic evaluation or ASD-specialized services at the time of the call (i.e., not having advanced to the next inflection point, and yet not dropping off of the cascade). As a result, bins were added between the inflection points where the waitlist outcome was relevant. Finally, the decision was made to operationalize ASD-specialized services as Applied Behavior Analysis (ABA), specifically. This was a relevant change for the final two inflection points: Recommended ABA (formerly Recommended ASD-Specialized Services), and Accessed ABA (formerly Accessed ASD-Specialized Services). This decision was primarily driven by data availability; the phone interview systematically asked about whether their child was recommended and/or had received any therapies designed specifically for ASD (listing ABA, and a variety of Naturalistic Developmental Behavioral Interventions [NDBIs]). ABA was the only name of an intervention regularly recalled and endorsed by caregivers, and no NDBIs were endorsed. Additionally, while children in the current sample may have been involved in other services in the community, such as speech therapy, this is an important and relevant outcome, though may not necessarily follow from receipt of an ASD diagnosis (i.e., often these services are accessible without a diagnosis, and children's involvement may have preceded previous steps on the cascade). Even if new services other than ABA or NDBIs were accessed due to receipt of an ASD diagnosis, it was not feasible to capture this fully and to determine the chronology of services beginning before or after the diagnosis. While this decision was made carefully, this operationalization will be discussed further, as access to ABA does not necessarily represent the only or best outcome following an ASD diagnosis (but is one intervention that is often contingent on receipt of a formal ASD diagnosis).

The final visual of the cascade was created using a web-based design tool called Canva. Boxes in green represent inflection points along the cascade, with frequencies within a box

indicating number of families who advanced through that step of the cascade. Arrows to the right lead to gray boxes representing end-points of families' journeys. Frequencies in gray boxes indicate drop-off. Yellow boxes indicate a deviation from the dominant care pathway, while not dropping off (e.g., indirect path to referral; remaining on a waitlist for evaluation or services at the time of the interview).

Analysis

After designing the cascade, binary outcome variables corresponding to each inflection point were created. During data quality checks, one family was excluded from final analysis given discrepancies in the chronology of interview responses (e.g., age at referral and ASD diagnosis falling well before age of first ASD concerns), resulting in a final sample of 69 caregivers included in the final cascade analysis. Frequencies of those completing each sequential step of the cascade were calculated. Percentages indicating retention for each inflection point were calculated based on those eligible for the step due to having completed the previous step ([*n* completed/*n* eligible based on completion of previous step]*100), as well as based on the original sample size ([*n* completed/*n* total sample]*100). Analogous percentages were calculated for cascade drop-off following each inflection point (e.g., [*n* dropped off after inflection point/*n* completed inflection point]*100; [*n* dropped off after inflection point/*n* total sample]*100). Additionally, for each end-point until Received ASD Diagnosis, the frequency of caregivers who remained concerned for ASD at the time of the interview is reported as a proxy for appropriateness of drop-off. Average child age in months, standard deviation (SD), and range are reported for each inflection point. Average child age at a given inflection point was also calculated among just those who completed the subsequent inflection point (e.g., average age at referral among those who went on to receive a diagnostic evaluation), in order to calculate the

difference in average age between the two inflection points, representing "average delay" between inflection points.

Finally, "cascade gain" was calculated to represent one potential usage of cascade analysis, which is to model the additional number of patients who would complete through a specified step, if an individual step achieved 100% performance, while all other steps remained constant (Wagner et al., 2019b). In this cascade, cascade gain was calculated through the step of "Accessed ASD Evaluation." In other words, this metric represents the number of patients who would have received an ASD evaluation if a previous step was optimized to 100%. ASD Evaluation was selected as the outcome to optimize through, given that we would not expect to optimize (to 100%) individuals receiving an ASD diagnosis. Cascade gain is calculated by multiplying the *n* who did not complete a step (i.e., those dropped-off), by subsequent cascade probabilities (i.e., by the proportion of those observed to complete subsequent steps). See Wagner et al., 2019b for an in-depth description of cascade gain calculations. While the cascade gain metric was trialed here to present potential benefit of this function, the utility of cascade gain for this particular use case will be further discussed.

Finally, additional descriptive data at each inflection point was gathered (e.g., frequencies of who first raised ASD concerns; type of provider involved in the first discussion about ASD; type of provider who made the evaluation referral), which provides relevant detail regarding actors commonly involved in advancing the cascade.

Results

Cascade analysis results (e.g., frequencies, retention and drop-off rates, average ages at each inflection point, cascade gain) are included in Figure 1, and additional descriptive information regarding actors along the cascade are included in Table 2, which both supplement

the following narrative description of results. Importantly, given the sample size and makeup, these results should be interpreted as a demonstration of results that our modified cascade analysis can yield, rather than a representative assessment of the ASD diagnostic process in this region.

Within Initial ASD Concerns, 55.1% of caregivers were the first to be concerned about ASD for their child, while for 18.8% of children, ASD concerns were first raised by a PCP. For 13% of families, another provider (e.g., EI provider, other physician) first raised ASD concerns. For 7.2% of families, a family member or friend first raised ASD concerns to the family, and for 4.3% of families, a daycare worker or early childhood educator first raised ASD concerns.

Of this initial sample (n=69), 98.6% (n=68) of families discussed ASD concerns with a professional (whether the caregiver or the professional initiated). 80.9% of these families (n=55/68) had this discussion with their child's PCP; 8.8% (n=6/68) had this discussion with an EI provider (e.g., speech language pathologist, physical therapist, occupational therapist); 7.4% (n=5/68) had this discussion with another physician (e.g., developmental pediatrician, neurologist, endocrinologist); and 2.9% (n=2/68) first discussed ASD concerns with an early childhood educator.

Of these families, 75% (n=51/68) received a referral for an ASD diagnostic evaluation. 19 of these 51 received a referral after their first discussion about ASD with a professional, while 32 of 51 did not receive a referral after their first discussion, but were later referred after a subsequent discussion with the same or another provider (i.e., the "indirect" path to referral). Evaluation referrals came from PCPs for 64.7% of families (n=33/51), from EI providers for 27.5% of families (n=14/51), and from another medical provider (i.e., physician or nurse

practitioner) for 5.9% of families (n=3/51). One family did not recall who provided their evaluation referral (2%, n=1/51).

Of families receiving an evaluation referral, 82.4% (n=42/51) accessed an ASD diagnostic evaluation. An additional 11.8% (n=6/51) of those referred for an ASD evaluation were on an evaluation waitlist at the time of the interview. Of children who accessed a diagnostic evaluation, 81% (n=34/42) received an ASD diagnosis. 91.2% (n=31/34) of children diagnosed with ASD received a recommendation for ABA Of those recommended ABA, 71% (n=22/31) went on to receive ABA, while 9.7% (n=3/31) remained on an ABA waitlist at the time of interview.

On average, the time between initial concerns and discussion of concerns with a professional was 2.14 months; time between discussion to an evaluation referral if based on a first discussion of ASD concerns (i.e., direct referral path) was 0.21 months; time between discussion to referral if referred based on a later discussion (i.e., indirect referral path) was 7.70 months; and time between a referral and diagnostic evaluation was 4.24 months.

Regarding system performance, the step with the highest retention was discussion of ASD concerns with a professional, where 98.6% (n=68/69) families with initial ASD concerns engaged in a discussion about ASD with some provider. The step with the highest preceding drop-off was referral for ASD evaluation, where 25% (n=17/68) of families who discussed ASD concerns with a professional were never referred for a diagnostic evaluation.

Regarding appropriateness of/satisfaction with drop-off, one family who initially had ASD concerns, but who dropped off prior to discussion of concerns with a professional, was no longer concerned for ASD at the time of the interview (i.e., this drop-off was likely a desired outcome). Of 17 families who discussed ASD concerns with a provider, but who never received

an evaluation referral, 35.3% (n=6) remained concerned about ASD. 100% (n=6/6) of families who were on an evaluation waitlist at the time of the interview remained concerned for ASD. 37.5% (n=3/8) of families who received a diagnosis other than ASD, or no diagnosis, following an ASD evaluation remained concerned for ASD.

"Cascade gain," or the additional number of families who would complete through 'Accessed ASD Evaluation', if an individual preceding step were optimized (i.e., achieved 100% performance) while all other steps remained constant, was calculated for 'Discussion with Professional' and 'Referral for ASD Evaluation'. For this calculation, *n* dropped-off was multiplied by conditional probabilities of completing subsequent steps. If Discussion with Professional was optimized to 100% (i.e., if n=1 family who dropped off *had* discussed ASD concerns with a professional), an additional .61 families would have completed through Accessed ASD Evaluation (n=1*.75*.824). If Referral for ASD Evaluation were optimized to 100% (i.e., if n=17 families who dropped off *had* been referred for an evaluation), an additional 14 families would have completed through Accessed ASD Evaluation (n=17*.824). If cascade gain is calculated only for families who remained concerned for ASD after drop-off, if Discussion with Professional were optimized, an additional 0 families would have completed through ASD Evaluation (n=0*.75*.824), and an additional 4.9 families would have completed through ASD Evaluation if Referral to ASD Evaluation were optimized (n=6*.824).

Table 2. Actors involved at inflection points

Person who first had ASD concerns	*n* (of 69)	%
Caregiver	38	55.1
PCP	13	18.8
EI provider	9	13.0
Another physician	1	1.4
Family or friend	5	7.2

Daycare or early childhood educator	3	4.3
Professional involved in first discussion of ASD concerns	*n* (of 68)	%
PCP	55	80.9
EI provider	6	8.8
Another physician	5	7.4
Early childhood educator	2	2.9
Provider who made ASD evaluation referral	*n* (of 51)	%
PCP	33	64.7
EI provider	14	27.5
Other physician or nurse practitioner	3	5.9
Unknown	1	2

Figure 1: Modified Cascade Analysis of Accessing ASD Diagnostic Evaluation and Services

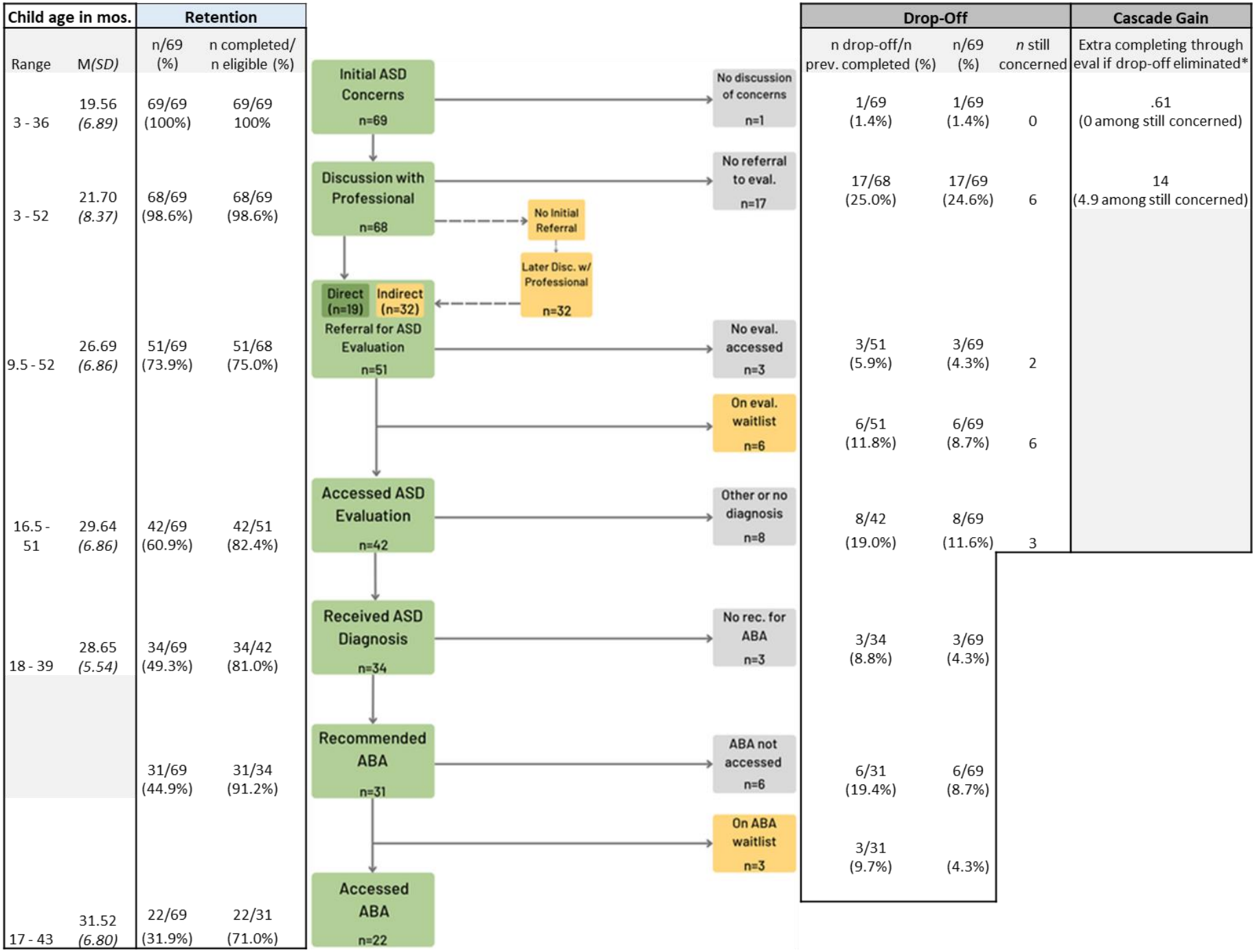


Figure 1 caption: Boxes in green represent inflection points along the cascade, with frequencies within a box indicating number of families who advanced through that step of the cascade. Arrows to the right lead to gray boxes representing end-points of families' journeys. Frequencies in gray boxes indicate drop-off. Yellow boxes indicate a deviation from the dominant care pathway, while not dropping off (e.g., indirect path to referral; remaining on a waitlist for evaluation or services at the time of the interview). Frequencies of those completing and dropping off at each sequential step of the cascade were calculated. Percentages indicate retention and drop-off for each inflection point, both based on those eligible for the step due to having completed the previous step, and based on the overall sample. "Cascade gain*," or the additional number of families who would complete through 'Accessed ASD Evaluation', if an individual preceding step were optimized (i.e., achieved 100% performance) while all other steps remained constant, was calculated for 'Discussion with Professional' and 'Referral for ASD Evaluation'.

Interim Discussion

To our knowledge, this is the first application of cascade analysis to the ASD evaluation and services pathway, which was modified to use caregiver report to characterize families' service delivery engagement following initial ASD concerns for their toddler. This modified cascade analysis is also novel in that it incorporates a time element to represent average delay from one inflection point to the next, which is a pertinent outcome for assessing families' experiences in this process.

The process of designing a cascade for this population and care pathway, and our experience using this method to characterize what happens following initial ASD concerns for families (and thus where there may be areas for improvement), revealed a number of considerations for potential future use of this method. With regard to designing the cascade, this process involved both theory-driven decisions about what would comprise a "standard" or "typical" care pathway leading to an evaluation and services, as well as data-driven decisions based on availability of information using caregiver report. For instance, the team initially posited that formal screening for ASD would be an important or common component of this cascade (e.g., as an inflection point between discussion of ASD concerns with a professional,

leading to referral for ASD evaluation). While this may be a clinically-helpful decision maker for providers (and would likely be included in the cascade if this method were implemented using clinic or health system data), we learned that at a group-level this step was not as salient to families, and would not be as informative to track at the group level using caregiver report. Possible explanations are that screening did not contribute to families' care pathways as much as expected in this sample, or that this step may occur but families may not be aware (particularly if not described clearly to families, if screening results did not indicate ASD likelihood, or if caregivers may be aware of general developmental, but not ASD-specific, screening being performed). This is consistent with other findings of low caregiver-reported rates of autism screening (e.g., 47.4% in Martinez et al., 2018), whether this reflects actual screening administration, or insufficient family awareness of whether screening occurred. Similarly, with regard to operationalizing "receipt of ASD-specific services," we originally would have hoped to preserve a broader definition of this outcome, beyond receipt of ABA (e.g., to include receipt of NDBIs, or autism-specialized speech, occupational, or physical therapies). However, given the constraints of available data, it made practical sense to constrain this inflection point to ABA. Caregivers tended to be aware of whether their child had received ABA, and it was more feasible to establish a timeline of when ABA began relative to their ASD diagnosis.

The team also grappled with a number of decisions about the granularity or specificity of inflection points along the cascade, particularly due to the cross-system nature of this cascade. For instance, decisions often arose about whether to specify the service system in which a given inflection point occurred. We originally considered "Discussion with PCP" as an inflection point, as opposed to "Discussion with Professional." While PCPs may have a more defined role in surveillance and screening, and may have a more formal role in placing referrals, we opted to

allow for the possibility that families "entered" the diagnostic pathway through discussions with other types of professionals. This also led to incorporating descriptive, supplemental data about actors along the cascade (rather than constraining inflection points to only include actions within a particular system). We also had to consider variability in what might constitute a "referral" for a diagnostic evaluation, as this could mean a formal order placed by a doctor to a specialty care clinic, or a recommendation made by a provider for the family to initiate an evaluation process somewhere (e.g., by self-referring). We opted for a similar decision to those described above, where the 'Referral' inflection point was inclusive of whether any provider, across systems, referred the child for an evaluation, and used descriptive information to supplement our understanding of how families engaged in this step of the cascade (i.e., who provided the referral). While it is possible that some families' retrospective report of this process contains inaccuracies (e.g., in terms of who influenced a given inflection point), this still represents caregivers' perceptions of how events unfolded and who participated in advancing the process. The above considerations might not be as relevant if cascade analysis is used in a specific health care system, clinic setting, or a local area, if there is a more uniform or prescribed process for engaging in this care pathway that does not need to account for such heterogeneity. Additional, more granular, inflection points could also be considered in that case; for example, including specific steps that may be required to follow up on a referral (e.g., completing intake paperwork, scheduling, etc.), as loss at these various steps may also be very relevant to improving outcomes in a given setting, but were not important for the breadth of the current application. A strength of cascade analysis is that inflection points can be tailored depending on the particular adaptation, while this also requires careful decision making based on theoretical definitions of what comprises the cascade, and data availability considerations.

This adaptation of cascade analysis also differed from most other uses in that it characterized service delivery along a care pathway for a behaviorally-defined diagnosis. In other words, contextualizing rates of continued participation and drop-off across this cascade is more challenging compared to other uses. To account for this, we opted to include the proportion of caregivers who remained concerned for ASD after drop-off at each endpoint. However, the possibilities remain that caregivers continued to have concerns despite ASD being improbable, or that caregivers were not concerned for ASD even if ASD was still likely. This concern might be mitigated if the cascade were able to include a behavioral indicator of ASD probability, such as a screening result. However, this remains a challenge for the field in general, that clinical decision-making about ASD probability prior to an ASD evaluation (for example, to inform appropriate referrals) is a complex and imperfect process, and that both providers and caregivers influence continued service delivery engagement.

A potential future use for cascade analysis in implementation efforts along the ASD evaluation and services pathway, in addition to being used to establish a baseline of system performance, is to use this method to statistically test the effects of an intervention in a pre-post design. An advantage of this method is that researchers would be able to evaluate the impact of their intervention across the care cascade, which is especially useful if using a multi-pronged approach, or to assess effects of the implementation at steps other than those directly targeted (e.g., reducing wait times for evaluations could inadvertently increase willingness to screen or refer over time).

Aim 2: Qualitative Analysis

Patient Journey Mapping

Participants

Journey mapping was used to illustrate a subset of individual family's trajectories (n=6), to depict variability between families in cascade outcome and trajectories through service delivery. Stratified purposive sampling was used (Creswell & Plano Clark, 2017; Palinkas et al., 2015; Sandelowski, 2000), where six sets of criteria were identified to reflect participation at different points along the cascade (in order to capture variability based on different paths/outcomes). The six categories identified were: (1) a family who had discussed ASD concerns with a professional, but was never referred for an evaluation; (2) a family who had received a referral via the "direct" path; (3) a family who had received a referral via the "indirect" path; (4) a family who had received an ASD diagnosis, with a <12 month interval between initial concerns and diagnostic evaluation; (5) a family who had received an ASD diagnosis, with a >12 month interval between initial concerns and diagnostic evaluation; and (6) a family who accessed ABA (reached the cascade endpoint). A list of eligible participants was created for each category, and a participant was randomly selected among this group for inclusion in patient journey mapping. Families were excluded from journey mapping if the ASD diagnostic evaluation was provided by the research team (n=6), as this is not likely to represent a family's typical journey in their local area accessing a diagnostic evaluation and services. While these six categories are not mutually exclusive, they were defined in order to maximize the likelihood of selecting information-rich cases to serve the goal of complementarity. Further, while saturation (e.g., thematic saturation, data saturation) is often relevant to consider in identifying a sample size in qualitative research, it is a less relevant outcome when the unit of

analysis is an individual informant (Saunders et al., 2018). The aim of the qualitative thread in this study was to complement a quantitative approach by illustrating select cases.

Analysis

Journey mapping consists of outlining all steps/encounters in a process across time, along with corresponding narrative details about patient experience. For these six participants, responses from the semi-structured phone interview were used to construct a chronology and path of the family's journey following initial ASD concerns including: documenting actors (i.e., who was involved), clinical encounters, handoffs between systems, and any other relevant actions taken.

A general visual format for the journey map was created that could be applied across all six journey maps, while content of the family's journey was able to vary (and included visuals that could aid in highlighting the variation between journeys). While the format of journey maps is highly adaptable to the composition of patient journeys depicted, journey maps tend to have elements in common, which may include: depicting the passage of time, the course of diagnosis/illness, or the course of care; highlighting important events or touchpoints with clinical services; delineating handoffs between clinical settings, systems, or physical locations; actions or input of key stakeholders or actors (i.e., who was involved in the process). A recent scoping review of patient journey mapping in healthcare research categorized a number of formatting approaches; a figure from this review representing these approaches to journey map design is reproduced in Figure 2 (Davies et al., 2019).

After participants were selected for inclusion in patient journey mapping, a written chronology and description of events was generated that included: timing (e.g., child age in months) and nature of any general developmental concerns the family had for the child

(including any responses to open-ended questions about what behaviors made them concerned, or to open-ended questions about what providers' responses were when concerns were raised); timing and nature of first ASD concerns, including who first had ASD concerns; any interactions the family had with the child's providers regarding concerns; any formal screening for ASD that occurred; any referrals for diagnostic evaluations that were made; any participation in EI services that intersected with the path to diagnostic evaluation; and accessing a diagnostic evaluation and referrals to/receipt of ABA. Note that, while participation in EI services is an important outcome whether or not that system plays a role in the family's path to a diagnostic evaluation, participation in EI was only recorded on the journey map if EI providers participated in any steps along the "cascade." For example, a family's participation in EI was depicted if an EI provider raised ASD concerns or if an EI provider was able to refer the child for a diagnostic evaluation, but was not included if the child's participation in EI services did not explicitly contribute to the diagnostic process.

Figure 2: Design approaches to mapping patient journeys, reproduced from Davies et al., 2019.

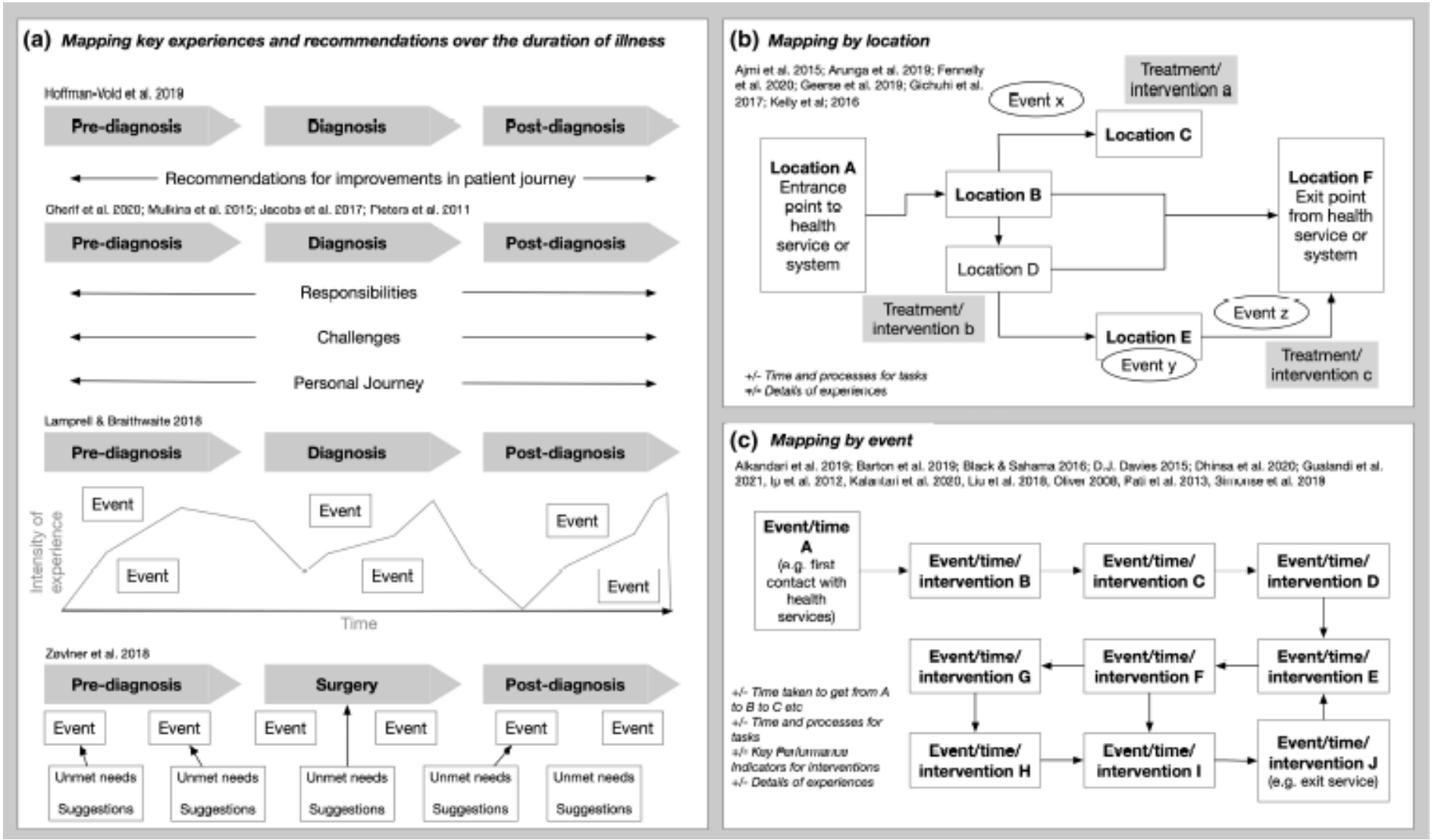
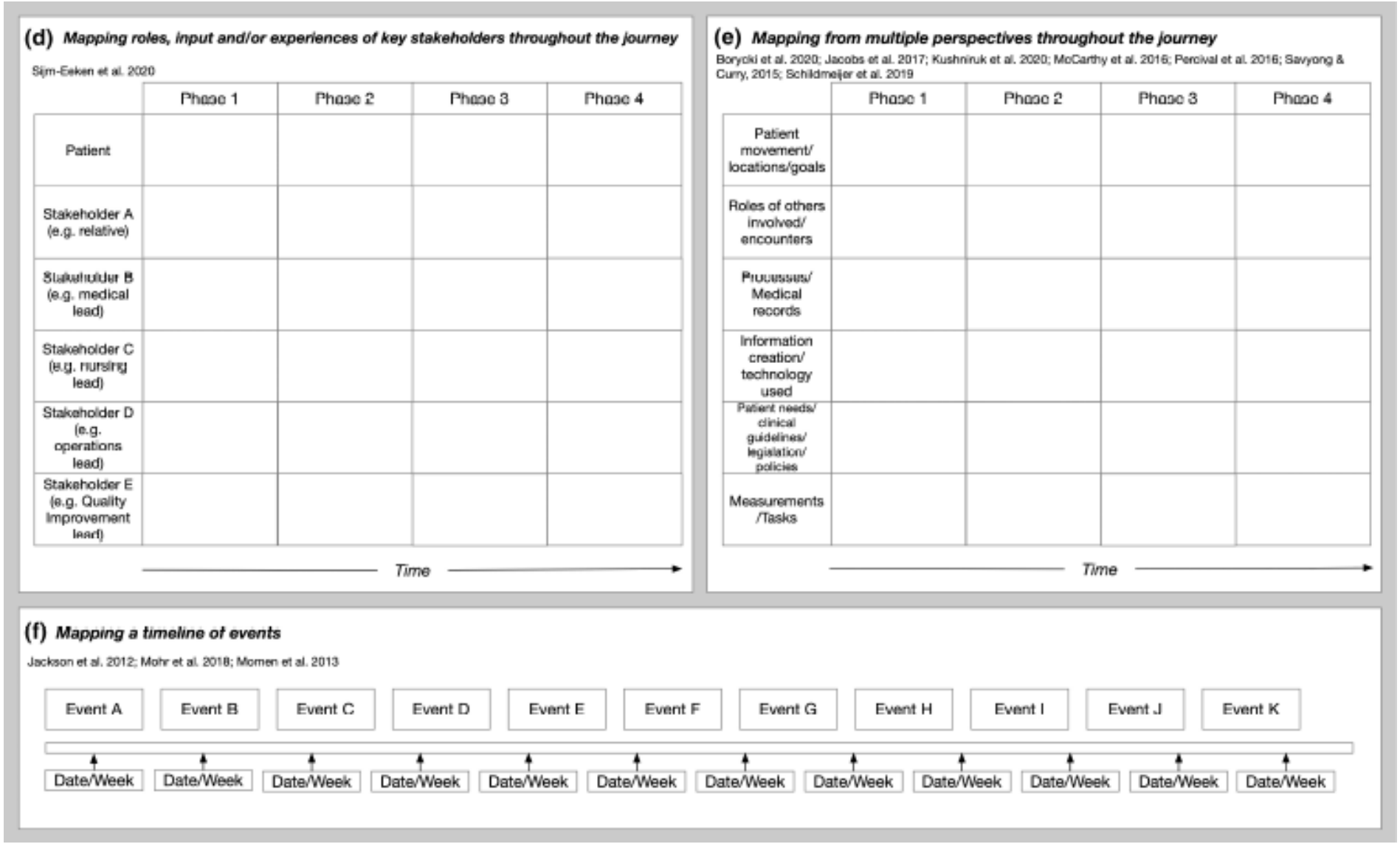


Figure 2: Design approaches to mapping patient journeys, reproduced from Davies et al., 2019 (continued).



Given the information that was relevant to patient journeys in the current study, a journey map template was created with columns representing time, and rows representing actors/stakeholders (e.g., caregivers, providers/service delivery systems), which will both be described. Columns were labeled with bins of child age in months (e.g., age 0-12 months, 13-19 months, 19-24 months, 25-30 months, 31-36 months, and 37+ months). A row was also created to depict "phases" that correspond to different periods of time in the process. Phases use color-coded labels to depict phases of the process (as they apply to the family), including: the phase when developmental concerns are present for the child (i.e., "developmental concerns phase"), a phase when ASD concerns are present for the child ("ASD concerns phase"), a "referral" phase once a diagnostic evaluation referral has been made, an "evaluation" phase when an ASD diagnostic evaluation takes place, a second "referral" phase if the child is referred for ABA, and a "services" phase if the child accesses ABA. Rows were created to represent actors/systems including: caregiver, family/friends (if applicable, not included if not relevant to the family), primary care, specialty care settings, Part C EI, and ASD-specific services. See Figure 3 for a Journey Map Key which includes symbols and colors used, and their meaning, that help to visualize chronology and events in the patient's journey. For example, picture icons were selected to represent different events occurring in the journey, which are connected by arrows to represent the flow of the journey. Typically, journey maps included depict: presence of developmental/ASD concerns; discussions with any providers; relevant quotes from the family regarding concerns or what they report the provider said during an interaction; actions taken by providers including screening or referral; a diagnostic evaluation taking place; and referrals for/accessing ABA. All journey maps were created in Canva.

Results

Figures 4-9 depict patient Journey Maps 1-6. A brief narrative description of each patient journey is included below.

Patient Journey Map 1: Drop-off Following Discussion of ASD Concerns with Professional

When the child is 27 months old, the mother starts to have concerns about development in general. At that time, she thinks "[Child] is reserved, and keeps to herself. She's smart but doesn't react to her surroundings." She raises concerns to the child's PCP at that time (27 months). The mother reports that the PCP's response was that there "might be cause for concern" about development, so the PCP administered a screening tool. The mother recalled that the results were "borderline" (i.e., on the cusp of being cause for concern), and that the PCP said to "monitor [concerns] over the years."

When the child is 36 months old, the mother's best friend, whose own son is on the autism spectrum, raises concerns about the child. When asked what behaviors made that friend concerned, the mother recalls her friend saying that "[Child] is reserved but when put in her own space, she does 'whatever.' She's too smart for her own good. She gets overwhelmed easily and has a bad temper." At that time (36 months) the mother begins to have concerns for ASD as a result of the discussion with her friend. She raises concerns to her child's PCP again (at 36 months). The mother recalls that the PCP administered another screening tool, and that the results were again "borderline." She recalls that the PCP said to monitor over the years.

At 53 months old (at the time of the interview), the mother remained somewhat concerned for ASD. She said she was slightly concerned for ASD still, though "not as much. She's been doing better in preschool."

Patient Journey Map 2: Referred to ASD Diagnostic Evaluation via "Direct" Referral Path

When the child is 20 months old, the mother began to have concerns about the child's development in general, because "[Child's] speech wasn't developing." At 24 months, she raises concerns about development to the child's PCP. The mother recalls that the PCP administered the Ages & Stages Questionnaire, and results indicated that the child was "behind on most milestones besides physical [milestones]." As a result (at 24 months), the PCP raised ASD concerns for the child. When asked how she first learned of autism, the mother recalls that it was a result of this conversation. The PCP made referrals for both a hearing test and an ASD diagnostic evaluation at that time.

The mother recalls that the hearing test results came back normal. After receiving the hearing test results, the mother began to be concerned for ASD (when the child was 25 months old). She recalls that despite receiving the ASD diagnostic evaluation referral from the PCP, they were told that the wait would be about 6 months; she describes this wait as "too long" and says "We weren't willing to wait." She begins to research autism online (e.g., on the Autism Speaks website) and completes the M-CHAT screening tool online.

The family self-refers to a diagnostic evaluation (when the child is 25 months old); she recalls that she contacted a local PCP who is authorized to provide ASD diagnoses as a designated autism "Center of Excellence" (Washington State Medical Home Partnerships Project, n.d.). Soon after (at 25.5 months old) the diagnostic evaluation is completed, an ASD diagnosis is provided, and the child is referred for ABA. At 29 months, the child starts receiving ABA, and was still receiving services at the time of the interview (58 months).

Patient Journey Map 3: Referred to ASD Diagnostic Evaluation via "Indirect" Referral Path

When the child was 15 months old, the mother begins to have concerns about ASD for the child. She recalls that at that time the "[Child] is sensitive to textures in clothing and food.

She's always had a problem with her hair being brushed and won't try certain foods. She was only using 5 words and should have been up to 20. We were Googling these behaviors and autism kept coming up. And her biological mom was diagnosed with autism as an adult."

At 18 months old, the child's mother raises ASD concerns with the child's PCP. She recalls that the PCP said that she "didn't meet ASD spectrum requirements based on guidelines," and that "nothing was wrong, she would catch up, every child develops differently." The mom recalls that "after some pushing" the PCP referred the child to speech therapy (also at 18 months old).

The child begins speech therapy at 18 months; while in EI the providers raise ASD concerns about the child. The mother recalls that they were "all on the fence," and said "if she is on the spectrum, she is very 'high-functioning.'"

When the child is 24 months old, the mother raises ASD concerns to the child's PCP, who administers a screening tool. The mother recalls that, regarding screening results, the PCP said "she didn't have enough points to qualify as autism risk," and "recommended going to a specialist if we wanted."

The mother recalls that when the child was 49.5 months old, the PCP formally made a referral for a diagnostic evaluation to a neurology and developmental medicine department at a children's hospital. At 51 months old, the diagnostic evaluation was completed and the mother reported that the child was given diagnoses of receptive/expressive language delay, "a little bit of ADHD," and feeding difficulties. Recommendations included continuing services the child was receiving (e.g., speech and occupational therapy) and later follow-up appointments.

At the time of the interview (when the child was 58 months old), the mother remained concerned for ASD. She said that "[Child's] teacher thought she had an autism diagnosis. She thinks I should [pursue another evaluation] so that she can receive ABA."

Patient Journey Map 4: Accessed Diagnostic Evaluation <12 Months After Initial ASD Concerns

When the child was 15 months old, the parents became concerned about the child's development in general. Regarding their observations of the child's behavior at that time, the parent recalls, "[Child] was lining up stuffed animals and had been talking and then stopped. He stopped responding to his name or looking at us, and was by himself a lot of the time." The parent says that at first, they wondered about his hearing.

At 16.5 months old, the parents became concerned for ASD, specifically. The parent recalled that "losing words" was the behavior that made them specifically consider autism. The parents "started reading about autism online. It wasn't a scary thing anymore."

When the child was 18 months old, they raised ASD concerns with the child's PCP. The parent recalled that the PCP "asked questions and gave a written form [a screening tool]" and that results were consistent with ASD concerns.

The mother recalled that soon after, at 21 months old, the PCP made a referral for a diagnostic evaluation to developmental behavioral pediatrics at a children's hospital. At 25 months old, the diagnostic evaluation was completed, and a diagnosis of ASD was given. At that time, a referral was made for ABA services. At the time of the interview (47 months old), the mother indicated that the child was still on a waitlist to receive ABA.

Patient Journey Map 5: Accessed Diagnostic Evaluation >12 Months After Initial ASD Concerns

When the child was 9 months old, the parents began to have concerns about development in general for their child. The parent recalls that they "knew there was something wrong." They noticed "lack of eye contact" and said that "[child] regressed from walking to crawling" and was "colicky and inconsolable."

At 12 months of age, the child's PCP raised concerns about development to the family. The mother recalls that the PCP made referrals to an ophthalmologist and to an ENT at that time (12 months).

When the child was 18 months old, the PCP raised ASD concerns for the child with the family. The mother recalls that the behaviors that were concerning for autism were "meltdowns," and that "[Child] had no internal coping skills." The PCP administered a screening tool, and the mother recalled that results indicated concerns about development. The PCP (at 18 months) made referrals to speech and occupational therapy. The mother reported that the child began speech and occupational therapy at 16 months (which may reflect a minor reporting error in the timeline described).

At this 18 month visit with the PCP, the mother began to have concerns for ASD for the child. She noted that they also read about sensory processing disorder, as it had been mentioned to them by an EI provider. She recalled that "red flags for sensory processing disorder and ASD were similar. The ASD red flag that stood out was having no language. [Child] had no language until age 4."

When the child was 19 months old, one of the child's EI providers referred the family for a diagnostic evaluation (to a psychologist in private practice). At 37 months old, the diagnostic evaluation was completed, and the child received an ASD diagnosis. At that time (37 months), a referral was made for ABA. The child started receiving ABA at 42 months old.

Patient Journey Map 6: Accessed Diagnostic Evaluation & ASD-Specific Services

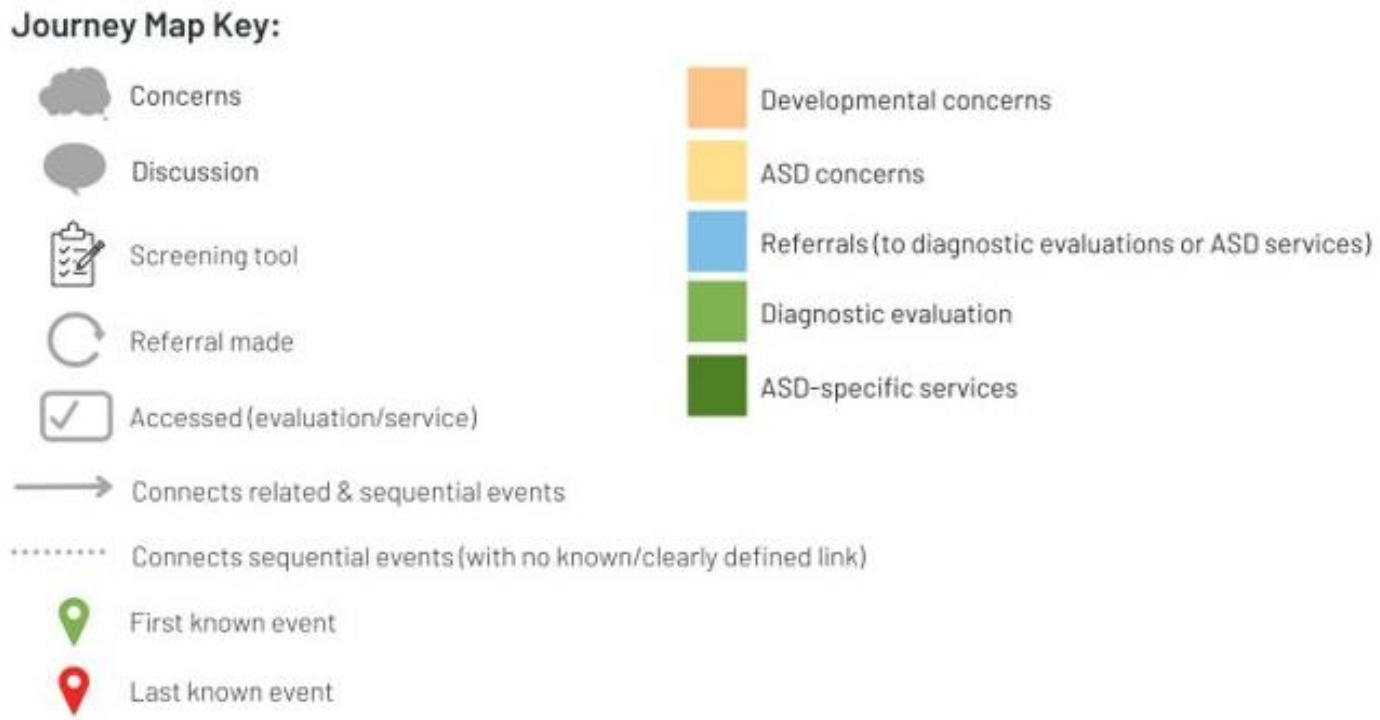
When the child was 23 months old, the father began to have concerns about ASD for the child. He recalls that the child "wasn't meeting key language milestones. He was interested in spinning fans, and made minimal eye contact. He wasn't engaging with people at his birthday party."

The father raised ASD concerns with the child's PCP at 23 months. He recalls that the PCP said "let's give it a little more time because some children are slower to develop. We will pursue testing if you'd like but let's wait and see."

At 30 months old, the family returned to the child's PCP to follow up regarding ASD concerns. At that time, the PCP made referrals to Part C EI and to a diagnostic evaluation with a neurologist.

At 30 months old, the diagnostic evaluation was completed and an ASD diagnosis was conferred. A referral was made at that time to ABA. The child began receiving ABA services at 37.5 months old.

Figure 3. Journey Map Key



These elements help the reader to follow the patient journey and identify important events and phases. A **green pin** marks the first event along the timeline, while the **red pin** marks the last known event in the journey at the time of the interview. **Solid lines** connect events that are related (i.e., one event that directly leads to another event occurring), while **dotted lines** connect two events that happen in sequence (i.e., a dotted line leads from one event to the next event in time). **Picture icons** depict important events, such as when concerns arose, when a discussion occurred between two actors, when a screening tool was completed, when a referral was made, and when an evaluation or services were accessed. **Child age** in months is noted when each of these events occur. Finally, phases are depicted by color coding: orange denotes the time when general developmental concerns are known for the child; yellow denotes ASD concerns being present for the child; blue denotes that the family has received/is pursuing referral(s) for diagnostic evaluation and/or ASD-specialized services; lighter green denotes an ASD diagnostic evaluation occurring; and darker green denotes ASD-specific services (e.g., ABA) occurring.

Figure 4: Journey Map 1: Drop-Off Following Discussion of ASD Concerns with Professional

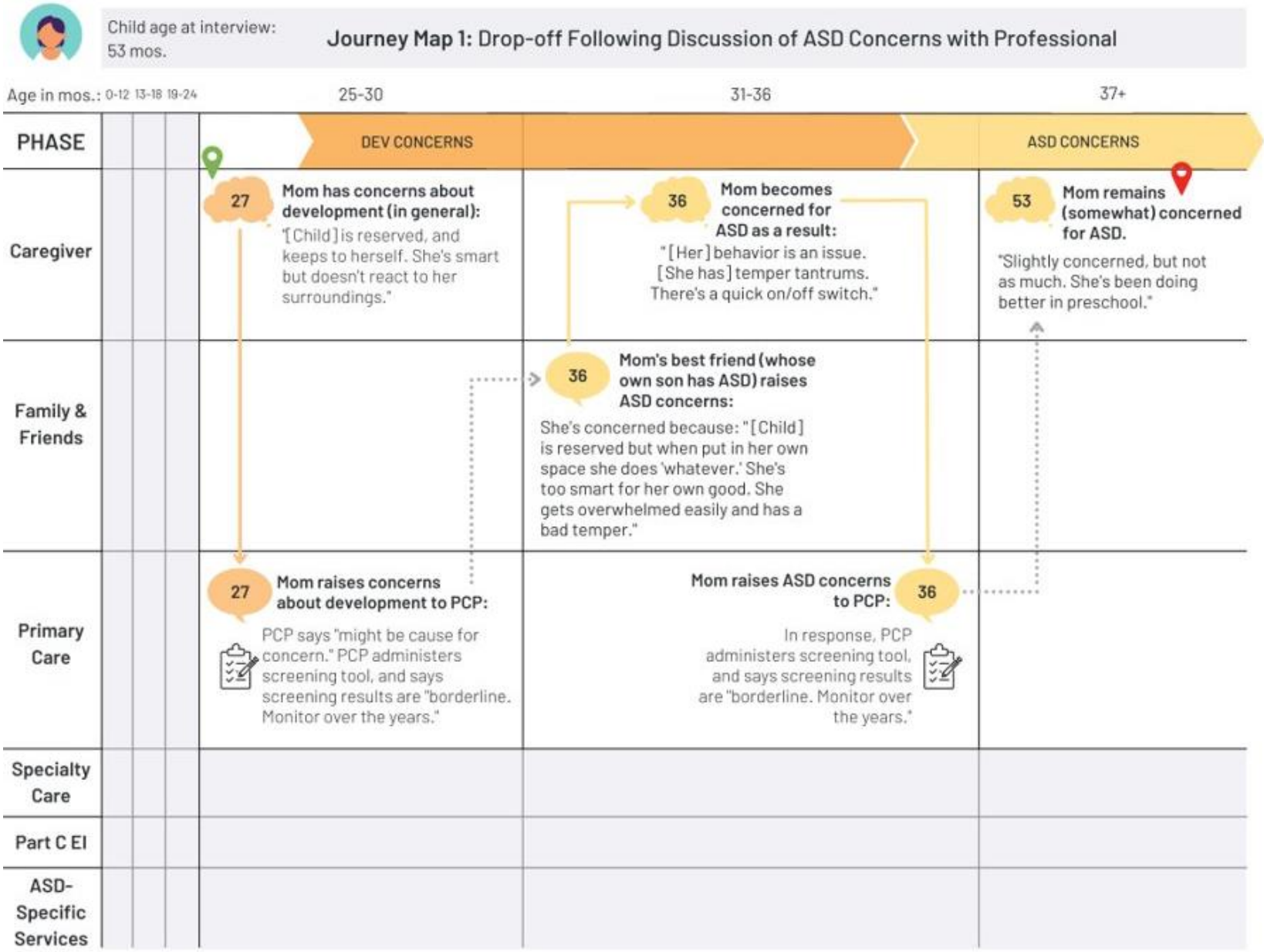


Figure 5: Journey Map 2: Referred to ASD Diagnostic Evaluation via "Direct" Path

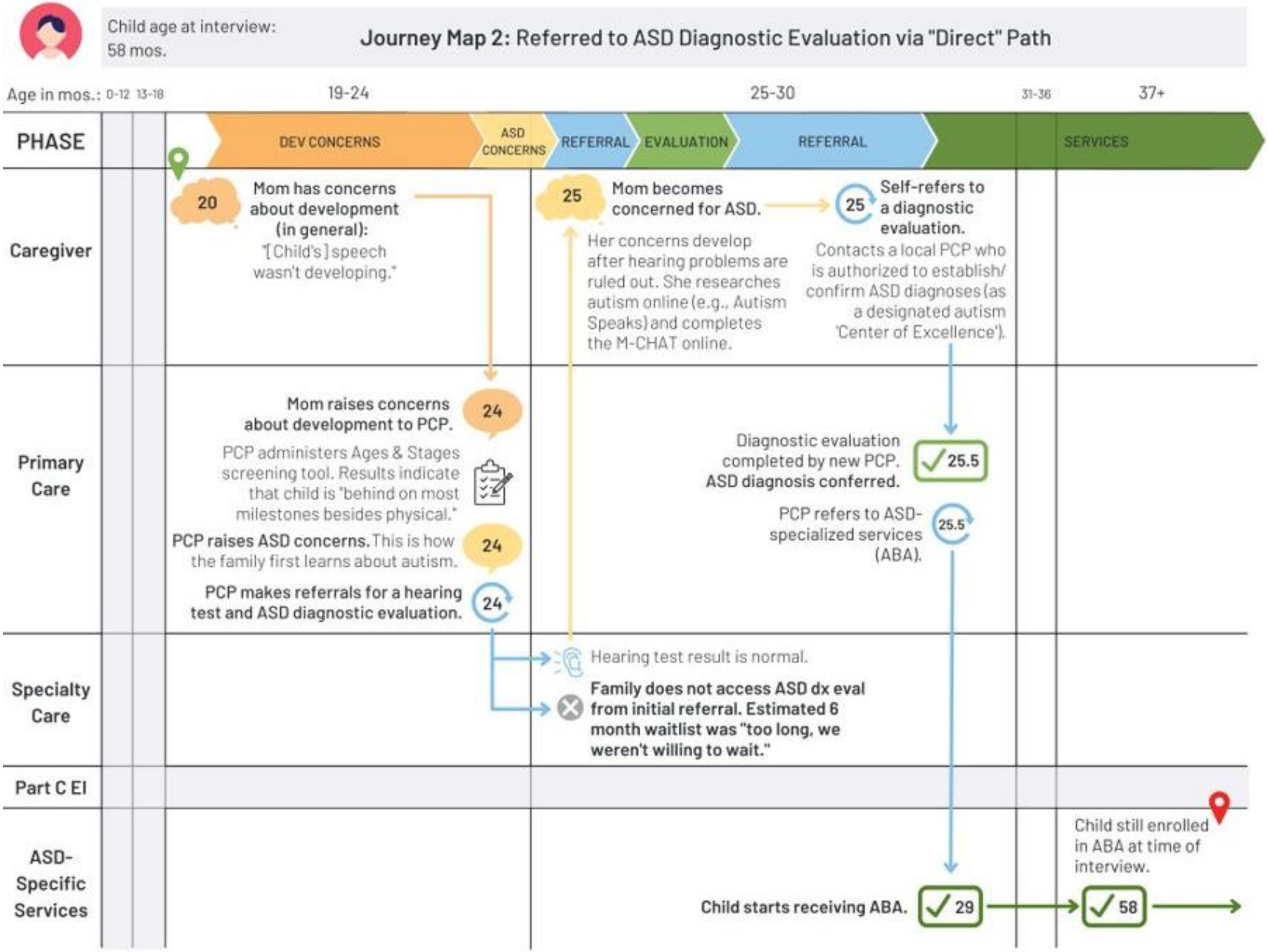


Figure 6: Journey Map 3: Referred to ASD Diagnostic Evaluation via "Indirect" Path

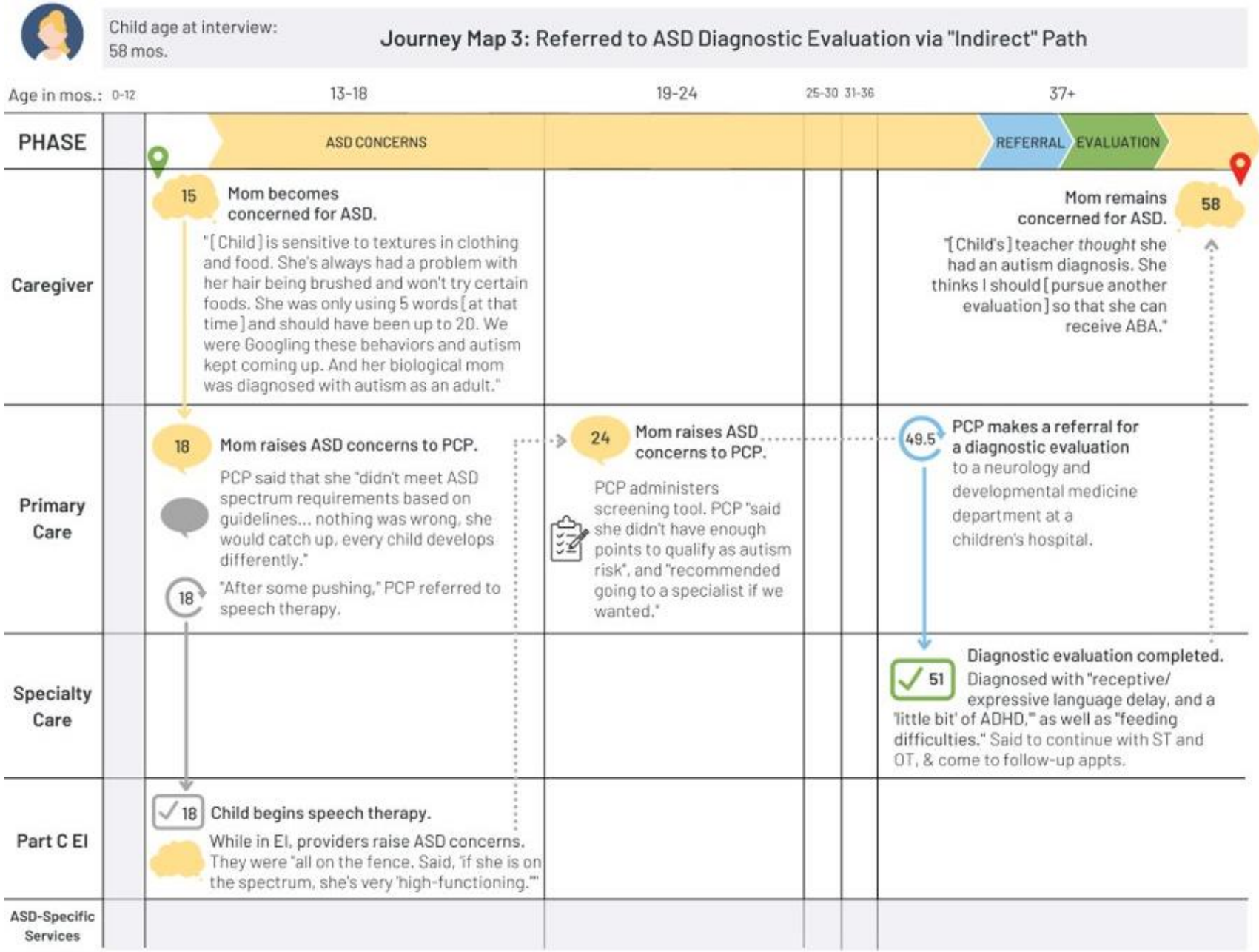


Figure 7: Journey Map 4: Accessed Diagnostic Evaluation <12 Months After Initial ASD Concerns

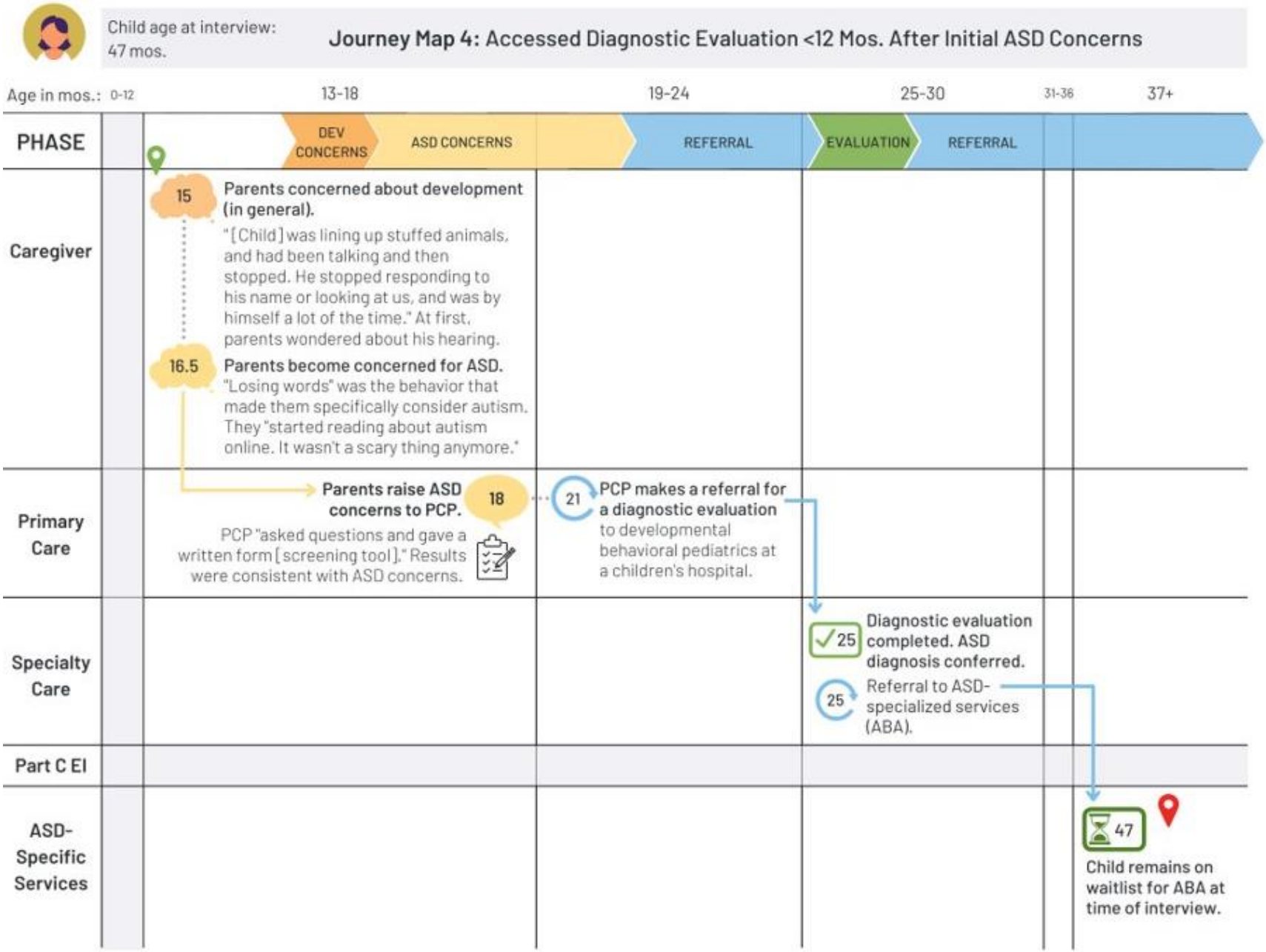


Figure 8: Journey Map 5: Accessed Diagnostic Evaluation >12 Months After Initial ASD Concerns

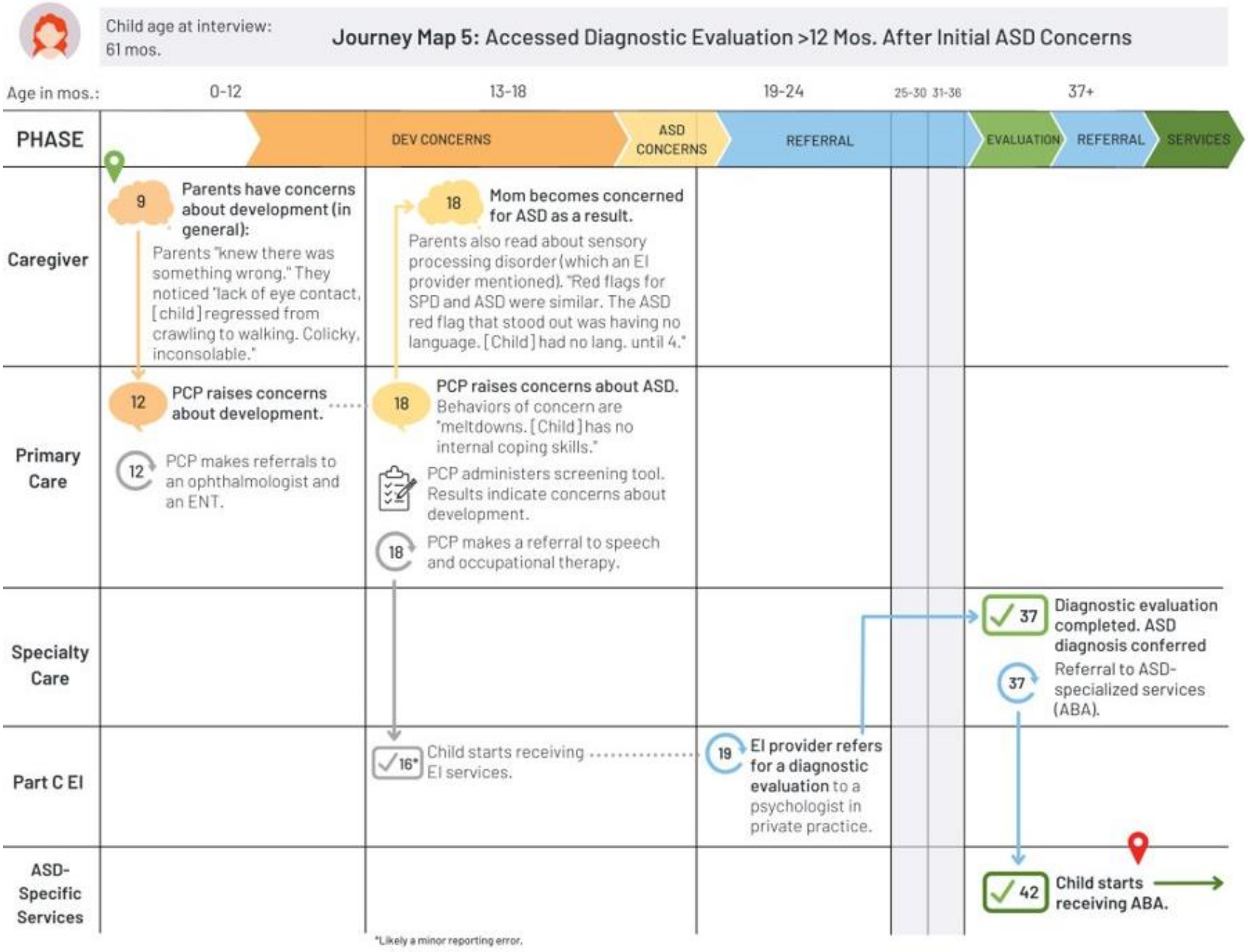
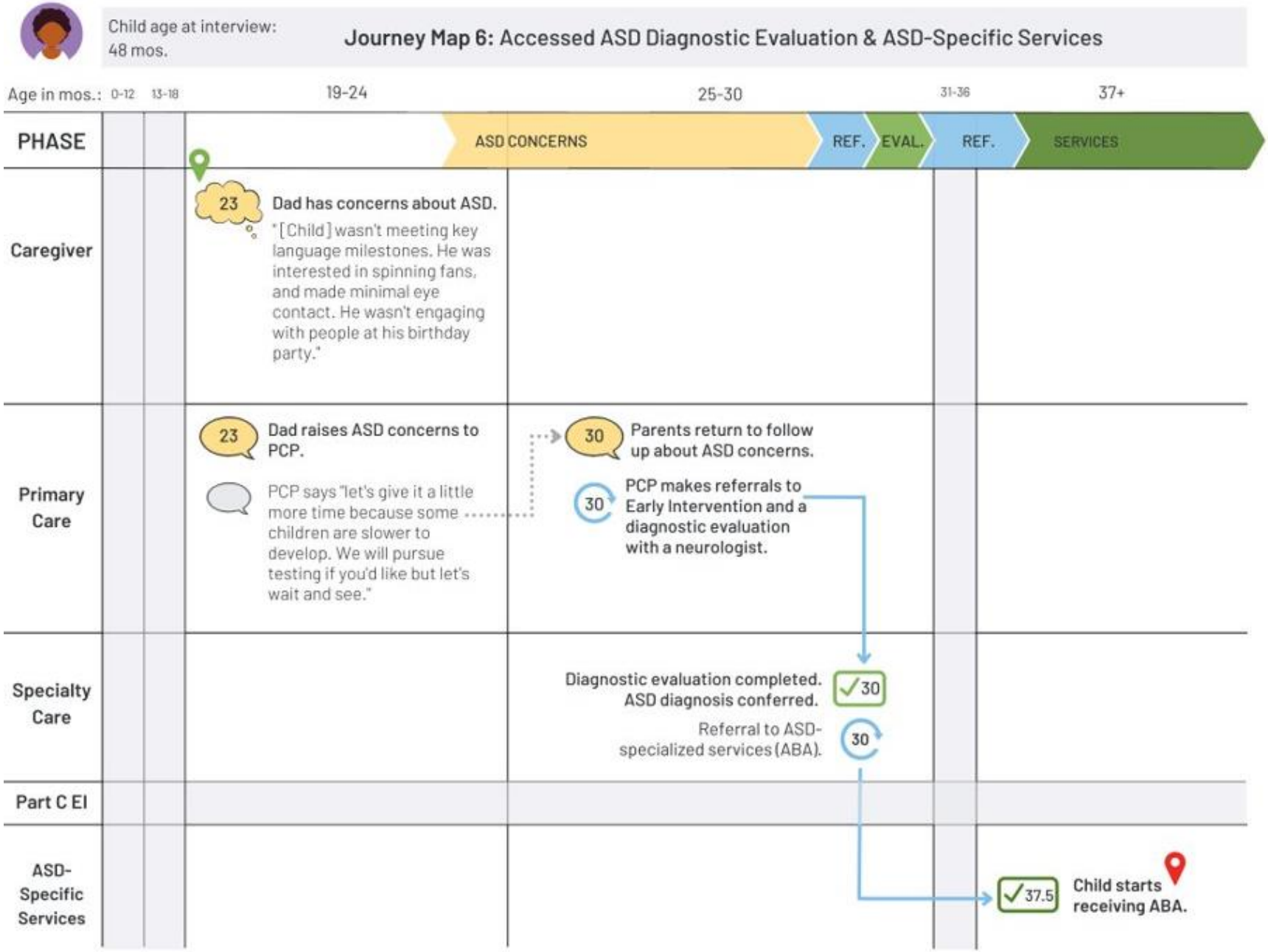


Figure 9: Journey Map 6: Accessed Diagnostic Evaluation & ASD-Specific Services



Integrated Discussion

Patient journey mapping complemented cascade analysis by providing additional depth and nuance regarding families' experiences and journeys through service delivery when ASD concerns are present. Mapping individual families' journeys in this process allowed for inclusion of relevant details even when analogous information was not available for other participants (e.g., to be used in a group-level analysis), and inclusion of details that were outside the scope of the specific cascade analysis inflection points. For example, a period of having general developmental concerns was included on some families' journey maps; this allowed us to depict when and how these general developmental concerns evolved into more specific ASD concerns (i.e., at what point families began to have an awareness that ASD might describe some of their child's behaviors, whether they or someone else first raised this possibility). Relatedly, while it has been discussed that families did not reliably recall whether a screening tool had been administered for their child, some families were aware of this step in their journey, and the journey map's individual focus allowed this to be represented. Importantly, journey mapping also allowed for the inclusion of narrative components, including quotes about the nature of caregiver's concerns. While the interview guide was not specifically designed to elicit the subjective or emotional experience of the family at each stage, this could certainly be incorporated in future applications of journey mapping.

The complementary use of journey mapping to cascade analysis also revealed areas where the group-level examination of cascade analysis "flattened" families' experiences. For instance, in Journey Map 2, the family was given a referral to an evaluation based on their first discussion with a provider, so they were considered to be in the "direct" path to referral (and their relatively short interval between discussion, referral, and evaluation would not have

suggested otherwise). However, journey map results are able to depict that the family opted not to follow-up on that first referral received, given that they were quoted a 6 month wait for an evaluation. This element of their journey underscores that a measure of "referral follow-up," as discussed previously, could be an important step to assess in the diagnostic pathway. Additionally, in Journey Map 1, the caregiver describes herself as still concerned for ASD (and her binary Yes response is accounted for in the count of caregivers who are still concerned in cascade analysis), though her more expanded response depicted on the journey map qualifies this by saying she is only somewhat concerned, and she's seen some improvement. Idiosyncratic paths can also be illustrated with this method; for example, in Journey Map 2, the child received an ASD diagnosis from a PCP designated as an Autism Center of Excellence in Washington State (Washington State Medical Home Partnerships Project, n.d.).

A number of considerations for future uses of journey mapping in ASD research were revealed. First, while this is a process that provides rich information, it can also be time intensive. While journey mapping was used here to complement and illustrate findings of a quantitative method that provided breadth, time and resource considerations would be especially relevant to consider if journey mapping were used with a larger sample size (and perhaps necessitated qualitative coding using a grounded theory approach) to generate broadly applicable themes. Additionally, while data collection procedures involved a semi-structured interview with opportunities for both closed- and open-ended responses that allowed a chronology and path to be constructed, the description of families' experiences on this journey may have differed if families were given the opportunity to describe this experience from start to finish with less scaffolding. As mentioned previously, data collection for future patient journey mapping efforts

may also choose to incorporate prompts to elicit information about families' subjective experience along this path.

General Discussion

This project addressed challenges in ASD diagnosis and services implementation research by: (1) examining a method (*cascade analysis*) that could be used to evaluate system performance across the entirety of a complex cross-system service delivery process; and (2) demonstrating use of a method (*patient journey mapping*) that centers the family's point of view and retains complexity of their specific individual experience in service delivery when ASD concerns are present. An additional strength of this dissertation was the mixed-method design, integrating quantitative and qualitative methods to achieve complementarity. The use of caregiver report applied to these methods represents both a strength, as it centers families' perspectives of the process, as well as a potential limitation—while caregivers were reporting on this process retrospectively, it remains a possibility that families may not recall specifics of this process, and a possibility that they may have never been privy to relevant information (e.g., about screening) if not shared by providers. In future work, potential methodological trade-offs between using caregiver and/or clinic/health system data should be considered. While there are limitations of the current study in terms of generating representative or generalizable areas for improvement along this care pathway, these methods demonstrate promise for future use in ASD implementation efforts, with respect to noted challenges in this area (Broder-Fingert et al,, 2019). It is likely that future work in this area will continue to grapple with the balance between representing individual experience and complexity of the diagnostic process, while trying to gain a broad understanding of this complex cross-system care pathway at a high level.

A remaining interrogation for future work in this area is what it means to truly "optimize" this process. For instance, optimizing could mean that more people reach a designated step in the service delivery process (i.e., less drop-off before an ASD evaluation if ASD concerns are still present), it could mean faster completion of service delivery steps (given a history of caregiver dissatisfaction with long waits), or both. However, not all children for whom there are ASD concerns require a resource-heavy comprehensive evaluation, nor would all families prioritize this even if available. Ongoing research evaluating this process will benefit from incorporating information about who influences ongoing participation or drop-off at each step, and/or whether provider and caregiver are aligned at various steps about what the next best step is for the child and family. Work that has incorporated the concept of shared-decision making in early identification of ASD shows promise for how to best navigate this balance (Sheldrick et al., 2019).

In conclusion, this study explored the utility of a mixed-methods approach, using two innovative methods, to characterize families' experiences on the path to an ASD evaluation and services. Despite a limited ability to yield generalizable insights about areas for improvement, the use of these methods (or other methodological innovations) are promising for use in ASD implementation efforts.

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Appendix A. Semi-Structured Phone Interview Guide

ASD Concerns and Services Phone Interview/Survey

SN_____ Date:_____ Age of child:_____ Caller:_____

County: _____ Cohort: □ Pre □ Post

Great, let's get started! I am going to put you on speaker phone now if that's ok so that my colleague can take notes and make sure I don't miss writing anything down. Please let me know if you have trouble hearing me and I can turn off speaker phone.

1. Prior to autism concerns, how old was your child (in months) when you, or someone else, *first* became concerned about your child's development in general? 18 months, 16
   - Who was the one to first raise these concerns (i.e., you, or someone else)?
     - □ Parent/caregiver
     - □ Provider (specify role and name if known: _____)
     - □ Someone else (specify relationship: _____)
   - What were the behaviors that made (person) concerned:

   IF PCP WAS NOT THE FIRST TO BE CONCERNED: Did you discuss these concerns with your primary care provider?
   - □ No
     - Why not?
   - □ Yes
     - When did you discuss your concerns (age in months)? _____
     - What did they say?

2. How old was your child (in months) when you, or someone else, *first* became concerned that s/he might have *autism or ASD*?
   - Who was the one to first raise these concerns about autism?
     - □ Parent/caregiver
     - □ Provider (specify role and name if known: _____)
     - □ Someone else (specify relationship):

   IF PCP WAS NOT THE FIRST TO BE CONCERNED: Did you discuss these concerns with your primary care provider?
   - □ No
     i. Why not?
   - □ Yes
     i. When did you discuss your concerns (age in months)? 30
     ii. What did he or she say?

3. What were the behaviors that *first* made (*someone*) specifically consider autism?

Ask if PCP or someone else was first concerned:

4. Have <u>you</u> ever been concerned about autism?
   - ☐ No
   - ☐ Yes
     - When did you first develop concerns about autism?
     - What made you concerned about autism?

Ask always:

5. Are you concerned about autism now?
   a. No
   b. Yes
   a. When did you first develop concerns about autism? _____
   b. What made you concerned about autism? _____

6. How did you first learn what "autism" is?

7. Did your child's doctor ever ask you to fill out a screening tool or questionnaire about your child's risk for autism?
   - ☐ No
   - ☐ Yes

   a. What was the name of the screening tool, if you know it (e.g., Ages and Stages [ASQ]; PEDS; M-CHAT; other)?

   b. How old was your child (in months) when you filled out this measure?

   c. How did you complete the screening tool (e.g., a paper version at my provider's office; an electronic version on a tablet at my provider's office; an electronic version through a link at home)?

   d. Were the results of the screening tool discussed with you?
      - ☐ No
      - ☐ Yes
        - What were the results?
          - ☐ Results were normal
          - ☐ Concerns about development (not autism specific)
          - ☐ Concerns about autism
          - ☐ Other
          - ☐ Not sure/don't remember

8. Has your child received a formal diagnostic evaluation for autism?
- ☐ Yes
- ☐ No

IF YES to DX eval:
- What were the results?
  - ☐ Autism Diagnosis
  - ☐ Other developmental disorder (Specify: _____)
  - ☐ Other (Specify: _____)
  - ☐ No diagnosis was conferred

a. Who referred your child for this evaluation (specify name/role):
b. When did they refer you for an evaluation (age in months and/or date)?
c. How long did it take you to follow-up about scheduling a diagnostic evaluation (if applicable; in months)?
d. At what age (in months) did your child receive this diagnostic evaluation? *(If doesn't remember child's age, ask for approx. date)*
e. Where did your child receive this diagnostic evaluation?
f. Who was the provider who assessed your child?
   - ☐ Did the provider conduct formal assessment activities with your child? Or just review previous evaluations or records?
   - ☐ How long was the evaluation?

g. Do you remember how long it took from when you first contacted _____ to get an evaluation?

h. What recommendations were made? Did you receive a prescription for a treatment called ABA (Applied Behavior Analysis) from this evaluation?

i. We'd like to get a copy of the report if possible. Can you send us a copy of the report through the mail or over email? Or can we request one from the provider directly using a signed HIPAA form?

IF NO to dx eval:
- Was your child ever referred for a diagnostic evaluation?
  - ☐ No
  - ☐ Yes
    i. Who referred you for an evaluation? _____
    ii. Where were you referred for an evaluation? _____
    iii. When were you referred for an evaluation? _____
    iv. Did you follow through with the referral?
      - ☐ No
        - If no, why not?

□ Yes

a. How long did it take you to follow through on the recommendation for an autism diagnosis?
_____

b. When did you submit your paperwork (if applicable):
_____

c. Is the appointment scheduled?
   □ No
   □ Yes (date: _____)

d. Is your child on a waiting list?
   □ No
   □ Yes (when did you get on wait list?
   _____)

9. There are different types of intervention that children receive. Early intervention is publicly available at no direct cost to you. Private intervention is paid either out of pocket or by insurance.

- Has your child ever attended public early intervention, a private intervention program, or both?
  □ Public
  □ Private
  □ Neither
  □ both

IF PUBLIC:

a. Where?

b. Who referred you there?

c. At what age (in months) was your child referred for these services?

d. At what age (in months) did s/he start receiving these services?

e. Did any of the providers in the EI program mention the possibility that your child might have autism/ASD?
   □ Yes
   □ No
   □ N/A (i.e., already has diagnosis)

f. Is she/he still receiving these services?
   □ Yes
   □ No

IF PRIVATE:

a. Where?

b. Who referred you there?

c. At what age (in months) was your child referred for these services?

d. At what age (in months) did s/he start receiving these services?

e. Did any of the providers in the EI program mention the possibility that your child might have autism/ASD?
   - ☐ Yes
   - ☐ No
   - ☐ N/A (i.e., already has diagnosis)

f. Is she/he still receiving these services?
   - ☐ Yes
   - ☐ No
     i. When/why did you stop receiving these services?
     _____

10. Has your child ever received any type of intervention designed specifically for children with autism (for example, Applied Behavior Analysis (ABA)? [others are Reciprocal Imitation Training (RIT), Pivotal Response Training (PRT), Early Start Denver Model, JASPER]
   - ☐ No
   - ☐ On waitlist
   - ☐ Yes
     - What was the name of the intervention?
     - Was there a waitlist? (Yes/No)
     - If so, how long were you on a waitlist?
     - How old in months was your child when s/he started this intervention? _____

b. Where did he/she receive this intervention?

c. Is s/he still receiving this intervention?

11. What about after age 3? Did your child attend a preschool program or receive other intervention after EI?

12. May we contact you if we have more questions about the services that your child is receiving?
   - ☐ Yes
   - ☐ No

13. We may get funding to follow children in our study for a longer span of time. Would you be interested in us contacting you in the future if this opportunity arises?

- Yes
- No