Chapter 13
FASD-Informed Care and the Future of Intervention

Heather Carmichael Olson, Misty Pruner, Nora Byington, and Tracy Jirikowic

Introduction

About 50 years ago, the full fetal alcohol syndrome (FAS) was recognized in the scientific literature as a condition resulting from prenatal alcohol exposure (PAE) and was soon acknowledged to last lifelong [1–3]. Over the next 25 years, studies revealed that a much wider range of neurodevelopmental conditions were associated with PAE [4, 5]. The overarching term "FASD" to denote "fetal alcohol spectrum disorder(s)" gradually came into use and was formalized in the early 2000s (e.g., [6, 7]). From the beginning of the field, effective treatment for FASD was of interest, although it was daunting to know what to do.

Starting early and building momentum, energetic family support networks emerged to respond to FASD through self-help, peer support, and advocacy in the 1970s and 1980s. Governmental public health and research initiatives also began in

H. C. Olson (✉)
Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine, Seattle, WA, USA

Center on Child Health, Development and Behavior, Seattle Children's Research Institute, Seattle, WA, USA
e-mail: heather.carmichaelolson@seattlechildrens.org

M. Pruner
Center on Child Health, Development and Behavior, Seattle Children's Research Institute, Seattle, WA, USA
e-mail: mpruner@uw.edu

N. Byington
Masonic Institute for the Developing Brain, University of Minnesota, Minneapolis, MN, USA
e-mail: bying015@umn.edu

T. Jirikowic
Department of Rehabilitation Medicine, University of Washington School of Medicine, Seattle, WA, USA
e-mail: tracyj@uw.edu

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the 1970s, appearing gradually over time in a growing number of countries. FASD screening and diagnostic efforts took off in the 1990s, though a constant barrier to diagnosis was the lack of effective treatment [8]. Families and providers continually asked: "Why get a diagnosis when there is nothing to do about it?" Yet, over the years, prevalence studies and advocacy efforts increasingly revealed those living with FASD as a surprisingly large, under-recognized, under-served global clinical population with neurodevelopmental disabilities that deserved (and needed) services over the lifespan (e.g., [9–11]). The high costs of FASD were periodically estimated, such as a 2019 estimate of the lifetime (global) cost of care per diagnosed individual (by age 43) of over $1 million US [12, 13], provoking interest in treatment as a way to reduce these costs.

FASD came to be understood as a set of "brain-based" conditions characterized by wide-ranging, individually variable teratogenic alcohol effects. Along with many correlated prenatal and postnatal risk factors, this meant lifelong neurodevelopmental complexity with additional health and mental health complications. But in the 1990s, US-based data uncovered a stark reality: there were also high rates of a full range of what have been called "secondary conditions" among those living with FASD, especially as they grew older. Current data gathered nearly 20 years later, echoed this unfortunate message. Evidence continued to reveal high rates of adverse life experiences and problems in daily life for those with FASD—even in Canada, a country with more responsive social services [14].

Starting in the 1990s, awareness of this difficult reality galvanized both necessary action and stigma [15]. Pressure for effective treatment and adequate service systems grew. Protective factors were identified, providing direction for treatment. It rapidly became clear that stable, nurturant caregiving, and adequate social and developmental disability services were central protective influences for those with FASD [16]. But what also became clear was the heavy, lifelong burden of FASD on caregivers and families—because there was no organized social safety net for FASD in any country. So, in the late 1990s, it became of vital interest to find and build caregiver and family support, because it was clearly lacking. In the 2000s, interest also turned to finding treatment for young children with PAE, given their high risk for FASD paired with the hope that later problems could be prevented by early intervention (e.g., [17–20]). However, early intervention was also lacking. In the 2000s, periodic calls to action and needs assessments were published (e.g., [21, 22]), a trend that continues to the present time [11, 13], pointing out many gaps in treatment research and services. While FASD was known to be a worldwide problem, in the mid-2000s, the global nature of FASD really began to sharpen into focus and, over time, magnify (e.g., [10]). This meant that the need for treatment services was also worldwide.

While momentum for action was growing, it was fortunate that a foundation of knowledge-based treatment was also being built. Solid basic research and study of animal models highlighted useful treatment directions for human studies (e.g., [23, 24]). As communities slowly began to recognize FASD, clinical wisdom accumulated on intervention for children, youth, and families. Parent support and advocacy networks, and a small group of "champions" in clinical practice and research, spread the word. Shared in newsletters, booklets, and a few books, and later online, this clinical wisdom was derived from the families themselves, interested providers, and specialized FASD diagnostic clinics. Knowledge was based on lived experience and clinical expertise (e.g., [25–29]). Efforts to remediate common areas of impairment among those with FASD emerged as an early treatment direction. At the same time, the range and variability of alcohol's teratogenic neurobehavioral effects were increasingly described by research. This dictated the need for individualized, multifaceted treatment, because each individual affected by PAE showed a unique, complex profile of cognitive-behavioral impairment (e.g., [30, 31]). More holistic efforts to provide family support emerged as another treatment direction. Through advocacy and creativity, family support services aimed to link families to a range of services. This type of treatment responded to the many unmet needs identified for individuals living with FASD (and their families)—and to the lack of available school and community resources and supports tailored to this clinical population (e.g., [26, 32, 33]).

In the mid-2000s, the term "FASD-informed care" was coined by "champions" in clinical care. Efforts began to define it, which have continued to the present time as applied to different types of programs and clinical situations (e.g., [29, 34–37]). Through the 2000s, grassroots efforts to help families have been maintained by dedicated parent support networks, self-advocates, community groups, clinical experts, and some governmental programs. Also, finally, starting in the early 2000s, spurred by coordinated advocacy and governmental action, funding for systematic intervention research began for individuals with FASD, and their families.

Systematic intervention research is vital because it can demonstrate what works. In recent years and in a growing number of countries, treatment efficacy research has become increasingly necessary. This is because of growing societal requirements for "evidence-based care" or "evidence-based treatments" in physical and mental health. This approach mandates evidence from published studies that meet strict systematic research criteria. These criteria are aimed to ensure treatments are effective (and having these research data is linked to whether or not permission is granted for insurance or governmental funding to pay for treatment). At this point, two decades of findings on intervention for FASD have come from two sources. One source has been a number of "service-to-science" program evaluation studies, sometimes not formally published, which are valuable but do not necessarily contribute to defining evidence-based care. Another source has been a relatively small number of controlled quantitative or mixed methods studies of innovative or existing treatments adapted to FASD/PAE, published for peer review, which do help to define evidence-based care.

All this research has been productive. Intriguing treatment ideas have emerged for individuals with PAE or living with FASD across the lifespan, and their families. Ideas have come from around the world. Advances have been made. But at this point the problems are much larger than the solutions found so far.

Progress on FASD intervention is at an important tipping point.

Where are we now? The field has reached good understanding on what defines many of the essential elements of FASD-informed care, presented in this chapter. A complement of interventions has been tested in controlled research, also presented here. This means that, despite limited recognition of FASD and other barriers, systematic research is proceeding and best practices for "evidence-based care" are emerging. A variety of systematic and critical reviewers have carefully analyzed existing data from different angles, with excellent ideas proposed for next research steps, also presented here. The strengths of those living with FASD, and those of their families, and the power of self-advocacy, have come to the fore. Stigma has been recognized as a major barrier to progress on FASD-informed care and providing intervention for those living with FASD. In response, the need to overcome stigma toward FASD has been recognized, no matter how large the task, and ways to do so have been proposed. Pressure to act has grown overwhelming. There are treatment dilemmas to solve and promising treatments to try. Telehealth, app-based, and online treatment methods allow treatment to scale up and be more accessible, and the recent global pandemic has led to new methods, flexible thinking, and global responses. There are decisions to make about strategic directions in FASD intervention, and information is available to make those decisions. All this is discussed here.

It is time to accelerate, shape the future, and move ahead, finding the right interventions to try. The ultimate goal is to change practice in meaningful and sustainable ways to truly help the many families worldwide living with PAE or FASD. The next decade will be exciting and pivotal. The hope is that the treatment response to FASD will now strategically expand more quickly with an increasingly global reach, and that communities and researchers will collaborate and respond on a larger scale.

The Overall Importance of Cultural Perspectives and Lived Experience

There is an important point to make before going further. At this point in history, there is growing awareness of the overall importance of cultural perspectives, and the idea that treatments should be culturally informed. A family's own culture and subculture—and, beyond that, the larger community and cultural context in which an individual with FASD and their family live—must be taken as fully as possible into account to ensure treatment is appropriate and effective. FASD is a global public health problem, so treatments must be created for a wide range of communities and cultures. Yet cultural awareness is simply a first step toward creating culture-centered practices, a process which must be led by individuals and families in the communities themselves.

In conversation with colleagues and inspired by a recent publication [38], it became clear this chapter was written from the standpoint of academics from a western tradition. This meant that careful reflection was needed. FASD is a global public health concern. Therefore, the authors wish to acknowledge the important historical and contextual implications for indigenous, Black, LatinX, Asian—and other diverse communities worldwide from a non-western tradition—for whom there are considerations grounded in cultural context that apply to FASD intervention. The current chapter has taken an inclusive approach by integrating lived experiences data. But the authors recognize that useful learning will come from other cultures and other researchers. The authors also acknowledge a requirement for genuine effort to work alongside our counterparts from diverse communities to be guided to deeper understanding and invite input from all.

This reflection fits well with other themes in this chapter. One of these themes is the importance of gathering lived experience data from groups (cultural, subcultural, community) to inform how treatments are created. Another is working alongside and being led by "stakeholders" (those who have a stake in the treatment) when designing interventions. This reflection also fits with the theme, discussed later, of keeping in mind the fundamental importance of self-determination and basic rights for those living with FASD when collaboratively designing treatments and choosing treatment goals for this important and valued group of individuals and families. Lived experience can illuminate what really matters to the quality of life for those living with FASD. This should be applied to creating interventions. As summarized in a perceptive social media source about FASD, which (among other insights) captures the voices of self-advocates: "*FASD: Nothing about us, without us*" [39].

Goals and Structure of This Chapter

To help direct and accelerate intervention in the field of FASD now and in the future, this chapter first discusses conceptual models, then brings these ideas together with findings from lived experiences research. This is done to define 12 essential elements of FASD-informed care related to intervention. Figure 13.1 captures these essential elements of FASD-informed care as a "visual." The current complement of published intervention studies systematically tested with those with PAE or FASD, from infancy to young adulthood, and their families, are presented in tables and briefly discussed, followed by a short research critique. Promising treatments, chosen from other fields as future research directions, are presented for consideration by readers, as they may help advance the field more quickly. The chapter ends with a discussion of dilemmas and promising directions for work on FASD intervention. The comprehensive reference section provides many resources on the topic of FASD intervention which readers can explore.

If readers are inspired to collaboratively share knowledge—and be led by communities to develop and participate in FASD-informed care, including culture-centered practices—this chapter will have met its most important goals.

Building the Foundation for FASD-Informed Care: Important Theories

FASD-informed care, as it relates to treatment, is built on the foundation of several influential developmental theories, which are important to understand and so are briefly explained here. Based on this solid theoretical foundation, the next section of this chapter presents 12 essential elements of FASD-informed care, that also take into account the "real world" knowledge of those living with FASD. These essential elements of FASD-informed care guide the design and development of useful and effective interventions at multiple levels.

Thinking About Both the Individual and the Family

Scientists have advocated that a *developmental systems model* be applied to understanding how alcohol's teratogenic effects on an individual play out over time, and to developing appropriate interventions (e.g., [18, 40–42]). Among other ideas, as seen in Chap. 2 of this book, this theoretical model suggests that important risk and protective factors be derived from study of typical development (which identifies universal factors), and from population-specific research. In 2009, FASD researcher Olson and her colleagues joined this developmental systems perspective with a *family systems approach,* integrating these two models to allow a focus on both the individual and family in intervention development [26]. Development of family support and positive parenting treatments for families raising those with FASD have been guided, in large part, by this combined model.

Developmental systems thinking suggests that, over time, characteristics of an individual interact back-and-forth with those of caregivers (and those of the larger ecological context, including the family and other larger societal influences, especially as the individual grows older). A developmental systems approach considers the whole lifespan, and how developmental outcomes and influences differ or change in importance at various life stages. Intervention is then designed to reduce disabling individual and environmental risks over the lifespan, while also enhancing protective factors (including strengths of the individual). That means care must be developmentally appropriate, since risk and protective influences change at different life stages. Using this approach, interventions should be designed to alter systems in order to support the life path of an individual with disabilities in a positive direction over time.

According to Olson and her coauthors, developmental systems thinking can be joined with a family systems approach in the field of FASD. This approach suggests that life paths, influences, and outcomes be measured not only at the level of the individual, but at other levels—such as the levels of the caregiver–child relationship and/or the family. Family systems thinking suggests that treatment also be directed toward family members as needed, so as to impact the entire family system. Using a family systems approach, interventions should try to alter family systems (and the impact of formal and informal systems that support families) in order to shape the path of family adaptation in a positive direction over time. Very recent thinking in treatment for FASD is using these ideas as a foundation to create increasingly precise, operational theoretical models that conform to additional elements of FASD-informed care. For instance, there is a very new model of family-directed intervention for FASD that shows how some existing practices match up to this model [38]. Other fields have also recently pursued the idea of joining developmental systems and family systems thinking, such as the field of early intervention [43].

Thinking How to Respond to Secondary Conditions and Mental Health Problems

Many individuals living with FASD or PAE have strong protective factors and personal strengths. Resilience, "grit," and a growth mindset (a belief that talents can be developed through hard work, good strategies, and input from others) are important characteristics shown by many of individuals with FASD or PAE [44]. It is vital to keep all these strengths in mind in thinking about treatment, as they are powerful influences on development.

But research data do show that individuals living with the biological risk presented by FASD or PAE also often have past or present experiences of psychosocial disruption, such as multiple home placements or living with parental substance abuse. Research so far suggests they may often contend with difficult relationships or problems with service systems and, as a group, show an elevated rate of trauma experiences (such as abuse or neglect, victimization, or even violence). They also face possible other biological risk factors of prenatal exposures and family history of mental health and learning problems. As a result, they may encounter these secondary conditions (real-world difficulties that might better be thought of as "secondary impacts"), such as school disruption or difficulties with independent living. They may also experience co-occurring mental health conditions (psychopathology) [45–47].

The *field of developmental psychopathology* is an approach that was born of out developmental systems thinking—but went further to help understand how psychopathology develops over the lifespan. Insights from this theoretical model are needed to build the foundation for FASD-informed care in treatment because so many with FASD face mental health challenges and trauma, and this model also lays a good foundation in other ways. For instance, the field of developmental psychology suggests that interventions focus on improving relationships and provides many insights into how treatment can be trauma-informed to reduce the impact of maltreatment on development.

Among other ideas, this model suggests that early appearing problems, such as the neurocognitive, self-regulation, and adaptive function difficulties that come from the teratogenic effects of alcohol, have a cascade of effects on development (and the capacity to form healthy relationships). Because these effects start early, over time they spread across many levels of function and have a major impact. Practically speaking, this means it is vital to provide comprehensive, intensive early intervention to head off the cascade of effects. That means that not only does treatment for FASD or PAE need to be ongoing, but it also needs to be flexible and collaborative, occurring in interdisciplinary teams and across multiple systems (such as in health care, school, social services, and more). This is because the cascade of effects often leads to problems that multiply and grow more troublesome as an individual matures over the lifespan and encounters new demands and roles in life. In other words, the field of developmental psychopathology holds that to act early and provide the right ingredients for healthy development from the start, produces better outcomes than trying to fix problems later.

A central (and complex) idea in this model is that development can be thought of as occurring in "pathways" toward mental health problems (psychopathology). To best create treatments, the model states that these atypical pathways should be studied and described. This means it is important to figure out what are the different processes that underlie different pathways that lead, over time, to the same problematic outcomes. For instance, it is now thought that conduct disorders can develop along one pathway characterized by problems in impulse control. Alternatively, they can develop along a different pathway characterized by limited prosocial emotions [48]. Practically speaking, to be effective, the pathway an individual is on has to be identified—and then the treatment tailored to the appropriate pathway. In this example, one pathway would require treatment to reduce someone's impulsivity, while the other would require treatment that teaches someone empathy. This idea of tailored treatment needs to be applied along with taking a neurodevelopmental viewpoint for those living with FASD, when mental health problems are being treated. This requires real insight on the part of the provider, who cannot simply use the treatment "usually" applied for a particular set of symptoms. They need to try to understand both the mechanism underlying the symptoms (such as conduct problems) <u>and</u> the unique cognitive-behavioral profile of the individual with FASD.

Thinking About Remediating Specific Areas of Impairment

The models discussed so far do not explain how to intervene to remediate specific areas of impairment that often occur because of the damage alcohol can do to the brain and central nervous system. Yet targeting individual-level impairments is so important it is actually one of the 12 essential elements of FASD-informed care. In 2010, FASD researcher Kodituwakku proposed a model of how to do this [31]. His model takes what is called a *neuroconstructivist view*. This view assumes that reciprocal interactions between neural activity and the brain's hardware gradually form (construct) neural connections, within and between regions of the central nervous system. This is a dynamic and interactive view of how development occurs. It is very true to developmental neuroscience.

Practically speaking, Kodituwakku describes behavioral interventions as a series of "guided experiences" for the child, typically led by an adult. Behavioral interventions, such as doing attention training or mindfulness practice, are designed to produce neural activation. In neural activation, a neuron (nerve cell) is activated by other neurons to which it is connected—and that neuron then stimulates other connected neurons to be activated. If effective, neural activation leads to plasticity of neural structures, which leads to substantial changes in experience. All this, in turn, leads to changes in brain structures, leading to progressive formation of neural circuitry supporting a specific skill. Research shows that there are certain skills that are more powerful predictors of long-term developmental outcomes, such as "executive attention" and "self-regulation." Because of this, Kodituwakku further hypothesizes that interventions targeting executive attention and self-regulation may produce outcome effects that are more generalizable than do interventions that try to enhance specific skills (such as literacy training).

Kodituwakku goes on to emphasize that a successful intervention should have a theoretical foundation. In other words, there should be both an underlying logic model and theory of change that aim to account for how the components (variables) of an intervention are related to each other, the processes involved, and how all this operates to create intervention effects. This actually also fits with insights from the field of developmental psychopathology. True to the idea that treatments should have an underlying logic model and theory of change, more recent researchers have sought increasingly specific theoretical models in order to more precisely understand and/or effectively treat common areas of deficit seen among individuals living with PAE or FASD, such as self-regulation [49] and executive attention [50].

From a practical perspective, based on this neuroconstructivist view, Kodituwakku suggests helpful treatment guidelines that may improve the outcomes of interventions designed for individuals living with the teratogenic effects of PAE and other associated risk factors. These guidelines are presented later in this chapter as part of the discussion of the essential elements of FASD-informed care.

Thinking About Self-Determination and Quality of Life

FASD is a lifelong challenge to health and well-being, recently described as a "whole body" diagnosis [51]. It might be further thought of as a "whole body, whole life" issue. An up-to-date definition of FASD-informed care must take this into account. The *life course health development framework* is a very wide-ranging synthesis of ideas, developed over the past few decades, that incorporates rapidly developing evidence on the biological, physical, social, and cultural contributors to the development of health and disease [52, 53]. While many ideas from this model fit well with those from theories already discussed, this framework adds to the foundation of FASD-informed care. Some key ideas are discussed here.

The life course health development framework prioritizes the goal of attaining a better state of health for all people, for both the short term and long term. Therefore, the goal is lifelong wellness and health equity for all groups. As part of FASD-informed care, this means building a useful "social scaffolding" (changed societal thinking and coordinated, effective systems of care) which can lift those with PAE or FASD toward well-being and health equity with other groups. This framework points the field of FASD toward state-of-the-art thinking from the field of intellectual and developmental disabilities (IDD) and basically suggests that a key measure of treatment outcome is "quality of life" (QOL). Recent ideas in IDD include a focus on self-advocacy and the application of strengths-based approaches to supporting individuals with IDD over the lifespan [54]. Current trends emphasize the goal of improving QOL as a way to drive service delivery for persons with IDD [55]. Current treatments are designed to result in outcomes in line with basic human rights and, importantly, the need for self-determination [56].

Practically speaking, using this framework mandates a shift in perspective in the field of FASD. Treatment design should shift from a primary focus on reducing secondary impacts or psychopathology, especially for older individuals, toward adding a focus on improving QOL, adaptive function and self-determination—and on emphasizing real participation in life activities [15, 57]. Treatments should take into account the actual circumstances (context) in which an individual and their family live, including their socioeconomic and cultural context. Treatments should take realistic, observable steps to improve and adapt the environment, and intervention should include specific, individualized actions to make a positive difference in the actual daily lives of those with FASD [57]. Treatments should aim toward practical outcomes that support full and meaningful life participation. This approach honors basic human rights. Further, a focus on self-determination suggests that treatment researchers be led by, and learn from, the lived experiences and self-advocacy of persons with FASD, and those who care for them. That means asking what outcomes they regard as important, and then designing supports to achieve those outcomes. This shift in perspective and in treatment research is accord with the view that (to the extent possible) individuals with FASD should be causal agents in their own lives [15, 54–56].

Defining 12 Essential Elements of FASD-Informed Care for Intervention with Individuals and Families

The theoretical models discussed above lay the foundation for defining the 12 essential elements of FASD-informed care as they relate to treatment. The next section brings life to these theories by informing them with evidence drawn from systematic study of the lived experiences of those affected by PAE or FASD, and their families. This research comes from qualitative research using data such as direct interviews and focus groups.

Recognizing FASD: An Important First Step

Before discussing the essential elements of FASD-informed care related to treatment and looking at Fig. 13.1, it is important to bring up a central insight from lived experiences research: *FASD is not fully understood or recognized* [58, 59]. While data documenting this fact are US-based, this appears to be true across most societies (e.g., [60]). This is deeply concerning. Without recognition, there can be no FASD-informed care. Lack of recognition means no diagnosis or qualification for services. Lack of recognition automatically limits resource availability and the opportunity for intervention. Without adequate recognition of FASD, no social safety net will be built. That means there will be none of the vital "social scaffolding" that can raise the health of those affected by PAE or living with FASD, and those who care for them. This group cannot achieve health equity, even compared to other neurodiverse groups (such as those with autism). In her definition of FASD-informed care for programs working with women with FASD (and their families), researcher Rutman notes that "having an awareness of FASD" is the starting point [35].

To recognize FASD means moving through a multiple-step process of education, identification and diagnosis that must be put in place in many communities and societies. Yet even now, in the 2020s and in countries that have paid attention to FASD, successful identification remains incomplete [11]. Fortunately, though, progress on identification is being made and, with determination, will continue. If we can continue to take these steps, we can offer access to intervention for the many who are in need.

Twelve Essential Elements of FASD-Informed Care for Intervention with Individuals and Families

Integrating theoretical models with insights gleaned from lived experience research yields the 12 essential elements of FASD-informed care as they relate to intervention, with specific examples provided in each section. Figure 13.1 presents these essential elements in a circular figure.

Briefly put, this model of FASD-informed care can be used to guide intervention at three different levels. The essential elements of FASD-informed care can guide care at the level of: (1) Person-centered planning (for the care of individuals with FASD); (2) Development of treatments for those living with FASD and/or their families (to ensure treatments have all relevant elements to meet the definition of FASD-informed care; and (3) Analysis of the overall complement of FASD interventions (to identify what treatments are still needed to fully offer FASD-informed care to this clinical population) [152].

Discussion starts at the top and inside of the figure, moves clockwise, and ends with a review of the elements presented around the edge of the circle.

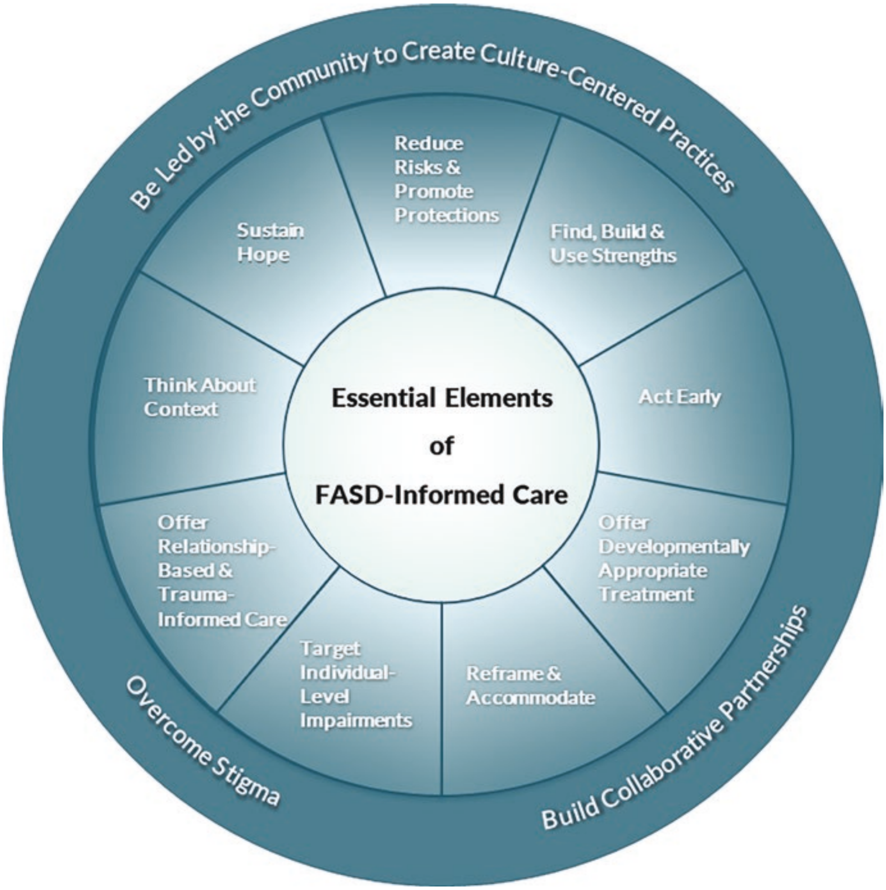

Fig. 13.1 Essential elements of FASD-informed care

Reduce Risks and Promote Protections

Starting at the top and inside of Fig. 13.1 is the element of “Reduce Risks and Promote Protections.” After identifying that an individual is affected by PAE, which is a risk factor, theoretical models suggest it is essential to identify other important risk and protective factors for an individual and a family. This is necessary in order to carry out treatment that is FASD-informed. Knowing these factors allows treatment to be designed so individual, family, and environmental risks can be reduced—and protective factors enhanced. The presence of PAE can be a signal to look for associated prenatal and postnatal risk factors, such as other prenatal exposures, or psychosocial risks such as multiple placements, or child maltreatment. However, evidence should be gathered rather than assumptions made. For instance, just because there was drinking during pregnancy does not mean that the family environment was disrupted during pregnancy, or that there is currently a troubled parent–child relationship.

Recent qualitative research on lived experiences has provided detail on treatment-related risk and protective factors regarding caregivers in this clinical population across the lifespan. Caregivers of children with PAE aged birth to 3 years expressed feelings of stress, exhaustion, and being overwhelmed, all parenting risk factors and potential causes of poor outcomes. These parents found value in the protective influence of social-emotional support groups, where they could speak freely without judgment to other parents going through a similar journey [61]. For caregivers with older children with FASD, recent survey data revealed increased rates of concern about caregiver QOL as individuals with FASD mature [62]. These data show that caregivers become the child's advocate and work tirelessly to create adaptations to make day-to-day life more manageable [63]. This can come at a cost of the caregiver's own well-being [59]. Lived experiences data show that needs and priorities vary by family structure, differing among biological, adoptive, and foster caregivers (e.g., [61]). For example, one study found that adoptive parents of adults living with FASD experienced moderate levels of perceived stress. Investigators concluded the risk of stress could be reduced by the protective influence of providing resources in areas specially flagged by these parents (e.g., help in transition into adult housing, support in managing finances for adult children) [64].

Find, Build, and Use Strengths

Moving clockwise around the inside of Fig. 13.1, theoretical models and lived experiences research both emphasize the importance of strengths-based treatment as part of FASD-informed care. In the past, however, treatment for those with FASD was largely deficit-focused. Yet there were earlier data that showed many children with FASD take pride in doing activities independently, are engaged with their families, and are willing to receive (and even seek) help [26]. New strengths data for children with PAE or FASD reveal character strengths such as high social motivation and positive effort/persistence, individual talents, positive mood states/personality—as well as positive influences on the family [65]. Recent evidence emphasizes the intrinsic strengths of those with FASD as older transition-aged youth and adults. These include character strengths such as strong self-awareness [66]. Also, no matter what the family structure, caregivers, and families of those living with FASD also have many strengths, find positive adaptations, have good basic parenting skills, and work to provide protective influences for their child and themselves [19, 26, 59, 63, 67–69].

Data such as these generate promising ideas for strengths-based treatments. Three examples are provided here, based on references cited above. First, birth mother support and mentoring networks can build social support, a factor identified as a strength among women who achieve positive recovery outcomes, using natural support as a treatment mechanism. Second, since many caregivers of individuals with FASD have good basic parenting skills, the focus in parent training can be on strengthening specialized parenting practices (such as learning positive behavior support techniques for school-aged children, or the strategies of monitoring/continency management and supporting autonomy skills for adolescents). Parent training can also focus on sustaining hope through caregivers realizing the "special benefits" of raising a child with FASD. Third, since self-awareness of one's own strengths and challenges is essential to success as an independent adult and is a strength in those with FASD, young adults can be helped toward an understanding of their FASD diagnosis and profile of strengths and challenges. In a collaboration, they can be helped to see what accommodations help them learn and function at their best—and as the key to (and reason for) services.

Act Early

All theoretical models discussed above strongly support the importance of early intervention in FASD-informed care. The capacity of the brain to learn from experience is greatest during the first 3 years of life [70]. The neuroconstructivist view highlights that early intervention has the potential to take advantage of the plasticity of the developing brain to improve at least some of the neurological impairment resulting from alcohol's teratogenic effects, improving brain "hardware" in order to lay a better foundation for later learning. It is notable that the early environmental experiences of children with PAE or FASD are often less than optimal, making early intervention also important to counter psychosocial risk [71]. Lived experiences data have started to detail what caregivers and providers believe should be the content of early intervention for children with PAE or FASD [61, 72].

One important goal of early intervention is to prevent later emergence of troubling secondary impacts and co-occurring mental health conditions. Lived experiences data gathered from caregivers of young children with PAE found that support for child social-emotional needs was apparently lacking in early intervention, even though caregivers did describe their children as receiving support for needs in other domains [61]. Also, the social-emotional well-being of caregivers did not seem to be a primary focus during these first years, as parents stated they lacked support for real-life stressors, problems of living, and respite care. Caregivers said they valued providers who offered reflective developmental guidance, who helped manage expectations for the future, and who connected them with peer support groups. The field of developmental psychopathology, which explains how mental health struggles develop, notes that the early years have a cascading effect on later development. All this means that an important part of FASD-informed care, if PAE and developmental problems can be identified when children are young, is comprehensive, sufficiently intensive, sustained, interdisciplinary early intervention—that takes a neurodevelopmental viewpoint. These early intervention services should fully support child development, caregiver needs, and the caregiver–child relationship.

Offer Developmentally Appropriate Treatment

Developmentally appropriate treatment, directed toward positive outcomes and adaptation, is recommended as part of FASD-informed care by all theoretical models discussed earlier. First, this means working to improve developmental outcomes, for the individual and the family, that typically matter at a particular life stage, such as improving security of attachment in infancy. This also means thinking about treatment that focuses on the developmental influences important at that life stage, such as offering treatment in infancy to increase caregiver sensitivity and responsiveness to a baby. Second, developmentally appropriate treatment means changing treatment goals over time. When children are young, treatment goals are for preventive intervention, to head off problems that might occur, and prevent a cascade of effects that multiply over time. As children grow through the school years and into adolescence, treatment goals center more on remediating deficits and supporting adaptive function. In the past, when individuals with FASD or PAE reached later adolescence and beyond, with needs growing more complex, treatment goals have shifted to more to a responsive approach of mitigating risk and reducing harm [45]. But in adolescence and emerging adulthood, treatment goals should also support the development of agency, autonomy, and self-efficacy. As lived experience research reveals, treatment in the older years should expand and reorient to also address successful accomplishment of the developmentally appropriate goals of increased self-determination and adult QOL.

Third, offering developmentally appropriate care also means coming up with (and applying) treatments aimed at remediating specific impairments arising from PAE at the time that makes the best developmental sense. This may be during critical or sensitive periods when developmental plasticity is heightened. One example is training what the neuroconstructivist view highlighted as the very important skill of "executive attention" at the right time in a "sensitive period." An example of this is the GoFAR metacognitive intervention (discussed later; see also Table 13.7), which is offered starting at age 5 years (just at the time that developmental capacity is just emerging). Fourth, true to the insights of the field of developmental psychopathology, offering developmentally appropriate care can mean customizing treatment to subgroups that are following different developmental pathways toward mental health problems so that treatment can succeed. This truly important (but complex idea) is considered more in the "Discussion" section.

Fifth and finally, to offer developmentally appropriate treatment also means providing intervention across the lifespan. Treatment can lead to improvement, even among older individuals, and this chapter discusses some treatments designed for adolescence and beyond. Because of the dynamic interplay of development, change is always possible. In some ways, change may become easier in the later years (as people mature, recognize they need assistance, and both self-advocate and accept help). In other ways, change may become harder when people are older, as brain plasticity lessens and individuals move down an increasingly fixed life path.

Reframe and Accommodate: Take a Neurodevelopmental Viewpoint

As both theoretical models and lived experiences research make clear, a central, essential part of FASD-informed care is to change perspective. For caregivers and providers, this means to take a "neurodevelopmental viewpoint." This important idea, which arises from understanding FASD is a "brain-based" condition, has been part of the collective clinical wisdom in the field of FASD for decades [18, 19, 27, 28, 31], and woven into some evidence-based treatments (e.g., [73–76]). As FASD researcher Olson has written, taking a neurodevelopmental viewpoint can make it easier to see when certain types of intervention are not appropriate, or how to adapt treatment approaches (and change expectations) to increase intervention effectiveness.

A central element of FASD-informed care (and treatment) is that a neurodevelopmental viewpoint allows caregivers, families, and providers to go through a process of "reframing," as a treatment mechanism. As it is defined here, to "reframe" means to view the challenges of learning, behavior, and daily function of the individual living with FASD as, at least in part, "brain-based." This requires knowing about that particular individual's cognitive-behavioral profile. For parenting or family support interventions, as FASD researcher Olson has written, reframing helps caregivers (and family members) gain a more positive "cognitive appraisal," or view of the individual impacted by PAE or living with FASD, and view of their relationship with that individual. A more positive view can help jumpstart improvements in motivation to change, a sense of parenting efficacy, and use of the most appropriate caregiving methods (positive behavior support) as a first line of treatment [19]. For interventions directed to the individual, an ability to reframe helps define what skills to build in treatment (and what guided experiences to suggest from the neuroconstructivist view) [31]. An ability to reframe prompts creation of tailored "accommodations" in treatment to modify the individual's context. Coming up with ways to accommodate improves how well the environment fits with an individual living with FASD so as to maximize adaptive function, self-determination, and QOL. Modifications of the environment can be extended to home, respite, childcare, school, job, recreation, therapy, and other settings [57].

Learning to take a neurodevelopmental viewpoint, and making efforts to reframe and accommodate, and then changing parenting practices, can help move both the individual and family down a more positive life path [77]. This is evidenced by several interventions (all derived from the standard Families Moving Forward (FMF) Program) that use this logic model and theory of change [19, 73, 78, 79].

Target Individual-Level Impairments

PAE brings wide-ranging neurobehavioral deficits that show up as cognitive-behavioral profiles that vary from one individual to another. With this in mind, in the neuroconstructivist view, FASD researcher Kodituwakku offers a useful set of guidelines for FASD-informed care to maximize treatment outcomes designed for children with PAE or FASD. Kodituwakku's original paper deserves to be read for more detail about these guidelines [31].

The first of Kodituwakku's guidelines is to "*pay heed to the child's overall cognitive-behavioral profile when designing an intervention program for [the child]*." Interestingly, lived experience data echoes the importance of FASD diagnosis, and the positive impact and utility of a feedback session about the diagnosis (and functional profile) for families and school staff, to help appropriately reframe [80]. Diagnosis and feedback can provide useful access to intervention recommendations—and an assessment can generate valuable feedback and linkages even without a definitive FASD diagnosis [81]. The lived experience literature also finds that older individuals with FASD often do not understand their diagnosis as a disability, making feedback to the individual themselves an important treatment [82]. Another important guideline from Kodituwakku is to "*provide enriched input in a guided fashion*," which builds on a vast animal and human literature showing that enriched environmental input (such as learning opportunities, or chances for the right kind of physical activity) enhances cognitive functioning. Kodituwakku goes on to explain and provide an additional guideline to show how input might be guided to enhance impact on neural structures and child development by staying just within the child's optimal learning zone.

Another guideline from Kodituwakku is to "*provide training in attention and self-regulation early*." Indeed, both self-regulation and attention are developmental capacities that unfold at different biological and cognitive levels, building on each other and gradually integrating together, from the start of life on. In treatment that is FASD-informed, these capacities should receive special support early on, as the neuroconstructivist model suggests improvement in these areas is most likely to generalize to other areas of cognitive and behavioral function. Real-world experience supports the importance of training to remediate impairments in these areas. For instance, impairment in behavior regulation is literally part of the definition used to describe conditions on the fetal alcohol spectrum in DSM-5, the diagnostic manual used by mental health providers [83]. Finally, Kodituwakku suggests that treatments "*combine evidence-based behavioral and pharmacological intervention,* *unless clinically contra-indicated*." The idea of using evidence-based treatments is key and will be discussed further later in this chapter. However, despite the frequent real-world use of medications for individuals with PAE or FASD, there is still quite limited guidance for pharmacological care in the field of FASD (see recent systematic reviews [84, 85] and a suggested treatment algorithm based on expert opinion [86]). Note that psychopharmacology treatments are outside the scope of this chapter. Importantly, behavioral and family support interventions are, at least in pediatric populations, nearly always recommended as the optimal first line of treatment.

Offer Relationship-Based and Trauma-Informed Care

The field of developmental psychopathology makes clear that healthy and secure early parent–child relationships are important to a positive life path, and that child maltreatment and trauma are significant risk factors in the onset of psychopathology. Descriptive research has highlighted the high rate of other prenatal and postnatal risks experienced by children with the biological risk factors signaled by PAE or FASD. They often have histories of early life stress and psychosocial disruption and sometimes have experienced maltreatment such as child abuse or neglect (e.g., [46, 87, 88]). It seems clear that young children living in families with the risks of parental substance use and/or psychosocial stressors can especially benefit from relationship-based early interventions. Such treatments are informed by attachment theory and aim to improve both family well-being and child developmental outcomes. They provide preventive intervention. Relationship-based interventions are designed to enhance the quality of parent–child interactions by supporting exchanges that are warm, sensitive, responsive, and adaptive to the young child's needs (e.g., [89, 90]). Improved exchanges can promote emotional security and social competence in the child and, for the caregiver, lead to an increased sense of parenting competence and reduced child-related stress.

Trauma-informed treatment, when relevant, is crucial for this clinical population, as made clear by the field of developmental psychopathology. Indeed, some studies have shown that children with FASD and maltreatment have less positive outcomes than children experiencing trauma who did not have the biological risk factor of PAE [91]. Even the risk of neurodevelopmental impairment may be greater for those who have both trauma and PAE (though this is not entirely clear) [88], suggesting that more intensive remediation of individual-level impairments may be required for those with trauma.

Trauma-informed treatment can be woven directly into treatment following the essential elements of FASD-informed care, as is done in many of the relationship-based interventions listed in Tables 13.1, 13.2, and 13.3, or the positive parenting programs listed in Tables 13.4, 13.5 and 13.6. This kind of care can also be offered an adjunct service that focuses on direct treatment of trauma. Research on responses to child maltreatment recommends various approaches depending on severity, ranging from intensive family preservation services to caregiver education on strategies to counteract lasting harm. There are also flexible and time-tested child-directed approaches such as teaching relaxation and desensitization skills, training concrete skills such as the "rules of touching," or providing therapeutic education using social stories or bibliotherapy [19]. One well-established, evidence-based intervention approach is called Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) [92]. This approach has been adapted to extend to younger children and their families, a process that appears feasible and for which there are published clinical considerations [93]. TF-CBT is stated to be appropriate for children and youth aged 3–18 years. It is notable that TF-CBT may have to be adapted using a neurodevelopmental viewpoint to be appropriate for those living with FASD or PAE, and their families. This is because core techniques used in TF-CBT (such as "cognitive coping" and "trauma narration and processing"), and other aspects of TF-CBT, may not function as expected for individuals with neurodevelopmental differences.

Think About Context

The theoretical models discussed earlier all emphasize the importance of considering the individual with FASD in context, and lived experiences data help in understanding how to "think about context." This brings wide-ranging implications for FASD-informed care, grouped here into three topics.

First, thinking about context as the individual's "ecology," this means the focus should not just be on supporting and treating the individual living with FASD. Instead, *FASD-informed care should also focus on providing treatment and consultation at increasingly broader levels of the child's ecological context,* such as at the levels of the caregiver, family, daycare and school, coaches and mentors, therapists, service systems, community, and culture. Lived experience research, for example, finds real difficulties for those with FASD in the school setting. A caregiver report study acknowledged there were ongoing child behavior and social problems at school, but also pointed out difficulties in the mainstream schooling context such as a lack of attitude shift from school staff after an FASD diagnosis was given [80]. FASD-informed treatment must also try to impact important levels of the child's "ecology." For instance, parenting intervention for caregivers raising children with PAE/FASD likely needs to go beyond coaching the caregiver on new parenting practices to include additional components—such as modules on school advocacy for caregivers, and targeted consultation directly offered to school staff and other providers, as is done in the positive parenting intervention called the Families Moving Forward Program.

Second, thinking about context in a different way, this means that *interventions that are FASD-informed may often focus on strategies to change the context (changing caregiver behavior, household routines, environmental structure),* rather than focusing on remediating specific impairments through training the individual showing effects of PAE. For example, FASD researchers Olson and Montague note that putting into place "accommodations" (or "antecedent-based behavior strategies," as termed in a positive behavior support approach) may be a more efficient and effective way to achieve more positive behaviors for someone living with FASD, compared to the technique of applying consequences to correct misbehavior. Very recent qualitative data from caregivers found that "accommodations" were perceived as generally effective parenting strategies for children diagnosed with an FASD. Study findings revealed that parents of children with FASD who used fewer accommodations reported less success with their behavior management plans. In fact, those parents who reported a specific target behavior was "still a problem" used an average of 1.50 accommodations—compared to those who said a target behavior was "no longer a problem" (who used an average of 3.54 accommodations) (research colleague and predoctoral trainee, University of Rochester, Kautz-Turnbull C, written communication, 2021, 22nd October and 2022, 26th July).

Third, additional insights about context come from an analysis of lived experiences data and, theoretically, from the life course health development framework. FASD researcher Skorka and her colleagues suggest *context should be taken into account in defining successful intervention outcomes for FASD-informed care, and an individual's strengths should also be assessed* [57]. These researchers point out that real-world environments need assessment to see what treatment strategies will meaningfully help an individual with FASD have the most adaptive outcome. For instance, it is not really a successful intervention outcome if a child with disabilities simply has access to soccer (yet constantly sits on the bench watching others play). But it is a potentially successful outcome if the child participates in soccer (and actually has a satisfying and active role in the game). Taking the ideas of these researchers further, context is important in defining what treatment outcomes actually lead to improved QOL in the real world. This is especially important as individuals with FASD grow older. This is because in adolescence and adulthood, QOL becomes harder to achieve as individuals move out into the world—and are expected to be more independent and operate in more environments day-to-day. This means that all the environments in which someone living with FASD needs to function, such as their job or living situation, and the client's strengths, require person-centered assessment to understand what treatment outcomes will really matter to that particular person in their own daily life. Thinking about context means that "person-centered planning" is important.

Sustain Hope

In 1997, some of the earliest and far-seeing thoughts about FASD-informed care were written by pioneering researcher Streissguth, who stated: "Hope and a good grasp of reality are two important characteristics of good [FASD] advocates" [28] (p. 180). In 2009, caregivers of children with FASD and behavior problems reported that one top unmet important family need was to "have help in remaining hopeful about my child's future" [26]. To build and sustain hope with families, providers must reflect on their own comfort level regarding FASD and obtain the support they need to act in a positive, realistic, non-judgmental way. FASD researcher Reid, writing with a group of experienced intervention researchers in the field, has described promoting hope as a key aspect of what they termed "family-directed intervention" in FASD, noting that hope predicts well-being. None of the theoretical models discussed above, that lay the foundation for FASD-informed care, explicitly discuss hope—even though lived experiences data and clinical wisdom in the field have so clearly highlighted this central element. To remedy this important theoretical gap, Reid led the integration of hope theory into a proposed description of FASD-informed care for families. Among other important points, Reid and her colleagues write that hope theory posits "there must be pathways for support in order for families to be hopeful about the future" [38] (p. 4). Indeed, some relationship-based, positive parenting and family support treatments designed for this clinical population have already been deliberately designed or adapted to increase caregiver attitudes related to hope (e.g., [32, 73, 78, 79, 94–97]).

Discussion now moves to the "overarching essential elements" around the edge of Fig. 13.1.

Overcome Stigma

Moving to the outside edge of Fig. 13.1 on the left, an important, overarching essential element of FASD-informed care is to "Overcome Stigma." It might seem jarring to move from the element of "Sustain Hope," to discussing the need to overcome stigma. Yet, as the very insightful FASD researcher Streissguth made clear, those who care and advocate for individuals living with FASD are not only hopeful, but are also realistic [28]. Lived experiences research reveals the stark reality that FASD is stigmatized. This means that FASD-informed treatment is limited, or even blocked, by the pressures of stigma. Early lived experiences research uncovered the heavy burden of stigma experienced by biological parents [98]. More recent data has revealed the many complexities of stigma, with layers ranging from self-stigma to stigma by association. The effects of stigma are wide-ranging, affecting not only the individuals with FASD and biological parents, but also their adoptive and foster parents, siblings—and reverberating further, even to providers [99, 100]. But recent theory and lived experience line up to emphasize the need to strive for health equity and design treatment that is in line with basic human rights [52–56]. That means that to provide intervention to much-deserving individuals with FASD and their families, an overarching essential element of FASD-informed care is to overcome stigma—first recognizing that it exists, and then tackling it—no matter how large the task. To sustain hope, it is necessary to overcome stigma so that advocacy can succeed, and doors can be opened to identification, diagnosis, service eligibility, and intervention.

In this cause, there has been a call for change toward dignity-promoting language regarding FASD [99, 101]. There has also been a call for a shift in perspective in the field of FASD—away from its historical "deficits" focus, and away from its single-minded focus on heading off risk factors and adverse outcomes. Instead, it has been suggested that the field of FASD should move toward: (1) an emphasis on self-advocacy; (2) the application of strengths-based approaches; and (3) a focus on improving measurable indicators of a more positive quality of life and adaptive function. It has also been suggested that this shift in focus can be a catalyst for equitable care that respects the rights of persons with FASD. Further, this shift in thinking may help providers understand why FASD diagnosis is needed—and act as a stimulus for meaningful intervention ideas that make a positive difference in the actual daily lives of those with FASD [15]. In itself, this shift in perspective may, in part, address the pervasive stigma that has impeded progress in the field of FASD [15, 100, 102]. But there is also a clear need for organized, widespread stigma reduction programs specific to FASD [99, 100]. Characteristics of effective FASD stigma reduction programs have been described, with more effective FASD reduction strategies going beyond simple education on PAE and FASD. The best route to decreasing stigma is by contact [103]. This includes meeting people with FASD, hearing them talk, hearing their stories. This helps others to understand the condition better. In a 2017 pre-conference collaborative discussion meeting, many ideas were shared for overcoming stigma. Among these were creating and sharing stories of success and thriving (rather than detriment, weakness or failure), talking about strengths and surviving, and developing continuous opportunities for conversation. Also mentioned was working in partnerships with individuals living with FASD and birth mothers. The idea was that providers and researchers could start to talk with (rather than talk for), and listen with intent to, those who actually live with FASD day-to-day [99, 100, 103].

Build Collaborative Partnerships

Moving down the outside edge of Fig. 13.1, on the right, is another important element of FASD-informed care as it relates to intervention. The field of developmental psychopathology makes clear that effective treatment needs to occur across multiple systems and be flexible and collaborative. Echoing this, the life course health development framework suggests building social scaffolding that includes coordinated and effective systems of care in the interest of health equity. This framework adds that, as much as possible, individuals with FASD should be causal agents in their own lives. Building collaborative partnerships, a continuum of care *and support* between professionals, families (and other support persons), and individuals living with FASD, is a much needed, overarching element of FASD-informed care.

Lived experiences data highlight the many unmet family needs that occur when living with FASD and emphasize that the caregiving process (while rewarding) is highly stressful for all families over the life course [26, 59, 61, 64]. In the field of FASD, lived experiences data (and clinical wisdom) suggest that one important treatment mechanism in FASD-informed care is providing caregiver support.

Caregiver support can reduce stress as parents contend with worry about the future and try to come to a realistic understanding of their child's behavior (e.g., [26, 61, 104]). In a recent dissertation that begins to shed light on treatment mechanisms, for example, researcher Kapasi has examined the role that resources and support for families play in caregivers' belief that self-regulation in adolescents with FASD can change for the better. It appears that support is one mechanism sustaining hope and promoting a growth mindset that can help with family functioning and reduce adverse outcomes [44]. Research from the field of developmental disabilities suggests that parents and families with the right kind of support do better later on [105]. Peer and informal parent support and assistance with advocacy, either through parent groups or one-on-one, informal relationships with other parents who have gone through the same situation, is one essential type of support. There are other types of support that are important, including social and emotional support, and therapeutic support.

Researcher Rutman offers more insights about support, building on the work of FASD clinical expert Dubovsky and others. She makes clear that FASD-informed programming recognizes the critical role that healthy family and support people play in the lives of adults with FASD. More fundamentally, she notes that *interdependent living* should be seen as a more accurate and positive reality for all people in society [35].

Research points out that externalizing behaviors and social difficulties/maladjustment are the two most prevalent real-world childhood challenges for families raising those with FASD or PAE, though cognitive difficulties are also mentioned [106]. The positive parenting literature, which guides treatment for families raising children with these difficulties, increasingly emphasizes the importance of close collaboration between therapist and caregivers in supportive, motivating, knowledgeable treatment, in a stance that empowers both family members and providers. This stance was used in early positive parenting and parenting support, education, and advocacy interventions tested with families raising those with FASD (e.g., [32, 73]). It is also a key aspect of what has recently been termed "family-directed intervention" by a group of experienced FASD intervention researchers [38].

Be Led by the Community to Create Culture-Centered Practices

The final element, at the top edge of Fig. 13.1, is vital. Several theoretical models discussed earlier, clinical wisdom, and lived experience data, all indicate that it is important to add creating culture-centered practices as an overarching element of FASD-informed care. The family's own subculture and community—and, beyond that, the larger cultural context in which the individual with FASD and family live—must be taken as fully as possible into account to ensure treatment is appropriate and effective. FASD is a global public health issue, so treatments must be created for a wide range of cultures. This means it is vital to understand the importance of cultural beliefs, values, conventions, and childrearing customs, as part of designing and carrying out interventions for the many different individuals living with FASD and their families all over the world (e.g., [38, 107–110]).

But this element of FASD-informed care is best stated as to "Be Led by the Community to Creating Culture-Centered Practices." The community also includes self-advocates. The idea is to ask community members what is getting in the way of quality of life (and what practices can really help make a difference)—and to ask those who may be offered treatment whether it is actually needed. Even the word "intervention" is not appropriate to some cultures, such as in Aboriginal Australia where it has acquired a negative meaning and raises issues of historical trauma. If treatment is needed, input from the community can lead decisions on what treatment goals and outcomes should be, what treatment should look like, and what are possible mechanisms for how treatment may work. This fits with the fundamental importance of valuing self-determination and basic human rights for those living with FASD.

Cultural and community context change what resources are needed, and what language and interpersonal approaches are used. But taking community and culture into account does not just mean offering community-specific resources. It does not simply mean using interpreters to translate the intervention that is provided or offering treatment in the primary language of the participants. It does not mean simply being culturally sensitive to interpersonal style. These are all important, but are not sufficient to creating culture-centered practices. Taking culture into account requires the participation of cultural navigators and community leaders in designing and implementing treatment that reflects the texture of the community and culture. Taking culture into account requires gathering lived experience data from groups (cultural, subcultural, community, self-advocates) to inform how treatments are created, and working alongside and being led by "stakeholders" (those who have a stake in the treatment) when designing interventions.

Current Peer-Reviewed Intervention Research with Samples of Those Living with PAE/FASD

As discussed so far in this chapter, the field has progressed over 50 years, and essential elements of FASD-informed care have been defined as they relate to treatment. Calls to action to advance services for FASD have been heard. Since the early 2000s, peer-reviewed intervention research with samples specifically identified with PAE or FASD has gradually grown. This body of research is presented here. Treatments discussed in this chapter focus on parent-child or family wellness and support, and/or on building skills for individuals living with FASD. Presented in Tables 13.1, 13.2, 13.3, 13.4, 13.5, 13.6, 13.7, 13.8, 13.9, 13.10, 13.11, 13.12, 13.13, and 13.14, studies are arranged from infancy through adulthood. In this section, existing research will be briefly discussed, and ideas for next research steps

Table 13.1 PUBLISHED relationship-based and multicomponent early interventions (birth to 5 years)

Intervention name	Description	Participants studied in key references	Key outcomes
Breaking the Cycle (BTC) [154, 155]	A comprehensive and relationship-focused program that includes early childhood intervention, addiction counseling, various parenting programs and other health and social supports[a,b].	Pregnant and early parenting mothers who are using alcohol or other substances, and their children, ages birth-3 years	Pre- to posttreatment improvements in child developmental outcomes, maternal mental health and relationship capacity, as well as decreased maternal substance use [154]. No group differences in child developmental outcomes [155].
Circle of Security (COS) [94]	An attachment-focused intervention designed to increase caregiver observation skills, sensitivity and responsiveness, and self-reflection. Involving a series of activities and repeated videotaped interactions with child-caregiver dyads, a therapist serves as a secure base and safe haven for the caregiver to explore new and unfamiliar feelings and behaviors[a,b].	Children with prenatal alcohol exposure (PAE) or fetal alcohol spectrum disorders (FASD), ages 2–5 years, and their caregivers	Pre- to posttreatment reductions in child behavioral challenges and increased capacity of children to communicate their needs to their caregiver. Improved ability of caregivers to attend to their child's cues and reduced caregiver stress.
Home-U-Go Safely (HUGS) program [156]	A home-based nursing intervention that monitors infant health and growth, provides parents with developmental information and emotional support, and teaches the use of a Snugli to promote close contact time between parent and child[a].	Children with prenatal drug and alcohol exposure, ages 1 week–18 months, and their caregivers	Improvements in child internalizing and externalizing behaviors (based on parent report) relative to comparison group. A trend toward reduced parent stress.

(continued)

Table 13.1 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Neurosequential Model of Therapeutics (NMT) [74]	A relationship and developmentally based intervention focused on improving the attachment relationship, symptoms of post-traumatic stress, and building caregiver self-reflection and mindfulness skills. Children and caregivers received child parent psychotherapy (CPP) and caregivers also received mindful parenting education (MPE)[c].	Maltreated children with FASD, ages 10–53 months, and their caregivers	Pre- to posttreatment improvements in child developmental functioning and regulatory capacity. Reductions in caregiver stress.
Strategies for Enhancing Early Developmental Success (SEEDS) [157]	A multicomponent intervention designed to promote school readiness by engaging caregivers to build their child's self-regulatory capacities through the development of collaborative parent–child, teacher–child, and parent–teacher relationships as a foundation for school readiness[a,d].	Children with PAE and early trauma, ages 3–5 years, and their caregivers	Pre- to posttreatment improvements in classroom behavior and caregiver interactions and care in two of three cases. Mixed results in one case.

Note: There is one additional published FASD early intervention referenced in the California Evidence-Based Clearinghouse (cebc4cw.org): the Safe Babies Court Team (SBCT) Project [153]. This is a community engagement and systems-change initiative focused on reducing trauma and improving how courts, child welfare, and child-serving organizations work together to support infants and toddlers in, or at risk of entering, the child welfare system, including but not limited to children with PAE. This intervention does not fit into the category of interventions covered in this table, but has been deemed by CEBC an effective practice useful for very young children with FASD or PAE

[a] Home

[b] Community

[c] Clinic

[d] Classroom

Table 13.2 IN DEVELOPMENT relationship-based and multicomponent early interventions (birth to 5 years)

Intervention name	Description	Participants studied in key references	Key outcomes
Families Moving Forward (FMF) Bridges Jirikowic et al. (in development)	Derived from the standard FMF Program (see Table 13.4), FMF Bridges is an intervention for infants/toddlers with PAE or FASD, birth to 3 years of age. FMF Bridges targets the developmental and relational needs of infants/toddlers with PAE and their caregivers. It is intended to enhance existing EI practices while retaining multiple core features of the standard FMF Program[a,b].	Children with PAE, ages birth to 3, and their primary caregiver	To be determined, study in design phase.
Relationship-Based Early Intervention (RB-EI) Kalberg et al. (under review)	A relationship-based, developmental enhancement to promote emotional security and social competence for children with PAE (ages birth to 3). Using the Heart Start Model, caregiver/child dyads work toward secure and positive interactions by being in a calm and alert regulatory state, by understanding the importance of close proximity and by sharing a specific focus[a].	Children with PAE, ages 9–36 months, and their mothers	Pre- to posttreatment improvements in caregiver involvement and responsivity, and also in children's living environments for both groups. Increases in positive interactions between child and caregiver, reflecting an increased quality of relationship. The greatest benefits were seen for the highest risk children.

[a] Home

[b] Early intervention centers

Table 13.3 FUTURE DIRECTIONS relationship-based and multicomponent early interventions (birth to 5 years)

Intervention name	Description	Participants studied in key references	Key outcomes
Attachment Biobehavioral Catch-up (ABC) [159, 160]	An attachment-focused intervention designed to help children develop regulatory capacities by helping caregivers learn: (1) to provide an environment that promotes regulatory development; (2) to re-interpret a child's alienating behaviors; and (3) to override their own issues that interfere with providing nurturing care[a].	Children in foster care, ages 1–39 months, and their caregivers	Children in the ABC group (and the comparison group who had never been in foster care) showed lower initial levels of cortisol (i.e., enhanced ability to regulate physiology) relative to those in the control intervention [160]. Children of parents in ABC group showed less avoidance after distressful episodes compared to in the comparison group [159].
Attachment Vitamins (AV) [161]	A trauma-informed, psychoeducational group intervention designed to address and repair the impact of chronic stress and trauma on the family unit. AV focuses on increasing: (1) trauma-informed parenting knowledge of emotional development and child individual differences; (2) emotional attunement; (3) mindfulness related to positive parent–child interactions; (4) executive functioning; and (5) reflective functioning[a].	Caregivers of children who are coping with toxic stress and trauma, ages birth to 5 years	Pre- to posttreatment increases in parenting sense of competence, emotional regulation, and warmth toward the child. An observed decrease in parenting stress was not significant.

Table 13.3 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Child-Parent Psychotherapy (CPP) [162, 163]	CPP is designed to support and strengthen the caregiver–child relationship as a way to restore and protect the child's mental health. Essential components of CPP focus on safety, affect regulation, reciprocity in relationships, the traumatic event and continuity of daily living. CPP also focuses on contextual factors such as culture, socioeconomic and immigration related stressors[a–c].	Children, ages birth to 5 years, who have experienced a trauma, and their caregivers	Children in CPP group showed significantly more improvements than those in comparison group. Reductions in child post-traumatic stress disorder (PTSD) symptoms and behavior problems. Reductions in mother's avoidant symptoms, general distress, and PTSD symptoms. At 6 month follow-up: reduction in problem behaviors compared to control group.
Early Start Denver Model (ESDM) [74, 162]	ESDM is a comprehensive early behavioral intervention. ESDM promotes developmental and social communication skills in young children with ASD. ESDM integrates applied behavior analysis with relationship-based and developmental approaches and is delivered by therapists and parents[a].	Children with Autism Spectrum Disorder (ASD), ages 18–30 months	Children who received ESDM showed significantly more improvements in IQ, adaptive behavior (communication, motor and daily living skills), and diagnostic status than those in the comparison group.
Nurse-Family Partnership [164]	A community health program aimed at reducing maternal and child mortality and promoting healthier pregnancies and child health outcomes in first-time low-income mothers and their children. Home visiting nurses promoted improvements in prenatal health behaviors and sensitive and responsive caregiving, helped build supportive relationships with family and friends, and linked mothers with needed services in the community[a].	Pregnant and early parenting women with at least two risk factors (i.e., unmarried, less than 12 years of education, unemployed), and their first-born child	A substantial program of research has shown overall improvements in birth outcomes, child abuse and neglect, injuries, and compromised parental life course (i.e., fewer subsequent pregnancies, greater workforce participation, reduced dependence on public assistance).

(continued)

Table 13.3 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Promoting First Relationships (PFR) [165]	Strength-based and attachment-based intervention that uses reflective consultation strategies and video feedback to focus on the deeper emotional feelings and needs underlying difficulties in the parent-child relationship[a].	Maltreated children in foster care, ages 10–24 months, and their caregivers	Observational ratings of caregiver sensitivity and attitudes improved more among dyads in the PFR condition relative to the comparison group.

Note: Treatment Foster Care Oregon is also available for preschoolers (previously termed Multidimensional Treatment Foster Care for Preschoolers [158]) (see Tables 13.13 and 13.14, which describes the adolescent version of this treatment)

[a] Home

[b] Community

[c] Clinic

Table 13.4 PUBLISHED parenting interventions

Intervention name	Description	Participants studied in key references	Key outcomes
(a) Positive parenting interventions			
Families Moving Forward (FMF) Program [73]	A caregiver-focused intervention that combines skill-building in positive behavior support with motivational interviewing and cognitive-behavioral treatment approaches to change key caregiving attitudes and behaviors. Can be customized. Caregivers are provided support, education on FASD and advocacy, coaching on skills and attitudes, and connection to community linkages. Targeted school and provider consultation are also offered[a–c].	Children with FASD, ages 4–12 years, and their caregivers	Relative to the comparison group, caregivers receiving the intervention reported improvements in sense of parenting self-efficacy and family needs met, self-care and FASD/advocacy knowledge, and, immediately posttreatment, reported their children showed less problematic disruptive behavior.

Table 13.4 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Families on Track Integrated Preventative Intervention [78, 110]	A multicomponent intervention designed to improve family functioning and reduce challenges later in life. Incorporates the FMF Program, a positive parenting intervention, with the Promoting Alternative Thinking Strategies (PATHS) curriculum, a weekly child-skills group that aims to prevent behavior problems by promoting social competence[a].	Children with FASD, ages 4–8 years, and their caregivers	Relative to the comparison group, the intervention was associated with improvements in caregiver knowledge, attitudes, targeted parenting practices, support, and self-care. Improved child regulation and self-esteem were also shown.
Parents Under Pressure (PuP) Program—adapted version [166]	A multi-component intervention designed to improve children's self-regulatory skills by focusing on improving the parent–child relationship and incorporating mindfulness techniques for both parents and children. Using an individualized approach, caregivers are provided psychoeducation about FASD and school consultation, in addition to strategies for enhancing child self-regulatory skills[a].	Children with FASD, ages 9–12, and their caregivers	For participants who completed the program, recruitment and intervention procedures were found to be feasible/acceptable and improvements in child's level of psychosocial distress, and quality of parent–child relationship were reported.
(b) Parent management training			
Parent-Child Interaction Therapy (PCIT) [73]	A behavioral parent training program designed to enhance parent–child relationships, increase appropriate child social skills, reduce inappropriate child behaviors, and institute a positive discipline program. Parents and children receive live, coached practice of behavioral parenting skills. This was a group adaptation of PCIT[a,b].	Children with FASD, ages 3–7 years, and their caregivers	Study compared two interventions: (1) Group adaptation of PCIT; (2) Parent-only Parent Support and Management Program (PSM) based on other effective behavioral programs. The PSM group offered psychoeducation and discussion/problem-solving about FASD and behavioral principles. Approximately half of each group completed treatment, not known if final data include non-completers. Improvements over time in child behavior problems and caregiving stress were seen for both PCIT and PSM groups, with no group differences.

(continued)

Table 13.4 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
(c) Parenting support, education, advocacy programs			
Coaching Families (CF) [32]	A program designed to educate families about FASD, provide access to community supports and teach advocacy skills to families and caregivers of children with FASD. The CF mentor and caregiver work together to establish high priority needs and goals for the program[a,d].	Caregivers of a child with FASD, ages 1–23 years	Pre- to posttreatment reductions in all areas of family needs, with the exception of mental health issues. An increase in goal achievement was also shown.
Key Worker and Parent Support Program [33]	Family-centered program that provides support, education and intervention services links caregivers to community services and support groups. It also provides consultation to other professionals to ensure a coordinated and effective approach to FASD management[a,b,d].	Families of children and youth with FASD, ages birth to 19 years	Pre- to posttreatment improvements in welfare outcomes among families as reported by caregivers. Positive caregiver perceptions of program were also shown.
Parent-Child Assistance Program (PCAP) [167]	A 3-year home visitation intervention designed to promote substance use recovery, reduce associated challenges and improve child outcomes. Program goals were that individualized and paraprofessional advocates linked mothers to community services such as health care, parenting classes, and therapeutic childcare[a].	Pregnant or postpartum women, reporting alcohol or drug use during pregnancy	Pre- to posttreatment improvements included alcohol/drug treatment completion, abstinence from alcohol/drugs; subsequent pregnancies with PAE. Increased maternal employment and linkages with services. More permanent child custody placements.
Parent Training Program [168]	The parent-focused component of the MILE (math interactive learning experience) intervention [169, 170] was delivered via a workshop or web-based format to compare effectiveness[a,b,e].	Caregivers of children with FASD, ages 3–10 years	Both workshop and web-based groups showed improvement in their knowledge of behavioral regulation principles, FAS and advocacy. Improvements in child behavior for workshop group only.

[a] Home
[b] Clinic
[c] Telehealth
[d] Community
[e] Web-based

Table 13.5 IN DEVELOPMENT parenting interventions and parenting support, education, and advocacy programs

Intervention name	Description	Participants studied in key references	Key outcomes
FMF Connect Mobile Health Intervention [97, 171]	Derived from the clinician-delivered standard FMF Program, the goal of this mHealth app is to provide information and tools directly to caregivers of children with PAE or FASD to help manage their children's condition. Unique features include a family forum for peer support, an in-app dashboard and video library[a].	Caregivers of children with PAE or FASD, ages 3–12 years	Beta-testing showed the FMF Connect intervention appears acceptable and feasible for caregivers of children with FASD, with results guiding additional app refinement prior to feasibility trial and large-scale randomized control trial testing.
Strongest Families FASD [172, 173]	A caregiver-focused, internet-based intervention that is designed to reduce challenging behavior of children with FASD, as well as parental distress. One new parenting skill is introduced each week via the online application and is supplemented by a weekly telephone coaching session to reinforce the skill, answer questions and provide support[b,c].	Caregivers of children with FASD, ages 4–12 years	Not yet available.
Triple P Positive Parenting Program (adapted for a remote community in Western Australia) [107]	Small group positive parenting intervention aimed at improving caregiver confidence and capacity to manage complex child behaviors. Learning strategies include discussion, visual teaching aids, modeling and role play, delivered by specially trained parent coaches. Using community-based participation research methods, this program was adapted to be culturally sensitive, as well as trauma-informed[d,e].	Caregivers of school-age children with complex needs (i.e., complex language environment, very remote community, historical and current trauma, social disadvantage)	Not yet available.

(continued)

Table 13.5 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Tuning Into Kids (TIK) [174–176]	A parent-focused group intervention designed to improve emotion regulation skills and reduce behavior problems of children with FASD. Using an emotion coaching approach, parents learn and practice effective ways of responding to their children's emotions and behaviors[e,f].	Caregivers of children with FASD, ages 4–12 years	Not yet available.

[a] Mobile Health app (for smartphone, tablet, or computer)
[b] Internet
[c] Phone coaching
[d] Home
[e] Community
[f] Clinic

Table 13.6 FUTURE DIRECTIONS parenting interventions and parenting support, education, and advocacy programs

Intervention name	Description	Participants studied in key references	Key outcomes
Family Check-Up Model [177, 178]	Prevention program designed for families at high psychosocial risk. Combines motivational interviewing techniques and promotes parent use of positive behavior support in visits at strategic developmental timepoints. Provides links to parenting support services. Delivered by specially trained parent consultants in a variety of settings[a,b].	Mother-child dyads; children ages 2–4 years, at high risk and involved in the Women, Infants, and Children (WIC) Nutrition Program	Reductions in child behavior problems, and increases in caregiver involvement and direct observations of positive behavior support practices relative to comparison group.

Table 13.6 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Research Units in Behavioral Intervention (RUBI) [179]	A parent-mediated intervention designed to decrease challenging behaviors in children with ASD. RUBI is delivered individually by trained therapists. Focused on identifying the function of a behavior, preventing disruptive behaviors from happening, promoting positive behaviors, and responding to challenging behaviors[a,c].	Parents of children with ASD and disruptive behaviors, ages 3–7 years	Reductions in parent-reported disruptive and noncompliant behavior were superior for the RUBI group compared with parent education group. Overall improvement rating by blinded clinician was greater for RUBI group.
Stepping Stones Triple P [180] Note: The Triple P Program has recently been adapted for use with children with FASD in a proposed protocol using the Stepping Stones curriculum, though findings are not yet published [107, 181, 182]	A positive parenting program, developed specifically for families of children with disabilities, aims to reduce problem behavior. Parents learn descriptive praise and planned-ignoring strategies, and how to encourage child communication. Uses a group format for teaching parenting strategies and individual sessions for observation, practice and feedback[a,c].	Parents of children with ASD, ages 2–9 years	Reduction in parent-reported child behavior problems and dysfunctional parenting styles (i.e., less reactive, less verbose) relative to the comparison group.

[a] Home
[b] Community
[c] Clinic

discussed. *At this point in time, the authors strongly believe that intervention research in the field of FASD could be strategically expanded, enhanced, and accelerated.*

Readers should note that although an effort was made to survey the literature as widely as possible, tables in this chapter could not be fully comprehensive. These tables are meant only to inform readers of the range of intervention literature available and are not presented as, or meant to be, a systematic review. In particular, Table 13.1 could include only a sampling of early interventions, given that many

Table 13.7 PUBLISHED child-focused skill-building interventions: self-regulation, social skills and communication, and behavioral outcomes (2–12 years)

Intervention name	Description	Participants studied in key references	Key outcomes
(a) Self-regulation			
Alert Program for Self-Regulation [183, 184]	An individualized intervention designed to improve self-regulation and executive function using sensory integration and cognitive strategies. Children engage in activities that focus on emotion sensitization and recognition, behavioral regulation, and social problem-solving[a].	Children with FASD, ages 8–12 years	Improvements in parent-rated child behavior and emotional regulation relative to comparison group [183]. Positive changes observed in brain regions critical for self-regulation among children in the Alert group relative to those in comparison group.
Cognitive Control Therapy (CCT) [122]	A progressive skill-building intervention that is designed to enhance a child's ability to understand their own learning style and learning challenges. Using a metacognitive approach, CCT teaches children self-regulation and self-observation strategies[b].	Children with FASD, ages 8–9 years	Improvements in teacher-rated behaviors of children (i.e., classroom behavior, academic achievement, writing and communication skills). Qualitative improvements in children's self-efficacy, motivation, cooperation, self-confidence, and emotionality.
GoFAR [75, 76]	A computerized intervention designed to improve adaptive functioning and disruptive behavior. GoFAR uses a metacognitive approach (FAR: Focus/Plan, Act, Reflect) to address hurried and impulsive problem-solving. Involves parent training on child behavioral regulation, and behavior analog therapy where parent and child implement the learning strategy[a].	Children with FASD, ages 5–10, and their caregivers	Children in the GoFAR intervention showed greater improvements in disruptive behaviors relative to comparison groups [75]. Children, whose computerized instruction was delivered consistent with parent training, showed greater self-regulation improvements than those receiving incongruent instruction [76].

Table 13.7 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Parents and Children Together (PACT), aka Neurocognitive Habilitation Therapy [73, 185]	A group-based intervention that integrates components of the Alert Program to improve executive function skills including memory, cause and effect reasoning, sequencing, planning, and problem-solving[a].	Foster/adopted children with PAE, ages 6–12 years, and their caregivers	Children in the PACT group demonstrated significant improvement in executive functioning skills relative to comparison group [73]. Improved parent-reported executive functioning and emotional problem-solving skills seen relative to comparison group [185].
Self-Management Intervention [186]	An individualized intervention designed to improve behavior. Informed by a functional behavior assessment, child was explicitly taught self-monitoring strategies and received contingent reinforcement[c].	Child with FASD, 11 years	Pre- to posttreatment improvements in behavior and independence with task completion.
Note: See also Table 13.4a–c. Many parenting interventions focus, in part, on improving child behavioral outcomes. Some positive parenting interventions, such as Families on Track and Parents Under Pressure, also focus on improving child self-regulation or decreasing psychosocial distress			
(b) Social skills and communication			
Children's Friendship Training (CFT) [187, 188]	A multicomponent intervention that focuses on developing friendship skills through didactic instruction, modeling, rehearsal and parent coaching. Includes parent-assisted activities to promote generalization of skills outside of intervention sessions[a].	Children 6–12 years with FASD, and their caregivers	Children in the CFT group showed improved knowledge of appropriate social behaviors, improved self-concept and improvements in parent-reported social skills relative to the comparison group.
Kid's Club [189]	A multicomponent, group-based intervention designed to improve social skills by accommodating the sensory needs of children with FASD and providing structure and consistency[d].	Children with FASD, ages 7–12 years, and their caregivers	Pre- to posttreatment improvements in parent-reported, child social skills.

(continued)

Table 13.7 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Social Communication Intervention [190]	An intervention designed to address social communication difficulties. Involved group role play of social scripts, a checklist with guidance for resolving social situations, and clinician modeling of socially appropriate responses[a].	Child with FASD, age 9	Increased use of language and generation of socially appropriate strategies for more effective management of social situations.
Theater-based Intervention [191]	A theater-based arts intervention designed to facilitate social communication and engagement in a group setting. Activities focused on collaboration, self-awareness/awareness of others and the environment, relaxation, listening, and curiosity and imagination[b].	Children with FASD, ages 9–14 years	Pre- to posttreatment improvements in child self-esteem, social skills, and emotional awareness as perceived by various stakeholders.
(c) Behavioral outcomes			
Good Behavior Game [192]	A group-based intervention designed to improve challenging behaviors. Involved therapist-delivered praise, corrective feedback, and positive reinforcement[b].	Child with FAS, age 4	Pre- to posttreatment reductions in disruptive behaviors.
Verbal Behavior Intervention [193]	An ABA intervention designed to improve adaptive skills and functional communication with 1:1 instruction. Intervention was informed by an assessment of child strengths and challenges[a].	Child with FASD, age 3 years, 10 months	Pre- to posttreatment improvements across all domains of functional communication, increase in verbal intellectual skills, improved adaptive functioning and emotional/behavioral functioning (per caregiver report).

Note: There are no known interventions IN DEVELOPMENT or with research underway for child-focused skill-building focused on child self-regulation, social skills and social communication, or behavior that are not already discussed in other tables

[a] Clinic

[b] Classroom/school

[c] Home

[d] Community

Table 13.8 FUTURE DIRECTIONS child-focused skill-building interventions—self-regulation, social skills and communication, and behavioral outcomes (2–12 years)

Intervention name	Description	Participants studied in key references	Key outcomes
Incredible Years Dinosaur School [194]	A classroom or group-based program designed to promote children's social competence, emotional self-regulation, and school behavior. Trained teachers promoted social skills and conflict management strategies through the use of puppets, homework activities, picture cue cards and games[a]. Note: The evidence-based IY Dinosaur School curriculum is available for children aged 4–8 years [195].	Students, in kindergarten and first grade, participating in a Head Start program	Students receiving the Dinosaur School curriculum showed more social competence and emotional self-regulation, as well as fewer conduct problems, than those in the comparison group.
Mindful Yoga Programs [196, 197]	Two yoga interventions designed to promote children's behavioral and attention regulation. Included physical postures, breathing techniques, meditation, and relaxation. Delivered by a certified yoga instructor or classroom teacher. Music, books, props and/or videos incorporated into yoga sessions[a].	Preschool students, ages 3–5 years, participating in a Head Start program	Increases in children's behavioral and attention regulation relative to comparison group [197]. Gains on a behavioral task of self-regulation and declines in teacher-rated submissive venting and total behavior problems relative to comparison group [196].
Promoting Alternative Thinking Strategies (PATHS) Program [198]	A universal classroom intervention designed to improve children's social competence and reduce problem behavior[a]. Note: The evidence-based PATHS curriculum is available through Grade 5 (for children through age 10–11 years) [199]. Note: PATHS has been used as part of the preventative, multicomponent Families on Track Program; see Table 13.4a.	Students in a Head Start program, ages 3–4 years	Children in the PATHS group had higher emotion knowledge skills and were rated as more socially competent and less socially withdrawn than the comparison group.
Tools of the Mind (Tools) [200]	A preschool curriculum designed to promote self-regulation skills, within the context of early literacy and math skills, and with a focus on play. The tools curriculum guides teachers' daily practices to help children develop and use tools to facilitate learning[a].	Preschool students, ages 3–4, from a low-income urban school district	The Tools curriculum was found to improve classroom quality and children's executive function skills relative to the comparison group.

(continued)

Table 13.8 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Mindfulness techniques [201] Note: This is presented as an example of a category of techniques to explore, with a reminder that a larger treatment plan is important. See interpretation of findings in righthand column.	A mindfulness exercise requiring children to perform small physical movements (e.g., “close your eyes,” “put your hands on your belly”). This was a 5 min, 40 sec task designed for children played on an Apple iPad that could be considered as a child version of a “body scan,” as it required children to focus their breath and attention on different parts of their body[b]. This was a feasibility study, and more research is needed.	Children with FASD, ages 6–10	Children with FASD were effectively able to follow mindfulness task instructions. Baseline respiratory sinus arrhythmia (RSA: physiological measure related to behavioral regulation) increased after the mindfulness task. Findings are interpreted to suggest: (1) when planning treatment, assessments of the caregiving environment should be included to guide interventions; and (2) if children are living in stressful environments, it is important that any mindfulness-based strategies be provided in conjunction with approaches targeting the broader family environment.

Note: Results of a recent series of meta-analyses aimed to assess all available evidence regarding the efficacy of different behavioral interventions promoting children’s executive function skills (working memory, inhibitory control, and cognitive flexibility) in one study to allow for comparison. Long-term effects were assessed via a meta-analysis examining follow-up data. Highlights for non-typically developing children were: (1) EF skills can be trained; (2) effects may not be sustained though more research is needed; (3) interventions offering new strategies of self-regulation, such as mindfulness, biofeedback-enhanced relaxation, and specific strategy interventions were found effective with a generally large average effect; and (4) explicit practice was only effective with a much smaller effect size. Authors concluded different interventions were useful for typically and non-typically developing children [138]

Based on these findings, to enhance executive function outcomes, possible treatment recommendations are: (1) EEG or EMG biofeedback-induced relaxation training; (2) the “Unstuck and On Target” or Alert Program curriculum or other specific strategy learning interventions; and (3) mindfulness meditation in everyday routines. Working these into a child’s enjoyable and meaningful daily routine, and a cost/benefit analysis for families, are important additional ideas

[a] Classroom/school

[b] Clinic

treatment studies have been done with “polysubstance-exposed” or “at-risk” young children. In many studies, prenatal alcohol exposure (PAE) is often not clearly specified (or not documented, even though it is likely present). Non-peer-reviewed program evaluation studies are not included, even though many have been done in the field of FASD. Intervention studies that are in-process or in the design phase are included, though some may not be known. Psychopharmacological and nutritional

Table 13.9 PUBLISHED child-and adolescent-focused skill-building interventions: toward varied other outcomes (3–16 years)

Intervention name	Description	Participants studied in key references	Key outcomes
(a) Attention and memory skills (see also note on Table 13.8)			
Dino Island/ Caribbean Quest [202] (in beta version, called Cognitive Carnival) [203, 204]	A computerized intervention program designed to strengthen attention and working memory skills using a series of game-like tasks. While being individually coached, in the final game five increasingly demanding cognitive tasks are presented as a motivating “serious” (designed for training and skill development) computer game. The final intervention includes metacognitive strategies provided by trained assistants to help generalization[a].	Children with FASD, ages 8–16 years (Cognitive Carnival: beta version); Children with FASD or autism, ages 6–13 years (Caribbean Quest: final version)	Using the beta version (Cognitive Carnival), children acquired 26 different metacognitive strategies which helped to improve performance during gameplay from pre- to posttreatment. Spontaneous strategy use increased over the course of the intervention [203, 204]. The final version (Caribbean Quest) was delivered within a school setting by educational assistants (EAs). This game-based process specific intervention was feasible, with improved working memory and attention performance, and improved reading fluency suggesting generalization to classroom performance. Preliminary results support use as part of an overall treatment plan [202].
Computerized Progressive Attention Training (CPAT) [205]	A computerized training program involving four sets of tasks that activate sustained attention, selective attention, orienting of attention, and executive attention. Task demands are advanced hierarchically based on a child’s improvements in speed and accuracy[a].	Children with FASD, ages 6–15 years	Pre- to posttreatment improvements in sustained and selective attention, spatial working memory, math, and reading fluency.

(continued)

Table 13.9 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Transcranial Direct-Current Stimulation (tDCS) and Cognitive Training (CT) [50]	An intervention combining CT (i.e., repeated practice of working memory, attention control and processing speed tasks) with tDCS, a non-invasive method of delivering low intensity electrical current to the brain[b].	Children with FASD, ages 9–16 years	Intervention was feasible and well tolerated in the tDCS group. Nominal improvement in attention compared to control group. Correlation between improvement in attention scores and decrease in parent-reported attention deficits in the tDCS group.
(b) Academic achievement			
Copy, Cover, and Compare Procedure in Spelling [206]	A self-managed proofreading drill and practice program involving a visual prompt and written cues (i.e., copy, cover, and compare) to improve the accuracy of written work (i.e., detect errors, correct spelling)[a].	Child with FASD, 7 years	Pre- to posttreatment increase in frequency of correct words spelled and reduction over time in frequency of spelling errors.
Literacy and Language Training (LLT) [207, 208]	Cognitive intervention focused on the development of phonological awareness and acquisition of early literacy skills. Used multi-sensory stimulation strategies[a].	Children with FASD, ages 9–10 years	Relative to comparison groups, the LLC group showed improvements in specific tests of language and literacy, but no significant gains in general scholastic assessments.
Math Interactive Learning Experience (MILE) [115, 169, 170]	A multi-component intervention, using a metacognitive approach (i.e., focus & plan, act, and reflect) to improve math ability and behavior. Children received individualized 1:1 math tutoring, while caregivers were trained on how to support math learning and behavior regulation at home[a–c].	Children with PAE or FASD, ages 3–10 years, and their caregivers	Greater gains in math performance for the MILE groups. Treatment gains were shown at 6-month follow-up.
Rehearsal training [209]	Rehearsal training designed to improve working memory for numbers[b].	Children with FASD, ages 4–11 years	Intervention group showed improvement in recalling numbers and increased use of rehearsal strategies relative to comparison group.

Table 13.9 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
(c) Adaptive function skills			
Fire and Street Safety Skills Training [210, 211]	A virtual reality game training designed to teach home fire or street safety skills in small incremental steps, while restricting incorrect or dangerous movements[a,b,d].	Children with FASD, ages 4–10 years	Pre- to posttreatment increase in knowledge of fire safety skills and generalization to real-world simulation 1 week later.
(d) Sensory-motor skills and physical activity			
FAST club: A physical activity (PA) intervention [212, 213]	An individualized, strength-based physical activity program developed to improve executive function. Intervention administered in a group setting (school gym)[a].	Children with FASD, ages 6–14 years	The PA intervention did not influence the stress response (i.e., no change in cortisol levels) in children with FASD [212]. Improvements in executive function skills post-intervention relative to comparison group were maintained at 3 month follow-up [213].
Sensorimotor Training to Affect Balance, Engagement, and Learning (STABEL) [214, 215]	A virtual reality intervention designed to improve sensory control of balance and motor performance. Tasks involved goal-directed movement demands, active problem-solving and adaptation to changes in the sensory environment in the context of the computer game[b,d].	Children with FASD, ages 8–15 years	Children who received the intervention showed greater improvements in balance (including overall ability and reaction to sensory conditions during standing and motor performance) relative to the comparison group.

Note: There are no known interventions IN DEVELOPMENT or with research underway for child and adolescent-focused skill-building that are not presented in other tables. See Chap. 16 on Education and Developmental Disabilities Systems for information on academic strategies and interventions

[a] Classroom/school

[b] Clinic

[c] Community

[d] Home

Table 13.10 FUTURE DIRECTIONS child and adolescent-focused skill-building interventions—toward varied other outcomes (3–16 years)—sleep, physical activity, and adaptive function outcomes

Intervention name	Description	Participants studied in key references	Key outcomes
Cognitive Orientation to Occupational Performance (CO-OP) [218]	A task-specific, cognitive-based, problem-solving intervention that guides individuals to independently discover and develop cognitive strategies to perform targeted tasks of everyday living such as dressing, grooming, writing, bicycling[a,b].	Children, 8–12 years, with developmental coordination disorder (DCD), and children with DCD and co-occurring attention deficit hyperactivity disorder (ADHD)	Improvements in self-perceived functional motor performance and movement quality were seen in both groups. Functional motor improvements were maintained at 3 months follow-up. Children with DCD only showed skill transfer to other motor skills.
Sleep Health in Preschoolers (SHIP) [219]	A family-centered and personalized intervention to address behavioral sleep problems (bedtime resistance, frequent night wakings, insufficient sleep duration) in young children. Provides parents with the knowledge, motivation and skills for setting and achieving goals, adapting to setbacks, problem-solving and improving their child's sleep[a].	Parents of preschool-age children with behavioral sleep problems	Not yet available.
Sleep Intervention for Kids and Parents (SKIP) [220]	A web-based, shared management intervention that emphasizes goal setting, action planning, and self-monitoring to improve sleep. Engages both children and parents to work together to select and later appraise sleep improvement activities. Includes education on the importance of bedtime routine, an optimal sleep environment, and sleep hygiene. Also incorporated elements of cognitive therapy for insomnia: relaxation techniques and stimulus control[c].	Children, ages 6–11 years, with asthma and behavioral sleep disturbances and their parents	Pre- to posttreatment improvements in child and parent sleep outcomes including wake after sleep onset, sleep efficiency, and bedtime range. SKIP was feasible and acceptable.

Table 13.10 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Sports Therapy for Attention, Cognitions and Sociality [221]	A sports-activity intervention designed to improve attention, social competency, and cognitive functions in children with ADHD. Children participated in a 90-min athletic activity twice a week including both aerobic (e.g., shuttle runs, jump rope) and goal-directed exercises[b]. Note: This is presented as a practical, meaningful example of a category of physical activity techniques to explore, but is not necessarily the "best" choice of an intervention. There are many aspects of physical activity interventions to consider. These include: (1) cognitively engaging, aerobic, etc.; (2) chronic (higher-intensity or vigorous) vs not; (3) differences when physical activity is a meaningful part of a child's life vs. not; (4) and more.	Children with attention deficit hyperactivity disorder (ADHD), ages 7–9 years	Children in the sports-activity group showed greater improvements in attention, cognitive functions (i.e., flexibility, impulsivity) and speed, and social competence relative to the comparison group.

Note: Results of a recent series of meta-analyses aimed to assess all available evidence regarding the efficacy of different behavioral interventions promoting children's executive function skills (working memory, inhibitory control, and cognitive flexibility) in one study to allow for comparison. Long-term effects were assessed via a meta-analysis examining follow-up data. Physical activity was examined. Results were imprecise, but indicated a significant, moderate effect for non-typically developing children with need for research on the physiological mechanisms underlying the impact of physical activity. In study of children with ADHD, physical activity is suggested as an adjunct treatment, and among those with ADHD or ASD more vigorous (chronic) physical activity does appear to increase some aspects of executive function and gross (but not fine) motor skills [138, 216, 217]

[a] Home and phone support

[b] Clinic

[c] Online support

Table 13.11 PUBLISHED adolescent, transition-aged youth, and adult interventions

Intervention name	Description	Participants studied in key references	Key outcomes
(a) Adolescent interventions			
Adapted Alert Program for Adolescents with FASD [222]	Designed to teach adolescents to monitor, maintain, and regulate their alert levels (high, low, just right). Sensory-based strategies were explored as a way to change alert levels in different contexts. The program was modified to ensure ecological validity in Canada and with the FASD population[a].	Youth with FASD, ages 11–17 years	Adolescents used both sensory and non-sensory strategies to regulate and they reported an increase in use of self-regulation strategies from pre- to posttreatment.
Project Step Up—Adolescent Group [223]	A multicomponent intervention designed to reduce alcohol consumption and alcohol-related negative outcomes. Included education, modeling, coaching, behavioral rehearsal, and performance feedback strategies. Caregiver groups were educated on the effects of PAE on the brain and how to handle associated parenting challenges[a].	Youth with FASD, ages 13–18 years, and their caregivers	Decrease in self-reported alcohol risk and in alcohol-related negative behaviors in light/moderate drinkers relative to the comparison group. Intervention found to be acceptable and helpful for both adolescents and caregivers.
Saturday Cognitive Habilitation Program [224]	A community intervention program designed to improve youth's ability to plan, organize, shift, and evaluate problem-solving strategies. Adapted from the MILE intervention[b].	Youth with FASD, ages 10–14 years	Pre- to posttreatment gains on measures of nonverbal reasoning, reading comprehension, or mathematics reasoning for 4/5 participants.
The Brain Unit [225]	A universal school-based program that combined mental health literacy and dialectical behavioral therapy (DBT) skills to improve students' self-concept, coping skills, and social support. Program was delivered by teachers, who were provided with core instructional goals, but could flexibly adapt instructional methods for their students (i.e., bibliotherapy, role play, videos, class meetings, visual scripts, or social stories)[c].	Youth with FASD and other developmental disabilities, in grades 3–12, and their peers without disabilities	Large effect sizes for intervention schools on all measures of self-concept, coping, and social support. Strong fidelity to the program reported by teachers.

Table 13.11 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
(b) Transition-aged youth and adult interventions			
Mind, Body, and Spirit program (MBS) [226]	Designed to develop and strengthen the ability of adult male offenders to transition from a correctional facility to the community prior to release. The MBS program focused on improving communication, interpersonal skills, personal strengths, and physical health using an activity-based format[d].	Incarcerated adult men with FASD, ages 19–50 years	Participant-reported improvements in anger and stress management, self-esteem, and coping skills over the course of the intervention. Increased self-awareness and insight into patterns of behavior and improved relationships with family and children.
Parent-Child Assistance Program (PCAP) adapted [167]	A paraprofessional home visitation and advocacy intervention aimed at decreasing the risk for future alcohol- or drug-exposed births. Case managers assist clients in accessing treatment, family planning needs, and connect patients with support groups and help secure stable housing[e].	Women with FASD or suspected FASD, ages 14–36 years	Pre- to posttreatment reductions in alcohol and drug use, as well as increased use of contraceptives, medical and mental health care services, and stable housing.
Step by Step Program [227]	A community-based intervention designed to reduce the risk of breakdown in families, strengthen life and parenting skills, and increase success and independence within families. Mentors support parents on a 1:1 basis to access supports related to housing, addiction treatment, finances and parenting[b].	Parents with FASD or suspected PAE, ages 19–47 years	Reduction in severity of needs specific to each parent (i.e., experience of abuse, social problems, housing and transportation, and community resources) and gains made toward achieving individual goals over the course of the intervention.

[a] Clinic
[b] Community
[c] Classroom/school
[d] Correctional facility
[e] Home

Table 13.12 IN DEVELOPMENT adolescent, transition-aged youth, and adult interventions

Intervention name	Description	Participants studied in key references	Key outcomes
Aware Program Parker et al. (findings in preparation)	An interactive, web-based program designed to teach mindfulness skills to adolescents with FASD to improve their self-regulatory abilities and decision-making skills. Parents are provided with online resources, including a guide describing the topics and skills that will be taught to teens, to support their teen's use of the Aware Program[a].	Adolescents with FASD	Pre- to posttreatment improvements in emotion regulation abilities and executive functioning. Adolescents successfully used the program and were engaged with the online program activities. Adolescents and parents provided positive satisfaction ratings.
My Health Coach app Petrenko and Tapparello (funded, grant underway)	A mobile health application that provides adults with FASD evidence-based education about their condition and tools to promote their own self-management and health advocacy goals. This app is being designed in partnership with adults with FASD.	Population to be determined	Not yet available.
Self-Regulation Intervention adapted from the Alert Program Rasmussen, Pei and Oberlander (in preparation)	The Alert Program, adapted for adolescents with FASD, was designed to improve a range of self-regulatory functions including cognitive, behavioral and physiological measures (sleep and cortisol regulation)[b].	Adolescents with FASD	Not yet available.

[a] Home
[b] Clinic

Table 13.13 FUTURE DIRECTIONS adolescent, transition-aged youth, and adult interventions

Intervention name	Description	Participants studied in key references	Key outcomes
Attachment, Regulation, and Competency (ARC) Program [228]	A multicomponent intervention framework designed to build developmental competencies, stabilize internal distress, and strengthen security of the care-giving system. Core components include establishing routines and rituals, increasing caregiver affect management, improving caregiver-child attunement, and increasing use of positive praise and reinforcement[a–c].	Children/ adolescents with complex trauma, ages 2–21 years, and parents	Pre- and posttreatment reductions in child behavior problems (internalizing, externalizing and total problems). Improvements in symptoms of PTSD and child/adolescent needs and strengths.
Cognitive Therapy for Insomnia (CBTI) for Adolescents [229]	Based on CBTI for adults, this protocol was adapted for the treatment of adolescents with insomnia. It consists of psychoeducation, sleep hygiene, restriction of time in bed, stimulus control, cognitive therapy, and relaxation techniques[c].	Adolescents with insomnia, ages 12–19 years	Both CBTI groups (group therapy and guided internet therapy) showed clinically significant improvements on sleep efficiency, sleep onset latency, wake after sleep onset, and total sleep time relative to comparison group.
Supporting Teens' Autonomy Daily, aka Supporting Teens' Academic Needs Daily (STAND) [230]	A multicomponent intervention delivered in the style of motivational interviewing to enhance family engagement in therapy. STAND targets identified academically important executive function skills for adolescents (i.e., organization, time management, and planning (OTP skills)) and parent-based behavior management practices (i.e., monitoring and contingency management)[c].	Children/ adolescents with ADHD, ages 11–15 years, and their parents	Children receiving the STAND intervention showed greater improvements in OTP skills, homework behavior, parent-teen contracting, implementation of home privileges, and parenting stress relative to comparison group.

(continued)

Table 13.13 (continued)

Intervention name	Description	Participants studied in key references	Key outcomes
Trauma Affect Regulation: Guide for Education and Therapy (TARGET) [215]	TARGET is a strengths-based, trauma-focused psychotherapy designed to regulate intense emotions, manage intrusive trauma memories, and promote self-efficacy. TARGET teaches skills using a seven-step sequence, the FREEDOM steps (focus, recognize, emotions, evaluate, define, option, make a contribution), to help individuals learn to process and manage trauma-related reactions to stressful situations[c,d].	Adolescents with full/partial PTSD, involved in delinquency, ages 13–17 years	TARGET showed a reduced severity of PTSD symptoms and gains on outcomes of depression, anxiety and, post-traumatic cognitions
Treatment Foster Care Oregon-Adolescents (TFCO-A) [231] Note: Previously referred to as "Multidimensional Foster Care"	TFCO-A is a model of foster care treatment. TFCO-A aims to create opportunities for youths to successfully live with families rather than in groups or institutional settings, and to simultaneously prepare their parents (or other long-term placement) to provide them with effective parenting. Four key treatment elements are: (1) a consistent reinforcing environment with mentoring and encouragement to develop academic and positive living skills; (2) daily structure with clear expectations and limits and well-specified consequences; (3) close supervision; and (4) helping youth avoid deviant peer associations while providing support for establishing prosocial peer relationships[a,c,d].	Youth with severe emotional and behavioral disorders and/or severe delinquency, ages 12–18 years Note: There are also versions for preschoolers (which has been tested) and for children (which has not been tested separately).	TFCO-A has received the highest rating of "1" (well-supported by research evidence) on the California Evidence-Based Clearinghouse for a wide variety of child welfare-related outcomes (e.g., reduced disruptive behavior, reduced placement disruption).

Note: Cognitive behavioral therapy (CBT), and approaches built on CBT such as trauma-informed CBT (TF-CBT), are often used with those living with FASD. CBT techniques, adapted appropriately for neurodevelopmental differences, may be helpful. These techniques can certainly help *caregivers* raising children and youth with FASD or PAE. But assisting the individuals living with FASD may often require specialized or multicomponent approaches for troubling symptoms (e.g., insomnia), difficult life tasks (e.g., academic success), more complicated presentations (e.g., complex developmental trauma), or major and chronic difficulties (e.g., delinquency). Presented in this Future Directions table are evidence-based, effective treatments that respond to these significant challenges

[a] Home

[b] Community

[c] Clinic

[d] Classroom/school

Table 13.14 FUTURE DIRECTIONS adolescent and transition-aged youth, and adult interventions—well-known mental health approaches beyond CBT to be studied with targeted FASD sub-populations

Intervention name	Description	Participants studied in highly selected key references	Key outcomes
Dialectical Behavioral Therapy (DBT) [232]	A multicomponent cognitive-behavioral intensive intervention that targets treatment engagement and the reduction of self-harm and suicide attempts. DBT focuses on teaching skills for enhancing emotion regulation, distress tolerance, and building a life worth living. Core components include individual psychotherapy, multifamily group skills training, youth and parent telephone coaching, and weekly therapist team consultation[a].	Adolescents who are highly suicidal, ages 12–18 years	Participants in the DBT group showed a reduction in suicide attempts and self-harm relative to the comparison group.
Functional Family Therapy (FFT) Model [233]	A systems-oriented, behaviorally based model of family therapy designed to reduce youth referral problems (i.e., delinquency, oppositional behaviors, violence, substance use), and improve prosocial behaviors by enhancing support and communication within the family[a–c].	Adolescent offenders, ages 11–17 years, and their families	Adolescents in the FFT group showed a reduction in youth behavioral problems, including felony and violent crime recidivism (when therapist adherence to the FFT model was high).
Multisystemic Therapy (MST) [234]	An intensive family-based intervention designed to reduce adolescent antisocial behavior (i.e., criminal activity, substance use, conduct problems) and improve their functioning across family, peer, school and community contexts. Family strengths (i.e., love for the adolescent, social support) are used to overcome barriers (i.e., caregiver substance use, stress, hopelessness) to caregiver effectiveness[b–d].	Adolescents with juvenile justice involvement, ages 12–17 years, and their caregivers	Youth who received MST showed a reduction in recidivism and improved youth functioning in the home, at school and in the community relative to the comparison group.

Note: DBT, FFT, and MST are effective therapies with large research literatures. These therapies are for use with adolescents and transition-aged youth who show very significant, chronic mental health, and lifestyle difficulties. Such problems can include suicide attempts, conduct disorders, and/or juvenile justice involvement. DBT has also been successfully used with adults, for prevention of problems with youth, and for target symptoms beyond suicide and self-harm. FFT and MST both focus on the entire family system, and so also include treatment for adults. MST also involves

Table 13.14 (continued)

working with other systems with which a youth interacts, such as peers, school and community systems. These three therapy approaches, which likely would require adaptation for use with those living with FASD or PAE, seem quite promising for those with serious secondary impacts

[a] Clinic

[b] Home

[c] Community

[d] Classroom/school

supplementation treatment studies are not included, though brief mention is made of these important intervention research directions in the Discussion. School-based studies are generally not included. Most published studies have been subjected to critical or systematic review elsewhere, so quality assessment is often available in other publications and is not presented here. Intervention studies included are listed with short descriptions and 1–2 key references, participants of interest (those with PAE/FASD), and delivery settings. Findings of key references are briefly discussed, *focusing on outcomes that have shown change*. For the purposes of these tables, only selected studies from larger research programs could be included. This means that only one of a series of studies may be presented, and readers are encouraged to further explore and find the full age range and types of participants to which these treatments can apply—and all outcomes which have been studied. A few notes are included.

To help catalyze intervention research, also listed in certain tables are the authors' recommendations of highly selected, wide-ranging existing treatments from other fields that address concerns common in FASD/PAE, with references and descriptions. Readers are encouraged to use these selected references to prompt further independent exploration of promising treatment ideas. These "future directions" treatments are theoretically sound and typically have a robust, or at least developing, evidence base. Among the promising options to be explored, some school-based treatments are included. This is because school-based mental health interventions (and enhancements to early intervention and other settings where children are already present) are cost-effective options for service provision. The authors believe these existing interventions are worth consideration for study with the clinical population of those with FASD or PAE, though these programs will likely need some adaptation taking a neurodevelopmental viewpoint. It is crucial to remember that all promising treatments should be informed by lived experiences data drawn from those living with FASD or PAE. True to the essential elements of

FASD-informed care, adaptation should be led by the community to create culture-centered practices. Even the fact of whether treatment is needed should be led by the community and the input of self-advocates.

Relationship-Based and Multicomponent Early Interventions (Birth to 5 Years)

Tables 13.1 and 13.2 include a range of approaches to relationship-based and multicomponent early interventions that have been specifically tested with samples of children aged birth to 5 years with PAE or FASD, and their caregivers. These tables should be considered a sampling of available interventions. There are many treatment studies that have been done with young children with polysubstance or drug exposure (where PAE is not a specific focus), or with "at-risk" young children (who may have PAE). These many other studies are not included here, but there is an in-depth synthesis article that reviews a large portion of this work [111].

Certainly, much more research remains to be done specifically with children with PAE or FASD, using bigger samples and a wider range of treatments. Many of these are pilot trials or are still in development. Fortunately, though, these treatments fit with most essential elements of FASD-informed care. For instance, all are designed to "act early" based on similar theories of change, and all reduce risks and promote protections. All share an aim to improve the caregiver–child relationship and are inherently trauma-informed. All offer developmentally appropriate treatment in that they promote mutual regulation between parent and child, or the way in which parents and children interact together and stay in a calm and responsive state—and build child self-regulation (a common area of impairment for children born with PAE).

One intervention, shown in Table 13.1, the Circle of Security, is an existing evidence-based treatment for caregivers used in this trial on an individualized basis. With adaptation, it was found to be efficacious for caregivers and children with PAE or FASD in a small study. Another, shown in Table 13.1, the SEEDS Program, is a novel multicomponent treatment, developed especially for young children with PAE and early trauma. The SEEDS Program aimed to provide comprehensive and interdisciplinary early intervention, promoting a spirit of collaboration between parent and teacher, with outcomes yet to be fully discussed.

To truly provide FASD-informed care, early interventions should include educating caregivers to reframe and accommodate (and thus take a neurodevelopmental viewpoint). As shown in Table 13.1, this is something Zarneger and colleagues clearly aim to do with their novel model, already published as a pilot study. This model integrates two evidence-based treatment approaches (Child-Parent Psychotherapy and Mindful Parenting Education). As shown in Table 13.2, one promising novel "early intervention (EI) enhancement" in development, called FMF Bridges, aims to do this by including a caregiver curriculum based on the existing, scientifically validated Families Moving Forward (FMF) Program. This curriculum educates caregivers of children aged birth to 3 years on the neurodevelopmental viewpoint as it applies to young children. FMF Bridges integrates developmentally appropriate material from the FMF Program with elements of an existing, well-studied evidence-based relationship-based intervention. Note that EI enhancements are integrated into settings already attended by young children with PAE, such as birth-to-three centers, intensive outpatient substance abuse treatment settings for parents, or home visitation programs.

Traditional early interventions typically aim toward building child self-regulation, but may not always try to target other individual-level impairments. However, the approach of Zarnegar and colleagues appears to customize skill-building to each individual child. This is an approach the neuroconstructivist view would suggest. Interestingly, the SEEDS multicomponent early intervention (with findings published so far as a case study series) appears to train a wider range of skills (such as precursors of executive function and other aspects of learning readiness).

Table 13.3 shows some very promising evidence-based, relationship-based interventions or multicomponent early intervention programs not yet studied with samples with known PAE or FASD. The full range of these treatments, often known as “infant and early childhood mental health interventions,” is discussed in more detail by Olson and Montague [19]. For the current chapter, the authors recommend several interventions that might strategically be tested next as future directions. These are designed for a variety of family structures, are developmentally appropriate and trauma-informed, and most target the parent–child relationship as a way to support child self-regulation. Many take place through home visiting or bringing families into clinics. Among these are the Attachment, Biobehavioral Catch-Up (ABC) Model (originally designed for foster parents), Promoting First Relationships (originally designed for high-risk parents), The Nurse-Family Partnership (originally designed for pregnant and early-parenting persons with risk factors), and others.

It is crucial to remember that all these promising treatments may need adaptation and should be informed by lived experiences data. Adaptation should be led by the community in which they are deployed to create culture-centered practices. As will be repeated throughout this chapter, even the fact of whether treatment is needed should be led by the community. This is even true of early interventions, which tend to target goals that are “universal” to all cultures, such as improving the quality of parent-child attachment or enhancing cognitive stimulation. Yet exactly how to go about improving the security of attachment between parent and child, or how to offer ways to help children improve their developmental potential, differs around the world. Measuring whether these early interventions are effective must be done in ways that are meaningful to those to whom treatment is provided.

All this means that early interventions should be examined across a variety of cultures using samples with PAE or FASD, adapting as needed, and ascertaining when novel treatments must be developed. Fortunately, this is starting to happen. For example, now being published is a study on an effort to provide a new, relationship-based early intervention enhancement in two rural communities in a South African context for children with PAE and their caregivers (see Table 13.2).

This treatment encourages caregiver-child dyads to attain a calm and alert regulatory state as a precursor to secure and positive engagement. This treatment adds value to natural settings children already attend. Benefits were seen for all children, with the greatest benefits for the highest-risk children (research colleague and investigator, University of New Mexico, Kalberg W, 2021, written communication, 22nd October).

Parenting and Family Support Interventions

Tables 13.4a–c and 13.5 include a robust set of what can be grouped into: (1) positive parenting interventions; (2) parent management training; and (3) parenting support, education and advocacy programs. Tested so far are treatments that are typically offered in-person (at home or in the clinic), with at least one known now to be offered via telehealth. Online treatments are now being developed. Several of these treatments, such as Coaching Families and the Key Worker Program, have been sustainably implemented for 10–20 years in several communities in Canada. Programs fit with almost all essential elements of FASD-informed care. For instance, these programs find, build, and use strengths, aim to overcome stigma, build collaborative partnerships, offer developmentally appropriate care, think about context (intervene at different levels of a youth's ecology), sustain hope, and more. With the possible exception of parent management training (Table 13.4b), all reframe and accommodate (take a neurodevelopmental viewpoint). Positive parenting interventions also attempt to target a range of individual-level impairments.

Positive parenting interventions in Table 13.4a are aimed toward families raising children in the preschool and elementary school years and include explicit use of a positive behavior support approach (drawn from the developmental disabilities literature) [112]. For these interventions, initial efficacy studies have been done, with at least some translational research. Some are novel treatments, such as the Families Moving Forward (FMF) Program, which has also been used with good feasibility in gradually growing real-world practice since 2010, including most recently through telehealth. The FMF Program offers parent training and advocacy education specialized for families raising children with PAE or FASD and behavior problems, with additional important elements such as a focus on child joys and rewards, caregiver self-care, and planning for the future with hope. Positive parenting interventions, which teach caregiving methods to deal with challenging behavior, have also been combined with child-focused skills-building in multicomponent approaches, such as the Families on Track Program, Parents Under Pressure Program, or the MILE Program (MILE components are listed in both Tables 13.4 (parent training program); and Table 13.9 (child skills-building component, discussed later).

Presented in Table 13.4c, the wide range of parenting support, education, and advocacy approaches are used with families raising an individual with PAE or FASD, with the broadest age range for any program from birth to young adulthood. These approaches offer specialized parenting education and typically also customized family support/case management that offers caregiver support and education and emphasizes connecting families with needed services. One program of interest offering education is the workshop or web-based parent training program that accompanied the MILE learning readiness/self-regulation program. Parent support programs range from the Key Worker and Parent Support Program and Coaching Families, which serve all families raising an individual with PAE, to the more targeted Parent-Child Assistance Program (PCAP). PCAP serves pregnant and parenting persons (birth mothers) at very high risk for chemical dependency and has spread widely to community practice in multiple states and countries.

Listed in Table 13.5, in efficacy studies now underway, are several parenting interventions that have moved beyond telehealth, to administration online in order to increase accessibility and scalability. One is a web-based parent training program based on an existing model for children with neurodevelopmental disorders, that includes supportive phone-based coaching, called Strongest Families FASD. Another is a mobile Health application ("mHealth app") called FMF Connect. This app takes content and treatment principles from the FMF Program and adds unique features such as an in-app Family Forum (moderated parent support group) and more. FMF Connect allows the intervention to be self-administered or coached. Also undergoing ongoing study of efficacy is a caregiver-focused intervention with a relationship-focused stance, using techniques of emotion coaching (which predict positive child outcomes), called Tuning into Kids.

To fully provide FASD-informed care as a positive parenting or family support intervention, further thought is needed about overcoming stigma, thinking about context, and being led by the community to create culture-centered practices. Specifically, outcomes should be measurably defined in terms of what is necessary to improve QOL for children, parents, and families. Measures should be meaningful and consider the influence of context (participation and environmental factors) on daily functioning. The logic model and theory of change underlying each intervention need to be defined and described and should be clear and precise. In addition, given the wide cultural variation of parenting practices, outcomes, logic models, and theories of change need consideration across a range of cultures. Interventions should be adapted to different cultures as needed, but novel treatments should also be developed when required.

Positive parenting interventions are especially suited to families raising children with PAE or FASD. There are several promising existing interventions with a developing evidence base that have features that complement the three positive parenting programs already tested with this clinical population. Listed in Table 13.6 are the Family Check-Up Model (designed to be offered as part of integrated primary care), the program known as Research Units in Behavioral Intervention (RUBI; delivers basic positive parenting skills and designed for children with autism, but might be adaptable), and the Stepping Stones Triple P Program (which can be used with groups).

In addition, there are a range of evidence-based parent management training methods available based on social learning theory, including those primarily developed for young children at risk for (or with) disruptive behavior disorders or ADHD, or focused on promoting school readiness. These tend to focus more on consequences for misbehavior and rewards for desirable behavior and may or may not fit well with samples with the neurodevelopmental problems seen in FASD. While the scientific literature for social learning theory-based parent training is very robust, of this category of treatments only Parent-Child Interaction Therapy (PCIT) has been studied explicitly with samples with PAE or FASD, with mixed evidence for efficacy. Recent reviews of the behavioral parent training literature continue to support that these are well-established, efficacious approaches for children with ADHD, who have symptoms similar to those of children living with FASD or PAE. The data are especially strong in the school years, but there are data showing these approaches work in the preschool years and, with the addition of other components, to a lesser extent in adolescence [113]. Therefore, it remains of interest to see if the "usual" treatments work for families raising children with PAE or FASD. It is also of interest to explore whether they can work with appropriate adaptation. Notably, the broad evidence base for these programs has not yet included secondary analysis to see if there is differential efficacy for children with PAE or FASD. This seems like an important omission in that literature. For more information, see discussion of both positive parenting and social learning theory-based approaches in Olson and Montague [19].

Child-Focused Skill-Building Interventions: Self-Regulation, Social Skills and Communication, and Behavioral Outcomes

Table 13.7a–c presents a range of skill-building, child-focused interventions aimed toward improving social and friendship skills, social communication, self-regulation, and behavioral outcomes (not including parent training). These are primarily aimed at remediating these areas of deficit among children in the preschool and elementary school years (about 2–12 years). Both descriptive neurobehavioral research and lived experiences data make clear that impairment in these domains creates daily life challenges, increased caregiving stress, and reduced family and child QOL. As a consequence, this has been an area of more intensive research activity, including programmatic research on some interventions with replication studies, and at least initial real-world translational research. Of course, more research is needed, and many of the samples have been small (or case studies using single subject design). All these treatments conform with at least some essential elements of FASD-informed care in that they take a neurodevelopmental viewpoint, target individual-level impairments, are developmentally appropriate, and take context into account.

True to guidelines of the neuroconstructivist view, self-regulation has been a significant intervention research topic (Table 13.7a). Early on, efforts were made to have children observe their own learning style using Cognitive Control Therapy and, more recently, using contingency reinforcement, with a goal of improving self-regulation. A newer, robust metacognitive approach to improve child self-regulation was designed as a computerized intervention (delivered along with trained parent assistance) called GoFAR (FAR: Focus/Plan, Act, Reflect). It is notable that GoFAR was actually a *multicomponent* program because the child skills-building component was combined with parent training on behavioral regulation and behavior analog therapy where the parent and child together implemented the learning strategy. A program designed by occupational therapists, called the Alert Program for Self-Regulation, has been successfully used in both an individualized and group format, and adapted in several ways, with both neurobiological (brain function) and behavior outcomes assessed. Multiple studies have been done on the Alert Program by several research labs. As shown in Table 13.7b, treatment to improve child social skills has been investigated most robustly in a series of studies by one lab on Children's Friendship Training (CFT) with promising efficacy data. It is notable, in a small study, that CFT was apparently more effective when coupled with a specific type of medication therapy compared to other groups [114]. There have also been several small exploratory studies of innovative treatments for group social skills improvement or individual social communication support for children with FASD. Most studies focusing on child behavior are actually included in Table 13.4a–c, as parent training programs often target reductions in child disruptive behavior. However, included in Table 13.7c are two case studies of children with FASD whose behavior (and functional communication) improved with classic applied behavior analysis techniques used as treatment.

Note that no "in-process" treatments of child-focused skill-building interventions aimed toward self-regulation, social skills and communication, and behavioral outcomes were identified for this chapter, so there is no corresponding table. However, this literature survey could not be fully comprehensive, so it is possible that some research underway was missed.

There are many other promising ideas for treatment of self-regulation, and of social skills and communication, for children with PAE and FASD. The authors recommend finding existing programs to treat these areas of common individual-level impairment that have an evidence base, and then adapting as needed taking a neurodevelopmental viewpoint. Listed in Table 13.8 are a wide-ranging set of programs with a convincing (or at least developing) evidence base. Thinking about the outcome of self-regulation, the preschool curriculum called "Tools of the Mind" is literally designed to promote self-regulation in a play-based learning format. Further, Mindful Yoga Programs are treatments that include physical activity, breathing, meditation, and relaxation to improve both self-regulation (and executive attention). Addressing the outcome of social skills, the Incredible Years Dinosaur School and Promoting Alternative Thinking Strategies (PATHS) Program are two child group programs (often delivered in the classroom, but which can also be delivered in community or clinic settings), which have a strong evidence base and concrete materials that could easily be adapted for children with PAE or FASD. In fact, PATHS has been combined with the FMF Program as a multicomponent intervention in the Families on Track intervention listed in Table 13.4 [78, 79].

Beyond just trying these promising treatments, intervention research in the area of child skill-building in self-regulation, social skills and communication and behavior should continue to assess both behavioral and neurobiological outcomes, following the lead of research with the Alert Program. Additional interventions focusing on increasing executive function skills are a particularly important area to consider, especially because they can enhance everyday function and overall quality of life. Also, considering guidance of the field of developmental psychopathology, to really make a difference in the cascade of developmental effects, intervention should be as intensive as possible in the early years. This makes more intensive multicomponent treatments, such as GoFAR, and treatments such as Tools of the Mind, which immerse a child fully in a preschool curriculum focused on self-regulation, more attractive intervention options. While these may be more costly in short term, they may ultimately prove more worthwhile in long term. It may also be vital to start self-regulation treatment even earlier, using relationship-based and multicomponent early interventions in the first years of life (as presented in Tables 13.1 and 13.2). These can help very young children with more basic levels of physiological, attentional, and emotional regulation, literally laying a better neurological foundation for attaining success in achieving developmentally more advanced levels of self-regulation (i.e., behavioral and executive regulation) [49]. It is also likely that child skill-building treatments in this area should sometimes be coupled with carefully individualized medication treatment, as suggested by Kodituwakku, to enhance treatment effectiveness [31].

As discussed earlier, those living with FASD or PAE often experience psychosocial risk factors, such as maltreatment or other adverse childhood experiences. Child-focused skill-building interventions aimed to improve problems in self-regulation, social skills, and behavior may be responding to symptoms that have emerged not only because of PAE—but because of these risk factors. Interventions in this area are likely to be especially important and respond to the essential element of FASD-informed care to "offer treatment that is trauma-informed."

Of course, to fully provide FASD-informed care in child skill-building interventions, further thought is needed about context and culture, especially when the target domains are social skills and social communication. For instance, there are thought-provoking questions as to whether "neurotypical" social skills are what should be taught to individuals who are neurodiverse (such as those with FASD). Also, social skills and social communication differ widely from culture to culture, so what is taught in treatment must also differ. Treatment goals, and even the fact of whether treatment is needed, should be led by the community and the input of self-advocacy.

Child and Adolescent-Focused Skill-Building Interventions: Toward Varied Other Outcomes

Table 13.9a–d presents skill-building child and adolescent-focused interventions aimed toward remediating additional areas of deficit identified in descriptive neurobehavioral research with the clinical population of those at high-risk because of PAE, or those living with FASD. These are aimed at youth from preschool through adolescence (3–16 years). Some are computerized and one is built on a virtual reality platform. Included are metacognitive interventions (such as attention and memory training), treatments designed to improve academic achievement, one adaptive function intervention (safety skills training), and sensory-focused and physical activity interventions. Also included are very new, innovative multicomponent interventions, such as the combination of transcranial direct-current stimulation and cognitive training. Of course, more research remains to be done.

These skill-building treatments are targeted toward children and youth in the preschool through early high school years (about 3–16 years). Treatments are proliferating because there are many domains in which this clinical population shows individual-level impairments, and this is a good age range for remediation. Several of these interventions have been studied in randomized control trials. Most thoroughly investigated (in the US) has been the Math Interactive Learning Experience (MILE) program. MILE is actually a multicomponent intervention, focused on developing math skills while accommodating and remediating underlying problems with neurocognition. In the primary trial of MILE, children aged 3–10 years received individualized 1:1 math tutoring using a metacognitive approach, while caregivers were trained on how to support their child's math learning and behavior regulation at home. This has been successfully replicated (in Canada) using child tutoring only, extended to include children with PAE only (rather than only those with FASD), and offered in natural settings like school or home, with a broader study design [115].

This set of treatments fits with some essential elements of FASD-informed care. Most centrally, all offer developmentally appropriate care, reframe and accommodate (take a neurodevelopmental viewpoint), and target individual-level impairments. Some find, build, and use strengths. What is now needed is to further incorporate a strengths-based view in design and deployment of these treatments. For instance, the typically high social motivation and desire for the attention seen among individuals with FASD (a clear strength) might be used to enhance learning, such as ensuring that treatments include adult assistance (and, importantly, mobilize the individual's attention as a reward). This was done, for example, in the MILE program. It is also vital to gather lived experience data to ensure that treatment goals are informed by the actual context in which children and adolescents with PAE or FASD function, and whether what is being worked on in treatment will help them during actual school participation and meaningfully raise their QOL. For instance, it is possible that children in the MILE treatment saw the value of getting better at math (and doing better at school). But they may not always have understood the value of outcomes targeted in some other interventions, and how that would make their daily life better. Also, like treatments listed in Tables 13.7a–c and 13.8, if there are hypothesized neurological changes resulting from the interventions in Tables 13.9a–d and 13.10, neurobiological outcomes should be assessed. This is clearly possible for attention and memory, academic achievement, or physical activity interventions, especially if these treatments are delivered sufficiently early in life—and would also be possible for sleep interventions, if they were tested.

Also important will be to adapt, or develop, interventions for these varied outcomes that fit different cultures, led by the community and self-advocates in creating culture-centered practices. This is a vital theme for every treatment section in this chapter.

There is an important point to make about adaptive function interventions, since Table 13.9c lists only one treatment study that has apparently done in this area. This is very surprising, since adaptive function is a broad domain and impairment in this area is very common among those living with FASD and affected by PAE. In truth, there are many, many treatments relevant to adaptive function. Why? First, adaptive function impairment is a fundamental criterion of the current proposed DSM-5 definition of "neurobehavioral disorder associated with prenatal alcohol exposure" (ND-PAE). In the diagnosis of ND-PAE, briefly put, adaptive function difficulties can occur as evidence of significant impairment in two or more domains, including: communication (past or present); social skills or social communication; daily living skills; or motor skills (past or present) [83]. This means that social skills and social communication treatments listed in Tables 13.7 and 13.8 are also relevant to adaptive function. Second, so are physical activity interventions in Tables 13.9d and 13.10. Third, treatments that impact behavior problems (which, in turn, lower adaptive function), listed in Tables 13.4c, 13.5, 13.6 and 13.7a–c, 13.8, are also relevant to the area of adaptive function.

Note that no "in-process" treatments of child-focused skill-building interventions aimed toward varied other outcomes were identified for this chapter, so there is no table that presents these in this chapter. However, this literature survey could not be fully comprehensive, so it is possible that some research underway was missed.

As listed in Table 13.10, there are several interventions with a developing evidence base the authors believe might be useful for future research with the population of those with PAE or FASD, and there are certainly many more than are mentioned here. Metacognitive interventions have already received considerable investigation and should continue to do so. Drawn from literatures on ADHD and neurodevelopmental disorders, the authors have identified the most important intervention domains for future research as: (1) sleep; (2) physical activity; and (3) adaptive function. Given clear evidence of sleep difficulties among individuals with PAE and its profound impact on the parent–child relationship and family QOL [116, 117], two sleep-related treatments are recommended (one for preschoolers and one for children in the school years). Because of the known efficacy of physical activity for improving attention and executive function, one physical activity intervention is suggested, simply as an example. The note at the top of Table 13.10 provides additional evidence from the broader literature on physical activity intervention to guide further research in this area. Finally, an interesting method for guiding individuals to independently discover strategies for how to perform daily living tasks, and improve adaptive function, is recommended as a promising research direction to pursue.

Interventions for Adolescence, Transition-Aged Youth, and Adulthood

Table 13.11a, b lists published treatments tested with adolescent, transition-aged youth (TAY; age 15–26 years) and/or adults with PAE or FASD. This area of study is only just emerging, with remarkable research gaps and opportunities. For this broad age range, holistic management or community interventions has also been tested, as listed in Table 13.4. Other tested treatments listed in Table 13.11a, b aim to build self-regulation, coping or other skills or to prevent secondary impacts and mental health conditions, or build knowledge and skills to reduce specific adverse conditions (such as alcohol misuse). Treatments listed in Table 13.11a, b conform to most of the essential elements of FASD-informed care, but considerable work needs to be done to improve the quality and range of treatments. Importantly, in these life phases, needs are highly individualized and person-centered planning is needed. At these later stages of life, it is important to also adhere to the essential element of FASD-informed care and "build collaborative partnerships" to create support.

Some interventions studied so far have been described as aimed at mitigating or reducing harm [45]. This is reasonable as, by this age, a surprising number of individuals with PAE or FASD may be experiencing a range of secondary impacts, such as difficulties in independent living, a disheartening fact documented first in 1996 and shown again in 2020 [14, 118]. Among those with typical development, the life stages of adolescence and TAY are vulnerable times for the onset of psychopathology, and this is also true for those living with FASD. For adolescents with FASD, there is generally increased risky behavior (including suicide) [119], and adults show increased rates of mental health difficulties [120]. Recent survey data has documented a wide range of concerning negative health outcomes for transition-aged youth and adults with FASD [51]. While health consequences associated with PAE in adult humans are not known, animal research suggests that humans may be more vulnerable to chronic diseases such as hypertension, diabetes, immune dysfunction, and cancer [121, 122].

But portraying these later developmental stages for those living with FASD only as a set of adverse life experiences is an incomplete, misleading and even detrimental picture. Only recently have lived experience data, and the efforts of self-advocates begun to document the many strengths and protective factors among older individuals living with FASD, and their families. For example, recent evidence emphasizes the intrinsic strengths of those with FASD, including older transition-aged youth and adults, such as strong self-awareness, receptiveness to support, capacity for human connection, perseverance through challenges, and hope for the future [66].

During adolescence and the time of transition-aged youth (TAY), relationships with caregivers and other adults are in flux. Adolescents/TAY are in search of an independent identity and more intimate interpersonal and romantic relationships. For these life stages, interventions must more fully take context into account, and squarely aim toward improvement in a sense of agency, self-determination, and QOL as outcomes. Finding, building, and using strengths in treatment are necessary and should be further emphasized. For instance, one intervention approach could be to teach the skills of self-advocacy, and teach awareness of the FASD diagnosis and one's individual profile of skill deficits and (especially) strengths. Interventions aimed at the phases of adolescence/TAY must involve a broader social context than the family, and so might include mentoring by a trusted adult, peer-to-peer interventions, and/or new ways for parents to be involved in assisting treatment. Interventions might also train caregivers on skills of "autonomy supportive parenting" [123, 124]. These life phases also require increased mental health support that is concrete, experiential, and adapted to the developmental level of the individual. Further, influences now pivotal in typical development at this time in cultural history, such as social media, mobile health apps, and online information, can be leveraged to provide FASD intervention in these later life phases.

These intervention ideas are also applicable to young adulthood, including the notion of "autonomy supportive parenting"—but as it applies to navigating young adult life tasks for someone whose functional level may not be the same as their chronological age. It is important to note that recent life experiences data have shown different rates of certain secondary impacts for adults living with FASD vs adolescents or youth [14]. This means that, in young and perhaps middle adulthood, there are different or additional intervention needs. Therefore, treatment must support outcomes relevant to young adulthood, such as successful independent living, effective management of health conditions, post-secondary education, employment, and creation of adaptive life partnerships. Focusing on these outcomes, developmentally appropriate to adulthood, supports the basic human right of self-determination, promotes agency, allows life participation (rather than just access), and ultimately raises adult QOL.

Table 13.12 lists several interventions with research underway. One feasible web-based mindfulness intervention with promising efficacy, the Aware Program, apparently improved indicators of self-regulation and executive function for adolescents and youth with FASD. Two other projects underway are an adaptation of the Alert Program for adolescents, and an interesting adult-directed FASD intervention now in development. The latter project is a mobile health app, called My Health Coach. True to the essential element of FASD-informed care to "be led by the community to create culture-centered practices," this app is being designed with concrete input from self-advocates who themselves are living with FASD. This app is designed to help young adults with FASD act as their own self-managers to achieve their own customized health and life goals.

As listed in Tables 13.13 and 13.14, there are many "promising" interventions with a developing or solid evidence base the authors believe might be useful to try with adolescents, TAY or adults living with FASD. In Table 13.13, highly selected intervention domains include (1) adolescent autonomy development paired with autonomy supportive parenting; (2) sleep; and (3) trauma/affect regulation. Offering developmentally appropriate treatment for the stages of adolescence and TAY centers around helping parents assist their offspring to attain the pivotal outcomes of autonomy and psychological well-being, which appear to be important across cultures as they are important to self-determination. Promising interventions applicable across this wide age range (and across cultures) have also been chosen given clear evidence of sleep difficulties among those living with FASD, and the frequent co-occurrence of trauma in this clinical population.

Beyond these promising treatment directions, the authors also note that many older individuals living with FASD are served in the mental health system for co-occurring mental health conditions, and sometimes contend with serious issues such as suicide. In these systems, providers will typically use well-known evidence-based practices, such as functional family therapy or dialectical behavior therapy. As shown in Table 13.14, a fruitful area of future research will be to examine, with samples of individuals living with FASD, whether these evidence-based practices show the expected treatment effects. If not, it will be important to determine what treatment adaptations are needed, or whether other mental health practices are more effective.

Of course, to fully provide FASD-informed care for older individuals living with FASD, and those who care for them, especially careful thought is needed about context and culture. For instance, a cultural framework is mandatory in consideration of diagnosis and treatment of mental health concerns. Cultural roles, values, and resources shape the roles and life paths of adolescents, transition-aged youth and adults, whether they are of a typical or atypical course. Treatment goals, and even the fact of whether treatment is needed, should be led by the community and the input of self-advocacy.

Critical and Systematic Reviews: A Brief Summary of Scientific Critique of FASD Intervention Research

As intervention data have accumulated in the field of FASD, critical and systematic reviews of research evidence have periodically been published. Such reviews help to shape, stimulate, and improve the field. Early reviews noted the small amount of intervention research and commented about limitations of the evidence as a whole, or suggested improvements for early research on behavioral and family support interventions. Later reviews reported encouragement by the slowly increasing breadth of evidence and examined treatment research from different angles. The very brief summary provided here will give an overview of these reviews [8, 45, 71, 110, 125–129]. Also included are a few key implications drawn from this information by the authors. (This summary does not include reviews of medication or basic science interventions.)

One consistent and repeated theme in critical and systematic reviews has been the gaps in research aimed at treatment for those with PAE or FASD in infancy/toddlerhood, and in adolescence and beyond. But now, as evident from Tables 13.1 and 13.2, and 13.11 and 13.12, these research gaps are slowly being remedied. Reviewers have also noted that many intervention studies have focused on samples drawn from clinic settings. In addition, reviewers have pointed out that epidemiological studies to establish prevalence in the general population, and in settings without many services (such as rural or remote areas, or areas without diagnostic clinics), are lacking, so the full scope and pattern of the problem of FASD are not known. All this means that treatment findings so far might not apply to the full range of individuals with FASD—such as those with milder central nervous system impairment or those not connected to services. It is certain that there are individuals with milder effects. It is quite likely that those not connected to services have different needs than those with access to community resources. An implication is that treatment may ultimately have to be set up as a "tiered" [34] or "stepped" system of care, from less intensive through more intensive care, with a wide range of resources, that can then serve everyone within communities.

Over time, reviewers have rated the quality of intervention research in several ways, finding multiple strengths in study design and outcome measurement. But clear methodological weaknesses have also been noted, even though there has been slow improvement in study methodology as the field has matured. Limitations have included small sample sizes, and design flaws such as the potential for selection bias and issues raised by lack of blinding of examiners and families, poor description of randomization, and limited choice of treatment targets and outcome measures. Reviewers have noted a restricted focus on immediate posttreatment outcomes (with less attention to examining sustained effects), and lack of attention to factors that moderate treatment outcome—or to factors that promote or maintain gains. To refine interventions, reviewers have suggested examining mechanisms of change, identifying active treatment ingredients, and examining the impact of modifiable parameters (such as treatment length) that affect feasibility and cost. They have also suggested looking at treatment "responders" and "non-responders," and trying to understand the reasons for why some respond and some do not. Further, reviewers have recommended exploring whether effects generalize to other settings or other outcomes, and building a more robust evidence base for treatments aimed at this clinical population by carrying out programmatic research. Reviewers have also recommended carrying out translational research to examine whether treatments work in the community.

Thinking About a Transdiagnostic Approach

Because alcohol is a teratogen, it has wide-ranging and individually variable effects. Despite years of high-quality research, a neurobehavioral "phenotype" (characteristic pattern that typifies a disorder) has not been fully described, though progress has been made. Some have questioned whether FASD is a discernable disorder separable from other conditions (e.g., [130]). At present, it is still considered a "proposed condition in need of study" (under the term "neurobehavioral disorder associated with PAE," or "ND-PAE") in the current DSM-5 manual of mental health conditions [83]. All this means it is difficult to "see" the central characteristics of FASD. It also means this clinical population has symptoms that overlap with others (such as those whom ADHD researchers categorize as having "complex ADHD").

Discussion of these issues is ongoing, important, and complicated.

All this raises several challenging questions for treatment. First, is treatment specialized for this population necessary or practical? Also, many times, PAE is not known because providers do not ask, stigma prevents birth parents from revealing PAE, or a child is adopted or in foster care and there is no way to know. So, there is a second puzzling question: is the application of specialized treatment even possible much of the time, since PAE is often unknown?

Because children and families need to be served, clinicians have moved forward, quite often, without answers to these two questions. Instead, clinicians have taken a "transdiagnostic" approach, or have applied other diagnoses and treated those instead. Essentially, clinicians have applied treatments for youth from other clinical populations who share symptoms with those seen in the clinical population. "Transdiagnostic" means that the same treatment logic and procedures can be applied beyond a particular diagnosis. This may have been done because PAE was unknown, or FASD was unrecognized—or, perhaps, PAE was known, but FASD could not be reliably diagnosed. This has allowed clinical work to go forward, but clinicians have not been able to take advantage of the developing evidence on FASD treatment.

The authors of this chapter have taken the stance that evidence-based treatment for individuals living with FASD, and their families, is important, practical and necessary. But even from this perspective, thinking about a transdiagnostic approach can still be very helpful. Several useful research ideas are discussed here.

Reflecting on a transdiagnostic approach suggests important research directions. Of course, research on FASD diagnostic systems is needed to reliably and validly discern the condition. But in the area of treatment research, a major need is to test existing evidence-based treatments (EBTs) for youth with similar symptoms, and their families, with those living with PAE or FASD. Clinicians are using these treatments, so it is important to see if they work or not. It does seem likely that these treatments need adaptation to become part of the complement of useful FASD interventions. Such testing has already been done with interventions such as the Alert Program, which was designed for youth with various diagnoses that include symptoms of self-regulation impairment. The Alert Program has needed adaptation, as have many of the existing EBTs tested so far.

Interestingly, the flip side of thinking of a transdiagnostic approach is the possibility that some innovative, specialized treatments specifically developed for those with FASD or PAE may be useful for youth from other clinical populations who share the symptoms that are the focus of those treatments. In other words, it is possible that some treatments developed for FASD may be able to be applied in a broader, "transdiagnostic" manner. One possible example is the Families Moving Forward (FMF) Program, which is composed of a number of "modules" which can be customized for families. The FMF Program was specifically developed for those with FASD or PAE and challenging behavior. But this program may actually be very appropriate for certain overlapping, complex, and very diverse clinical subpopulations of individuals with neurodevelopmental differences from other or multiple causes coupled with problematic behavior. These might include those diagnosed with complex ADHD arising from a variety of causes, or those with *suspected* PAE and documented prenatal polydrug exposure. One future research direction is that the FMF Program, though specially developed for those with PAE, could be tested for efficacy with these groups and might be found to have broader applicability.

Discussion

Progress on intervention for those living with FASD and PAE, and those who care for them, is at a tipping point. Interest in effective treatment has never been higher. Recognition of FASD is still a major stumbling block. But there are a growing number of providers and policymakers, and especially families, who know about the condition of FASD—and are concerned about the risks presented by alcohol's teratogenic effects from the prenatal period on.

As shown in Fig. 13.1, the essential elements of FASD-informed care related to treatment have been defined, based on solid theoretical foundations. It is validating that other researchers have named some similar principles for children with polysubstance exposure [111] and for women with FASD and their families [35, 111]. Especially validating is discussion of the guiding concept of "thriving" in the field of FASD. Researchers Petrenko and Kautz-Turnbull propose ways to move science forward to promote thriving when living with FASD, using what they term the "*From Surviving to Thriving*" model. This model illustrates a proposed paradigm shift from deficit-based to strengths-based research and intervention in order to recognize strengths and improve quality of life for people with FASD [131]. The elements of FASD-informed care outlined in the current chapter fit well with their model—and align well with the powerful concept of "thriving" with FASD.

As laid out in this chapter's tables, there is a small but expanding body of treatment literature specifically tested with samples with PAE or FASD, which matches up well with the essential elements of FASD-informed care. But there are many gaps in the complement of treatments that are available. We do need to create an adequate set of effective interventions across the lifespan, and we need to build evidence to define a solid standard of best practices. To help families, we also need to move rapidly to implement these evidence-based practices with fidelity in a sustainable manner in community settings. It is fortunate that very recent calls for grant applications have begun to solicit treatment studies in the field of FASD.

But what is really required in the field is a strategic plan for progress on FASD intervention with funding to support this plan. The field faces a set of tasks. Each task presents a set of dilemmas (some quite complex), which must be solved. This Discussion section lays out many of those tasks and their underlying dilemmas and proposes solutions framed as action steps.

Enhance FASD Recognition

Dilemma: In most countries, FASD is not well-recognized. The public, providers of all types, and most service systems still lack sufficient awareness of FASD. Providers fail to screen because they do not ask about PAE, or do not ask in an adequate manner. That means they do not refer for diagnosis. All may be halted by stigma. Treatment that is FASD-informed cannot even be delivered. If FASD is not recognized, families, agencies, and service systems (and funders) do not see the full scope of the public health problem, and community uptake of treatments is minimal, even when treatments have been shown to be efficacious. What does this mean for a strategic plan for progress on intervention for those living with FASD, and those who care for them?

Solutions: Community education about the effects of PAE and FASD must continue. Professional education about screening must increase, including how to sensitively ask about PAE (and, importantly, the need to systematically document PAE data to make it available). This is needed across many systems (obstetrics, primary health care of all types, mental health, child welfare, education, justice, and more). In addition, funders and treatment researchers must divert some of their energies toward effective stigma reduction. Guidance exists on how to proceed. Recently, stigma about FASD and alcohol use during pregnancy have been described as pervasive and multilayered [99, 100]. Ideas for effective programs for stigma reduction have been identified and should be tested (e.g., [103]). As an essential element of FASD-informed care, the effort to "overcome stigma" must be woven into family support and education treatments, relationship-based interventions, all types of parenting interventions—in fact, into all treatments for this clinical population.

Provide Basic "Evidence-Informed" Care

Dilemma: Despite the fact that many efficacious treatments have been developed for individuals and families (see Tables 13.1, 13.2, 13.4, 13.5, 13.7, 13.9, 13.11, and 13.12), there is still limited community availability of these treatments. Treatment is simply not very accessible. Few providers have been trained across disciplines, and most geographic locations do not have adequate services. Systems of FASD-informed care are under development, but do not exist in most countries. Funding for appropriate treatment is limited or unavailable. Evidence-based best practices *are not fully known, as there are major gaps in what is known about treatment. What should be done?*

Solutions: At the very least, providers and systems could follow the consensus advice of experts that is already available. If *"evidence-based"* care is not yet fully available, providers and systems could at least provide *"evidence-informed"* care appropriate for FASD. How can this be done?

Scientifically accurate, clinically useful provider education about PAE and FASD could be required across multiple disciplines. PAE screening programs that refer for diagnosis could be initiated or, if they exist, enhanced. At a minimum, providers and systems could adopt a neurodevelopmental viewpoint to modify their usual practices. This means incorporating the essential elements of "reframe and accommodate" into treatment as usual, which helps providers (and their clients) see problems differently and act accordingly. This should be combined with the essential element of "offering relationship-based and trauma-informed care," given the high frequency of adverse childhood experiences among those with PAE or living with FASD.

Some resources for training providers on evidence-informed care in FASD are already available. Developed through expert consensus, the Treatment Improvement Protocol #58 on Addressing FASD (TIP #58), created by SAMHSA in the US, provides clinically relevant, evidence-informed guidance on FASD-informed care, at least for mental health and substance abuse treatment settings [36]. Evidence-informed care can also be raised to a higher level of sophistication through the use of formal training curricula for providers. One effective method for this is through models of learning and guided practice, such as the ECHO model. This type of provider education increases workforce capacity to provide evidence-informed (or even evidence-based) care and is now beginning in the field of FASD treatment [132].

Evidence-informed care can also be made accessible to families by offering it directly to the public. As research has taught more about intervention for those living with FASD, there have been many evidence-informed educational efforts. Some are very high quality. These have not necessarily been evaluated, but often have anecdotal evidence or final reports that document their usefulness. For example, Triumph Today, an evidence-informed parenting education program, is now in a video-based format offered freely online via YouTube through the Ohio Guidestone website [133]. As another example, the US Centers for Disease Control and Prevention offers training and education opportunities (i.e., videos, podcasts, links to training), materials, and multimedia (i.e., infographics, fact sheets, brochures, posters) [134].

Offer Person-Centered Planning

Dilemma: As a teratogen, prenatal alcohol exposure has wide-ranging and individually variable effects. A neurobehavioral "phenotype" (characteristic pattern that typifies a disorder) has not been fully described. What methods can be *used to efficiently offer intervention for those living with FASD, without disparities, to this widely variable clinical population? At least in certain cultures?*

Solutions: Person-centered planning is recommended, as it is in the field of intellectual and developmental disabilities (IDD)—and efficient methods are needed to carry out person-centered planning and make sure it is the standard of care in the field of FASD. Person-centered planning is thought to apply across the lifespan, from the early years through the end of life, and is integral to the very definition of FASD-informed care.

Person-centered planning fits with all theoretical models discussed earlier and is often the story told in the lived experiences data from the field of FASD. Person-centered planning is a method that fits well with the essential elements of FASD-informed care presented in this chapter. FASD researcher Rutman, writing about programs for women with FASD, makes "person-centered accommodations" one of her core principles of FASD-informed care for adults [35]. In this chapter, person-centered planning is seen as an approach in which the person is placed at the center of the services, and individualized services (including accommodations) are developed collaboratively and in partnership between professionals, families, and the individual living with FASD. The focus is on the person and what they can do, not on their condition or disability. This fits with other essential elements of FASD-informed care, such as "thinking about context," and "being strengths-based." It also fits with emphasizing self-determination and self-advocacy. This person-centered planning process would likely differ a great deal by culture.

Explore Existing Evidence-Based Treatments

Dilemma: Practically speaking, providers are using unmodified, existing evidence-based treatments (EBTs) all the time to respond to symptoms among those with PAE or FASD. This is because PAE is often unknown (or no one has asked), FASD is unrecognized, or providers know about FASD but are not yet offering FASD-informed care. With good reason, clinicians often ask: Why can't I just use the interventions I already have available to me?

Solutions: The fundamental assumption that EBTs do not work for this clinical population needs critical examination using controlled research. This can be done through intervention studies that include groups with FASD or PAE and appropriate comparison groups. This can also be done through secondary data analysis of interventions for youth with similar symptoms (such as ADHD), if treatment researchers in those fields adequately assess PAE.

It is essential to know if existing interventions work with the clinical population of those with PAE or FASD. This is especially true in mental health settings, where a range of EBTs are employed. Flannigan and her colleagues have written that commonly used mental health treatments, such as cognitive behavioral therapy (CBT), or therapies for especially serious symptoms [such as functional family therapy (FFT), dialectical behavior therapy (DBT), or multisystemic therapy (MST)], really need research because they are so broadly applied to those living with FASD [45]. There is also need to further explore the efficacy of the "third wave" mental health treatments that are increasingly in use, such as mindfulness-based approaches or strategies such as acceptance and commitment therapy (ACT).

Understand What Treatment Adaptations Are Needed for Existing EBTs (and Should Be Built into Novel Treatments)

Dilemma: Over the years, clinical wisdom and caregiver report has led to the fundamental assumption that existing EBTs do not work well for those with PAE or FASD. This has led to the further idea that EBTs must be adapted. At times, this assumption has motivated development of interesting novel treatments to add to the complement of existing EBTs. The assumptions that existing EBTs do not work as efficiently or effectively for those living with FASD or PAE (or do not work at all) are convincing, but so far only based on lived experience. What should be done?

Solutions: Research on the efficacy of existing, non-adapted EBTs with groups living with FASD or PAE is needed, as there is no real source of data to confirm the hypothesis that non-adapted EBTs do not work. But continued systematic research is also needed on what adaptations are needed for existing EBTs, and on the efficacy of novel treatments. This is because adapted and novel treatments may sometimes be needed, because assumptions drawn from lived experience could well be true for some types of intervention (and for different cultural contexts).

For example, family support or positive parenting programs for those living with FASD do basically look different from those in other fields. They necessarily include new types of parent support, as they sometimes require creation of innovative community resources and often involve specialized, thorough education and assistance on advocacy. This is because societal service systems have not yet been built for FASD, eligibility criteria often exclude those with FASD, and stigma must be overcome. As another example, given that FASD is a global health problem, family support programs look very different when developed for English-speaking Western populations living in mixed urban/suburban/rural locations vs. multilingual Indigenous communities living in remote locations.

In addition, this assumption could be true in some cases because individuals with FASD or PAE may travel a range of developmental pathways to problem outcomes that look similar to those of other children (but really aren't). These pathways may be quite complicated given alcohol's wide-ranging, individually variable effects. For example, taking a neurodevelopmental viewpoint, some individuals in this clinical population may show conduct problems because of *impulsivity* arising from PAE, while others show conduct disorders due to *delays in emotional understanding* related to their clinical condition [135]. That would mean some individuals with FASD truly might not respond to "usual" treatments—but not so much due to the simple fact that individuals have the diagnosis of FASD. Instead, the reasons may be much harder to figure out. Why? Because individuals within this group are following variable, diverse developmental pathways influenced by different innate characteristics (that only partly come from the impact of PAE on the brain). In neuroscience, this is termed the “heterogeneity problem” [136]. The usual treatments do not always work because, from individual to individual, the symptoms occur for different reasons than expected, or because PAE results in variable symptoms, and so these individuals require different treatments.

A few researchers have provided practical guidance for how to adapt treatments using a neurodevelopmental viewpoint (how to “reframe and accommodate”). For example, FASD researchers Olson and Montague [19], in a useful resource, offer examples of suggested adaptations for EBTs that can be generally applied, which are described and added to here. First, *services should be offered over a longer period of time,* perhaps with more sessions and/or repetition as needed. Second, *slower intervention progress should be expected*, given the need for considerable review and practice, and caregiver assistance to help children consolidate learning. Third, for individuals with PAE or FASD, *sensory sensitivities and behavior regulation problems should be accommodated in treatment,* which can be done in many ways. Fourth, *treatment procedures and goals should be adapted to the functional level and different cognitive-behavioral profiles of the treated individuals, including strengths.* (For example, use visual prompts if visual processing is a strength, limit verbal input if verbal processing is a challenge, and rely on experiential methods such as roleplay or real-world practice. Also try to focus on improved adaptive behavior in every intervention.) Finally, no matter what the intervention, *individual and caregiver emotional support should be built in.* This is important so everyone can tolerate slow progress, deal with high stress and personal distress, and improve their sense of competence.

Build the Evidence-Base and Address Treatment Gaps (Which Points to Future Research Directions)

<u>Dilemma</u>: There is a developing evidence base of controlled research, as laid out in the tables in this chapter. Clinicians should learn about this evidence base, and use it when they can. But systematic and critical reviewers have noted many gaps in the treatment research. Simply put, research has not yet produced an adequate complement of interventions for those living with FASD or PAE, and their families, and there is certainly not a complete set of evidence-based best practices. What are fruitful future research directions?

<u>Solutions</u>:

<u>Intervention for different developmental phases</u>: Given its importance from so many theoretical perspectives, early intervention with samples with clearly diagnosed FASD or adequately assessed PAE has not received enough attention, and should be an area of intense research interest, with larger samples. Recently,

researchers found that a wide range of early interventions were generally effective in reducing ADHD symptoms and enhancing working memory, a promising finding [137]. Enhancing services that can be integrated into existing early intervention settings are of special interest, because they are cost-effective and can reach larger numbers of children. For the preschool years, there are also multiple skill-building interventions that take advantage of neuronal plasticity and sensitive periods in development that have been (or could be) tested to move the field forward.

Clearly, treatments for transition-aged youth and older individuals living with FASD are sorely needed. Beyond this, however, geriatric care for those living with FASD must become a focus. It is now being revealed that this population may face more (and perhaps earlier) significant bodily health conditions as they age [121], and recent data show they continue to contend with challenging mental health issues [120]. In Tables 13.1, 13.2, 13.3, 13.4, 13.5, 13.6, 13.7, 13.8, 13.9, 13.10, 13.11, 13.12, 13.13, and 13.14, and earlier in this chapter, the authors have discussed what might fill treatment gaps at different developmental phases.

Remediation of individual-level impairment: For individuals with PAE or FASD, important research directions continue to emphasize intensively enhancing self-regulation and executive function skills across the age range. Examples of promising treatments and ideas are given in Table 13.8. For instance, a series of meta-analyses suggested that promising interventions for non-typically developing populations included the categories of strategy learning (such as the Alert Program or a curriculum called "Unstuck and On Target") and biofeedback-enhanced relaxation training [138]. Remediation of sleep deficits appears vital, and physical activity interventions appear important at least as an adjunct treatment. These physiological interventions can have multiple benefits. Academic interventions are discussed elsewhere in this book. As can be seen in the tables, authors of the current chapter could find no "in process" intervention studies for outcomes for a wide variety of child-focused skills. While this could simply be that these studies are underway and not yet published, it seems vital to expand research to remediate individual-level impairment so treatments are available for person-centered planning.

One especially interesting intervention, presented as a promising direction in Table 13.10, is the Cognitive Orientation to Occupation Performance (CO-OP). This is a task-specific, cognitively-based, problem-solving intervention that guides individuals to independently discover and develop cognitive strategies to perform specific everyday tasks of living. While this may require adaptation for different levels of intellectual function, and careful strategy learning approaches, the CO-OP approach could potentially be used as a treatment to increase adaptive function for specific outcomes that are meaningful for a youth living with FASD or PAE.

Multicomponent interventions: Another important research direction is toward use of multicomponent interventions bringing together treatments that, each on their own, are promising. Together, these can leverage even more positive outcomes—and the "whole may be greater than a sum of the parts." However, multicomponent interventions often become more complicated, less feasible and flexible, and more costly. Sometimes a multicomponent intervention means combining parent-directed and child-directed treatment. But it can also mean bringing together different types of treatments—such as combining direct consultation to parents with consultation with community providers, or applying several types of treatment to the child, youth, or adult. It can even mean providing a preschool curriculum (such as Tools of the Mind), modular treatments (such as STAND), or a longer term, multilayered treatment, such as Treatment Foster Care Oregon (TFCO, which has many components and versions for preschoolers, children, and adolescents; see Tables 13.13 and 13.14), which can be very complicated but effective. Multicomponent interventions have been tested with efficacy in the field of FASD, such as the MILE program or Families on Track, yielding sustained treatment effects or a broader range of impact on child outcomes. Multicomponent treatments may be especially important for lasting neurobiological change, for more complex problems (such as serious trauma, foster care, or delinquency), and for older individuals living with FASD.

Also bringing together multiple components is the innovative idea of integrating child-directed neurobiological and metacognitive strategies. A prime example is new, feasible FASD intervention research combining transcranial direct-current stimulation and working memory training (see Table 13.9). Applying this integration technique to other metacognitive strategies, especially those thought to have more generalizable effects across neurocognitive domains (such as attention training), may be an intriguing direction to explore.

Tiers of care: FASD researcher Olson [34] has proposed the idea of three "treatment tiers" as a solution, which can be helpful in identifying what treatments are most needed to fill gaps in the continuum of care, and what could be a major focus of the effort to create best practices [34]. The notion is that the complement of FASD interventions can be organized into types and levels of treatment on a practical basis. The *first tier* involves a range of preventive interventions, preventing or reducing early harm from PAE, even though some of these interventions may involve more cost. Examples include brief intervention to reduce or stop alcohol use (and therefore prenatal impact) among pregnant persons showing social or binge drinking during a current pregnancy, intensive early intervention, or lower-cost enhancements offered to very young children with PAE involved in existing early intervention services. The *second tier* includes less resource-intensive interventions useful when alcohol-related problems have already made themselves known, but are less functionally impairing. For example, these might be group interventions for particular symptoms, such as controlled social skills training or self-regulation training for groups of children. As other examples, these might include a 1–2 session therapeutic feedback with a transition-aged youth or adult with FASD to offer them self-awareness of their own cognitive-behavioral profile, self-administered app-based interventions, web-based parent education, or networks of natural parent support. The *third tier* includes more resource-intensive interventions for individual or family problems that are more functionally impairing. For example, these might be group or individualized positive parenting interventions, individualized school-based child tutoring to improve math and meta-cognition, or intensive case management support for women who themselves have FASD or who show serious chemical dependency and associated psychosocial risks.

Outcome measurement at the level of neurobiology: When appropriate, FASD intervention research should examine brain–behavior relationships, going beyond outcome measurement through interview, questionnaires, or observations of change in behavior. The central concern about alcohol is that it is a neurobehavioral teratogen and, ingested during pregnancy, can damage central nervous system (CNS) development. More than this, PAE is often associated with serious psychosocial risks (such as trauma) which can also negatively impact CNS development and function. For treatments that may improve underlying neurobiology, it seems vital to examine the impact of treatment on CNS structure and function through neuroimaging methods and neurochemistry. If a treatment can improve underlying neurobiology, it is even more possible that developmental trajectories made atypical by PAE and associated risk factors can be normalized.

Potential experimental treatments derived from basic research: Although not a topic for this chapter, it is worth mentioning promising treatment directions arising as potential experimental treatments derived from basic research. Categories include blocking alcohol's teratogenic effects, enhancing neuroprotective factors, and providing nutritional supplementation. An earlier, seminal overview of these ideas by Idrus and Thomas is available to readers [23]. There are many intriguing updates of these ideas, with the focus still primarily on basic research. For example, a recent paper discusses possibilities derived from research in animal models examining the impact of antioxidant treatments on adverse outcomes of PAE resulting from the presumed mechanism of oxidative stress [139]. But it is research on choline, a nutritional supplement first identified as promising in animal models and then in careful human study, that has really moved forward as an FASD intervention. Choline has been identified as a substance that may be effective in reducing the impact of PAE when administered during pregnancy, which may possibly even be effective during some periods of postnatal development. One set of studies on choline by FASD researcher Wozniak and his team tells an interesting story. An initial, randomized, double-blind placebo-controlled pilot study of choline vs. placebo was carried out with children with FASD, finding choline safe and well tolerated. Additional studies were carried out, with mixed findings on choline effectiveness. Then participants from the first two trials were examined at a 4-year follow-up. When this sample of 31 children with FASD were seen at an average of 8.6 years of age, there were group differences. Compared to 16 children who had received a placebo, the 15 who had been given choline as young children had better scores across a number of domains. These included nonverbal intelligence, visual-spatial skills, working memory, and verbal memory ability, and they showed fewer behavioral symptoms of ADHD [140, 141].

Psychopharmacology is also not a topic for this chapter. However, given Kodituwakku's guideline regarding the need for appropriate pharmacologic intervention to accompany the behavioral treatments [31] discussed in this chapter, one point is important here. Psychopharmacology is an area strikingly in need of systematic treatment research. There are two recent systematic reviews of medication use in FASD [84, 85] that reveal how much research needs to be done, with a strong recommendation for doing clinical trials. At present, there exist no empirically based guidelines for treatment of children in this clinical population. There is only a recent treatment algorithm, based on expert opinion, designed to treat the complex symptoms of this clinical population. But this algorithm needs validation. The stated aims of this algorithm are to reduce polypharmacy and result in functional improvements. But the authors acknowledge multiple limitations presented by the absence of specific experiments that inform diagnostic symptom clusters, and the lack of clinical trials that support the efficacy of selected medications [86].

Create Scalable Treatments

Dilemma: *Prevalence data show that FASD is a remarkably common problem, and, as the process of FASD identification accelerates, that means a great many families to serve. Treatments tested so far have been efficacious. But they have not been especially scalable or cost-effective. Some require labor-intensive home visiting, and some have multiple components hard to offer in real-world settings because of the need for lengthy training or materials that are hard to use. Many have been studied outside natural community environments. Further, interventions for those with PAE or FASD actually developed in "grass roots" clinical service settings have rarely been fully evaluated. What should be done?*

Solutions: Treatment looks different in the transformed digital age. Some individual and family-level treatments can readily be translated to a less expensive, more flexible telehealth delivery modality, as has been done for the FMF Program. Some existing tested treatments are suitable for (or designed for) online delivery, or for mobile health (mHealth) application formats, or are being developed (see Tables 13.5 and 13.9). Online and mHealth app treatments can be self-administered or supported by text-based coaching or phone- or video-based clinician assistance.

For increased efficiency, interventions can be offered in natural environments where individuals already gather, such as schools (e.g., MILE [115], Alert Program [142, 143]), early intervention settings (FMF Bridges [95, 96]), or prisons (see Table 13.11). Online networks are also efficient and potentially very cost-effective interventions that are also strengths-based. These have been used in the community but not necessarily evaluated, yet could be examined in well-designed studies. Ideas include birth mother support networks or transition-aged youth/young adult self-advocacy social media networks.

Treatments developed in actual clinical service settings should be evaluated. This is important so their efficacy can be fully documented, with data to show whether or not they are effective. Finally, "active ingredients," or components of treatments that are found to work well, should be identified, treatments streamlined, and then these more efficient treatments scaled up.

Build a Robust Evidence Base and Set of Best Practices Through Research and Use of Implementation Science

Dilemma: Beyond just developing an adequate complement of interventions, it is also necessary to build a robust evidence base for the most promising treatments. It is then necessary to define a set of best practices. How can this be done?

Solutions: The solution here requires programmatic research. To do this, independent research groups validate a treatment's efficacy used with fidelity (delivered according to actual treatment model). Studies are also conducted to show that a treatment is effective when actually used in the community, in what is called translational research. This programmatic research generates the evidence that, if sufficient, can allow a practice to be deemed an "evidence-based treatment" or EBT. In the US and in some countries, there are "evidence-based registries" that rate treatments according to the quality and amount of evidence available, such as the California Evidence-Based Clearinghouse [144]. Funding that allows treatments to be delivered to youth and families, such as insurance or Medicaid funding in the US, is increasingly dependent upon how robust is the evidence base for a treatment. It is difficult to build this evidence base, especially for novel or innovative treatments (even when they are needed for a population with new characteristics). This is because treatment research is lengthy, labor-intensive, and (therefore) costly. But with a good evidence base, "best practices" emerge. Ultimately, according to systematic and critical reviewers, best practices (and concomitant policy change to encourage use of best practices) are what is really needed to make intervention for those living with FASD and PAE a reality.

In building treatments, studies need to aim for a scientific understanding of how and why, and for whom and when, problems arise and treatments work. In fact, the conceptual models used to define the essential elements of FASD-informed care emphasize that it is vital to understand the underlying logic model and theory of change of each intervention. With that understanding, treatments can be streamlined down to their active ingredients so the least amount of resources can be used when they are moved into the community. The solution here is also programmatic research.

It is also vital to ensure that treatments are moved out into the community—and, once used in real-world settings, are used as intended. Implementation science offers solutions. This is the scientific study of methods and strategies that help the uptake of evidence-based practice and research into regular use by providers and policy makers. The field of implementation science tries to close the gap between what we know and what we do by finding and addressing the barriers that slow or stop the uptake of proven evidence-based interventions [145]. This usually involves the input of all key stakeholders in an important process of collaboration. In the field of FASD, it is imperative to systematically examine how best to disseminate, implement, and sustain treatments with fidelity, so they are actually delivered as designed, over time—and thus most likely to yield expected outcomes in community settings. Among other important questions, examining a treatment using implementation science techniques means studying barriers to and facilitators of treatment at all different levels—or using special research designs that more quickly provide information on real-world effectiveness than do the usual study-after-study approaches to programmatic treatment research. The typical time for “bench-to-bedside” intervention research is 20 years. For the field of FASD, this needs to speed up.

Of course, there are also cultural considerations given the fact that FASD is a global health problem, discussed in the next section. Cultural considerations make it even more of a challenge to speed up the intervention research process.

Be Led by the Community to Create Culture-Centered Practices

Dilemma: The 12 essential elements of FASD-informed care may have a relatively “universal” definition that applies across societies and cultures. But, to be effective, specific treatments developed, tested, and implemented must either fit well with the culture and context in which they are deployed—or be appropriately adapted. How can culture-centered practices be created in a process that involves being led by the community?

Solutions: Interventions not only need to be developed, tested, disseminated, and implemented. But they also must adapted (or created anew) for different cultural contexts, and then disseminated and implemented in these diverse contexts. As FASD researchers Petrenko and Alto have written, each cultural context presents unique elements—and barriers to the implementation process. These researchers note that it is crucial to keep building the complement of published interventions, and to publish all results (even those that are nonsignificant) as well as writing up less rigorously designed community trials. This allows those developing interventions for FASD to be aware of all intervention options. They raise the need for research on cultural barriers to addressing FASD, from awareness to treatment. Further, they advocate for partnerships that extend across countries, and sharing of expertise and experience as widely as possible across local, national, and international levels [110]. Fortunately, international research collaborations do exist, such as that of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD), funded in the US by the NIAAA, but these have only recently moved to a strategic focus on treatment [146].

But how can culture-centered practices be created in a process that involves being led by the community? This is an essential element of FASD-informed care. It is important to conduct community-engaged research, which involves collaborative inquiry with a diversity of stakeholders. This aligns research and service goals with community priorities. Community members should be involved as leaders and co-creators of culturally relevant FASD-informed care and treatment. When needed, developing treatment that is culture-centered means gathering lived experience information that can be used to adapt treatments or even create novel interventions. This is a deeply important, complex process that takes time, sensitivity, and respect for the culture and the people. Here, the process is best illustrated in examples.

One team of Australian researchers collected information from caregivers in individual interviews, and another from community members and providers through a workshop. Information-gathering was via an Australian First Nations conversational process of "yarning," or telling and sharing stories and information, which is both a process and an exchange. In one study, by talking directly with caregivers, researchers learned more about cultural patterns in responses to diagnostic processes for neurodevelopmental impairments and FASD among both Aboriginal and non-Aboriginal caregivers. This could allow needed cultural and contextual adaptation of the diagnostic process [147, 148], which would take time and many additional steps.

Also from Australia is an example of strong community leadership and community-research partnership in creating culture-centered practices: the Marulu Strategy. This was an overall community response developed to respond to FASD and early life stress in a set of almost solely Indigenous remote communities in Western Australia [109]. FASD (and early life stress) prevalence studies in this area had been requested by and conducted alongside, and in collaboration with, those living in the communities. Community leaders had further requested that these prevalence studies be strategically followed, in community partnership, by intervention efforts (and studies) to respond to problems identified by prevalence efforts and to follow the children over time. True to the Marulu Strategy, treatment steps were taken after the prevalence studies were completed. The steps taken were to adapt existing evidence-based interventions to the cultural context, which is a truly challenging process. Among these efforts was the school-based adaptation of the evidence-based Alert Program in these remote Aboriginal Australian communities (e.g., [142, 143]). Another effort was a modification of the Triple P parent training program, which was simultaneously adapted both for FASD and for use in these Aboriginal Australia remote communities to become Jandu Yani U ("For All Families") [107]. The Marulu Strategy has been implemented over a number of years.

Build a Successful Continuum of FASD-Informed Care

Dilemma: *There is usually no organized continuum of care for those living with FASD, and their families. When useful services do exist, a major critique has been lack of coordination and continuity of services from one developmental phase to another across the lifespan, without methods for clear transitions* (e.g., [58, 61]). *For example, researcher Pruner and her colleagues, who gathered lived experiences data from caregivers of children with PAE aged birth to 3 in the US, found that parents did not feel adequately prepared for systems transitions, such as into the school system* [61]. *Successfully making transitions is also a problem when individuals with FASD are older and expected to be independent and coordinate across multiple types of systems, as there are simply few (or no) methods set up to support change and transition for those who cannot navigate without support. Beyond this,* *supporting transitions is a particular problem for youth with FASD in complex systems, such as foster care. What are solutions to building a successful continuum of care?*

<u>Solutions</u>: Providers need help in building a successful continuum of care for those living with FASD, and their families. Earlier sections of this chapter have discussed what programs have been tested, how research can be done to fill treatment gaps, how to organize treatment into tiers so families can be referred in an organized manner, how to create evidence-informed and evidence-based care, and how to be led by the community to create culture-centered practices.

But families need help in using the care systems that are built. Across different societies, individuals with FASD and their families need organized procedures that route them from one system to another. They need help with transitions. This is important when individuals living with FASD move from one developmental phase to another, when families move to a new geographic location, when eligibility criteria change, and more.

So far, there have been different efforts to solve the problem of building a continuum of FASD-informed care and moving through transitions. At the "grass roots" level, some holistic FASD case management-type interventions, such as the key worker program or Coaching Families program, have been built to solve this problem. Using person-centered planning, these programs place a major focus on helping families establish linkages and navigate systems, to build individual care systems and improve system coordination. This fits well with the essential element of FASD-informed care of "building collaborative partnerships." These programs have been in place in a few Canadian provinces for several decades with good success.

Some agencies, communities, and state systems are trying to build organized care networks for FASD at higher administrative levels in different types of systems. For example, one US state public health system is attempting to strategically build an FASD system of care focused on mental health in a multi-year process. This is a statewide effort, based in community mental health agencies, to provide: (1) mental health provider education on FASD; (2) screening for youth at risk because of PAE who also have behavioral and/or developmental issues; and (3) treatment for youth at risk with either evidence-informed or evidence-based mental health services that are both FASD-informed and trauma-informed (i.e., the Michigan State Department of Public Health FASD State Initiative [149]). Ideally, formal program evaluation would be conducted for any of these efforts to see if outcome change takes place. Governments are also working on transformational policy to create FASD-informed care, such as a strategic policy effort in South Africa [150].

FASD researcher Pei and colleagues have written that the societal response to FASD, at least in Canada, is moving toward a more integrated model. This includes a cohesive process of: (1) early screening, referral, and support for pregnant and postpartum persons; (2) early identification; (3) inclusion of neurological impairment and secondary social and environmental dysfunction with diagnostic criteria; and (4) multilevel and multisystem care and support throughout the lifespan for individuals living with FASD [151]. This Canadian response is a model solution for other countries.

Conclusions

FASD is a global public health problem. Despite progress in community education and prevention efforts, drinking during pregnancy still occurs nearly everywhere. This means every society must face the challenges raised by FASD. Bringing FASD-informed care to communities using culture-centered practices is imperative around the world and will need country-specific health care policy to support it. A vital part of FASD-informed care is to have an adequate complement of treatments that are effective in real-world settings, that can serve to create "best practices." The challenge before us all is to strategically and swiftly move forward in a planful way, and create, test, disseminate, and implement treatments in the real world that raise health, well-being, and quality of life for the courageous individuals living with FASD and PAE, and those who care for them.

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The authors note that Dr. Carmichael Olson is a developer of the Families Moving Forward (FMF) Program, and participant in derivative works. Drs. Pruner and Jirikowic are developers of the in-process FMF Bridges intervention. This could influence discussion of these interventions as they are used as examples. However, the authors have made every effort to be objective in their review throughout this chapter.

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Heather Carmichael Olson, Ph.D. is a Clinical Professor at the University of Washington School of Medicine, and a faculty member at the Seattle Children's Research Institute and Hospital. As a clinical and developmental psychologist, for over 30 years she has explored the effects of prenatal substance exposure on child and family development in research, teaching, public policy, and direct service to children and families. She has dedicated her career to development, testing and implementation of effective interventions for youth at high risk because of prenatal alcohol exposure and fetal alcohol spectrum disorders (FASD), and the families who care for them.