American Journal on Intellectual and Developmental Disabilities The Strengths and Positive Influences of Children With Fetal Alcohol Spectrum Disorders --Manuscript Draft--

Manuscript Number:	AJIDD-D-20-00152R1				
Article Type:	Research Report				
Keywords:	fetal alcohol spectrum disorders; fetal alcohol syndrome; FASD; prenatal alcohol exposure; strengths				
Corresponding Author:	Carson Kautz-Turnbull University of Rochester Rochester, NY UNITED STATES				
First Author:	Carson Kautz-Turnbull				
Order of Authors:	Carson Kautz-Turnbull				
	Tangeria Adams, Ph.D.				
	Christie L.M. Petrenko, Ph.D.				
Manuscript Region of Origin:	UNITED STATES				
Abstract:	People with disabilities have not been adequately represented in strengths-based research. This study is the first to examine strengths and positive influences of young children with fetal alcohol spectrum disorder (FASD). Thirty adoptive and relative caregivers of children with FASD reported their children's strengths and positive influences and completed measures on family functioning. Using a conversion mixed design, we described themes in strengths and influences, degree of caregiver positivity and relationships with child and family functioning. Caregivers reported wide-ranging strengths and positive influences. Frequency of adaptive strengths correlated with measures of family functioning, but thematic strengths and positive influences did not. Strengths and positive influences are distinct from measures of functioning and are not well captured in deficit-focused research.				

Title: The Strengths and Positive Influences of Children With Fetal Alcohol Spectrum Disorders **Abstract:** People with disabilities have not been adequately represented in strengths-based research. This study is the first to examine strengths and positive influences of young children with fetal alcohol spectrum disorder (FASD). Thirty adoptive and relative caregivers of children with FASD reported their children's strengths and positive influences and completed measures on family functioning. Using a conversion mixed design, we described themes in strengths and influences, degree of caregiver positivity and relationships with child and family functioning. Caregivers reported wide-ranging strengths and positive influences. Frequency of adaptive strengths correlated with measures of family functioning, but thematic strengths and positive influences did not. Strengths and positive influences are distinct from measures of functioning and are not well captured in deficit-focused research.

Keywords: fetal alcohol spectrum disorders; fetal alcohol syndrome; FASD; prenatal alcohol exposure; strengths

Introduction

Fetal alcohol spectrum disorders (FASD) are estimated to affect 2-5% of children in the United States (May et al., 2018). FASD is an overarching term that describes diverse patterns of neurodevelopmental and physical differences associated with prenatal alcohol exposure (PAE). Although the deficits often seen in FASD are relatively well understood (Mattson, Bernes, & Doyle, 2019), limited research has been conducted on strengths in this population, and what has been conducted is almost exclusively case studies of older adolescents or adults. Psychology research has shifted towards the idea of a positive or strengths-based approach in recent years (Niemiec, Shogren, & Wehmeyer, 2017), but people with disabilities have largely been excluded from this movement (Shogren, 2013). Deficit-focused research offers insight into only one aspect of an individual; models of disability must take into account an individual's personal competencies and quality of life, including strengths and positive experiences (Buntinx & Schalock, 2010). Strengths-based research is essential to guide effective accommodations and supports for individuals with FASD to allow them to thrive in accordance with their personal goals and values.

The limited strengths-based research in FASD has highlighted strengths in social relationships and prosocial behaviors, specific talents and passions, and resilience (Brown, Rodger, George, St Arnault, & Sintzel, 2008; Burles, Holtslander, Bocking, & Brenna, 2018). Perhaps the most common reported strength in individuals with FASD is in social relationships and prosocial behaviors (Currie, Hoy, Legge, Temple, & Tahir, 2016; Knorr & McIntyre, 2016). Research also documents a theme of individual talents and passions, including tactile strengths, artistic ability, and athleticism (Burles et al., 2018; Currie et al., 2016; Sanders & Buck, 2010). Individuals with FASD show significant resilience and abilities to adapt (Knorr & McIntyre,

2016), especially important given the high rate of individuals with FASD who have experienced some sort of trauma or maltreatment (Price, Cook, Norgate, & Mukherjee, 2017).

It is important to consider not only the individual strengths of people with FASD, but also how they positively influence others around them. Research on family influences of people with FASD have emphasized caregivers' experiences of stress and considerable barriers to services (Olson, Oti, Gelo, & Beck, 2009; Paley, O'Connor, Kogan, & Findlay, 2005; Watson, Coons, & Hayes, 2013); the positive influences of people with FASD on others have received little attention to date. Most studies investigating family experiences have been conducted with foster, adoptive, and relative caregivers, as a large percentage of children who receive an FASD diagnosis are placed in some form of out-of-home care during early childhood (Popova, Lange, Shield, Burd, & Rehm, 2019). Caregivers describe receiving joy and companionship from spending time with their children with FASD, and taking pride in their accomplishments (Brown et al., 2008; Mukherjee, Wray, Commers, Hollins, & Curfs, 2013). Children with FASD may also contribute to the family by way of relative strengths in domestic skills such as chores and helping around the house (Jirikowic, Kartin, & Olson, 2008).

The aims of the current study were to: (1) explore the strengths of young children with FASD and evaluate how adoptive and relative caregivers perceive their children to positively influence their family, and (2) to understand how caregivers' perceptions of strengths were related to other aspects of child and family functioning. We hypothesized that caregivers would report a wide range of strengths and ways in which their children positively influence the family. We also hypothesized that these strengths and positive influences would be distinct from caregiver stress and satisfaction, and child emotion regulation and behavior.

Methods

Study Design

This study utilized a concurrent mixed methods approach and content analysis to characterize adoptive and relative caregivers' perceptions of the strengths and positive influences of young children with FASD. This approach was selected for the purpose of initiation, or developing new perspectives and rethinking results (Greene, Caracelli, & Graham, 1989) as our intent was to analyze a novel construct in FASD. We selected a qualitative component to elicit a wide range of answers and avoid excluding novel responses that would be theoretically informative in this emerging area of research. We incorporated a quantitative component to understand not only caregivers' perception of their children but also to contextualize our results in the broader family system. The current study used a conversion mixed design (Schoonenboom & Johnson, 2017) in which qualitative data were considered the core component and the quantitative results were considered a supplemental component (QUAL+quan; Morse & Niehaus, 2009).

Caregivers were interviewed about their child's strengths and positive influences using a semi-structured interview as part of a baseline assessment for participation in an intervention trial. A quantitative 14-item measure of adaptive strengths was embedded in the interview to supplement qualitative data. The interview was conducted without children present by one of two female bachelor's level research assistants who had received training in FASD and qualitative interviewing and analysis. Caregivers had some telephone contact with the interviewers prior to the study visit but did not have an existing relationship with them. Interviews took place face-to-face in a testing room in an academic setting and lasted 20-30 minutes on average (as part of a larger 2-2.5hr assessment session). Information is reported consistent with the consolidated criteria for reporting qualitative research (COREQ; Tong, Sainsbury, & Craig, 2007). The

University Institutional Review Board reviewed and approved all study procedures and informed consent was obtained from all participants.

Our analysis incorporated an analytical point of integration (Morse & Niehaus, 2009) in which the qualitative results were first analyzed, then quantitized in order to examine their correlational relationships with other study measures. Interview data were first analyzed and described qualitatively. Codes derived from the data were also examined quantitatively. We selected standardized measures of child emotion regulation and problem behavior to delineate the degree to which caregiver perception of child strengths and positive influence was related to child behavior and emotion regulation. Similarly, we examined caregiver report of their own satisfaction with parenting and parenting-related stress to understand how this related to caregiver perception of the child. Selection of these measures allowed us to test our hypothesis that caregiver perception of strengths and positive influence would be distinct from child functioning or caregiver experiences.

Participants

Participants in the study were 30 caregivers of children with FASD or prenatal alcohol exposure (PAE). All participants were adoptive, foster, or relative caregivers. Participants were originally recruited as part of a small-scale pilot randomized controlled trial of a multi-component intervention trial [redacted for anonymized review]. Study information was shared with local providers and agencies serving children with FASD and within family support groups and conferences. Interested families then contacted the research team. At the time of screening, families reported they were primarily referred by local clinicians. To be included in analyses for the current study, participants had to have a child with a diagnosis of an FASD or confirmed PAE between the ages of 4 and 8. Diagnosis was determined or confirmed as part of the study

protocol, using case conference methods integrating neuropsychological test data, dysmorphology measurements, and record review. Further participant characteristics can be found in Table 1.

Insert Table 1 about here.

Table 1. Participant demographics.

Measures

Strengths and Positive Influence Interview: This interview was developed by Heather Carmichael Olson and colleagues at Seattle Children's Research Institute as part of a novel parenting intervention for FASD (Olson et al., 2009). First, caregivers were asked: "Tell me about three of your child's strengths". Then, they were read 14 items assessing adaptive behavior strengths, such as "seeks help from caregiver when needed," "will help do household chores when asked," and "participates in family activities." For each of these items, caregivers were asked to rate how true the statements were for their child on a three-point Likert scale, with 0 "No,", 1 "Yes, somewhat," and 2 "Yes, very." Ratings were summed for a total score. Internal consistency for these 14 items was good, $\alpha = .82$. Finally, caregivers were asked: "Tell me how [child's name] is a positive influence on the family."

Eyberg Child Behavior Inventory (ECBI): The ECBI (Eyberg & Pincus, 1999) is a rating scale measuring conduct problems in children ages 2 through 16. The ECBI consists of 36 items that are each rated on a 7-point Intensity scale to indicate the frequency of the behavior, as well as a Yes-No Problem scale to indicate whether or not the behavior is problematic for the caregiver. Scores are presented as T-scores (M=50, SD=10), with higher scores indicating higher frequency behavior problems. Internal consistency has been reported to be as high as .98 for both

subscales (Robinson, Eyberg, & Ross, 1980). Internal consistency in the current sample was high, with $\alpha = .94$ for both subscales.

Parenting Sense of Competence (PSOC): The PSOC (Johnston & Mash, 1989) is a 16-item self-report measure of the parent's sense of parenting efficacy and satisfaction. The items in the PSOC are answered on a 6-point scale ranging from "strongly disagree" to "strongly agree". The scale assesses two factors: Satisfaction, or extent to which the individual enjoys the parenting role and parenting frustration and anxiety; and Efficacy, or perceived competence, problem solving ability, and capability. Higher scores indicate higher feelings of satisfaction or efficacy. The measure has demonstrated adequate internal consistency scores for both the Efficacy (α =.76) and Satisfaction (α =.75) scales as well as adequate validity (Johnston & Mash, 1989). In the current sample internal consistency was adequate to high, with α = .80 for Satisfaction and α = .72 for Efficacy.

Parenting Stress Index, fourth edition, short form (PSI-4-SF): The PSI-4-SF (Abidin, 2012) is a 36-item, abbreviated inventory evaluating the magnitude of stress in the parent-child system. The PSI-4-SF is made up of three domains, including Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI), and Difficult Child (DC). Responses are given on a 5-point Likert scale ranging from Strongly Disagree to Strongly Agree. Scores are presented as T-scores (M=50, SD=10), with higher scores reflecting greater levels of stress. The PSI-4-SF has demonstrated adequate internal consistency for all three scales (PD α =.90; PCDI α =.89; DC α =.88) and validity (Abidin, 2012). In the current sample internal consistency was high (PD α =.88; PCDI α =.90; DC α =.91).

Emotion Regulation Checklist (ERC): The ERC (Shields & Cicchetti, 1997) is a 24-item caregiver report scale measuring child emotion regulation. It is made up of two subscales:

Lability/Negativity and Emotion Regulation. Items are rated on a 4-point scale ranging from "never" to "always". Internal consistency has been estimated to be high, with alphas at .83 to .96 for the subscales (Shields & Cicchetti, 1997). Internal consistency in the current sample was adequate, a = .90 for Lability/Negativity and a = .79 for Emotion Regulation.

Qualitative Analysis

Participant interviews were transcribed verbatim. Two independent coders (second and third authors) reviewed and assigned initial codes to the data. They reviewed initial coding, utilized code mapping strategies to categorize and refine coding schemes, and engaged in discussion and further review of the data to arrive at consensus (Saldaña, 2015). In addition to codes categorizing types of strengths and positive influences, coders developed magnitude codes to capture the degree of caregiver positivity when speaking about strengths and positive influences (Saldaña, 2015). The magnitude of positivity was influenced by any negative or qualifying statements, degree of hesitation or difficulty in response, and amount of elaboration on responses.

Following completion of the codebook, one of the original coders (second author) and a third new coder (first author) independently coded the data. Inter-rater reliability was adequate to good, with agreement above 80% for all categories, with two exceptions. These were the emotional contribution category and the positivity of influence scale, which had agreements of 71.4% and 67.9%, respectively. Average agreement was 85.2%. Codes were compared and, in the case of discrepant codes, coders came to consensus.

Quantitative Analysis

Data were entered into SPSS and manually rechecked. The primary goal of the current study was to examine caregiver report of child strengths and positive influence and its

relationship with measures of caregiver experience and child functioning. Therefore, analyses were descriptive in nature. Qualitative results were quantitized in order to examine relationships with measures of child and family functioning. Thematic categories of strengths and positive influence codes were coded 0 or 1 based on whether the caregiver reported at least once during the interview. Caregiver responses to the 14 adaptive behavior strengths were summed with 0 indicating "No", 1 indicating "Yes, somewhat", and 2 indicating "Yes, very". Correlational analyses were conducted to examine the associations between the strengths and positive influence variables and measures of caregiver stress, efficacy, and satisfaction and child problem behavior and emotion regulation. Given that these data originate from a small pilot RCT, post-hoc power analyses indicated that correlational analyses were only powered to detect medium to large sized effects. These results are thus considered exploratory, but given the dearth of research on strengths in this population are useful to guide future research.

Results

Qualitative Analysis

Strengths. Strengths fell into four thematic categories: social motivation, positive effort/persistence, individual aptitude/skills, and positive mood state/personality characteristics. Almost all caregivers reported at least one child strength in **social motivation** (n=29, 96.7%). Caregivers described their children as loving, affectionate, helpful, generous, and funny. One noted that "he's very engaging and people generally like him and he can make friends very easily. But the best is his laugh." Other children were described as "loving", "kind-hearted", and "caring". Responses falling into the **positive effort/persistence** (n=6, 20.0%) category referenced challenges faced by the children and how they overcame them. For example, one caregiver said, "Just to think of what he's gone through and how hard it must be for him not to

be able to do certain things, he doesn't have that quitting...he'll try, you know? And I just have a lot of respect for that." Caregivers also mentioned resiliency and adaptability. **Individual aptitudes and skills** (n=12, 40.0%) were also mentioned, with caregivers describing talents in athleticism, creativity and arts, and intelligence. Some connected these strengths to their child's deficits; for example, one stated "we think he's bright, he doesn't test well but there's more in there than...what he can show us". Finally, caregivers described strengths in **positive mood states and personality characteristics** (n=11, 36.7%), calling their children happy, curious, eager, and having a "love for life". Several caregivers described others noticing their child's positivity, with one stating, "joy just flows out of her. Other people notice it...complete strangers notice it."

Caregiver positivity about the child's strengths was coded on a scale from 1-6 and had a mean of 4.21 and a standard deviation of 1.11. See Table 2 for examples and frequencies of each level

Insert Table 2 about here.

Table 2. Coding levels for caregiver positivity of child's strengths.

Positive Influence. Caregiver report of the child's positive influence on the family fell into five categories: four thematic categories including tangible contribution, parental growth, social/family togetherness, emotional contribution, and one category for a repeat of strengths without connection to the broader family. For the first theme, caregivers noted that children tangibly contributed to the family (n=9, 32.1%) by doing chores or helping with household tasks. Some noted specific chores such as setting the table or feeding pets, with one saying their child would "clean up when we ask him to, set the table and he'll help make breakfast, and he'll

help with dinner...feed the dog." Others described the child as generally helpful and willing to lend a hand whenever it was needed.

Caregivers also reported **parental and personal growth** (n=8, 28.6%) brought about by the child. Some reported that the child introduced them to new experiences that helped the caregiver grow as a person. One caregiver noted, "she's showing me what the world is like for an extrovert. So entertaining." Several felt that watching their child persist and succeed despite challenges inspired them, with one stating "I go to bed at night and what all she had to do during the day and saw that she could do that then I should be able to handle anything." Also included in this code was mention of increased parenting skill, such as "he's taught us to how to...think outside the box in ways of discipline and in ways of just trying to redirect the behaviors."

Children were described as bringing about **social and/or family togetherness** (n=17, 60.7%). Caregivers noted increased time spent together, a sense of unity as a family, and described a sense of belonging and completeness brought about by the addition of the child to the family. One participant summed this up by saying "You know, we often say ... no matter how physically that child comes to you, that child is your child. And we talk about that and we watch some things that he does...like 'Oh yes, he is *so* our kid.'" Another caregiver described their child as "pretty much the daughter that we always wanted." Finally, caregivers reported that children **emotionally contributed to the family** (n=21, 75.0%), by loving or showing affection toward the family and by bringing joy or happiness into the home. One caregiver described their child as "a joy. In spite of all the problems;" Another described how their child can make them laugh, saying "he used to have...he used to have different walks. Like he'd do a little old man walk. Oh—hysterical! He can make me giggle".

Caregiver positivity about the child's influence on the family was coded on a scale from 1 to 7 and had a mean of 4.43 and a standard deviation of 1.5. See Table 3 for examples and frequencies of each level.

Insert Table 3 about here.

Table 3. Coding levels for caregiver positivity of positive influence.

The sum totals of caregiver responses to the 14 adaptive behavior strengths had a mean of 17.47, a standard deviation of 4.65, and ranged from 9 to 28. By far the most endorsed item was "takes pride in being able to do some activities independently", with nearly the entire sample (29 caregivers, 96.7%) selecting "Yes, very". The item "participates in family activities" also had a high rate of endorsement, with 25 caregivers, or 83.3%, selecting "Yes, very". The least endorsed items were "makes changes and transitions satisfactorily" and "accepts consequences for undesirable behavior", with 11 caregivers (36.7%) selecting "No" for each item.

Mean scores for the ECBI, ERC, PSI, and PSOC are presented in Table 4; further characterization of the sample has been published elsewhere [redacted for anonymized review]. *Correlational Analysis*.

Significance criterion was set at .01 to be conservative given the exploratory nature of all correlational analyses. First, correlations were examined among variables quantitized from the thematic analysis of strengths and positive influence. No significant correlations at p<.01 were identified (rs ranging from -.23 to .45).

Next, Pearson correlation coefficients were computed for the measures of caregiver positivity of both strengths and positive influence, the sum total of the 14 adaptive strength items, and the child and family functioning measures (see Table 4). Correlations between the adaptive strengths and child and caregiver functioning were generally in the medium to large

range. The strengths and positive influence positivity scales were not significantly related to any of the child and caregiver functioning variables.

Insert Table 4 about here.

Table 4. Means, standard deviations, and correlational results. ERC = Emotion Regulation Checklist; ECBI = Eyberg Child Behavior Inventory; PSI = Parenting Stress Index; PSOC = Parenting Sense of Competence; *=p<.01, **=p<.001

Discussion

The literature on FASD almost exclusively focuses on the deficits and challenges associated with this condition. This provides a single-sided view that contributes to stigma. Strengths-based research is essential to provide a more holistic view of people with FASD and guide effective person-centered planning in line with individuals' goals and values. This is the first known study to characterize the strengths and positive influences of young children with FASD. It also demonstrated that the strengths of children with FASD identified by their caregivers are not adequately captured in common research or clinical assessments.

In the current study, strengths fell into four thematic categories: social motivation, positive effort/persistence, individual aptitude/skills, and positive mood state/personality characteristics. Caregivers' descriptions of their children's positive influence emphasized tangible contributions, parental growth, social and/or family togetherness, and emotional contributions. The current results, especially caregivers' report of social motivation and tangible and emotional contributions, are consistent with those found in the small literature detailing the strengths in social relationships, helpfulness, generosity, and affection of adolescents and adults with FASD (Currie et al., 2016; Knorr & McIntyre, 2016).

These perceived strengths and positive influences may be protective for children with FASD as they get older. Individual talents and interests and lasting social relationships may be

especially important later in life (Gilligan, 2000; Knorr & McIntyre, 2016), and positive effort and persistence in young children may translate to resilience in adolescence and adulthood (Pei, Leung, Jampolsky, & Alsbury, 2016; Tait, Mela, Boothman, & Stoops, 2017. Similarly, positive mood states and personality characteristics in young childhood may provide an early basis for those seen in older individuals with FASD; they report a sense of hope and optimism despite facing challenges in their lives (Pei et al., 2016).

Children were also described as bringing a sense of completeness to the family. Parents of individuals with intellectual disability describe feeling that the child brought the family closer together (Grant, Ramcharan, McGrath, Nolan, & Keady, 1998), and the current study extends these results to those with FASD. Caregivers recounted how they have grown as a person and as a parent. Caregivers of children with FASD can experience reduced satisfaction and efficacy as a parent (Paley, O'Connor, Frankel, & Marquardt, 2006), making ways in which they feel they have grown and improved as a parent especially valuable. Typical parenting strategies may not be as effective in this population (Olson et al., 2009; Petrenko, Pandolfino, & Roddenbery, 2016) so it may be especially helpful for these parents to recognize how their parenting approaches have adapted to fit their child.

The current sample, largely made up of adoptive parents, was generally positive about their children in the semi-structured interview, in line with literature about adoptive parents of children with disabilities (Glidden et al., 2006). All caregivers could identify at least one strength for their child, and almost all felt the child positively impacted their lives. Although some caregivers qualified their child's positives, not all of these statements were negative or critical in nature. Statements like these could reflect an awareness of their child's limitations. However, some adoptive caregivers did include critical statements about their child, and some reported that

they were unable to think of a way in which the child positively influenced their family. These responses may relate in part to the significant barriers to services including education supports, child care, and financial resources faced by caregivers of children with FASD (Olson et al., 2009; Paley et al., 2006; Petrenko, Alto, Hart, Freeze, & Cole, 2019). These may also reflect frustration or grief associated with the child's difficulties, especially as many adoptive parents of children with FASD are unaware of the disability at adoption (Chasnoff, Wells, & King, 2015). Although sample sizes limit comparisons, relative and foster caregivers had similar levels of positivity about their children's strengths and positive influences as did adoptive parents.

Analytic integration of qualitative and quantitative analyses revealed that, in line with our hypotheses, caregiver report of and positivity about their child's strengths and positive influences was distinct from parenting satisfaction and stress, and child behavior and emotion regulation. This suggests that how caregivers think about their children's strengths and positives influences is not strongly associated with these measures of parent and child functioning. The qualitative aspect of the current study allowed caregivers to report what they felt was salient about their child's strengths, regardless of how frequently or consistently the child exhibited the strengths. Quantitative measures, especially those measuring ability or behavior, inherently compare an individual to some expected norm or level, thereby dismissing the importance of a strength or positive influence that may be infrequent yet meaningful to the family. Characterizing an individual's strengths or positives with one composite score captures their averaged or relative ability, but provides an overly simplified and often overly negative picture of the individual. In line with this, the caregiver report of adaptive behavior strengths was strongly related to measures of child problem behavior, child emotion regulation, and caregiver stress and

satisfaction. It is likely these items actually measured child ability and lost the more complete picture provided by the interview.

Strengths and Limitations

The current study offers an important contribution to a severely understudied area, building on prior literature by expanding description of the strengths of individuals with FASD to a much younger age range and larger, although still modest, sample. This study also identifies meaningful diversity in the types of strengths that children with FASD possess and the myriad ways in which they positively impact their loved ones.

Results of the current study should be interpreted in the context of a number of limitations. Birth parents were not represented in the current sample and results may not generalize to this important population. Greater outreach and relationship building is needed to engage and support biological parents in FASD research. Caregivers were predominantly women and Caucasian or white, and the majority of children were male. Participants were treatment-seeking and enrolled in a larger intervention study. They may differ from families who were not actively seeking treatment.

All data were caregiver-report. While this allows data collection regarding children of younger ages who may not be able to articulate their own strengths, it may be biased. Further, strengths and positive influences may differ in older age groups. The current study was cross-sectional, meaning we cannot draw conclusions about these strengths over time. Future research should use longitudinal designs to understand how caregiver perceptions change over time.

Implications and Conclusions

The lack of research on strengths and positive influences of children with FASD means that much of what is known about FASD is missing an integral piece. The results of the current

study imply that child strengths and positive influence are likely unique constructs that deficitfocused research and assessment fail to adequately characterize. It is imperative that research on
the functioning and abilities of individuals with FASD characterizes the whole person, not just
the deficits. A greater focus on strengths and positive influences may reduce the significant
stigma related to FASD and create a more balanced view of the disability. Future studies on
functioning in children with FASD should utilize an open-ended strengths and positive influence
interview; additionally, existing strengths measures should be expanded to capture a more
subjective caregiver experience.

While caregiver interview allows for a more comprehensive picture of their impression of the child's strengths, future research should also work to develop additional ways of assessing child strengths and positives. Older children may be able to self-report their strengths, much like adolescents in existing literature. For younger children or children with lower functioning, self-report measures could incorporate play or creative expression such as art. An observer could also be utilized to assess child strengths and positives, for example with a coding paradigm like those used for measures of parent-child interaction (Robinson & Eyberg, 1981) or attachment (Ainsworth & Bell, 1969).

Interventions for children with FASD should work to build on their already existing or emerging strengths. Perhaps most notably, children with FASD are highly socially motivated; therapeutic rapport and social connections may be especially important for treatment. Children with FASD should be encouraged to develop their unique passions and talents, and teachers, caregivers, and other professionals should encourage their positive attitudes toward the world around them. The positive influence these children have on their families should also be emphasized. Families of children with FASD face significant burden, yet, as shown by the

current study, garner important rewards from the presence of the child. Future research should also investigate the effect of an emphasis on personal strengths and positive impacts on the self-esteem and self-worth of individuals with FASD.

References

- Abidin, R. R. (2012). Parenting stress index, (PSI-4). Lutz, FL: Psychological Assessment Resources.
- Ainsworth, M. D., & Bell, S. M. (1969). Some contemporary patterns of mother-infant interaction in the feeding situation. *Stimulation in early infancy*, 133-170.
- Brown, J. D., Rodger, S., George, N., St Arnault, D., & Sintzel, J. (2008). Rewards of parenting a child with a fetal alcohol spectrum disorder. *The Open Family Studies Journal*, 1, 23-30
- Buntinx, W. H., & Schalock, R. L. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7(4), 283-294.
- Burles, M., Holtslander, L., Bocking, S., & Brenna, B. (2018). Strengths and Challenges: A Young Adult Pictures FASD Through Photovoice.
- Chasnoff, I. J., Wells, A. M., & King, L. (2015). Misdiagnosis and missed diagnoses in foster and adopted children with prenatal alcohol exposure. *Pediatrics*, *135*(2), 264-270.
- Currie, B. A., Hoy, J., Legge, L., Temple, V. K., & Tahir, M. (2016). Adults with Fetal Alcohol Spectrum Disorder: Factors associated with positive outcomes and contact with the criminal justice system. *Journal of Population Therapeutics and Clinical Pharmacology*, 23(1).
- Eyberg, S., & Pincus, D. (1999). Eyberg child behavior inventory (ECBI) & Sutter-Eyberg student behavior inventory-revised (SESBI-R). *Professional manual. Odessa*, FL: Psychological Assessment Resources.
- Gilligan, R. (2000). Adversity, resilience and young people: The protective value of positive school and spare time experiences. *Children & society*, 14(1), 37-47.
- Glidden, L. M., Billings, F. J., & Jobe, B. M. (2006). Personality, coping style and well-being of parents rearing children with developmental disabilities. *Journal of intellectual disability research*, *50*(12), 949-962.
- Grant, G., Ramcharan, P., McGrath, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of intellectual disability research*, 42(1), 58-71.
- Greene, J. C., Caracelli, V. J., & Graham, W. F. (1989). Toward a conceptual framework for mixed-method evaluation designs. *Educational evaluation and policy analysis*, 11(3), 255-274.
- Jirikowic, T., Kartin, D., & Olson, H. C. (2008). Children with fetal alcohol spectrum disorders: a descriptive profile of adaptive function. *Canadian Journal of Occupational Therapy*, 75(4), 238-248.
- Johnston, C., & Mash, E. J. (1989). A measure of parenting satisfaction and efficacy. *Journal of Clinical Child Psychology*, 18(2), 167-175.
- Knorr, L., & McIntyre, L. J. (2016). Resilience in the face of adversity: Stories from adults with fetal alcohol spectrum disorders. *Exceptionality Education International*, 26(1), 53-75.
- Mattson, S. N., Bernes, G. A., & Doyle, L. R. (2019). Fetal Alcohol Spectrum Disorders: A Review of the Neurobehavioral Deficits Associated With Prenatal Alcohol Exposure. *Alcohol Clin Exp Res.* doi:10.1111/acer.14040

- May, P. A., Chambers, C. D., Kalberg, W. O., Zellner, J., Feldman, H., Buckley, D., . . . Honerkamp-Smith, G. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. *Jama*, *319*(5), 474-482.
- Morse, J. M., & Niehaus, L. (2009). Principles and Procedures. Walnut Creek.
- Mukherjee, R., Wray, E., Commers, M., Hollins, S., & Curfs, L. (2013). The impact of raising a child with FASD upon carers: findings from a mixed methodology study in the UK. *Adoption & Fostering*, *37*(1), 43-56.
- Niemiec, R. M., Shogren, K. A., & Wehmeyer, M. L. (2017). Character strengths and intellectual and developmental disability: A strengths-based approach from positive psychology. *Education and Training in Autism and Developmental Disabilities*, 52(1), 13-25.
- Olson, H. C., Oti, R., Gelo, J., & Beck, S. (2009). "Family matters:" fetal alcohol spectrum disorders and the family. *Developmental Disabilities Research Reviews*, 15(3), 235-249.
- Paley, B., O'Connor, M. J., Frankel, F., & Marquardt, R. (2006). Predictors of stress in parents of children with fetal alcohol spectrum disorders. *Journal of Developmental & Behavioral Pediatrics*, 27(5), 396-404.
- Paley, B., O'Connor, M. J., Kogan, N., & Findlay, R. (2005). Prenatal alcohol exposure, child externalizing behavior, and maternal stress. *Parenting: Science and Practice*, *5*(1), 29-56.
- Pei, J., Leung, W. S. W., Jampolsky, F., & Alsbury, B. (2016). Experiences in the Canadian criminal justice system for individuals with Fetal Alcohol Spectrum Disorders: Double jeopardy? *Canadian Journal of Criminology and Criminal Justice*, 58(1), 56-86.
- Petrenko, C. L., Alto, M. E., Hart, A. R., Freeze, S. M., & Cole, L. L. (2019). "I'm Doing My Part, I Just Need Help From the Community": Intervention Implications of Foster and Adoptive Parents' Experiences Raising Children and Young Adults With FASD. *Journal of family nursing*, 1074840719847185.
- Petrenko, C. L., Pandolfino, M. E., & Roddenbery, R. (2016). The association between parental attributions of misbehavior and parenting practices in caregivers raising children with prenatal alcohol exposure: A mixed-methods study. *Research in developmental disabilities*, 59, 255-267.
- Popova, S., Lange, S., Shield, K., Burd, L., & Rehm, J. (2019). Prevalence of fetal alcohol spectrum disorder among special subpopulations: a systematic review and meta-analysis. *Addiction*, 114(7), 1150-1172.
- Price, A., Cook, P. A., Norgate, S., & Mukherjee, R. (2017). Prenatal alcohol exposure and traumatic childhood experiences: A systematic review. *Neuroscience & Biobehavioral Reviews*, 80, 89-98.
- Robinson, E. A., & Eyberg, S. M. (1981). The dyadic parent–child interaction coding system: Standardization and validation. *Journal of Consulting and Clinical Psychology*, 49(2), 245.
- Robinson, E. A., Eyberg, S. M., & Ross, A. W. (1980). The standardization of an inventory of child conduct problem behaviors. *Journal of Clinical Child & Adolescent Psychology*, 9(1), 22-28.
- Saldaña, J. (2015). The coding manual for qualitative researchers: Sage.
- Sanders, J. L., & Buck, G. (2010). A Long Journey: Biological and Non-Biological Parents' Experiences Raising Children With FASD. *Journal of Population Therapeutics and Clinical Pharmacology*, 17(2).
- Schoonenboom, J., & Johnson, R. B. (2017). How to construct a mixed methods research design. *KZfSS Kölner Zeitschrift für Soziologie und Sozialpsychologie*, 69(2), 107-131.

- Shields, A., & Cicchetti, D. (1997). Emotion regulation among school-age children: The development and validation of a new criterion Q-sort scale. *Developmental psychology*, 33(6), 906.
- Shogren, K. A. (2013). Positive psychology and disability: A historical analysis. *The Oxford handbook of positive psychology and disability*, 19-33.
- Tait, C. L., Mela, M., Boothman, G., & Stoops, M. A. (2017). The lived experience of paroled offenders with fetal alcohol spectrum disorder and comorbid psychiatric disorder. *Transcultural psychiatry*, *54*(1), 107-124.
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International journal for quality in health care*, 19(6), 349-357.
- Watson, S. L., Coons, K. D., & Hayes, S. A. (2013). Autism spectrum disorder and fetal alcohol spectrum disorder. Part I: A comparison of parenting stress. *Journal of Intellectual and Developmental Disability*, 38(2), 95-104.

Demographic Variable	Value
Caregiver Age Mean (SD)	46.98 (8.52)
Caregiver Biological Sex Frequency (%)	
Female	26 (86.7)
Caregiver Race/Ethnicity (non-exclusive categories) Frequency (%)	
Caucasian/White	28 (93.3)
African American/Black	1 (3.3)
Hispanic/Latino	1 (3.3)
Native American	2 (6.7)
Other	1 (3.3)
Caregiver Type Frequency (%)	
Relative of child	6 (20.0)
Adoptive parent	21 (70.0)
Foster parent	3 (10.0)
Caregiver Marital Status Frequency (%)	
Single, never married	2 (6.7)
Separated/divorced	5 (16.7)
Married or living with partner	22 (73.3)
Not reported	1 (3.3)
Caregiver Educational Attainment Frequency (%)	
High school diploma or less	4 (13.3)
Some college or Associate's degree	9 (30.0)
Bachelor's degree	8 (26.7)
Master's degree or higher	7 (23.3)
Not reported	2 (6.7)
Annual Family Income Frequency (%)	
Less than 35,000	2 (6.7)
35,000-49,999	3 (9.9)
50,000-74,999	8 (26.7)
75,000-99,999	9 (30.0)
More than 100,000	8 (26.7)
Child Age Mean (SD)	6.55 (1.27)
Child Biological Sex Frequency (%)	
Female	23 (76.7)
FAS/pFAS Diagnosis Frequency (%)	13 (43.3)

Table 1. Participant demographics.

Code	Description:	Example:	N (%) of
	Caregiver		sample
1	cannot report any strengths	N/A	0 (0.0)
2	identifies strengths but has difficulty doing so evidenced by verbalizations or hesitancy/long latency OR makes statements about the child's identified strength(s) that negate or diminish the positivity of the identified strength implies the child's choice in exhibiting the strength OR makes critical statements directly about the child	 "He can be a stink brat" "You think it's easy to think of and then now you[5 second pause] he's a very positive kid" 	3 (10.0)
3	makes a qualifying (but not critical) statement <u>about the child</u> that may prevent the strength from consistently being apparent OR qualifies the consistency in which the child demonstrates the strength	 "He's an easygoing kid for the most part" "When his behavior is good, he's fun to be around" 	4 (13.3)
4	provides qualifying situations or circumstances that prevent the child's strength from being consistently apparent. This qualification does not negate the child having that strength but serves to contextualize the strength based on limitations outside the child's control or cites external situations in which the strength is most apparent.	 "She wants to please adultsshe can't always do it in the moment but she really desires that, that approval" "He is a very loving child when he has the opportunity" 	8 (26.7)
5	identifies the child's strengths and does so without much elaboration or illustrative examples (e.g., the parent provides the strengths in a list-format or in 3 short sentences). No qualifying or critical statements are made.	"He is really funny, he loves to help, and he loves to learn."	13 (43.3)
6	only identifies the child's strengths and provides examples or elaboration on ways in which the child demonstrates the strength(s). The parent's tone is frequently proud, humorous/amused.	• "[She] is a very loving little girl. Very lovingit's almost like she has an inside radar and let's say that someone comes in and it's a very gentle person she will sense it right away and they will become—almost like an	2 (6.7)

	instant rapport. She's always amazing me at that."	
--	--	--

Table 2. Coding levels for caregiver positivity of child's strengths.

Code	Description	Example	N (%) of
	Caregiver		sample
1	reports being unable to describe any way in which the child is a positive influence, reports that the child is not a positive influence or provides multiple examples of the child being a negative influence.	"It sounds awful but I can't think of any"	2 (7.1)
2	only mentions child's strengths, no clear indication of how child's strengths relate to his or her positive influence on the family/others.	"He's just a good kidand everything he says is positive"	1 (3.6)
3	briefly (in short phrases or sentences without elaboration) provides positive statements indicating the child's positive influence on the family/others and provides qualifying or critical statements about the child. These negative statements typically serve to negate the child's contributions to the family. These statements serve to negatively characterize the child versus the behavior or the situation.	 "He's always trying to help somebody, when he's not having his moments" "Sometimes he can be a little tender heart and then other times he can be a little stinker" 	3 (10.7)
4	sentences without elaboration) provides positive statements indicating the child's influence on the family/others and provides qualifying statement about the situation(s) in which the child's positive influences may not be apparent. This qualification serves distinguish the situations in which the child's positive characteristics/influence may (or may not) be as apparent and does not negate the child's contributions to the family.	 "He's a loving child, he is. If he just get that attention, that stability, he really will come out his shell" "She and [sibling] feed off each other and escalatebut she's verygood with [other sibling]" 	7 (25.0)
5	briefly (in short phrases or sentences without elaboration) provides positive statements	"Oh my gosh, he's taught us so much about compassion. Oh my golly! Umpatience. He,	8 (28.6)

	indicating the child's positive influence on the family/others. No qualifying or negative statements are included.		um, loves family, he loves to be together, he loves to have everyone together."	
6	describes multiple, elaborative examples of the child's positive influence on the family/others. A challenging behavior may be briefly identified but does not serve to negate or qualify the many positive statements said about the child's contribution to the family.	•	"Well, she's responsible for giving the dogs their treats. And she umshe very much likes to do that. She takes the dishes to the sink for dinner. She has chores. Still working on cleaning up her toys and her pretty clothes, but my sister has that problem with her 23-year-old, so[laugh]."	6 (21.4)
7	<u>only</u> describes multiple, elaborative examples of the child's positive influence on the family/others. No challenging behavior or qualifying statements about the child or the situation is reported.	•	Everyone loves him And he loves all of them. He fits into our family very well and very easily. The kids like to play with him. [CHILD] is great at make-believe and play Our kids, really—the grandkids really enjoy him. So, they can come over and [CHILD] can play house and where someone's the baby and the mommy, and the girls can will come over, or he can play guns with the boys, and stuff. He fits in very well with them.	1 (3.6)

Table 3. Coding levels for caregiver positivity of positive influence.

		Mean (SD)	1	2	3	4	5	6	7	8	9	10	11	12	13
1. 5	Sum of 14	17.47													
a	adaptive	(4.65)													
	behavior					_			_						
S	strengths		1.00	0.11	0.25	0.73**	0.42	-0.58*	0.61**	-0.36	-0.60**	-0.63**	-0.61**	0.49*	0.04
	Positivity of	4.23													
	strengths	(1.10)		1.00	0.33	0.00	-0.14	-0.04	0.11	0.24	0.10	-0.10	0.09	-0.11	0.18
	Positivity of	4.43													
	influence	(1.50)			1.00	-0.29	0.13	-0.07	-0.13	-0.29	-0.12	-0.32	-0.26	0.13	0.22
	ERC Emotional	39.26					_								
	Lability	(7.72)				1.00	0.47*	0.62**	0.81**	0.36	0.72**	0.54*	0.63**	-0.45	-0.13
	ERC Emotion	23.80						-	-						
	Regulation	(3.88)					1.00	0.69**	0.66**	-0.53*	-0.70**	-0.65**	-0.73**	0.71**	-0.18
	ECBI Problem	64.70													
		(12.52)						1.00	0.80**	0.45	0.80**	0.74**	0.77**	-0.72**	0.01
7. I	ECBI Intensity	67.07													
	,	(10.52)							1.00	0.36	0.81**	0.65**	0.71**	-0.59*	-0.19
8. I	PSI Parental	50.47													
I	Distress	(9.47)								1.00	0.62**	0.54*	0.81**	-0.66**	0.06
9. I	PSI Difficult	60.90													
(Child	(12.20)									1.00	0.77**	0.92**	-0.67**	-0.12
10. I	PSI Parent-														
(Child														
I	Dysfunctional	56.40													
I	Interaction	(11.33)										1.00	0.88**	-0.64**	0.00
11. I	PSI Total Stress	56.37													
		(10.43)											1.00	-0.75**	-0.02
	PSOC	35.17													
S	Satisfaction	(7.17)												1.00	-0.24
13. I	PSOC Efficacy	20.07													
	•	(5.04)													1.00

Table 4. Means, standard deviations, and correlational results. ERC = Emotion Regulation Checklist; ECBI = Eyberg Child Behavior Inventory; PSI = Parenting Stress Index; PSOC = Parenting Sense of Competence; * = p < .01, ** = p < .001