Received: 19 November 2020 | Accepted: 23 February 2021

DOI: 10.1111/acer.14586

ALCOHOLISM CLINICAL & EXPERIMENTAL RESEARCH

COMMENTARY

A shift in perspective on secondary disabilities in fetal alcohol spectrum disorders

Heather Carmichael Olson[1,2] | Joanne Sparrow[2]

[1]Department of Psychiatry and Behavioral Sciences, University of Washington School of Medicine, Seattle, WA, USA

[2]Center on Child, Health, Behavior and Development, Seattle Children's Research Institute, Seattle, WA, USA

Correspondence: Heather Carmichael Olson, Center on Child, Health, Behavior and Development, Seattle Children's Research Institute, Building Cure, 1920 Terry Avenue, 3-221B, Seattle, WA 98101, USA.
Email: heather.carmichaelolson@seattlechildrens.org

Funding information
Support for Dr. Carmichael Olson and Dr. Sparrow provided by the James A. Bernard Memorial Fund.
Additional support for Dr. Carmichael Olson provided by the Jack R. MacDonald Research Fund.

Keywords: disabilities, fetal alcohol spectrum disorders, prenatal alcohol exposure, quality of life, stigma

Individuals with fetal alcohol spectrum disorders (FASD) often contend with daily life challenges. For many years, these have been called "secondary disabilities." Ranging widely, these are described as school disruption, legal problems, independent living needs, mental health difficulties, and more. Starting in the mid-1990s, in multiple countries, clinic-based and national register studies documented elevated rates of problems in adaptive behavior and secondary disabilities occurring for individuals with FASD (e.g., Streissguth et al., 1996; Streissguth et al., 2004; Spohr et al., 2007; Temple et al., 2011; Rangmar et al., 2015). Accumulating data revealed these challenges as ongoing, functionally impairing, and especially troubling as individuals with FASD advanced into adolescence and adulthood.

EARLIER DATA ON SECONDARY DISABILITIES IN FASD

Discussion of secondary disabilities in FASD often references the ground-breaking clinic-based work of Streissguth et al., (1996, 2004). This USA-based natural history research focused on a gradually accrued sample of 415 individuals with diagnoses on the fetal alcohol spectrum, ranging from 6 to 51 years of age. Of these, 253 were adolescent (12 years of age) or older. Findings revealed strikingly high rates of secondary disabilities, assessed over the lifetime until time of data collection. This study included a detailed analysis of the associations of various secondary disability outcomes with demographic and life experience "risk" and "protective" factors (i.e., factors that increased or reduced odds of later outcomes). Findings had a profound impact on the field, bringing to national and then global attention many concerning outcomes for individuals with FASD, especially in adolescence and beyond.

Yet this pioneering research study, as expected, had limitations. During the years the sample was accrued, diagnostic classification systems focused more on fetal alcohol syndrome (FAS) and partial FAS. Appropriately, however, this sample included many participants representing the full spectrum of individuals impacted by prenatal alcohol exposure (PAE), but necessarily labeled with the less well-defined term of "fetal alcohol effects" (FAE) available at that time. [Eventually, after critique and subsequent evolution of diagnostic classification systems, the "FAE" term was replaced with a range of more precise diagnostic labels that are still being refined (Aase et al., 1995; Coles et al., 2016).] Based on retrospective life event interviews, this early work had no comparison group, and there was likely a detection (or surveillance) bias toward those with more difficulties. This is common in clinic-derived samples, but does raise threats to validity and issues of generalizability (Drake et al., 2017; Chen et al., 2018). These must be considered in data interpretation for both earlier and more recent clinic-based studies. Study participants in this pioneering research were unable to benefit from systematic FASD-informed care, as community awareness, diagnostic methods, and models of care were still early in development. Nevertheless, study findings gave impetus to prevention and treatment, mobilized advocacy efforts, validated family concerns, and prompted funding for services and research. Understanding secondary disabilities among those with FASD, or with PAE, became an ongoing research interest in the field.

NEW CLINIC-BASED DATA ON SECONDARY DISABILITIES IN FASD

A useful recent update on secondary disabilities was published in ACER, entitled "Difficulties in Daily Living Experienced by Adolescents, Transition-Aged Youth and Adults with Fetal Alcohol Spectrum Disorder" (MacLachlan et al., 2020). This clinic-based study improves on earlier methodology. Focusing on a demographically diverse sample, gathered between 2016 and 2019, cross-sectional data from a large group (N = 726) of individuals with PAE, aged 12 years to 60 years, were collected. Diagnosis was performed via a multidisciplinary team assessment, employing a single standardized FASD diagnostic system (2016 Canadian FASD Diagnostic Guideline), and current (not lifetime) data were gathered about well-defined small sets of important potential risk factors and secondary disabilities. Information from four Canadian regions was collected in a database consistently used throughout much of the country. A primary study aim was to ascertain rates of difficulties in daily living (using nine categories) across a range of conditions on the fetal alcohol spectrum, including subgroups of individuals diagnosed with FASD with and without sentinel facial features (SFF), in contrast to subgroups of those considered at risk for neurodevelopmental disorder and those who did not receive a diagnosis. An additional study aim was to explore associations of secondary disabilities with possible risk factors.

Findings revealed that, overall, the sample of adolescents (61%), transition-aged youth (19%), and adults (20%) with PAE displayed wide-ranging neurodevelopmental impairment (measured as a sum of impaired domains), and half the group had experienced postnatal trauma. Regarding secondary disabilities, overall, independent living needs emerged as the most prevalent challenge (63%), with significantly higher rates among those with FASD (with and without SFF) compared with other groups. Other secondary disabilities, overall, occurred at lower percentages from 46% down to 3%. Those with FASD (with or without SFF) experienced significantly higher levels of difficulties in daily living occurring at the time of assessment (measured as a count of endorsed difficulties), compared with other groups. Although only current difficulties were assessed, in the full sample most individuals (81%) were experiencing at least one difficulty at the time of assessment, many faced ≥ 3 difficulties (40%), and some dealt with ≥ 5 current difficulties (15%). A detailed analysis of associations between disability categories and risk factors was performed. "Risk" factors associated with odds of more negative outcomes differed to some extent from those found in the earlier USA-based study, as did rates of various disabilities.

The central and concerning message of the 2020 study by MacLachlan and colleagues is that secondary disabilities among those with FASD (and PAE) remain prevalent and debilitating at these older ages—even in countries such as Canada, which makes available at least some FASD-informed care at a societal level. Unfortunately, the concern signaled by the earlier USA-based research still persists. This line of secondary disability research clearly demonstrates that individuals with FASD comprise a vulnerable population moving through the transition to adulthood. Vulnerability is of real concern because this time in life is a critical juncture in the course of psychopathology and mental health (Schulenberg et al., 2004). Yet despite known vulnerability, a developmentally appropriate, socially inclusive system of support for those with disabilities is often not available or sufficient to aid in this vital life transition (Osgood et al., 2010), including for those with FASD.

IMPACT OF THE SECONDARY DISABILITIES LITERATURE: A PROMPT FOR ACTION, AN UNINTENDED CAUSE OF STIGMA

Across the years, research on secondary disabilities in FASD has been a galvanizing force. In multiple countries, data on elevated prevalence rates raised concern about high societal costs, inspiring advocacy, governmental action, and efforts toward policy change. The high prevalence of secondary disabilities has prompted descriptive research aimed toward generating solutions. Examples include study of systemic barriers contributing to these adverse outcomes (which can prompt solutions that remove these barriers) (Petrenko et al., 2014), and a state-of-the-art review of transition planning tools for youth with FASD (Coons-Harding et al., 2019). Concern about adverse life outcomes increased interest in FASD diagnostic methods appropriate for older individuals with PAE, since identification of disabilities can mean eligibility for and/or modification of adult services.

Secondary disabilities data have also stimulated interest in provider education and development of standards of care among "key champions" in service systems in which these data suggest that individuals with FASD will present (e.g., legal/judicial systems, juvenile and adult corrections, substance use treatment, mental health services). An overarching goal to head off secondary disabilities, coupled with information on population-specific risk and protective factors from this line of research, shaped early design of treatment approaches for FASD (e.g., Bertrand, 2009). Further, concern about secondary disabilities has inspired basic research on mechanisms by which certain adverse outcomes arise among those with PAE, which may suggest prevention or treatment methods. For instance, there is an intriguing line of animal research on fetal programming due to PAE occurring through long-term alterations in hypothalamic–pituitary–adrenal (HPA) regulation and responsiveness to stressors. Using a diathesis–stress hypothesis, this basic research helps explain mechanisms involved in the emergence of internalizing disorders (e.g., depression, anxiety), secondary disabilities found at high rates among those affected by PAE or with FASD (Hellemans et al., 2010).

Regrettably though, research on secondary disabilities, part of the overall historical "deficits" focus in the field of FASD, may have come at a cost. Emphasizing adverse outcomes in FASD has prompted action, but likely also increased caregiver stress and promoted stigma. Stigma has recently been acknowledged as a significant issue in the field of FASD (e.g., Choate & Badry, 2019; Roozen et al., 2020). While understandable (and successful) in the effort

to reveal the existence and importance of FASD as a condition of public interest, the focus on secondary disabilities may have perpetuated stigma by showcasing negative outcomes. Writing about stigma, Choate and Badry (2019) state that when social and health policy, and public discourse, originate from the more serious cases, the image of individuals impacted by FASD is made to appear catastrophic. As a result, the idea that the condition exists on a spectrum is lost—and stigmatization continues. These authors also mention that negative public discourse "can predominate with little attention being paid to possible areas of success." (p. 36) Stigma about FASD has many sequelae, including isolating families, reducing personal agency, causing provider unwillingness to learn about or ask about PAE, promoting discrimination, and more. There have been growing calls for stigma reduction programs and use of dignity-promoting language in the field of FASD that does not stigmatize. For instance, language guidelines were suggested by the Canada Northwest FASD Partnership in 2017 (e.g., https://canfasd.ca/wp-content/uploads/2018/01/LAEO-Language-Guide.pdf, Accessed January 24, 2020). While the "secondary disabilities" term is well understood in the field, less stigmatizing labels have been recommended, such as "secondary impacts" or "secondary conditions" (e.g., Petrenko et al., 2014). The latter term will be used in the remainder of this commentary.

SUGGESTIONS TO EXTEND THE "SECONDARY CONDITIONS" LITERATURE

Extending the body of literature on secondary conditions in FASD could better guide targeted prevention and intervention efforts, and direct policy change. The work of MacLachlan et al., (2020) has already updated the field in important ways, but their database could be extended to prove even more valuable. *Indeed, all FASD databases and patient registries could benefit from extending their scope by considering the suggestions offered here.*

Adding assessment of strengths and positive adaptive behaviors into the database is a step MacLachlan and her colleagues already plan to take, and is an excellent step for other FASD databases. Beyond that, another suggestion is adding regularized assessment of environmental influences, including protective factors that enable success for youth and adults with FASD (to inform intervention ideas)—and a range of key quality of life (QOL) and daily activity indicators. Specifically, as Imms et al., (2017) have suggested, databases could be expanded to include elements from the WHO International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY, WHO, 2007). The ICF-CY resource is recommended reading for those working to meaningfully extend research on FASD. As one example, the ICF-CY notes that participation in a daily life activity (such as a work-related training or support group) has two essential components: attendance (just being there) vs. involvement (the experience of participating when attending). Involvement is the real aim, since it is active and positive participation that may enhance QOL. Assessing degree and type of involvement, in addition to simple attendance, may be key to creating interventions that truly matter to enhancing long-term health and well-being of individuals with FASD.

There are further suggestions. If set up as a patient registry, the Canadian database (and other FASD databases) could become platforms from which to select patients for focal longitudinal research projects—and for vital studies that assess the lived experiences of individuals with FASD and their families. Data on real-life perspectives could help to improve assessment and diagnosis. Such research could assess the benefits (and downsides) of diagnosis from the actual viewpoints of the individuals and families involved. Understanding the pros and cons of diagnosis might help providers from many disciplines become more interested in FASD diagnosis—and increase referrals, if data reveal (as expected) that the benefits of diagnosis outweigh the risks. Real-life perspectives could also help in formulating strengths-based approaches to better inform diagnosis, as suggested by Choate and Badry (2019)—as well as guide how treatment and advocacy for services should proceed.

FASD is a global health problem. Therefore, it occurs in societies that offer different levels and types of social services. Cross-sectional data on outcomes of persons with FASD and associated factors from large clinical databases or national register-based studies, carried out in multiple countries, each using a consistent FASD diagnostic system (at least within the study), remain much needed. In general, though, comparisons of clinic-based data should be made to general population data or appropriate matched contrast groups, to help contextualize these data (including secondary conditions) relative to other vulnerable populations or to the larger community. Adverse and resilient outcomes, and associated risk and protective influences, need to be carefully described across different developmental phases and varying societal support systems, to shape prevention and treatment for different settings.

To further extend the secondary conditions literature, natural history and testing information should be gathered from larger samples of older adults with FASD, including health data, into at least middle adulthood. This is because there are compelling recent data to suggest important adverse health outcomes may occur as individuals with FASD grow older, including concerning cardiac and metabolic problems, which merit serious public health attention (e.g., Akison et al., 2019; Cook et al., 2019; Himmelreich et al., 2020). One new research project with this aim is now underway (https://cifasd.org/research/#Coles, Accessed November 8, 2020).

In addition, as MacLachlan et al., (2020) state, longitudinal data are vital to follow up on key points identified by cross-sectional clinic-based data. Longitudinal data allows understanding of life trajectories (and developmental influences) leading to both adverse and resilient outcomes. Some intriguing prospective longitudinal data, following individuals with PAE through young adulthood, already exist. For instance, Lynch and colleagues (e.g., 2015) have followed a prospective sample of individuals with PAE from high-risk backgrounds, whose mothers were recruited during pregnancy, through young adulthood. Findings have profiled adaptive function and secondary conditions, and important correlates (such as gender, physical effects, cognitive

effects) among those with PAE in young adulthood—compared with both a socioeconomic control group (also recruited during pregnancy) and a disability contrast group (recruited during adolescence). Because matched group comparisons have been made, results set findings for those with PAE in better context than do clinic-based studies. For instance, it is interesting (and perhaps surprising) that the early adult experiences of those with PAE were similar in many ways to that of other young adults requiring special education during high school. In the future, longitudinal research should be extended to additional samples, including those at lower environmental risk. As suggested by Skorka et al., (2020), future directions for longitudinal research could include study of lived experiences (perspectives, daily activities, and specific life challenges), and environmental influences that act as pivotal risk or protective factors over time.

A SHIFT IN PERSPECTIVE TO A FOCUS ON STRENGTHS AND QUALITY OF LIFE IN FASD

A recent systematic review of interventions found that the needs of individuals with FASD (and PAE) become more complex in later adolescence, emerging adulthood, and adulthood. This review noted that existing interventions for older individuals were designed with a more responsive approach to mitigate risk and reduce harm (Flannigan et al., 2020). Yet in the larger field of intellectual and developmental disabilities (IDD), over the past four decades, there has been a movement away from this type of "deficits approach," to a focus on self-advocacy and the application of strengths-based approaches to supporting individuals with IDD over the lifespan (Wehmeyer, 2020). In part, this strengths-based focus emerged when the QOL construct was applied to sensitize those in the field to a new way of thinking about the population of those with developmental disabilities. Briefly put, the QOL conceptual model used to drive service delivery for persons with IDD consists of eight domains: (1) rights; (2) self-determination; (3) social inclusion; (4) interpersonal relationships; (5) personal development; (6) emotional well-being; (7) material well-being; and (8) physical well-being. A discussion of measurable indicators of QOL, aligned with the rights of persons with disabilities, is available and could be used to guide multiple intervention ideas, especially for older individuals with FASD, and their families and service systems (Gómez et al., 2020). This could be a useful resource, as strengths-based interventions have increasingly been called for in the field of FASD (e.g., Flannigan et al., 2020).

A shift in perspective from designing treatment to reduce secondary conditions toward creating interventions to improve QOL and adaptive function may be a catalyst to help providers understand why FASD diagnosis is needed— and a stimulus for meaningful intervention ideas. To realize this shift in perspective in a practical way, research is needed assessing daily function among older individuals with FASD, with a focus on how performance of community-based activities is impacted, how barriers could be removed to optimize environments, and how therapy and other services can be adapted to best support those with FASD in improved function across the full range of settings they encounter. Skorka et al., (2020) make this point and provide guidance on what information is needed. This research team carried out a critical review of existing data on the impact of FASD (and PAE) on child function (ages 5 to 18 years) during daily activities in different environmental contexts. While this review was aimed at younger ages, they noted major gaps in assessment of strengths and of the lived experiences of individuals with FASD for all ages. These authors further noted that for older age groups, a wider range of environments should be assessed, beyond home and school, such as health facilities, courts, employment settings, and more. Skorka et al. comment that context-based approaches, which focus on how to improve and adapt the environment, are promising for intervention in the field of FASD. Context-based approaches have long been advocated as clinical wisdom, used in some interventions for younger children with FASD and their families (e.g., Bertrand, 2009), and are promising as interventions for older individuals with FASD.

The ultimate aim of this shift in perspective in research and practice is to take action to make a positive difference in the actual daily lives of those with FASD. To bring this to life, a practical example is offered here. The QOL construct of *self-determination* suggests that researchers learn from the lived experiences and self-advocacy of persons with FASD, and those who care for them, asking what outcomes they regard as important. This is done with the view that (to the extent possible) individuals with FASD should be causal agents in their own lives. With this in mind, there is an interesting recent example of research spearheaded by young adults with FASD. This study was prompted by self-advocacy (and reflects the QOL domains of *self-determination and physical well-being).* Motivated by informal peer discussion, a group of young adults with FASD gathered health survey data from a group of 541 respondents with FASD (or PAE), aged 16 to 60 years, with an average age of 27.5 years. Findings documented remarkably concerning, high rates of negative health-related outcomes (Himmelreich et al., 2020). Sparked by these and other recent adverse health data characterizing those with PAE, an idea emerged for a proposed mobile health (mHealth) intervention to build an app that adults with FASD could use for health self-management. In carrying out this project, a group of self-advocates in the field of FASD will act in an advisory capacity. As this group, called the "FASD Changemakers," state as their motto: *"Nothing about us, without us."* In keeping with this, the app will be developed, in part, through participatory research with involvement by the users themselves (Petrenko, 2020). Indeed, approaches such as participatory research and mixed methods research are likely to be increasingly important in defining QOL for FASD in a truly meaningful way.

CONCLUSIONS

The recent work of MacLachlan and colleagues brings renewed concern about high rates of secondary conditions among those with

FASD. Recent trends in the field of FASD, like those in the larger field of developmental disabilities, suggest a shift in perspective in responding to this concern that applies to the work of MacLachlan et al.—and to the overall FASD literature. Suggested here is a move away from a "deficits" focus to learning from self-advocates and lived experience data, and adding a focus on strengths and improved QOL. This may, in part, address the pervasive stigma that has impeded progress in the field of FASD (Choate & Badry, 2019). As MacLachlan and her colleagues state, "adopting a strengths-based approach and involving individuals with FASD and their circles of care, across a wide range of communities, cultures and settings as stakeholders in future research, are also critical." (p. 1622) This shift in perspective, defined here with many specific ideas, leads research in new directions and may yield even more effective and meaningful assessment, diagnosis, and interventions. The central point is that this shift in perspective supports the overarching goal in the field to provide equitable care that respects the rights of persons with FASD.

CONFLICTS OF INTEREST

The authors have no financial or other conflicts to declare.

ORCID

Heather Carmichael Olson https://orcid.org/0000-0003-0903-4031

REFERENCES

Aase, J.M., Jones, K.L. & Clarren, S.K. (1995) Do we need the term FAE? *Pediatrics*, 95, 428–430.

Akison, L.A., Reid, N., Wyllie, M. & Moritz, K.M. (2019) Adverse health outcomes in offspring associated with fetal alcohol exposure: a systematic review of clinical and preclinical studies with a focus on metabolic and body composition outcomes. *Alcoholism, Clinical and Experimental Research*, 43, 1324–1343. https://doi.org/10.1111/acer.14078

Bertrand, J. & Interventions for Children with Fetal Alcohol Spectrum Disorders Research Consortium (2009) Interventions for children with fetal alcohol spectrum disorders (FASDs): overview of findings for five innovative research projects. *Research in Developmental Disabilities*, 30, 986–1006.

Chen, L., Chan, J.A., Alligood, E., Rosen, A.K. & Borzecki, A.M. (2018) Does surveillance bias influence the validity of measures of inpatient complications? A systematic review. *American Journal of Medical Quality*, 33, 291–302. https://doi.org/10.1177/1062860617730900

Choate, P. & Badry, D. (2019) Stigma as a dominant discourse in fetal alcohol spectrum disorder. *Advances in Dual Diagnosis*, 12(1/2), 36–52. https://doi.org/10.1108/ADD-05-2018-0005

Coles, C.D., Gailey, A.R., Mulle, J.G., Kable, J.A., Lynch, M.E. & Jones, K.L. (2016) A comparison among 5 methods for the clinical diagnosis of fetal alcohol spectrum disorders. *Alcoholism, Clinical and Experimental Research*, 40, 1000–1009. https://doi.org/10.1111/acer.13032

Cook, J.C., Lynch, M.E. & Coles, C.D. (2019) Association analysis: fetal alcohol spectrum disorder and hypertension status in children and adolescents. *Alcoholism, Clinical and Experimental Research*, 43, 1727–1733. https://doi.org/10.1111/acer.14121

Coons-Harding, K.D., Azulai, A. & McFarlane, A. (2019) State-of-the-art review of transition planning tools for youth with fetal alcohol spectrum disorder in Canada. *Journal of Development Disabilities* 24, 81–98.

Drake, B., Jonson-Reid, M. & Kim, H. (2017) Surveillance bias in child maltreatment: a tempest in a teapot. *International Journal of Environmental Research and Public Health*, 14, 971. https://doi.org/10.3390/ijerph14090971

Flannigan, K., Coons-Harding, K.D., Anderson, T., Wolfson, L., Campbell, A., Mela, M. et al. (2020) A systematic review of interventions to improve mental health and substance use outcomes for individuals with prenatal alcohol exposure and fetal alcohol spectrum disorder. *Alcoholism: Clinical and Experimental Research* 44, 2401–2430. https://doi.org/10.1111/acer.14490

Gómez, L.E., Monsalve, A., Morán, M.L., Alcedo, M.A., Lombardi, M. & Schalock, R.L. (2020) Measurable indicators of CRPD (Convention of the Rights of Persons with Disabilities) for people with intellectual and developmental disabilities within the quality of life framework. *International Journal of Environmental Research and Public Health*, 17, 5123. https://doi.org/10.3390/ijerph17145123

Hellemans, K.G., Sliwowska, J.H., Verma, P. & Weinberg, J. (2010) Prenatal alcohol exposure: fetal programming and later life vulnerability to stress, depression and anxiety disorders. *Neuroscience and Biobehavioral Reviews*, 34, 791–807.

Himmelreich, M., Lutke, C.J. & Hargrove, E.T. (2020) The lay of the land: fetal alcohol spectrum disorder (FASD) as a whole-body diagnosis. In *The Routledge Handbook of Social Work and Addictive Behaviors* (Begun, A.L. & Murray, M.M. eds), pp 191–215.Routledge, New York.

Imms, C., Granlund, M., Wilson, P.H., Steenbergen, B., Rosenbaum, P.L. & Gordon, A.M. (2017) Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. *Developmental Medicine & Child Neurology* 59, 16–25. https://doi.org/10.1111/dmcn.13237

Lynch, M.E., Kable, J.A. & Coles, C.D. (2015) Prenatal alcohol exposure, adaptive function, and entry into adult roles in a prospective study of young adults. *Neurotoxicology and Teratology*, 51, 52–60.

MacLachlan, K., Flannigan, K., Temple, V., Unsworth, K. & Cook, J.L. (2020) Difficulties in daily living experienced by adolescents, transition-aged youth and adults with fetal alcohol spectrum disorder. *Alcoholism, Clinical and Experimental Research*, 44, 1609–1624.

Osgood, D.W., Foster, E.M. & Courtney, M.E. (2010) Vulnerable populations and the transition to adulthood. *Future of Children*, 20, 209–229.

Petrenko, C.L.M. (2020) *Increasing access to care for people with FASD and their families. Keynote address presented at ProofCon 2020: FASD in a New Era*. On-line conference sponsored by Proof Alliance, St. Paul, MN. https://www.proofalliance.org/conference/

Petrenko, C.L.M., Tahir, N., Majoney, E.C. & Chin, N.P. (2014) Prevention of secondary conditions in fetal alcohol spectrum disorders: identification of systems-level barriers. *Maternal and Child Health Journal*, 18, 1496–1505.

Rangmar, J., Hjern, A., Vinnerljung, B., Strömland, K., Aronson, M. & Fahlke, C. (2015) Psychosocial outcomes of fetal alcohol syndrome in adulthood. *Pediatrics*, 135, e52–e58.

Roozen, S., Stutterheim, S.E., Bos, A.E., Kok, G. & Curfs, L.M.G. (2020) Understanding the social stigma of fetal alcohol spectrum disorders: from theory to interventions. *Foundations of Science*, https://doi.org/10.10067/s10699-020-09676-y

Schulenberg, J.E., Sameroff, A.J. & Cicchetti, D. (2004) The transition to adulthood as a critical juncture in the course of psychopathology and mental health. *Development and Psychopathology*, 16, 799–806.

Skorka, K., McBryde, C., Copley, J., Meredith, P.J. & Reid, N. (2020) Experiences of children with fetal alcohol spectrum disorder and

their families: a critical review. *Alcoholism, Clinical and Experimental Research*, 44, 1175–1188.

Spohr, H.L., Willms, J. & Steinhausen, H.C. (2007) Fetal alcohol spectrum disorders in young adulthood. *Journal of Pediatrics*, 150, 175–179.

Streissguth, A., Barr, H.M., Kogan, J. & Bookstein, F.L. (1996) Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE): Final Report to the Centers for Disease Control and Prevention. University of Washington, Fetal Alcohol and Drug Unit, Seattle, WA.

Streissguth, A.P., Bookstein, F.L., Barr, H., Sampson, P.D., O'Malley, K. & Young, J.K. (2004) Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental and Behavioral Pediatrics*, 25, 228–238.

Temple, V., Shewfelt, L., Tao, L., Casati, J. & Klevnick, L. (2011) Comparing daily living skills in adults with fetal alcohol spectrum disorder (FASD) to an IQ matched clinical sample. *Journal of Population Therapeutics and Clinical Pharmacology*, 18, e397–e402.

Wehmeyer, M.L. (2020) The importance of self-determination to the quality of life of people with intellectual disability: a perspective. *International Journal of Environmental Research and Public Health*, 17, 7121. https://doi.org/10.3390/ijerph17197121

WHO (2007) *International classification of functioning, disability and health: Children and youth version: ICF-CY*. Geneva: World Health Organization.

How to cite this article: Olson HC, Sparrow J. A shift in perspective on secondary disabilities in fetal alcohol spectrum disorders. *Alcohol Clin Exp Res*. 2021;00:1–6. https://doi.org/10.1111/acer.14586