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Fetal Alcohol Spectrum Disorder (FASD): Thirty Reasons Why Early Identification Matters

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Introduction

Previous articles in the *Children's Mental Health Matters* series (Hodas, 2012, 2015, 2016) have addressed the nature and challenges of Fetal Alcohol Spectrum Disorders (FASD). Given that the primary deficits in FASD – namely, those related to the direct effects of in-utero alcohol exposure on the developing brain – are irreversible, some might be tempted to dismiss early identification as a waste of time. In fact, such thinking is erroneous. In what follows, we consider thirty reasons why early FASD identification truly matters.

What is "early identification"?

While there is frequent mention of early identification in the literature, often this term is not explicitly defined. With progress in research and technology, the operational definition of early intervention can be expected to change, making it easier to identify FASD early in a child's life and perhaps even in-utero.

For purposes of discussion here, early intervention refers to early childhood, with a range from birth to 6 years, and with identification ideally occurring by age 2 years. It should be appreciated that, for all children, brain plasticity and therefore the potential capacity for growth are greatest early on. This is the case even for children with in-utero brain damage, such as children with an FASD.

Thirty reasons why early identification of FASD matters

Early identification of FASD matters, and can benefit *family*, *child*, and *schools/service providers*. When the child's strengths and FASD-related limitations are understood, the following can occur:

Family

- The specific FASD diagnosis serves as a cognitive anchor for parents, enabling them to better understand their child, offering them a sense of relief, and increasing their sense of mastery.
- Parents can more easily understand the child's realistic capabilities and limitations and thereby have appropriate expectations of the child – e.g., they can be developmentally competent with their child.
- It becomes less likely that parents will blame the child for challenging behaviors, limited academic performance, and apparent failure to cooperate – all of which may be due to neurologically-based limitations.
- It is less likely that the child will be subject to maltreatment on the part of a frustrated family.

- It is less likely that others will blame the child's parents for the child's behavior and other limitations. In addition, siblings will less likely be targeted, and will be better prepared to respond appropriately to unkind comments.

- The child's family can be helped to understand that the child will likely require greater supervision and oversight to ensure safety than an unaffected child of the same chronological age.

- The child's family can learn about and seek evidence-based and promising practices for children with FASD.

- Parents can seek the support of other parents dealing with similar challenges.

- The family, by learning how to navigate complex systems and community resources and by maintaining realistic goals, is better able to be hopeful and strengths-based throughout the child's development.

- The biological mother of a child with an FASD, once informed about the deleterious effects of prenatal alcohol exposure and given nonjudgmental support, is less likely to use alcohol during future pregnancies.

Child

- The child can be helped to understand the likely reasons for various behavioral, cognitive, and interpersonal struggles.

- The child's strengths and interests can be identified and cultivated.

- In a developmentally appropriate way, the child can be assisted in addressing areas of weakness at the same time that areas of strength are supported.

- Others can learn how to best communicate with the child. This includes parents, teachers, and involved human service professionals, and also siblings, extended family, neighbors, and other community resource persons.

- Commonly co-occurring disorders can be identified and treated, without the underlying FASD being overlooked.

- The child's capacity to maintain personal safety and respond to unsafe situations can be assessed, and appropriate interventions implemented.

- The child is less likely to engage in self-blame and more likely to continue to put forth efforts to improve.

- Shaming of the child becomes less likely.

- Small successes that might otherwise be ignored or taken for granted can be highlighted, enabling the child to feel supported and competent.

School and Service Providers

- It becomes easier to work in partnership with the family to develop and implement a plan of care.

- It is more likely that Early Intervention services will be sought and provided.

- There is a compelling reason to convene a child and family team, and embrace a system of care approach to intervention.

- Involved professionals can work to strengthen the family's safety net, so that the community becomes safer and more responsive to child and family needs.

- A more informed decision can be made regarding what type of educational setting is most appropriate for the child at different times.

- Teachers can learn how to best teach the child, building on strengths and making necessary accommodations.

- Teachers and service providers are more likely to avoid interventions that are ineffective and punitive, and instead use interventions appropriate for a child with an FASD.

- Involved adults can ensure that teaching is multi-sensory in nature and makes use of modeling and role-playing, with less reliance on just verbal communication.

- More intentional efforts can be made to help the child deal with change and transitions.

- Involved mental health and other human service professionals can explore whether other children or adult family members might also be affected by an FASD.

- The family physician can monitor possible physical health problems associated with FASD, offer the family anticipatory guidance, and promote wellness.

Discussion

When a child presents with problematic behavior or is underperforming for unknown reasons, the family is stressed and well aware that something is wrong. Under these circumstances, a medical diagnosis is often experienced as "a gift." It removes a paralyzing sense of uncertainty, instead providing much greater clarity regarding what is going on. A medical diagnosis can empower parents, whose concerns may have been dismissed by others or who may have been unjustly blamed for their child's behavior. With a valid medical diagnosis at hand, child and family can now learn about the disorder and, with the help of others, explore what can be done.

For all of us, what we think influences how we act. If we believe that a child is being defiant and spiteful, it becomes difficult to show compassion. Anger and an urge to punish the child are more likely. However, children with an FASD are not acting spitefully, and most of their limitations are beyond their control. A very different response is needed – involving empathy, encouragement, and patience. Parents who unknowingly raised a child with an FASD in years past not uncommonly experience profound regret years later. Fully aware of the importance of early identification in retrospect, many such parents have thought, if not said, "If only I'd known at the time – what a difference it would have made."

In working with children with an FASD, effective intervention for parents and others requires at least two fundamental skills:

- The first skill involves the ability to recognize that the child's maladaptive functioning is *not intentional* – e.g., in the words of Diane Malbin, that it's not that the child "won't," but rather that she "can't" (2017).

- The second essential skill involves learning to be *developmentally competent*. This involves determining over time the child's actual capabilities, so that realistic expectations can be developed and maintained.

These specific skills, together with relentless persistence, enable the family to offer the child encouragement and support, and can help the child experience success despite significant concurrent limitations.

Children with a chronic illness or medical disorder can lead meaningful, productive lives. Early identification promotes such positive outcomes. It opens doors, restores morale, and helps us discover next steps. For the wellbeing of individual children and their families as well as the larger community, we need to become more aware of FASD and better able to identify it – the earlier, the better.

References

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