

## FETAL ALCOHOL SPECTRUM DISORDER - POVERTY TRAP?

*NX Thanh<sup>1,4</sup>, E Jonsson<sup>2,3,4</sup>, J Moffatt<sup>4</sup>, L Dennett<sup>4</sup>*

*<sup>1</sup>University of Alberta School of Public Health; <sup>2</sup>University of Alberta Department of Medicine; <sup>3</sup>University of Calgary Department of Community Health Sciences; <sup>4</sup>Institute of Health Economics, Edmonton, Alberta, Canada*

**T**he disease or injury poverty trap refers to a relationship between ill-health and poverty in which poverty is a result of ill-health. At the household level, non-poor people may be pushed into poverty by their ill-health as a result of paying for health care in combination with productivity and income losses. Poor people with ill-health may be pushed into deeper or persisting poverty from which they cannot escape. This kind of trap is well reported for infectious diseases and unintentional injuries in developing countries where people have to pay for the cost of health care at the same time that their incomes are likely reduced by ill-health.<sup>1,2,3</sup>

Also, the cycle of disability and poverty is mentioned in both developed and developing countries. Generally, people living in poverty are more likely to expose risks of disease, injury, and disability. On the other hand, people with disability and their families spend more on their medical, educational, and daily living needs, but earn less income because of their limited capability or inability, in comparison with people without disability.<sup>4</sup>

However, the concept of poverty trap has not been applied in the field of fetal alcohol spectrum disorder (FASD) - a lifelong disability caused by exposure to alcohol during pregnancy and characterised by physical, mental, behavioural and learning disabilities. The incidence of this disorder reportedly varies depending countries, geographic locations, and groups of population. In North America, the incidence of FASD is averagely estimated at 9 per 1000 live births.<sup>5</sup>

In this paper, we report a discussion of available evidence regarding the association between poverty and FASD, and regarding the economic consequences of FASD on individuals and families which may materialize an FASD - poverty trap.

### **Association between Poverty and FASD**

The association between poverty or low socioeconomic status (SES) and mothers of children with FASD is well documented. According to May et al.<sup>6</sup>, the risk of bearing a child with FAS is about 16 times higher for women of lower SES even with comparable drinking levels. In many population-based studies, women with FASD children have lower levels of education, lower income, and more frequently are unemployed or underemployed. The followings are some examples:

Astley et al. (2000)<sup>7</sup> conducted a cross-sectional survey among women who had given birth to a fetal alcohol syndrome (FAS) child in Seattle, USA. Each woman participated in a structured one-on-one interview developed to generate a comprehensive profile of socio-demographic characteristics, history, social and healthcare utilization patterns, adverse social experiences, alcohol treatment history, and mental health status. The study found that 78% of interviewed women had a low income (less than 10,000 per year) and 61% of them did not complete high school.

May et al. (2005 and 2008)<sup>8,9</sup>, Urban et al. (2008)<sup>10</sup> and Viljoen et al. (2002 and 2005)<sup>11,12</sup> conducted case-control studies in South Africa to assess the maternal risk factors of FASD. The characteristics of mothers with FASD affected children (cases) were compared to mothers without FASD affected children (controls). All the studies found income, educational attainment, and full-time employment were significantly lower among cases when compared to controls.

Of note, all of these studies were cross-sectional, therefore, all we can say is there is an association between FASD and poverty, and the

question: "is poverty a result of FASD?" is still unanswered. In the next section, we provide available evidence and a brief discussion surrounding the answer to this question.

### **Economic Consequences of FASD**

The economic consequences of FASD on individuals and families are reportedly profound, including both direct costs (i.e. the out-of-pocket payments by the families) and indirect costs (i.e. the lost income and lost human potential to earn income of the affected individuals and their caregivers).

#### ***Direct Costs***

The annual cost per person with FASD in Canada is estimated at \$25,000, of which 20% (or \$5000) is paid by family.<sup>13,14</sup> This out-of-pocket cost includes additional costs from transportation and parking for visiting health care providers, and externalizing behaviours (including acts of violence against persons, animals, and/or property; and stealing were elicited directly in the inventory). Based on Stade et al<sup>14</sup>, up to 70% of households with people with FASD have the annual income of \$34,000 (range \$10,000-\$50,000). Compared to this, the out-of-pocket cost accounts for 15% (range 10%-50%). These proportions are comparable with the extra spending by parents for a child with disability in UK.<sup>15</sup>

In North Dakota, USA, the annual cost for parents with a child with FAS, is estimated at US\$17,400, which includes costs associated with travel, meals and lodging, insurance deductible, vacations and sick leave, child care, and telephone costs.<sup>16</sup> This amount is equal to 36.4% of the median gross household income in North Dakota, which was \$47,800 in 2009.<sup>17</sup> This economic burden is so substantial that may drive households into poverty, especially those households which have lower income and/or more children with FASD.

#### ***Indirect Costs***

Individuals with FASD may have significant difficulties with memory, attention, self-care, decision making, and social skills, and they may have problems with organization and planning

their activities, difficulty controlling their emotions and completing tasks.<sup>18</sup> In addition, secondary disabilities, which are the disabilities that are not apparent at birth but present in later years of life, are prevalent among them. According to Streissguth et al.<sup>19</sup>, among people with FASD, more than 90% have mental health problems, 60% disrupted school experience - suspensions, expelled or dropped out, 60% trouble with the law, 50% confinement including inpatient treatment or incarceration, 50% inappropriate sexual behavior, 30% alcohol and drug use problems, 80% needing dependent living situations, and 80% have problems with employment.

It is immensely challenging to truly capture the indirect costs of these secondary disabilities. The lost earnings of people with FASD is unknown. However, Kessler et al.<sup>20</sup> reported that people with serious mental illness had 12-month earnings averaging \$16,306 less than other people without the condition. Since more than 90% of people with FASD have mental health problems as mentioned above, one can somehow estimate how much their lost earnings are. For children with FASD, the lost earnings are of the caregivers who are usually the mothers.<sup>21</sup> Studies indicate there is a reduced rate of maternal employment among families with a child with disability and that entries to and exits from poverty are primarily influenced by changes in labour-related income and employment status.<sup>22</sup>

In addition, FASD is often complicated by medical issues, including a higher rate of heart disease, hearing and vision problems, among others.<sup>19</sup> Both mental and physical issues can impede the ability of an individual with FASD to work and earn a decent living. Their families have to pay additional costs in raising them. Consequently, long term productivity of the individuals with FASD and their families is impacted because of reductions in savings or reduced investment in children's education due to urgent needs (e.g. medical...).

In summary, individuals with FASD and their families face a double type of costs, including the direct costs for taking care of individuals with FASD and the indirect costs of lost productivity and human potential. This economic burden may force them into poverty

from which they hardly escape. Such a hypothesis is well supported by Emerson et al.<sup>22</sup> who longitudinally investigated the poverty transitions among families supporting a child with intellectual disability. The authors found that compared to families not supporting a child with disability, families supporting a child with intellectual disability were more likely to become poor and less likely to escape from being poor. This is exactly the poverty trap being discussed in this paper. One can expect the same poverty transitions among families supporting a child with FASD because leaning or intellectual disability is a characteristic of FASD.

In conclusion, the economic consequences of FASD and the poverty trap of intellectual disability suggest a possibility of the existence of an FASD-poverty trap – an area that needs further studies, probably longitudinal, to be determine and identify the pathways leading people with FASD to poverty. Such information will be vital to inform the policies preventing individuals with FASD and their families from falling into, and supporting those who are already poor to escape from, the poverty trap.

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#### **Conflict of Interest**

There is no conflict of interest to declare.

**Corresponding Author:** [tnguyen@ihe.ca](mailto:tnguyen@ihe.ca)

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