



# The Importance of Building Bridges among Parents



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## Abstract

In 2007, five women participated in a photo voice project entitled, "Picture" This: Life as a Parent of Children with FASD" [1]. The women used cameras and engaged in group discussion to describe their experiences of parenting children with FASD through pictures and narratives. The project was transformed into a photo exhibit, podcast and DVD film production. Using a Participatory Action Research (PAR) model, this researcher brought the five original photo voice participants back together to expand on their experiences and ideas. The research was designed to find out what would be needed in order to prevent the onset of secondary disabilities for their children and to promote healing. We also wanted to understand the impact of participation in the original project.

The women felt that because of photo voice they had more hope for their children as well as increased confidence as caregivers and advocates. They realized that they possessed important expertise in the area of FASD and could use their experience to educate others. They became better at parenting as they discovered more about the disability and learned to forgive themselves for making mistakes. But most of all, by building bridges among women affected by FASD, from all circumstances, they were able to use the empathy and love they had developed to build relationships with other birth, foster and adoptive mothers in their lives, and the lives of their children.

## Literature Review

### Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder (FASD) refers to damage that is caused to a fetus when exposed to alcohol prenatally. During pregnancy, alcohol crosses the placenta at the full concentration and enters the circulatory system of the fetus. Because the fetus cannot eliminate the alcohol at the same rate as the mother, it is exposed to the alcohol for longer periods than the mother. Alcohol is a toxic agent that can damage cells in the developing organs. Damage to the cells causes malformation in growing organs and all fetal organs can be adversely affected. Fetal Alcohol Spectrum Disorder (FASD) is the umbrella term that describes the spectrum of disabilities and diagnoses associated with prenatal alcohol exposure. FASD is not a diagnostic term – the diagnoses under the FASD umbrella include, Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome (pFAS), Alcohol Related Neurodevelopmental Disorder (ARND) and Alcohol Related Birth Defects (ARBD) [2].

### Parenting Children with FASD

People with FASD are born with brain damage and may not always behave in ways that others expect them to. This brain damage can permeate even the best of environments to cause behavior problems and create serious parenting challenges. Parents can struggle with the overwhelming demands of parenting children with FASD often in isolation and not knowing what is causing their child's behavior. They are frequently told the

problem is poor parenting. Early diagnosis and intervention is the key for families trying to mitigate against the effects of alcohol exposure. It helps families to change their expectations in order to build on the strengths of the child [3].

The constant vigil that parents must engage in with children who are living with FASD can be exhausting [4]. Brown and Bednar [5] found that families faced challenges such as experiencing setbacks with their children, finding time for themselves, making plans with their child, collaborating with the school, keeping the child involved in social activities, keeping their family involved in social activities, and managing behavior problems.

One theme emerged that had not been demonstrated in prior studies: parents felt that their expertise regarding the needs of their children was not well received or well accepted by other professionals. They did not feel valued. The research demonstrated that being involved with other service providers when parenting a child with FASD sometimes increased the stress felt by parents. Stress was further compounded by a lack of service coordination. Parents need support, not criticism [4].

## Method

### Participatory Action Research

Participatory Action Research (PAR) is a qualitative research method in which the participants design the questions, collect the data, analyze the information and create an action agenda [6].

Though PAR projects can differ in their methods and scope, they generally have several basic steps, including problem definition, getting to know the community, gathering participants, problem formulation, research design, data gathering, data analysis and utilization of results [7]. PAR can transform participants' lives through empowerment and social change [7-9].

### Setting

This project reconnected five women who were involved in "Picture This": Life as a Parent of Children with FASD. Each participant has parented children who have been diagnosed with an FASD. All participants reside in the community of Sioux Lookout, Ontario. They include two adoptive mothers, two foster mothers and one biological mother. Two of the mothers were parenting without partners, while the other participants were parenting with partners in the home. The researcher was also a participant parenting four children with an FASD diagnosis.

### Strategies for validating findings

To ensure internal validity, the researcher used a variety of strategies identified by Creswell [6], including member checking, using rich thick descriptions, clarifying researcher bias, demonstrating expertise, participatory verification and conducting of a peer review.

### Research Design and Data Collection

The dialogue was initiated and driven by participants throughout the process and this generated all of the data. A total of 5 group sessions were conducted. Each session was audio taped and transcribed. The final session occurred four months after session four. The participants were provided with information about the data analysis, results and discussions. They had an opportunity to review and edit the results. Changes were made accordingly.

### Data Analysis

An interpretive qualitative analysis described by Tesch [10] was used to analyze the data. Each session was carefully reviewed by the researcher. As themes, concepts and patterns began to emerge, pieces of data that represented a concept were tagged, color-coded and a brief description was put in the margins. A modification of the "cut out and put in folders" technique was used to organize the data, with specific color-coded sections being placed together under the appropriate descriptors [10]. The coded data was then reviewed. This process was completed approximately six times before significant themes were concretely identified. Once the themes were established, quotations were selected that best represented each theme. The identified themes and quotations were brought back to the group for verification.

## Results

### Hope and Confidence

The women felt that they had developed hope for themselves and their children.

**They stated:** It's incredible. My problems don't seem so bad either. You know what I mean? After doing this project and turning it into something that becomes something that encourages my life.

The participants believed that they were able to proceed on their journey as parents with more confidence.

**One participant stated:** But photo voice helped me to realize that. It helped me to start talking about it and not be ashamed to talk about it and finding out where we need to go and what we need to do. My life has changed dramatically.

### Education and Advocacy

The women felt that they had become educators and strong advocates for themselves, their children, birth mothers and other people living with FASD.

**They stated:** Just about raising kids with FASD... they said that they learned so much... So now I am an educator and a trainer, instilling hope, almost like a mentor to people who are in a different stage. I think that we all have that role. We have been put in that role. When we came here, we were just all talking, but I think we were just trying to figure life out and now we have shifted.

### Improved Parenting

The women felt that their parenting skills had improved and, as such so had their relationships with their children.

**They stated:** My whole parenting style improved 110%, and I never get frustrated with my kids when you have to tell them 10 hundred times a day, to do something. (all laughing). No exaggeration what-so-ever... And I have come out of here feeling like a more adequate parent than I was before going in and we will use it to influence positive action. So it has helped me to be a better parent and it has helped me to be less frustrated, less stressed at times. I am way better in that place.

### Building Bridges

The participants agreed that the photo voice project was more than just a research project. They discussed healing that took place between women. Since participating in the photo voice project, the mothers formed connections to support one another through difficult times and continue to do so.

**They stated:** The fact that photo voice had adoptive, foster and birth parents really made a difference and really brought out the differences in the situations. And that is what created the understanding factor. Absolutely.

The foster and adoptive mothers in the group were grateful for the insight and understanding that they had developed from the biological mother in the group, and her alcohol use during her pregnancy. They felt that they had a better understanding of the issues faced by biological mothers and could offer understanding to the mothers of their children because of this.

**They stated:** And for what insight, the blessing has been to be able to work with all of you guys and for the impact that "Deyanne" has had on my life -, coming from a biological aspect - and her dealing with it in her own family. She has given me a new and deeper... look into her own heart, as a biological mom, in dealing with not only her woundedness but also trying to reach out to her kids and try to be there for them on an incredible level. Like, what courage!

The women advised that learning about the biological mother's perspective helped them to build stronger relationships with birth mothers.

**One participant stated:** It helped me with my relationship with kid's Mom too - Big Time!

One of the mothers had spent a portion of her childhood in foster care and her experiences were less than positive. Getting to know the adoptive and foster parents in the research group helped her to heal.

**She stated:** I guess it just puts another side on what you didn't know either... You guys taught me a lot too, I seen these foster homes just as people who wanted money and then I met you guys, and like, well they are not all like that, thank God. (all laughing) And I see now, what an amazing job you guys do. Look at you - driving around all crazy (all laughing).

### Conclusion

The women believed that participation in the photo project, and its end product, has had a significant impact on their lives. They express more hope for their children as well as increased confidence as caregivers and advocates. They can see that they possess important expertise in the area of FASD and now use their experience to educate others. They have become better at parenting as they discovered more about the disability and learned to forgive themselves for making mistakes. But most of all, by building bridges among women affected by FASD, from all circumstances, they were able to use the empathy and love they had developed to build relationships with other birth, foster and adoptive mothers in their lives and the lives of their children .

The experiences of the women were similar to those articulated by other caregivers who have come together to share common stories about parenting children with FASD [11-15]. It is both a release and empowering for caregivers to understand that they are not alone in their challenges as parents. They will have more hope as they begin to advocate for their children and realize that they do have support [11]. The PAR methodology coupled

with the group process has significantly promising implications for future social work research and social action. The process builds on the personal strength of participants and empowers them to create change both on a personal and societal level, which would prove valuable when researching any social problem. Krista Lauer [1] discuss' this theme in her dissertation about the original photo voice project. She writes: Most of all, the mutual support and goodwill I watched flourish between the adoptive, foster and birth parents is the most encouraging outcome of the entire project. The photo voice process proved to be an effective mechanism for building bridges across disparate individuals- 41.

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