AN EXPLORATION OF THE EXPERIENCES AND PERSPECTIVES OF NEW ZEALANDERS WITH FETAL ALCOHOL SPECTRUM DISORDER

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ABSTRACT

Background
The experiences and perspectives of New Zealanders with fetal alcohol spectrum disorder (FASD) need to be heard since no research to date has been performed. FASD, a neuro-developmental disability with life-lasting effects, is irreversible. The condition is caused by prenatal exposure to alcohol.

Objectives
This study aimed to explore and understand the daily challenges of New Zealand individuals with FASD.

Methods
Our sequential mixed methods design used two discrete but compatible qualitative methodologies – transcendental phenomenology in Phase One and classic grounded theory in Phase Two – framed by the meta-theory of pragmatism, which allows the use of 'what works' in research. One methodology alone would not have answered our research question. Using the same sample of 14 individuals, 14 to 37 years, two separate data sets were produced sequentially using face-to-face unstructured interviews. Participants had been diagnosed with either fetal alcohol syndrome (FAS) or fetal alcohol effects (FAE). Data credibility was checked using triangulation.

Results
Six themes common to the participants' experiences emerged: daily challenges in the classroom; daily challenges in the workplace; coping with mental health issues; memory problems; socialization difficulties and involvement with the law and authority. Phase Two's emerging theory revealed that because the participants perceived they had been under-supported by the social/health systems, many engaged in illegal behaviours (secondary disabilities) and experienced employment and social problems. Many disavowed having the disability, but with maturity and knowing the signs and symptoms, accepted it. They suggested ways in which their concerns could be resolved.

Conclusion
In order that progress in this field can take place, health and social agencies, educational and criminal justice systems and policy-makers need to have increased awareness of the disability and the complex problems that individuals with the disability and their families face.

Key Words: *Fetal alcohol spectrum disorder, fetal alcohol syndrome, fetal alcohol effects, challenging behaviours, transcendental phenomenology, classic grounded theory*

Exposure to alcohol in utero, is the leading cause of neuro-developmental disabilities of known aetiology.[1] One consequence is fetal alcohol syndrome (FAS), which is the severe diagnostic form of a spectrum of birth defects (fetal alcohol spectrum disorder or FASD).[2] FASD is a clinical term and not a diagnosis. The other diagnoses under the FASD umbrella are partial FAS (p-FAS), alcohol-related birth defects (ARBD) and alcohol-related neuro-developmental disorder (ARND), which in 1996 under the US Institute of Medicine's nomenclature, replaced the

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earlier diagnostic term fetal alcohol effects (FAE). Since 50% of the participants in this study were diagnosed with FAE, this is the term that will be used in this paper.

The term FAS was first coined in 1973 by Jones and Smith to describe the characteristic dysmorphological abnormalities of children born to chronically alcoholic mothers.[3] Previous studies[4] have described cognitive, behavioural, adaptive, social and emotional impairments (primary disabilities) among individuals with FASD, plus intellectual and learning disabilities. These individuals also face challenging secondary disabilities that include mental health problems, school failure, alcohol/substance abuse, delinquency, trouble with the law and authority.[4] The cost of failing to prevent FASD is significant in mainstream health systems[5,6] where despite debate around the definitive diagnosis of FAS and the other diagnoses, the estimated prevalence of FAS is at least 2 to 5 per 1,000 with the prevalence of the other combined diagnoses estimated to be 2 to 4%.[7] The New Zealand Paediatric Surveillance Unit[8] predicted that between 20 and 112 children were born each year in New Zealand with the disability. This figure is considerably less than the expected number from overseas figures and it is not clear whether New Zealand actually has a lower prevalence than overseas or whether the estimate is just low and thus, falsely reassuring.[6]

Research is needed to build on previous studies in New Zealand[9] where the prevalence of alcohol use among women of reproductive age is high (>4 standard drinks per week)[10] reflecting a culture that normalises heavy alcohol use.[11] The characteristics of FASD described in previous research concern the effects of prenatal alcohol exposure on the day-to-day lives of those living with the disability.[4] Other research has focused on living with FASD from the perspective of young adults,[12,13] Canadian children[14] and parents and their children.[15] However, no study has sought to describe and understand the disabling effects of FASD from the perspective of New Zealanders. This paper therefore, reports a three-year doctoral project in New Zealand which was completed in May 2010. It gave the study participants a voice to describe and give meaning to their experience of living with FASD.

METHOD

This study sought to explore the lived experiences, perceptions and perspectives of New Zealanders aged 14 and over with FASD. Therefore, qualitative methodologies and pragmatism, as the philosophical basis for this mixed methods inquiry, were used. Ethics approval was obtained from the University of Auckland Human Participants Ethics Committee. Pragmatism uses the methods that are best able to answer the question posed in each situation. It gave us a method that philosophically embraces the use of mixed methods and eschews (if wished) the use of metaphysical concepts (truth, reality) that have caused much endless (and often useless) discussion and debate and presents a very practical and applied research philosophy.[16] It also defended our use of the ontologies and epistemologies of phenomenology and grounded theory in a single study as well as the ‘method slurring’ issue.

The study involved two phases whose methodologies are congruent in their assumptions about the nature of reality and knowledge. Phase One used transcendental phenomenology (TP) as the study’s supplemental component to produce descriptive accounts of people with FASD. Phase Two then used classic grounded theory (CGT) as the dominant component to understand the meanings grounded in participants’ experiences of their condition, as described in Phase One. We additionally applied CGT to the Phase One data to gather up and integrate textural findings that could not be used by the initial methodological analysis. This sequential mixed method design enabled us to address the study aim by triangulating different types of qualitative data, which were examined at different levels of analysis.

Purposive sampling was sequentially used for both phases, the sample being identified through three FASD agencies throughout New Zealand. Eligible participants were aged 14 and over, professionally diagnosed on the FASD continuum and able to converse verbally. The age of selection was chosen in order to elicit data relating to school and onwards. Recruited participants were interviewed once. Audio-recorded, face-to-face in-depth, unstructured questioning was used to elicit participant narratives that responded flexibly to their cognitive needs, avoiding

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complex questioning that could increase suggestibility, confabulation and acquiescence. Initial questions asked participants to describe their experiences of living with their disability.

Questions posed in Phase Two emerged from Phase One. Two participants were cognitively unable to retrieve information (ID3; 5). Each participant was given a food voucher in appreciation of their project assistance. Transcripts were sent to participants to approve. Those that were returned generally stated there was nothing to alter other than the spelling of New Zealand Maori place names. Five were not returned so were taken as read.

The data for the two phases were collected and analysed concurrently. Phase One used Moutaskas's modification of the Stevick-Colaizzi-Keen method of analysis[17] which suspends researchers' perspectives to focus on those of the participants and identify themes from non-repetitive and non-overlapping significant statements in their narratives. The analysis synthesised these themes into descriptions of what the participants experienced and how they experienced it, followed by a composite description of the meanings and essences of the experiences of the group.[17] Phase Two used Glaser's constant comparative method of analysis[18] in order to fracture the data into concepts, categories and themes with theoretical propositions emerging. Glaser[19] insists that the theory must respect and reveal the perspectives of the subjects.

RESULTS

Of 16 invited participants (many with a dual mental health diagnosis), 14 agreed to participate. The characteristics of the study participants are described in Table 1. From the interviews with these participants, Phase One generated six main themes essential to the participants' experiences.[16] Each theme is discussed in turn.

TABLE 1 Participants' Characteristics

Informant ID. No.	Age (years)	Sex	Ethnicity	Diagnosis	Related Medical Condition	Employed	School
1	16	F	Maori	FAE	Attention-deficit hyperactivity disorder		Special Needs
2	17	F	Maori	FAS	Seizures		Special Needs
3	16	M	Maori	FAS	Pectum cavas and scoliosis		Mainstream
4	14	M	NZ European	FAE	Attention deficit hyperactivity disorder		Special Needs
5	15	M	NZ European	FAE	Sotos Syndrome		Special Needs
6	18	M	American	FAS			Special Needs
7	27	F	Maori	FAS	Rheumatic fever and heart problems	No	
8	22	M	Maori	FAE		No	
9	24	M	Maori	FAE	Cerebral Palsy	No	
10	23	M	NZ European	FAE		No	
11	30	F	NZ European	FAS		No	
12	32	F	NZ European	FAS		No	
13	36	M	NZ European	FAS		Yes	
14	37	M	Cook Islander	FAE		Yes	

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Phase One

The disability revealed itself through invariant characteristics that constitute a thematic continuum of life events, beginning with the classroom. Movement along the continuum was impacted by substructures of the overall themes of daily challenges and coping issues.

Daily Challenges in the Classroom

Facing many challenges during their school years because of cognitive, attention and motor-performance difficulties, participants looked for ways to cope. The most frequently reported learning problems were [lack of] attention and repeatedly incomplete school-work[20] as confirmed by ID9: *"I've got school reports that said 'I would do well if I finished my work'".* Schooling appeared not to be valued. For example: *"If someone wrote something on the board and said 'You've got to write this down and understand it', I'd write it down alright and then I'd close my book. It was never important to me" (ID10).* Completing high school was a big challenge. One reason was being in trouble with the teachers. ID12 shared: *"I was always naughty. I was always in trouble with the teachers".*

Believing they were seen as 'different' from their peers, participants said they were 'picked on' and did not have friends. ID7 stated: *"I didn't have any friends. Nobody wanted to be my friend because I was different…they were bullying me hard".* ID11 commented: *"I started getting bad grades and I'd skip classes because I was afraid of the students".*

Struggling with class-work, feeling insecure and lacking self-confidence and self-esteem, many of the participants thus became truants or drop-outs, were expelled from school or sought solace in isolation. Issues that were identified as helping them overcome learning difficulties were: small groups of students (could withdraw when frustrated or overwhelmed);[21,22] visualization of classroom material; interest in subjects, which helped to engage their attention. ID6 stated: "*My attention-span; if it interests me, I pay close attention, but if it bores me to death, I just choose not to do it".* Also, school can be a positive experience if the teacher-student relationship is right.[19] ID13 explained: *"I had a good teacher at primary school who got the relationship right with me and I thrived".*

Daily Challenges in the Workplace

Cognitive and behavioural difficulties throughout their schooling were carried into the workplace. ID9 shared: *"Holding down a stable job is difficult; my attention goes very quickly. If I'm interested in something, I can hold my attention".* The search for meaningful activity therefore, was a driving force in their work lives as in their schooling. ID10 was *"…always having to ask the same thing over and over again"*

Many people with FASD also tire easily from having to think and concentrate harder than others. As a consequence they can generally only work part-time. ID8 stated: *"If I work more than 15 hours, I lose it. Then I get fired".* Other participants got 'fired' for not turning up for work, having frequently to be reminded of how to do the job or being too slow. ID14 disclosed*: "I've got fired for not turning up and speaking my mind when I'm frustrated".*

Some older participants also reported experiencing discrimination by employers and colleagues, ID13 recounting: *"…passed the drug test, got eight weeks into the job and then they found out that I had a criminal record. They said: 'Your work ethics good, your work is top-notch, but we can't keep you on'".*

In response, participants suggested that doing things differently was a solution, not merely a problem, because it allowed them to overcome some difficulties. ID14 said: *"I think outside the square to make things easier for me",* which he used to explain why he had generally managed to find paid work that gave him value and self-esteem.

Coping with Mental Health Issues

Mental health issues were on-going with many participants taking medication. Their lived experiences of failure, marginalisation, oppression and violence underlay their poor mental health as reflected in mood swings, anxiety and feeling insecure. Depression appeared to be linked to losing a job, despair over childhood abuses, lack of hope for the future and excessive drinking. ID13 stated: *"At times I get run down. I get very pissed. I miss my kids".* The use of alcohol and drugs was another common mental health concern. The same person disclosed: *"I'd go and drink to cope. That was my only relaxant";* so

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alcohol was a cause and consequence of mental ill-health. These experiences affected virtually all areas of the participants' lives, including their employment, education, family and other social relationships (e.g. custody of children).

Impulsive thoughts appeared the most challenging mental health issue for all participants. Unable to process information and follow rules, they reported acting without thinking.[23] ID14 explained: *"You get these impulses and you act on them. You know they're wrong, but you can't control it".*

As a consequence, some of the participants reported difficulty in managing money; others spoke of their anger problems, borne of frustration or gullibility. ID13 was: "*…as gullible as hell and I've been ripped off many times. Then I get frustrated and take it out on the closest person to me".*

Anger could quickly turn to rage fuelled by alcohol use: *"I would drink to get drunk and then try to fight people"* said ID10. Impulsivity also led to stealing[9] with ID13 acknowledging: *"If I saw something that I liked and there was nobody around, it was mine".* Stealing cars gave the eldest male (ID14): *"an adrenaline rush and an addictive thrill".* Said ID9: *"I'd think of the consequences, but it didn't matter".* The youngest participant (ID4), when bored, *"would light fires".*

Also reported was suicidal ideation: "*I used to cut my wrists when I can't handle [life] any more"* (ID8). A quarter of young people with FASD threaten suicide and more than 10% attempt suicide.[20]

Memory Problems

All participants reported daily forgetfulness.[23] For example: *"My memory blocks itself out so that everything to me is new. Every day is a new day, everything that I do is a new thing and even though I might have done it a thousand times before, it's still new. My long-term memory is the one that reminds me of the things that I've done before*" (ID10).

Some participants forgot to make appointments,[23] whilst others commented that they repeat similar mistakes since they do not learn from past experiences.[24] ID10 and ID1 could be exceptions since the former said he "*Never did the same thing again";* the latter adding: *"It's pretty much once a year, I always have one mistake and the rest is fine".*

Socialization Difficulties

Socialization difficulties included communication problems as ID13 confessed: *"I'm not very good at getting out what's in here* [pointing at head]. *I find that what's in here and what I want to say are two different things. People take it the wrong way".* As a result people with FASD frequently feel socially excluded, lonely and desperate for friendship and intimate relationships. Many participants described how they chose the 'wrong' people to associate with and the friendships they made seldom lasted.[25]

The participants attributed their difficulty in making and keeping valued friendships to others seeing them as 'different.' ID9 explained: *"People don't realize that I have stuff going on with me until I've told them and it's changed their perception of me totally! Then they don't want anything to do with me. It's almost like they think it's contagious*". ID10 added: *"Every partner I've had, it's turned into disaster. I'm too high maintenance".*

Socially and emotionally much younger than their years, they tend to intrude on others' personal space. Learning difficulties, faulty information processing, impulsivity and poor decision-making skills add to their socialisation difficulties.[26,27]

There was an increased risk of others exploiting their on-going pursuit for friendship.[25] Wrong choices of peers led to inappropriate activities with them.[27] *"I seem to be attracted to the wrong type of people. I was hanging out with the bad guys and went on the drink when I was 17",* stated ID8. ID13 added, *"I bent over backwards to make people like me and they just turn round and shit on you".* However, ID2 chose her friends wisely since she *"…would not mix with the naughty crowd".*

Involvement with the Law and Authority

Most of the participants had been in trouble with the law, but only one had been incarcerated. He said: "*I've had everything from community work to jail. I'm not scared of any of it*" (ID10). ID14, suffering voyeurism, was "*…into cars, shops and burglaries. I've got an extensive record, but I've never been to jail*". ID12 was still at school when she encountered the law: *"I got done for shoplifting in a school uniform"*. ID9 who stole, felt: *"I was more intelligent than the law 'cause I never got caught".* The 17 and 30 year old females were the

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only participants who said that they had never stolen (ID2; 11). ID13 and ID12 mentioned drink-driving related offences; the former admitting: *"I've got about 46-odd driving-related charges and nine drink-driving charges".* The latter confessed: *"I'm coming up to my fourth DIC"* (drunk in charge).

Authority for ID8 meant 'the law' – *"When someone asked me something (judges), I wanted to say it the right way, 'cause I don't want to get in trouble".* Many of the participants expressed their dislike for authority: "*When it came to the police and the court system and anyone else who would try and put that authority in my face, I didn't want to know*" said ID10. Four others exclaimed individually: *"I don't like being told what to do"* (ID7; 9; 10; 14). That difficulty is common among people with FASD.[27] Frustration with and truancy from school, workplace difficulties, relationships with peers involved in crime and impulsive behaviour all appear contributing risk factors.

Phase Two

Related concepts and relationships from Phase Two data analysis were drawn upon in order to reveal the emerging theory. This theory, as discussed below, sought to explain and help resolve the main descriptive challenges as well as revealing the perspectives of the participants in Phase One.[17]

People with FASD Feel Under-Supported in the Social and Health Systems

Older participants raised concerns with the social and health systems and their professionals in respect of their reported attitudes towards them. In one reported case of discrimination, an offspring had been removed from the care of his biological parents by a social agency. As ID7 stated: "*They are discriminating against us because we have a disability".* The chronic stress, unpredictability and isolation produced by this perceived social stigma of people on the margins of society added to their difficulty in functioning as parents with FASD. ID13 reported near-poverty issues: "*I was finding it so hard to get by. I owed the landlords two and a half thousand dollars in rent".*

Receiving a professional diagnosis of FASD also appeared difficult. *"It is of no help"* was the reason that ID10 believed he was not initially diagnosed. Some participants felt that they could not trust the health professionals because of negative comments and stigmatisation. ID9 commented: "*When someone tells me that you can't do that and it's a negative thing, I'm like, 'Yeah, I can do that'".* Perhaps doctors' negative remarks were intended to motivate their patients into proving otherwise.

Incorrect medication and lack of knowledge by doctors, as perceived by the participants, further eroded their trust. ID12 elaborated, *"I've taken this medication and I've been going to pits. The psychiatrist put me on these. I don't think he knows much about fetal alcohol".* Many had been prescribed Ritalin (mephylphenidate), which is generally prescribed for attention-deficit hyper-activity disorder (ADHD) and experiencing side-effects, gave it up. ID10 exclaimed *"Made me more psycho, so I stopped taking it".*

People with FASD are seen to have Criminal Behaviours

All participants in the middle and older age groups reported mental health behaviours from alcohol and recreational drug usage. Pain and anxiety relief, boredom, addiction and impulsivity were major reasons. For five individuals marijuana calmed them down: *"I was pretty stressed when I was younger. When I had a smoke, it used to go away. It was my pain-killer in a way,"* said ID10. Hyper-reactivity to stress may contribute to this drug use which can lead to the development of psychiatric and behaviour problems as well as to legal system trouble.[28] They begin abusing tobacco, marijuana and alcohol at an early age, perhaps because these substances have been part of their prenatal environment and biologically predetermine them to 'self-medicate' to feel normal.[20] ID 13 confirmed: *"My mother let me have a cigarette to put me off them when I was two years old. Apparently, I smoked it like I'd been smoking for years!"*

Keeping oneself occupied is a means by which one can quit drinking.[29] ID10 recounted: *"When it comes to the alcohol side-of-things, I really need to stop, but I find it hard to do when boredom kicks in".* Through its consumption, anger resulted*: "I got so wound up, I stormed out of the house, stormed up the road, got 3-4 kilometres, when a cop grabbed me. I turned round and beat the shit out of him!"* exclaimed ID13. It is thought that the problems of

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adolescence subside when young people with FASD enter their late twenties.[30]

A few older participants became involved with the justice and/or legal system, e.g. through sentencing, assessment of fitness to stand trial and dealing with people working within the justice system. They reported that the police were uninterested in them having FASD. ID13 commented: "*As far as they were concerned, I was just drunk and disorderly and they were going to subdue me however. I was charged with assaulting police".* ID10 added: *"All the police care about is making sure they've got a conviction. It's for the judge to decide if he cares: even then, they've got my report. I don't expect to be getting off with a slap on the wrist, but they don't offer any help".*

The principles of sentencing are based on cognitive functioning and reasoning abilities that may not be present in people with FASD[31] as ID8 discovered: *"The courts had to examine me to see if I was fit to stand trial because I didn't know what was 'yes' and 'no'".* These individuals appear to others to understand more than they do. For them to receive fair treatment and appropriate support, their disabilities need to be accommodated within the criminal justice system.

Of note is that only four individuals were reared or being reared by their biological mothers. Ten individuals had been in trouble with the law, twelve individuals dropping out of or being expelled from school. This disrupted school experience may help to account for their involvement with the criminal justice system.[20]

People with FASD Grow Up and Look Back

Some older and middle-age participants acknowledged their FASD and its impact on their families and themselves by identifying with its signs and symptoms. They described what they felt society should do to help improve their quality of life. Many initially disavowed[32] having the condition in order to look and appear 'normal'. ID11 disclosed: *"When I look at photos of me when I was a kid and a baby, I don't think I look different".*

The literature and other people's stories describing FASD behaviours enabled two participants to identify with it. ID13 confessed: *"Now that I've heard other stories, I can see it".* Their own knowledge of signs and symptoms can act as a support strategy as it helps them to understand themselves and be understood by others.[29] Reported signs and symptoms included forgetfulness, being attracted to the wrong people, naiveté, victimization and immaturity. ID6 shared: *"I'm as forgetful as a weasel!"* As regards victimization[33] ID13 explained: "*I've given things to people, then been ripped off. They were only out for whatever they could get. I see that now".* Others, being far younger than their chronological age, are often attracted to children as friends.[29] ID9 stated: *"I'm immature. I have a younger circle of friends".*

A few older participants believed that with maturity came the ability to realize that as naughty children, their parents suffered. ID14 confessed: *"When I was growing up, I was a little shit – totally did the opposite of what I was told to do".* Because of challenging behaviours in their formative years, stress and frustration became the perceived norm for their parents – which are documented problems when caring for individuals with FASD.[34]

Some older participants stated that the loss or weakening of relationships, friendships, self-esteem and identity during their lives were major issues. ID10 said: *"…it's destroyed a lot of things in my life – relationships, friendships, everything! I don't even know who I am…thinking that I was this. I was insecure being told that I was stupid, dumb".* They have heard parents and teachers describe them as 'stubborn', 'deviant', 'not motivated', whereas in fact, they are overwhelmed with the sights, sounds, smells, textures and information bombarding them.[35]

ID8 and ID13 felt that a support person in the workplace and home would help them cope with numerous issues: "*I reckon if I had a support person at work, I wouldn't have to rely on anyone"* said the 22 year-old. They also require a quiet environment and slow-paced work[36] with people trained and knowledgeable in FASD. Investment in such ideas and policies could decrease their involvement with the law.

ID11 believed that people of her age should be allowed independence: *"It's unfair, my age and still living with mum and dad and not having the freedom to go out and I'm 30!"* Group homes are an option. She requested more 'safe places': *"If they had activities where they socialize, feel safe, taught they are worth something, there wouldn't be the crime and a lot of gangs won't exist".* The final word on what needs to be done was expressed by the eldest participant: *"Fetal alcohol is not recognized here and needs to be. When they get done for it, they go to jail. If people recognized it, I feel that wouldn't happen"* (ID14).

CONCLUSION

Successful school experiences and positive outcomes can enhance the lives of children with FASD[26], but for these benefits to be achieved, the children require more structured support for a much longer time than do typically developing children.[37] Participants were born with cognitive, behavioural and psychological life problems, but their challenging behavioural and social problems were first widely noted on entering school. They conveyed a powerful and colourful picture of their experiences of having FASD. Throughout their lives they have struggled to survive and maintain a decent quality of life within a society where they have felt misunderstood, regarded as high maintenance, stigmatized, oppressed and different or deviant.

Since in many cases, a diagnosis was not made before six years of age, it was felt that secondary problems arose whereby primary and secondary disabilities filtered into all phases of their lives. Targeted interventions in childhood have been shown to reduce the risk for later secondary disabilities.[24] The participants meeting challenges as soon as they were born, continued to meet them at every step of the life-cycle, e.g. in the educational and health systems, the welfare state, employment and criminal justice systems. Accordingly, their lives were conveyed in paradoxical and dynamic terms. They revealed helplessness, depression, lack of self-esteem and self-confidence, alcohol/drug abuse, trouble with the law and attempted suicide. Yet hope also shone through for different ways of thinking, coping and overcoming challenges and restrictions within the community. They felt self-admiration in gaining paid employment in the face of adversity; frustration at not being normal and unable to carry out a job in a quick time; yet gratitude for maturity, which enabled them to look back on their lives and perhaps lessons learnt.

The study was based on a small sample. We cannot claim that its findings are transferable beyond the individuals studied who exhibited variations in intelligence. No attempt was made to validate the retrospective accounts from these individuals, two of whom could not cognitively-retrieve information or to elicit perspectives from other stakeholder groups. However, the use of both methodologies has been novel and advantageous in enriching and illuminating the research, with CGT enabling identification of what society should be addressing in order to help with improved quality of life for such disabled individuals.[38] The findings corroborate and build upon existing knowledge in the field. Some of the issues find wide support in the literature, such as lack of teaching strategies, primary and secondary disabilities of the disorder, isolation and segregation from community life, the complexities involved in making a diagnosis of FASD and the medications prescribed for this condition.

The study adds to understanding of how prenatal alcohol exposure can impact development across the life-course and suggests new paths to managing FASD. Understanding what individuals with FASD struggle with and what they look like from a clinical perspective is essential in helping clinicians diagnose and treat them and alleviate some of their more debilitating behaviour. It is hoped that this research, which has given voice to people with FASD, will advance the knowledge, attitudes and behaviour of professionals working with these individuals and their families in the field as well as providing an impetus for future policy development. Future research is needed to estimate prevalence and incidences of FASD but, for incidence rates to be calculated, the New Zealand Government will need to establish a national FASD Registry database.

There is much work yet to be done in understanding and improving the quality of life for individuals with FASD. To this end, hearing the experiences, perspectives and perceptions of individuals with this disability constitutes an important step. Our study supports a growing body of literature that attests to the ability of neuro-developmentally disabled individuals to bring insightful and meaningful commentary to their experiences, capacities, needs and quality of life. These findings invite future endeavours that foster adaptation, engagement in care and the growth and well-being of people with FASD.

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Declaration of Conflicting Interests

None declared.

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