

Submission on: The Green Paper on Vulnerable Children

From the: Fetal Alcohol Network New Zealand

This submission is made following consultation and a mandate from the Fetal Alcohol Network New Zealand (FANNZ)¹ to participate in this important public consultation. Key points are highlighted at the end of the submission with recommendations as to a positive way forward.

FANNZ is concerned with preventing and addressing brain damage that occurs in a baby when alcohol is consumed during pregnancy. Fetal Alcohol Spectrum Disorder (FASD)² is preventable. However in a society where the regular consumption of alcohol is pushed as essential to everyday life and identity and harmful levels are the norm, then children will continue to be born brain damaged by the product. That culture makes these children the responsibility of us all – not just the alcohol consuming mother. FANNZ has continually called for greater recognition and action for the problem associated with FASD because it can be helped and it is critical and cost-effective to do so.

The Issues

According to recent research, pregnant women in New Zealand are drinking and using other drugs during pregnancy at a rate that is at least four times that of the United States (Wouldes, 2012 unpublished; see graph in appendix 1). The conservative estimated rate of FASD in the USA is one percent of all birth making the potential rate of FASD in the New Zealand population

¹ The Fetal Alcohol Network New Zealand (FANNZ) is a group of several hundred individuals and agencies with a shared interest and expertise in FASD prevention and intervention. FANNZ is linked through an e-mail information network, face to face meetings, educational activities and affiliation internationally with other organisations with coordination provided by Alcohol Healthwatch www.fan.org.nz

² Fetal Alcohol Spectrum Disorders (FASD) is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications. The term FASD is not intended for use as a clinical diagnosis but includes a range of diagnosis that include Fetal Alcohol Syndrome. The majority of affected individuals with FASD, do not exhibit any outwardly physical signs of the syndrome but can have equally significant impairment to the central nervous system. This is diagnosed as Alcohol-related Neurodevelopmental Disorder (ARND) where such expertise is available.

four times higher at the very least. This difference is not surprising. Unlike the USA, New Zealand has no comprehensive plan to prevent FASD or to identify and assist affected children and families. The promotion and protection of liquor accessibility is given more attention than the harm it causes. In this environment, FASD will continue unabated while remaining overshadowed, ignored, stigmatised and at time disbelieved across society.

New Zealand has a hidden crisis with FASD and efforts to address it more comprehensively have continued to be dismissed and marginalised. After years of bringing the matter to Government attention, we do not believe our concerns are shared or have been taken seriously. We would like to think that this submission to the Green Paper on Vulnerable Children will not be lost in the avalanche of issues and that our continued efforts may eventually bring forth some appropriate and positive Government response.

The reasons in favour of working more intensively to prevent and ameliorate the harms associated with FASD are compelling. ***There is no more vulnerable child in society than the child whose brain and genetic potential has been permanently compromised by prenatal alcohol exposure.***

Alcohol is a teratogen, a substance that from conception onwards can mutate DNA and alter the course of normal cell development until birth. The primary insult to the brain can be compounded when combined with other drugs, but alcohol is singularly the most damaging of all recreational substances. This organic brain damage is hidden, yet it is very likely underpinning some of the big issues that New Zealand is grappling with - poverty, violence, crime, under-achievement, unplanned pregnancy and alcohol and drug abuse – which in turn is perpetuating the generational cycle of these problems.

A child whose genetic potential has been severely compromised in this way will struggle to understand and manage their learning and behaviour in a world that struggles to understand them. Without appropriate knowledge, understanding and support, these individuals become the adolescents, adults and parent who are readily judged as failures in our society – through no fault of their own. It does not have to be that way but it will take courage and commitment to change.

Babies do not begin at birth. During the first 9 months of prenatal development, the whole brain is susceptible to the teratogenic effects of alcohol with the result that multiple domains of the brain can be adversely affected - cognition, adaptation, attention, memory and executive function to name a few. The impact of alcohol before birth is as important as considering the impact that the post-natal environmental may have on the child's development.

The child damaged by alcohol, that is raised in an environment ill equipped to recognise and understood the brain difference and needs, is THE MOST vulnerable of all children. Children with FASD can be difficult and frustrating to parent. This can compromise the bonding process, increase the risk of attachment disorder and, in the absence of support, increase the chance of abuse and neglect. This has the effect of compounding the impact on an already damaged brain, rather than providing an environment conducive to optimum learning and development. However despite the evidence of multiple deficits, FASD is not being recognised and even when it is, it is not considered eligible for disability support in New Zealand. If it is not recognised the numbers of affected children remain unknown.

A loving stable environment is vital for every child's development and welfare. That is a given. However this alone is not sufficient to undo alcohol-related brain damage. Where there is knowledge, recognition and an understanding by the people caring for the child, there is a better chance the child will reach their potential – albeit limited – and the child thrives. Take away the positive supportive environment and the child's learning and behaviour rapidly deteriorates. The brain damage does not go away so neither should the support to accommodate the deficits. For the family it is an exhausting never ending battle and while most fight for their child's needs valiantly despite the obstacles, many others reluctantly give up at which point the child becomes someone else's problem to manage.

To date, the knowledge and recognition of FASD and what the vulnerable child with FASD needs to thrive has been seriously lacking among our health, justice and social service providers. Thanks to the small efforts of FANNZ, many do understand more clearly but the task is impossible without funding. The absence of well informed attention and care of the primary brain differences in a child with FASD – however well-meaning - can seriously undermine the child's mental health, create extreme stress in the family and lead to a spiral of more complex and entrenched layers of dysfunction and disorder.

Children with FASD are at extreme risk of developing secondary disabilities as they grow up³. Secondary disabilities are thought to occur largely because of the lack of recognition of the primary organic brain disorder and subsequent lack of appropriate treatment to accommodate and compensate for this throughout childhood and adolescence.

Secondary disabilities include the significantly increased risk of mental health problems, school suspension or expulsion, alcohol and drug problems, unemployment and trouble with the law. When they are present in a child or adolescent they have usually escalated to the point that they are difficult and complex to unravel. Nevertheless, knowledge of the brain difference from

³ Burd, 2003; Fast & Conry 1999; Spohr, 2006; Streissguth et al, 1996.

prenatal alcohol damage can make the vital difference in helping the individual back on an acceptable pathway through life.

Judges in the New Zealand Youth Court have spoken out over their concern about the likely over-representation of youth offenders who may be affected by FASD⁴. There have been calls for a prevalence and assessment study to be undertaken to try and ascertain the likely numbers coming before the Court and to develop appropriate interventions. An application for a one-off funding grant for such a project has been before the Ministry of Health for consideration since October 2011.

Early identification of FASD is the opportunity to put in place measures that protect the vulnerable child from factors known to increase the risk of such problems emerging in the first place. Viewed in this way, intervention is prevention.

The FASD disability does not go away when the child reaches adulthood. ***The child with FASD today, becomes the parent of tomorrow.*** While they can be a very loving parent, the young adult with FASD will struggle to parent successfully and without extra support their parenting decisions can have disastrous consequences. Many find it difficult to find or maintain even unskilled employment and have to rely on welfare to survive. If they have been able to maintain the custody of their children, then it is usually thanks to the efforts of others, particularly their caregivers who must carry the double burden of caring for two generations (three if they are also caring for elderly parents). Families dealing with FASD need the type of respite and support that the system is currently denying them. Adults with FASD will be part of the poverty picture – though rarely does this connection come up in poverty discussion and policy.

When there is poor decision-making because of FASD, about their own alcohol and drug use during pregnancy, the cycle becomes trans-generational; damaged parents giving birth to damaged children. This is a situation all too common for children placed into the care of Child, Youth and Family Services (CYFS). However, that the parents might also be similarly affected can be overlooked when children are placed back with the birth parents. This is an area that needs careful consideration and attention.

There is no doubt that this paints a bleak picture that seems insurmountable. It is not and there are numerous ways in which the situation can be improved. Other countries have led the way and the time for New Zealand to rise to the challenge is well overdue.

⁴ O'Driscoll. NZ Law Journal 2011.

The Way Forward

We call on the Government to work collaboratively with the experts within the Fetal Alcohol Network – including the families who have raised affected children - on effective approaches to minimise the harm to children who have been rendered vulnerable by prenatal alcohol abuse.

We ask that FASD be accepted for the significant disability it is and be eligible for appropriate accommodations that are accorded other disabilities within Government funded services. Remaining hidden, neglected and misunderstood, FASD is not only adding to the burden of harm for families and placing unnecessary cost on society, it contributes to the continued high rate of alcohol use during pregnancy. Behaviour won't change if the problem keeps being swept under the carpet.

Children with FASD are already among us, so identifying them will not increase their numbers or their need for more services. Identifying which children have FASD means that - services can more appropriately direct their services; families can raise the affected children in a more enlightened and constructive way than before. That prevents deterioration and that is cost effective. It will require the reorientation of existing services so that they are able to do what they are already doing, a little differently. Services need to be sensitive, non-blaming and caring of women who have consumed the alcohol that caused the problem. FASD is the result of a societal culture, not one where the finger of blame can be pointed at the individual.

Establishing services that orient toward FASD, requires a short term investment until they become self sustaining over time. Failure to do so, results in the continual waste of time and resources on ineffective therapies and unsuitable programmes, designed for some other condition or expectation. If the current situation continues, we can expect the 'revolving door' of expensive, inappropriate care that never meets anyone's needs, to continue. A centre of excellence for FASD to guide clinical training, assessments and research is needed in New Zealand. The one-off ad-hoc approach is ineffectual and insufficient for a problem of this magnitude.

New Zealand does not need to reinvent the wheel. We have countries such as Canada that have worked to improve the lives of children with FASD and their families for decades and their willingness to support and guide us in the way forward. Alcohol Healthwatch on behalf of FANNZ has been able to utilise this help effectively for the small progress steps that have been made and are very grateful for all that these dedicated and generous people have contributed to date.

The USA and Canada in particular has recognised the cost of ignoring FASD and have in place comprehensive strategies for prevention, identification and intervention. Australia is moving in that direction. FASD in Canada is recognised as being a significant issue for children in care. In

British Columbia for example, strategies have been developed that better support these vulnerable children and their families. One example is to assign families with a **Keyworker** to facilitate services and interventions needed by the family and affected child (see Appendix 2).

The Keyworker model is not only to make life simpler and less stressful for families and the affected child, it reduces the constant problem of service duplication that ties up the workforce that is best used elsewhere and ultimately saving the taxpayer's money. Perhaps New Zealand is not so much short on services, but short on the rational coordinated and effective use of the services it has.

Identifying and diagnosing FASD is not the major problem it is often portrayed as. To diagnose it accurately, does require a comprehensive team approach by trained professionals. However the difficulty is not the ability to do this. The problem is that New Zealand has failed to invest in consistent and comprehensive diagnosis.

Recently a small group of clinicians, thanks again to a one-off grant, have provided some training in multidisciplinary diagnosis and intervention planning and this has been integrated into existing assessment services. That work has shown that the investment of time has improved outcomes for the child, family and community services⁵. The child has their needs better understood and addressed; the family/whanau is better supported by information about what works best; community services are better informed and more able to respond appropriately; the community awareness of FASD and its prevention is increased; the diagnostic team is better equipped to provide adequate differential diagnosis of developmental disorders.

FASD multidisciplinary diagnosis is also an effective prevention tool. Not only does it help to prevent deterioration for an affected child and family, the awareness of the causal pathway of harm raises the opportunity to inform and prevent further children from being affected in that community.

However at present the vast majority of child health services (CHS) and/or child and adolescent mental health services (CAMHS) throughout New Zealand are not structured in a way that enables multidisciplinary assessments appropriate for FASD to set up easily. This is not so much a funding issue as it is a structural barrier issue. FASD involves multiple brain domains that require assessments that do not fit neatly into existing contracted services, making it more difficult for multidisciplinary teams to form and work together collaboratively. For example, CHS may not include neuropsychological services which, where they exist, are more likely to be part of a CAMHS team – that does not assess for FASD. CAMHS services assess referrals for mental health problems not developmental problems – which may be the root cause of the

⁵ Alcohol Healthwatch - Fetal Alcohol Spectrum Disorder Multidisciplinary Diagnostic Services Training Project: Final Report to the Alcohol Advisory Council June 2011.

mental health problem. Access to speech language⁶ assessments are limited and rarely available for adolescents and yet these are fundamental to an accurate FASD assessment.

Currently there is only one service that has been able to integrate a comprehensive referral and assessment pathway for FASD diagnosis and that is effective because they were set up to operate in this way in the first place. The Developmental Assessment Programme at Hawkes Bay DHB is a model of how FASD assessment can be integrated and work successfully in a region.

The lack of appropriate FASD –focused services, does nothing more than push the problem onto other services and back onto struggling families – the dysfunctional revolving door syndrome. Fundamentally, a policy shift is needed to free up some initial funding of a centre of excellence to provide the training and mentoring to build FASD diagnostic capacity.

There is no doubt that assessment of FASD is comprehensive. Usually this is due to the often high and complex needs cases that are part of the presenting problems. However, these cases exist regardless and it is unacceptable and vitally important that they are receiving comprehensive, thorough and timely differential assessment that includes expert assessment for FASD. This is preferable to ignoring it and continuing with multiple visits to multiple services that leave everyone in the dark and increase the risk of deterioration.

These children are the collateral damage of our pro-alcohol society. If we care about vulnerable children then do something about alcohol. The babies, children and adolescents with FASD in our midst deserve a much better deal they have been given so far.

Key points in this submission about vulnerable children with FASD in the current system

- *The potential rate of FASD in New Zealand is four times that of the USA which has a rate of one percent of all births.*
- *There is no more vulnerable child in society than the child whose brain and genetic potential has been permanently compromised by prenatal alcohol exposure.*
- *Children do not begin at birth but at conception.*
- *The child damaged by alcohol, then raised in an environment ill equipped to recognise and understood their brain difference and needs, is THE MOST vulnerable of all children.*
- *A loving stable environment is vital for further development, but it cannot undo alcohol-related damage that has altered the underlying structure and function of the brain.*

⁶ Difficulties with speech language communication, is shown to be one of the most important indicators of FASD and a fundamental aspect of the team approach to diagnosis.

- *The absence of well informed attention and care of the primary brain differences in a child with FASD – however well-meaning - can seriously undermine the child’s mental health, create extreme stress in the family and lead to evermore complex and entrenched layers of dysfunction and disorder.*
- *What is not happening regards these secondary social issues, is the link back to prenatal exposure to alcohol and other drugs. By doing so, we can begin to shift the status quo back in a positive direction.*
- *The child with FASD today, becomes the parent of tomorrow.*

Key points in this submission about what is needed to improve the outcome

- *Children with FASD are already among us, so identifying them will not increase their numbers or their need for more services.*
- *Identifying them and their needs can help to prevent deterioration - and that is cost effective.*
- *New Zealand does not need to reinvent the wheel.*
- *The Keyworker model is an example of a way to not only make life simpler and less stressful for families and the affected child, it is a role that can reduce the constant problem of service duplication, tying up of other skilled workforces and ultimately saving the taxpayers money.*
- *Where training in multidisciplinary diagnosis and intervention planning has been integrated into existing assessment services, outcomes for the child, family and community services have improved.*
- *FASD multidisciplinary diagnosis is an effective prevention tool.*
- *Assessment of FASD needs to be comprehensive due to the often high and complex profile of the disorder. One comprehensive and thorough assessment is preferable than multiple visits to services for presenting symptoms and problems that never get appropriately and accurately assessed.*

Recommendations in this submission on vulnerable children with FASD

We call on the Government to:

1. Work collaboratively across Government and with this network to develop strategic direction and guidelines for FASD.
2. FASD as it affects children is not an issue that is the sole responsibility of one Ministry but it is one which requires a strong lead Ministry.
3. Acknowledge that FASD need to be a funded policy priority across health and social services so that children born affected might better reach their potential and so that fewer may be born affected in the future.
4. Remove barriers that prevent FASD being recognised as a disability and ensure individuals are treated according to need, not some arbitrary measure designed for a different type of disability.
5. Ensure children who come into the care of others are able to be accurately assessed for FASD in a timely manner so that their specific needs can be more appropriately directed to services who understand what is needed. Ideally early preliminary identification of FASD needs to be followed up around age 8 years by a team skilled in FASD diagnosis when executive function can be more fully and accurately assessed and intervention and protective factors can be applied that prevent secondary disabilities from arising .
6. Improve policy that ensures access to FASD diagnosis is appropriately and consistently being provided across all regions. This requires the guidance of a clinical centre of excellence for FASD that can guide and ensure consistent assessment across New Zealand. This will improve outcomes for individuals, prevent deterioration that can be the result in secondary disabilities and help to prevent FASD from occurring in the first place.
7. Improve the workforce for children by ensuring FASD knowledge, recognition and intervention education is fundamental for all social workers, teachers, police, youth justice workers and health professionals and delivered in a consistent sustainable basis.

8. Reorient programmes to better meet the special needs of children and their family/whanau affected by FASD. Traditional methods may not be as effective for FASD and there needs to be scope to try differently for this population.
9. Recognise that children do not begin at birth and this requires better integration and information sharing between maternal and child health services.
10. Ensure A&D services are sufficiently equipped and suitably skilled to positively and supportively meet the needs of women with children where there is a substance use disorder.
11. Facilitate the collaboration between services by removing barriers that preclude different services from working together toward effective change and innovation. This is particularly important for building FASD diagnostic capacity.
12. Ensure FASD is recognised as factor for vulnerability and ensure its implications and harm reduction strategies are accorded priority in any Action Plan for Vulnerable Children and Adolescents.
13. Fund these justified, much needed and overdue FASD-related services by hypothecating a proportion of the annual \$800 million liquor excise tax that currently end up in the consolidated fund.

For further information about FASD go to the Alcohol Healthwatch website www.ahw.org.nz or the Fetal Alcohol Network NZ website www.fan.org.nz or contact:

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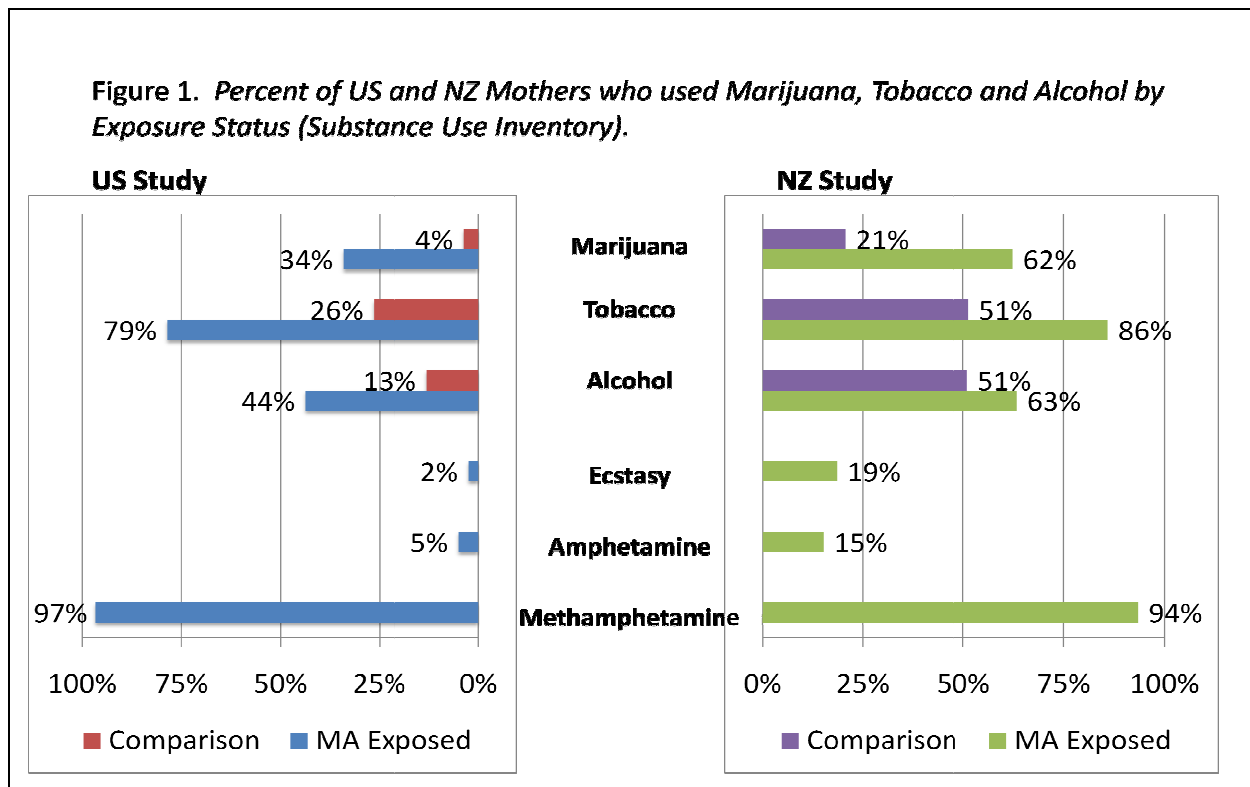
Appendix 1.

Wouldes et al, 2012 (University of Auckland unpublished)

A collaborative longitudinal study was developed at the Brown Center for the Study of Children at Risk at Brown University between 4 US sites located in Honolulu, Hawaii; Los Angeles, California; Tulsa, Oklahoma; Des Moines, Iowa and 1 international site located in Auckland, NZ at the University of Auckland which is under the direction of Dr Trecia Wouldes.

The US and NZ collaborative study provides the opportunity to study effects of social and legal policy and differing health systems on the management of maternal drug use as well as developmental effects of children exposed to methamphetamine and other drugs:

1. NZ Mothers in **both** the Methamphetamine group and the Comparison group were using more drugs than US mothers during their pregnancy and using them in larger amounts.



Appendix 2

Ministry of Children and Family Development KEY WORKER AND PARENT SUPPORT PROGRAM Time 1 Summative Evaluation Report: Executive Summary April 2008

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EXECUTIVE SUMMARY

What is the Key Worker and Parent Support program?

The BC Key Worker and Parent Support program, funded by the Ministry of Children and Family Development (MCFD), was initially based on research and practice evidence from four areas: research in Fetal Alcohol Spectrum Disorder (FASD) such as that conducted by Dr. Anne Streissguth and her colleagues (1996, 2004); Diane Malbin's Oregon-based FASD project (www.fascets.org); research in the disabilities field; and community-based, FASD-related parent support projects that were operating in BC at the time of the program's inception.

The purpose of the Key Worker and Parent Support program is to provide early intervention and support for families dealing with long term behavioural challenges associated with their children's developmental-behavioural conditions. The program evolved during the early stages of implementation to incorporate the following characteristics:

- Regional service delivery model that allows for regional variation and modifications to meet unique local needs and family circumstances

- Availability of an expert in FASD to provide consultation to regional MCFD offices and contracted agencies, in order to help facilitate learning and strategies related to use of appropriate environmental accommodations

- The Key Worker as a 'facilitator' who assists parents, family members, caregivers and service providers in the child's environment to come to a common understanding of the child's/youth's needs and to develop supportive environmental accommodations accordingly

- Key Worker supervision by a qualified professional
Training

What was the Key Worker and Parent Support program evaluation studying?

An independent and ongoing formative and summative evaluation was included as part of the program's implementation. The summative evaluation is examining whether the program's intended outcomes have been achieved. The overarching research questions for the Key Worker and Parent Support summative evaluation are:

- What difference have the Key Worker and Parent Support services made to *parents/families and/or caregivers?*

- What difference has the Key Worker and Parent Support services made to *children and youth* with FASD/CDBC?

What difference have the Key Worker and Parent Support services made to *community service providers and community partners*?

To answer these questions, the summative evaluation has involved a time series design, and qualitative and quantitative methods of data collection. Data were collected provincially from all Key Worker agencies; in addition, data were gathered face to face in 10 BC communities - two communities per each of the five MCFD regions. For the Time 1 summative evaluation, multiple methods of data collection were employed, including:

- Intake Evaluation Questionnaires with parents/caregivers

- Qualitative, semi-standardized interviews or focus groups with samples of program participants, (e.g., parents/caregivers)

- Qualitative, semi-standardized interviews or focus groups with samples of community providers and/or community partners

- Monthly output data, collected electronically

What are the key findings of the Time 1 Summative Evaluation?

The Time 1 Summative Evaluation Report provides descriptive findings regarding the characteristics of the families and children being served by the Key Worker and Parent Support program. Based on Intake Questionnaire data from parents/caregivers (n = 198 respondents):

- 32% were foster parents

- 23% were birth parents

- 20% were adoptive parents

- 16% were grandparents

Based on the cumulative output data, nearly two-thirds (64%) of the children/youth served by the Key Worker program were male. In all regions except the Fraser, at least half of the children/youth served by the program were of Aboriginal heritage and 34% were Caucasian.

About 75% of the parent/caregiver evaluation questionnaire respondents in all regions reported that stress was the most frequent challenge they faced. In addition, a high percentage of parents/caregivers reported facing the following challenges:

- Finances

- Parenting concerns

- Accessing community support services, and

- Isolation.

All questionnaire respondents identified one or more 'significant strength' for each child in their care who was the focus of the Key Worker program. The following qualities were rated most frequently by parents/caregivers as being a 'moderate' or 'significant' strengths for their child(ren):

- Experiential learner

- Relational

- Desire to please

- Visual learner

- Determined

In terms of secondary behaviours, parents/caregivers perceived that their child experienced a variety of secondary behaviours that were both school-related and of a more social/emotional nature. The most frequently reported secondary behaviour was **being frustrated in school**; school frustration was reported to exist for 73% of the children seeking Key Worker services. The social/emotional secondary behaviours most frequently identified by parents/caregivers to occur on a (very) frequent basis were: **anger**; **blaming others**; **disruptive behaviours**; **anxiousness**; and **aggression**.

Findings regarding selected secondary behaviours based on the child's age revealed that a

notably higher percentage of adolescents (12+ years of age) were experiencing certain social/emotional secondary behaviours, including: blaming others; suspension from school; depression; trouble with the law; and alcohol/drug use. Such age-related findings may not be surprising given that these high-risk behaviours are generally associated with teenagers rather than with younger children.

In relation to what difference the program is making for parents/caregivers, a strong theme in the community-based interviews with parents and caregivers concerned parents'/caregivers' understanding of FASD as a brain-based disability. The new information received about FASD helped parents and caregivers realize their child's behaviour was not as a result of wilfulness on the child's part, but as a result of their neuro-developmental disability. This understanding in turn led to different expectations for the child, and to a reframing of and response to their child's behaviours. Most importantly for parents/caregivers was the importance of thinking in terms of their child's developmental age rather than chronological age.

Learning about FASD also helped parents and caregivers gain a better understanding of their child's strengths and needs.

Dealing with the education system was a major issue for parents and caregivers, about which Key Workers often provided support and advocacy assistance. Successful meetings with schools contributed to reduced stress and frustration for caregivers and parents.

In relation to what difference the program is making for children, the community-based interviews revealed that, when parents/caregivers had the support of the Key Worker, and when the schools were receptive to learning how best to work with the children, parents reported that their children began to learn, stayed in school (instead of getting "kicked out"), liked going to school, and in some cases, received vital help in making the transition from elementary school to high school.

In relation to what difference the program is making for communities, the community-based interviews revealed that community-based practitioners of various disciplines were increasingly viewing Key Workers as a resource and a source of information and support regarding FASD. The enhanced understanding by community practitioners of FASD as a neuro-behavioural disability increased practitioners' understanding of a child's behaviour and thus their response to it, including making environmental accommodations. By turn, this led to changes in practice, approaches and skills.

At the same time, community practitioners involved in working with people with FASD wanted more professional and/or personal support in order to work more effectively with children/youth who have FASD and other neuro-behavioural disabilities. Less clear was whether community service providers felt that they were part of a broader network, or whether they primarily regarded the Key Worker as their sole source of information and support.

What were the implications of the findings?

There was great diversity in the types of families with whom the Key Workers are working – the differing family structures potentially presented unique sets of needs and challenges. Along these lines, parents/caregivers faced a number of challenges including stress and financial concerns. Furthermore, birth parents seemed to experience a greater number of stressors relative to other parents and caregivers. The information regarding the constellation of demographic information, the challenges parents face, and the relationship between the challenges and parents'/caregivers' sense of their own competence has implications for Key Workers' practice in relation to meeting the needs that parents/caregivers may experience as a

result of their circumstances. Along these lines, Greco and Sloper (2007) found that when Key Workers were sensitive to the needs and circumstances of the family as a whole, families experienced better outcomes overall.

Early outcomes for families and for children/youth

Qualitative findings from this evaluation show that the Key Worker program has been highly successful in providing families and caregivers with practical and/or emotional and advocacy related support. Similar to the findings from Greco and Sloper (2007), parents/caregivers identified the following as characteristics of the service that made a difference for them and their children:

- Assistance in accessing services;

- Assistance in helping parents and caregivers strengthen their voice with other service providers in the community, in particular with the education system;

- flexibility - being able to work across a variety of mandates to attend to the needs of the whole family.

Further, the provision of relevant, up to date information and education for parents about their child's abilities, along with information about appropriate environmental accommodations, was profound and contributed to changes in parents' and caregivers' behaviours and feelings of stress. In contrast, and not dissimilar to the findings from Greco and Sloper (2007), when parents and caregivers expressed frustration in this evaluation, it was in relation to:

- The lack of understanding, on the part of other service providers, of FASD as a brain based disability and of its impact on children's behaviour

- The difficulties and stress in accessing programs and services for their children.

Intermediate outcomes for families and for children/youth

Findings in this report indicated that there has been progress toward achieving some of the intermediate outcomes associated with social support, connections with community resources and parent/caregiver confidence. According to many parents and caregivers, the Key Workers have been instrumental in helping them strengthen social supports amongst their family and friends and in connecting them and their children with community programs and services. At the same time, while there is some suggestion that the program is helping to improve parents'/caregivers' confidence, it is also clear that those parents/caregivers who are experiencing stress, anxiety, and financial challenges, feel less confident in their parenting. While it is very early in the program implementation, there was early evidence that for some families, the overall program goal of maintaining and enhancing the stability of families with children and youth with FASD/CDBC was being achieved. Given that a stable living situation is a strong protective factor for children with FASD/CDBC (Streissguth et al, 1997), this is potentially very powerful.

Early outcomes for communities

In relation to outcomes for communities, what emerged was the importance of the broad nature of the Key Workers' position, as well as the relational nature of the role in creating positive relationships between the Key Worker and community service providers, and between parents/caregivers and community service providers. As described by Sloper and Greco (2006), "key working crosses the boundaries of different agencies and disciplines" (p. 452). This means that Key Workers need to be knowledgeable about a variety of community resources, services, professionals and organizations, and at the same time to be knowledgeable about FASD and families' circumstances. To the extent that Key Workers were able to successfully navigate their dual roles (i.e. with communities and with families), their success was based in part upon their ability to establish positive working relationships and to act as a bridge between community

service providers and families. When Key Workers were successful in maintaining that delicate balance between being an advocate for families and developing trusting relationship with service professionals, all parties reported benefiting through increased knowledge, more effective strategies for the children, and reduction in stress for the adults.

Another important outcome was that the Key Worker program was having a positive impact on the agencies in which the Key Workers were situated. The Key Workers were instrumental in broadening their host agencies' understanding of FASD as a brain-based disability, thereby further enhancing both the agencies' and communities' capacity to understand and work with those living with FASD. The addition of the Key Worker program also increased the ability of multi-service agencies to offer integrated and coordinated services by providing a unified conceptual framework for working with children and families with FASD/CDBC.