CROSS PARTY GROUP ON IMPROVING SCOTLAND'S HEALTH: 2021 AND BEYOND MEETING

26TH FEBRUARY 2020, 5.30PM TO 7.00PM

IN COMMITTEE ROOM 4 OF THE SCOTTISH PARLIAMENT

MINUTE

PRESENT

MSPs

Brian Whittle MSP	Chair and Co-Convener
Kenneth Gibson MSP	Co-Convener

INVITED GUESTS

Aliy Brown	FASD Hub
Fiona Aitken	Adoption UK Scotland
Carolyn Wilson	Scottish Government
Ashley Goodfellow	Scottish Government
Sarah Brown	NHS Ayrshire & Arran
Jennifer Shields	NHS Ayrshire & Arran
David Zammitt	NHS Ayrshire & Arran
Mary Ross Davie	Royal College of Midwives

OBSERVERS

Hannah Appleton	University of Edinburgh Medical School
Lisa Abraham	University of Edinburgh Medical School
William Campbell	University of Edinburgh Medical School
Sophie Creamer	University of Edinburgh Medical School
Ella Crowther	University of Edinburgh Medical School
Zac Finch	University of Edinburgh Medical School
Seraphima Goeldner-Thompson	University of Edinburgh Medical School
Anna Nahebel	University of Edinburgh Medical School

NON MSP MEMBERS

Christina Buckton	The Institute of Health and Wellbeing, University of Glasgow
Shona Cardle	Glasgow Children's Hospital Charity
Alison Douglas	Alcohol Focus Scotland
Sheila Duffy	ASH Scotland
Laurence Gruer	Individual Member
Kristin Hartman	ASH Scotland
Mathis Heydtmann	NHS Greater Glasgow and Clyde
Elizabeth Hurst-High	ASH Scotland
Simon Jones	Alcohol Focus Scotland
Jaden Jules	Intern with Brian Whittle MSP
Lindsey Murphy	NHS Health Scotland

Brian Pringle	West Lothian Alcohol Drug Partnership
Aidan Reid	Alcohol Focus Scotland
Helen Reilly	Royal Pharmaceutical Society
Jonathan Sher	Queen's Nursing Institute Scotland
Rebecca Sibbett	Alcohol Focus Scotland
Valerie Smith	ASH Scotland
Louise Slorance	Royal College of Paediatrics and Child Health Scotland
Debbie Storm	ASH Scotland
Diane Thomson	Alcohol Focus Scotland
Lorraine Tulloch	Obesity Action Scotland
Laurence White	University of Edinburgh

APOLOGIES

David Stewart MSP
Miles Briggs MSP
Alex Cole-Hamilton MSP
Alison Whiteman MSP
Anas Sarwar MSP

Annie Anderson	Scottish Cancer Foundation
Eric Carlin	Scottish Health Action on Alcohol Problems (SHAAP)
Julie Cavanagh	Faculty of Public Health in Scotland
Emma Crawshaw	Crew 2000 (Scotland)
Yasmin Erginsoy	Communications Manager to Kenneth Gibson MSP
Andrew Fraser	NHS Health Scotland
Holly Gabriel	Consensus Action on Salt, Sugar and Health
Kenny Harrison	Local Licensing Forum, Argyll & Bute Council
Shruti Jain	Scottish Obesity Alliance
Colwyn Jones	Individual Member
Glenys Jones	Association for Nutrition
David Liddell	Scottish Drugs Forum
Andy MacGregor	Scotcen Social Research
Nicola Merrin	Alcohol Focus Scotland
Laurence Moore	MRC/CSO Social and Public Health Services Unit, University of Glasgow
Muriel Mowat	Befriending Networks
Elma Murray	Scottish Obesity Alliance
Jamie Pearce	University of Edinburgh
Bruce Ritson	Scottish Health Action on Alcohol Problems (SHAAP)
Tina Sabbagh	Obesity Action Scotland
Jardine Simpson	Scottish Recovery Consortium
R J Steele	Scottish Cancer Foundation
Drew Walker	NHS Tayside
Laura Wyness	Association for Nutrition

PART ONE		
		Action
1.	**Welcome by the Convener, Brian Whittle MSP** The Convener welcomed everyone to the meeting, in particular the guest speakers: Aliy Brown of the FASD Hub; Ashley Goodfellow of NHS Lanarkshire and the National Preconception Framework Group; Sarah Brown from NHS Ayrshire & Arran and Mary Ross Davie from the Royal College of Midwives. Co-convener David Stewart MSP was unable to attend the meeting.	
2.	**Declaration of Interests (Standing Item)** Members were asked to declare any updates to their original declared interests, and to highlight any conflicts of interest specific to today's meeting. There were no declarations.	
3.	**Topic Discussion: The National Preconception Health and Care Framework and opportunities to reduce risks to parents and children from health-harming products** The Chair introduced the guest speakers, and it was noted questions and discussion would follow. <u>Ashley Goodfellow, Consultant in Public Health, NHS Lanarkshire and Chair of the National Preconception Framework Group</u> Ashley Goodfellow began with background on the National Preconception Health Framework, explaining that we know that the health of mothers and fathers influences that of children. This area of work has received limited focus in policy and practical terms to date. Several areas across Scotland have been working on issues related to preconception, but the goal of the National Preconception Framework was to bring this work together at the national level. The Framework comes under Public Health Priority 2: A Scotland where we flourish in our early years, and the commitment to it arose from the *A Healthier Future* report. A working group with the Scottish Government, COSLA, ISD, several local Health Boards as well as individual experts was formed. There was also scope for 'critical friends' to be involved given that preconception health touches on many areas and input from other sources should be considered too. The working definition of preconception health focused on the mental and physical wellbeing and health of men and women during reproductive years, before and between pregnancies. Everyone could benefit from good preconception health, whether or not they planned to have a baby now or in the future. Preconception care sought not only to support people before pregnancy occurs, but to reduce the risk of unintended pregnancy. It was a continuum of care based on individual needs.	

Local work in Scotland indicated a lack of awareness of preconception health. Coverage of care was a challenge due to the roughly 50% of pregnancies which were unintended/unplanned as well as levels of provider and individual compliance with practice known to be beneficial.

The vision behind the framework was of a Scotland where parents and parents-to-be experience a safe pregnancy, thriving baby and rewarding parenthood. This included underpinning principles around enabling and empowering people, engaging meaningfully with people, promoting social justice and tackling inequalities, a whole systems approach and the continuum of care to be tailored to individuals' needs.

Wider determinants of health would be addressed in the National Framework along with a life course approach, making for a broad document. Its primary beneficiaries should be people of childbearing potential, both people who intend to become pregnant and those at risk of becoming pregnant unintentionally.

A wide range of supports, including contraceptive services, were necessary for individual health outcomes and societal or community interventions related to them.

Ashley also outlined some work around the development of the framework to date. A scene-setting chapter was being developed, in concert with ISD, and policy connections were being sought to see how this document could add value to existing strategies elsewhere. Health Scotland were assisting with an evidence review – while there was considerable evidence on what needs to exist, there was less on how this might be applied or what specific interventions might be most helpful. Logic modelling had been undertaken to identify actions and outcomes over a range of time periods. A health inequalities impact assessment had already been undertaken and had informed development of the strategy. A children's equalities impact assessment was planned too.

It was hoped to have the draft Framework finalised in Summer 2020, with consultation currently planned for mid-June.

<u>Dr Sarah Brown, Consultant Paediatrician at NHS Ayrshire and Arran</u>

Sarah Brown opened her presentation saying that FASD was caused by alcohol exposure in the womb and was the world's most common, yet unrecognised, neurodevelopmental condition. Autism prevalence stood at 1.2%, but even conservative estimates of 3-5% FASD in general population would mean that 165-275k people in Scotland were living with FASD. Research based on measuring biomarkers in meconium suggested that the true prevalence may be substantially higher. Some 40% of pregnancies assessed in a Glasgow Royal Infirmary study showed signs of alcohol exposure, and 15% had high levels indicating high, frequent binge exposures. A Canadian study of 6,000 pregnancies over 10 years suggested a life expectancy of 34 years for individuals living with FASD.

Scotland had one of the highest rates on earth for drinking during pregnancy. Alcohol exposure to the brain was essentially a brain injury before you are born – brain cells develop over time in the womb, but in an alcohol exposed time this development could be thwarted, causing a range of symptoms we recognise as FASD.

People often imagine that FASD arises from parental dependence, however it was now known that if there are 3 exposures to alcohol during pregnancy it would be worth

considering FASD as a diagnosis. People could drink to that level before knowing they are pregnant, with a binge exposure being 6 units. This is a particular problem in unintended pregnancies.

People with FASD had to work far harder to undertake the same tasks as people without FASD. Assessments of brain activity showed substantial levels of effort for people with FAS – "like having a 10 second child in a 1 second world" as the parent of one child with FASD put it.

People with recognised learning disabilities tended to do better, in part due to support, but FASD might not manifest in the same way and its effects crossed a disparate set of behavioural criteria. The demands of life were substantially harder for people with FASD.

The societal impact of FASD was dramatic, as the effects were life-long, rendering adults living with FASD particularly vulnerable. Lack of support and understanding for the needs of people with FASD was pervasive from early years, with one third of people under 12 studied by the FASD team exhibiting suicidal thoughts.

If we did not act the outcomes would be poor - 83% of people with FASD would be dependent on support, others would have trouble with the law, with maintaining family relationships and other elements of what we usually consider a fulfilling life. The response to these issues needed to cross infrastructural boundaries, with services and strategies to meet the diverse range of problems faced by people living with FASD throughout the course of their life.

<u>Aliy Brown, FASD Project Lead, FASD Hub Scotland</u>

Aliy Brown – explained that the FASD Hub Scotland was funded by the Scottish Government. It launched in June 2019 and was hosted by Adoption UK.

It was a tiered service with 4 people in the team. Tier 1 was a helpline available to all with specialist FASD advisors.

Tier 2 was direct support for parents/carers and professionals, with closer support for peer support or 1:1 help, and included two Facebook groups monitored by advisors, which was now a thriving online community with 184 members. Bespoke support for families could be ongoing telephone support or support to prepare for and attend school meetings, for example. Training was also available, delivered by people who were often parents or carers for C&YP with FASD.

Tier 3 would involve therapeutic services for people. It was not yet totally operational but would be coming online.

Aliy described a case study of the challenges of a family where one child lives with FASD and the interactions they had had with the service. The team began working with the family shortly before the hub launched, after being contacted through the helpline. The mother described her baby as "perfect, confident, bright until the age of 2" when things "changed overnight, like a volcano going off" with strange sensory behaviours and aggression or violence, including an apparent enjoyment in causing pain to the adoptive mother. Aliy pointed out that the mother in this case was a medical professional with lots of experience working with people with complex additional needs.

Aliy pointed out that this case had strong similarities with what the team knew of FASD. The mother had since said she felt the team was the first place she was listened to and by people who understood their experience. The family was now in a much better place, linked into peer support meetups and with telephone support through the journey to diagnosis. There had also been counselling for them as parents, as one parent relayed: "a lot of the problem isn't our kids, it's dealing with all the other things around it. Yes your children can be upset, dysregulated at times, but it's hard to deal with the rest of the world around your children." The family had spoken very highly of the support from the team, saying it was transformative and life changing.

Mary Ross Davie, Scotland Director of the Royal College of Midwives

Mary Ross Davie spoke about the impact smoking had on preconception. Erectile dysfunction among men and reduced fertility in women were substantial issues related to smoking. Midwives become involved at the point of pregnancy, during which smoking was known to dramatically increase the likelihood of various issues including miscarriage, placental damage and others.

These issues had huge, long-term psychological ramifications for the women who were affected. Smoking during pregnancy was associated with a 3x higher rate of being small for gestational age, 1.4x higher rate of preterm birth, increased risk of abnormalities and a more than 2x increase in the rate of neonatal morbidity. One in three cases of Sudden Unexpected Death were attributable to early days smoking or smoking in pregnancy. In addition there were significantly more upper respiratory tract infections in their first year for children raised in smoking households.

In more positive news, there had been a substantial decrease in the % of smokers being detected in neonatal care though the rates, especially among women from lower socioeconomic backgrounds, remained concerning.

Significant changes had been seen in Midwifery practice in the past 25 years, related to mothers' health. Discussion of health topics used to be avoided, so as not to risk the relationship with the mother or appear judgmental but now motivational interviewing and discussion in a positive manner were active elements of practice.

All women were now screened for smoking cessation at first booking appointment with midwife. Pregnancy could be a really positive point to discuss behaviour change with women, motivation was often high, but smoking cessation outcomes among women who smoke were poor. One programme gave cash vouchers to encourage smoking cessation during pregnancy, and saw 3x higher rates of quitting than the control group.

The link between smoking and stillbirth was substantial – a Scottish Government campaign around reducing stillbirth had 3 key messages for women during pregnancy: going to sleep on your side, monitoring your baby's movements and stopping smoking.

Questions and Discussion

The Chair thanked the speakers for their contributions and noted a personal interest having coached two different athletes who suffered with FASD but for whom sport was a substantial benefit. He asked about father's health as an issue.

Ashley Goodfellow said that during the discussion of the healthcare inequalities impact assessment as part of the National Preconception Framework it was strongly agreed that the health of both parents should be understood and supported.

Carolyn Wilson made the point that fathers had to be part of preconception health and to help support positive changes by their partners.

Sarah Brown welcomed the point about positive outcomes, recalling her presentation's description of the wide range of problems people may face but that a good quality placement or family setting – with capable advocacy around the child – could be very helpful. She added that as corporate parents and people around these children it was important to recognise the strengths they have, rather than ignoring them based on their performance in routine tasks or in reaching educational milestones at school. She added that positive settings could ameliorate so many of these issues.

Kenneth Gibson MSP said it was important that the father supports the partner by not drinking themselves. Having a partner who drinks or smokes makes it harder for women to quit. On FASD there was still confusion and lack of awareness amongst among the general public. The message not to drink at all during pregnancy was undermined by some medical practitioners who implied that some amount of drinking was acceptable.

Sarah Brown said that different genetic makeups might account for alcohol being metabolised differently by the mother and fetus. As a consequence there are groups who might have more or less effects from drinking during pregnancy. She said there is a problem of mixed messaging or poor understanding, partly facilitated by online discussions. She noted it was different for alcohol than other substances, such as tobacco and illegal drugs, that would never be seen as acceptable during pregnancy. She added that the evidence suggested that telling women not to drink in pregnancy was not effective. Instead a family-based approach was needed involving fathers and grandparents, to reduce the pressure on mothers to drink.

Mary Ross Davie said that Scotland is far ahead of England on this – the CMO in Scotland had been clear on never drinking during pregnancy for many years.

Laurence Gruer thanked the speakers for their contributions. He chaired a group for the Advisory Council on the Misuse of Drugs which led to the report "Hidden Harm." There was little thinking at that time on the involvement of other drugs. He asked if the speakers, specifically Ashley Goodfellow, had considered the response to illegal drug use and their links with other substances, whether tobacco or drugs.

Ashley Goodfellow responded saying it was something that there had been consideration of illegal drugs, prescription drugs and over the counter medications. The Framework's scene-setting chapter would include data related to the use of different drugs in pregnancy, and other sections would deal with this too.

Sarah Brown added that in a US study in the mid-1990s it was found that alcohol was the drug with the widest-ranging impact globally in pregnancy, but she did have concerns about the impact of synthetic cannabinoids alongside alcohol on fetal development. This wasn't currently asked about, so our knowledge of alcohol use typically relied on case notes. Alcohol use was commonly recorded without specificity, for example as "problem

drinking"– though *any* drinking during pregnancy is a risk. Sarah added that alcohol was the last taboo, we were getting there, but there are still hurdles.

Laurence Gruer observed that the revised prevalence estimates for FASD suggested as many as 200,000 people might be living with FASD across Scotland. He said this was astonishing - a population the size of Dundee.

Sarah Brown noted that the figure represented a massive jump compared to previous estimates but it was supported by statistics and anecdotal evidence. She pointed to issues in achieving diagnosis, which had a high threshold, and the fact that there were no current facilities for adult diagnosis of FASD, even in settings where it is commonly encountered like prisons, homelessness, criminal justice settings.

Aliy Brown added that FASD was seen across the care sector; in those settings it might be nearer a third of children affected. Exposure to alcohol during pregnancy did not necessarily imply FASD but it would be higher than in the general population. If alcohol exposure was not recorded adequately before birth and at the neonatal stage this made diagnosis far harder.

Sarah Brown added that attachment was commonly talked about, incorrectly as a response. Parents of children with FASD may be excellent parents, dealing with profoundly difficult, and changing, circumstances in their children. It was not a question of bonding, it was a question of the challenges they had to deal with.

Alison Douglas asked about prevention, given the challenge that many women would be drinking before they know they are pregnant. From a prevention perspective, she asked, how could we approach this in primary care? GPs may downplay the risks of drinking in conversations with mothers. How could we point out the risks of drinking and have the conversation much earlier, even when people are talking about fertility or contraception?

Sarah Brown responded saying there had been work on this; it had been part of the curriculum in some communities. Long-acting contraceptives were another key help in planning for pregnancy in the longer term, rather than relying on more instantaneous methods.

Ashley Goodfellow agreed with the need to ask about prevention, saying there were definitely missed opportunities. She said drinking could be asked about more, but was often not brought up. Work from the US suggested that "the one key question": *do you plan to get pregnant in next 12 months? (* https://powertodecide.org/one-key-question) was a good starting point to guide primary care interventions. This would also be addressed within the Framework.

Jaden Jules, asked what challenges there were around identification and diagnosis.

Sarah Brown said they are seeking to improve supports for young people, but pointed out that there were no adult services which could help people who felt they may have been misdiagnosed or undiagnosed. If you looked at the criteria for disabilities there were real problems – many children fell through the cracks and were seen with elements of developmental delay, dyspraxia or conduct disorders. Sometimes children might experience half a dozen partial diagnoses, 3 foster placements and few healthy attachments; instead it would be best to catch FASD early.

	Jaden Jules followed up with a question about how teachers and educators could best support students with FASD. Sarah Brown said there had been local resources developed on this. One was for understanding FASD for educational staff including dealing with diagnoses, trying to see these children through a different lens. She was happy to share these resources more widely across Scotland (N.B can be found in the infographic from NHS Ayrshire and Arran). Brian Whittle indicated his intention to bring this to a wider audience in the Parliament. Kenneth Gibson would work with him on this, building on his previous work highlighting FASD.	**BM/KG**
PART TWO		
4.	**Welcome to New Members and Apologies for Absence** The meeting welcomed several new members and organisations: Laura Andre a Master of Public Health student, the Association for Nutrition and the Glasgow Children's Hospital Charity. Public Health Scotland's membership application had been received and would take effect on 1st April 2020 when they begin operations. Scottish Families Affected by Alcohol and Drugs had left the group. The number of apologies received, as detailed above, was 5 MSPs and 25 non-MSP group members.	
5.	**Minutes of meeting – 18th September 2019** The Convener requested any changes to the minutes to be made known to the Secretariat as soon as possible.	**All**
6.	**Any Other Business** The Convener noted that The Royal Society of Edinburgh and The Physiological Society had asked to publicise their event "Improving Health and Wellbeing: Opportunities for Public Health Scotland" on 31 March 2020 at the Scottish Parliament. The Convener added that he went to an event on peer research in communities with young researchers in schools and was happy to share learning from the event, welcoming requests via his office.	
7.	**Further Meetings 2020** 17th June, chaired by David Stewart MSP 5.30pm-7,00pm, suggested topic: Future-Proofing Legislation [N.B. This meeting was cancelled due to the coronavirus pandemic]. 16th September, AGM, chaired by Kenneth Gibson – also AGM. It was hoped that the Minister for Public Health and Sport would be able to attend, as well as Angela Leitch, Chief Executive of Public Health Scotland.	