



Submission:

**Inquiry and review of current health assessment programs for children and young people**

June 2021

About ACTCOSS

ACTCOSS acknowledges Canberra has been built on the land of the Ngunnawal people. We pay respects to their Elders and recognise the strength and resilience of Aboriginal and/or Torres Strait Islander peoples. We celebrate Aboriginal and/or Torres Strait Islander cultures and ongoing contributions to the ACT community.

The ACT Council of Social Service Inc. (ACTCOSS) advocates for social justice in the ACT and represents not-for-profit community organisations.

ACTCOSS is a member of the nationwide COSS Network, made up of each of the state and territory Councils and the national body, the Australian Council of Social Service (ACOSS).

ACTCOSS’s vision is for Canberra to be a just, safe, and sustainable community in which everyone has the opportunity for self-determination and a fair share of resources and services.

The membership of the Council includes the majority of community-based service providers in the social welfare area, a range of community associations and networks, self-help and consumer groups and interested individuals.

ACTCOSS advises that this document may be publicly distributed, including by placing a copy on our website.

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Acronyms

ACTCOSS ACT Council of Social Service Inc.

ACTHD ACT Health Directorate

ADACAS ACT Disability, Aged and Carer Advocacy Service

AFI Advocacy for Inclusion

AMOS Adolescent Mobile Outreach Service

ASD autism spectrum disorder

CASP Community Assistance and Support Program

CSD ACT Community Services Directorate

CYPS Child & Youth Protection Services

FASD Fetal Alcohol Spectrum Disorder

FFT Functional Family Therapy

GP general practitioner

HCCA Health Care Consumers Association

NDIS National Disability Insurance Scheme

OOHC out-of-home care

Summary

The ACT Council of Social Service Inc (ACTCOSS) welcomes this opportunity to make a submission to the inquiry and review of current health assessment programs in the ACT for children and young people. The issues raised in the review span several areas of concern for ACTCOSS. Broadly, the ACT Government will need to commit to a real increase in spending on health services. There is also a need to implement key worker strategies to attract and retain health workers in the ACT. More specifically, this submission makes nine recommendations aimed at improving health outcomes for children, young people and their families/carers. Recommendations focus on the key areas of:

* Early diagnosis and early intervention for children with disability
* Health screening and access for young people involved with the youth justice and out of home care systems
* Taking seriously the role of families/carers in health and providing adequate supports.

In the course of developing this submission, we consulted with the ACT Council of Parents & Citizens Associations, ACT Disability, Aged and Carer Advocacy Service (ADACAS), Advocacy for Inclusion (AFI), Families ACT, and Health Care Consumers Association (HCCA). We understand that AFI and HCCA respectively are also making submissions, which we encourage the Committee to pay close attention to.

# Introduction/Context

ACTCOSS advocates for social justice in the ACT and represents not-for-profit community organisations. We believe that Canberra can be a just, safe and sustainable community in which everyone must have the opportunity for self-determination and a fair share of resources and appropriately funded services, including health services.

Child youth and health screening and assessment is vitally important for preventing long-term health and social issues. As ACT Health Directorate (ACTHD) and the ACT Community Services Directorate (CSD) acknowledge, ‘providing support early in the life of a person or problem may reduce the long-term impacts on individuals and tertiary care services.’[[1]](#footnote-2)

Yet, despite the importance and benefits of early support for both the healthcare system and individual receiving care, we note that, as of 30 June 2020, there were about 3,700 children under 16 waiting for an initial appointment with a specialist.[[2]](#footnote-3) Median wait times for a child to get a dermatology appointment were as long as four years, while for some urology patients it was more than three years.[[3]](#footnote-4)

We also hear – from disability and consumer peaks – of families travelling interstate for treatment for a range of common conditions, including but not limited to leukaemia, osteosarcoma (bone cancer), brain cancer, craniofacial abnormalities, cystic fibrosis, epilepsy, genetic conditions, Down syndrome, musculoskeletal issues, and severe gastrointestinal disease.[[4]](#footnote-5) This travel has significant, and sometimes devastating impacts on Canberran families both personally and financially.[[5]](#footnote-6)

We note and welcome the draft Territory-wide Health Services Plan 2021 contains ‘a particular focus on ... children and young people who need to travel between the ACT and NSW for their care or are transitioning from paediatric to adult services.’[[6]](#footnote-7) Yet more work needs to be undertaken to assist children, young people and families.

Broadly, the ACT Government will need to commit to a real increase in spending on frontline ACT Government and community health services to raise ACT service standards up to those of other jurisdictions. There is also a need to implement key worker strategies to attract and retain health workers. As the recent move towards commissioning appears to acknowledge, it will be vital to form partnerships with the community sector where there are shared workforce goals.

More specifically, our submission focuses on particular pressure points and gaps, which, while non-exhaustive, indicate areas for increased attention in the ACT health system’s engagement with children and youth:

1. Early diagnosis and early intervention for children with disability
2. Health screening and access for young people involved with the youth justice and out of home care systems
3. Taking seriously the role of families/carers in health care and providing adequate supports to families/carers including timely access to diagnostic services and therapeutic support programs.

This submission takes a broad view of health, encompassing not only physical but also mental health and wellbeing.

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| Recommendations* Commit to a real increase in spending on frontline ACT Government and community health services to raise ACT service standards up to those of other jurisdictions.
* Implement key worker strategies to attract and retain health workers in partnership with the community sector where there are shared workforce goals.
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# Scope of the Inquiry

The Terms of Reference are as follows:

1. That the Standing Committee on Health and Community Wellbeing inquire into programs in place in the ACT providing for children and young people to-assess the adequacy, availability, and implementation of the following:
	1. identify and review all aspects of current screening and health assessment programs and processes in the ACT for hearing, vision, speech, motor-skill difficulties, and general health of children and young people;
	2. identify and review in particular all aspects of current preventative programs and associated programs for screening, diagnosis, assessment and treatment in the ACT for Fetal Alcohol Spectrum Disorder (FASD);
	3. Identify and review current programs in the ACT providing services that address the support, treatment and assessment arising from diagnosis of anything requiring treatment in a) and b); and,
	4. any other relevant matters arising during the Committee’s inquiry.
2. That, as part of its inquiry, the Committee report on the implementation of the [*National FASD Strategic Action Plan 2018-2028* (the National FASD plan)](https://www.health.gov.au/sites/default/files/national-fasd-strategic-action-plan-2018-2028.pdf)[[7]](#footnote-8) in the ACT.
3. That, as part of its inquiry, the Committee report on the implementation of the [*National Action Plan for the Health of Children and Young People 2020-2030* (The National Action Plan)](https://www1.health.gov.au/internet/main/publishing.nsf/content/4815673E283EC1B6CA2584000082EA7D/%24File/FINAL%20National%20Action%20Plan%20for%20the%20Health%20of%20Children%20and%20Young%20People%202020-2030.pdf)[[8]](#footnote-9) in the ACT.
4. The Committee is to report its findings to the Assembly by the end of November 2021.

This submission focuses on early diagnosis, family centred responses and the implications of inadequate responses, including in the justice system.

# Early diagnosis and early intervention

There is consensus amongst health professionals, researchers and experts that early intervention and prevention programs support better outcomes for children, young people and their families in relation to physical health, mental health and psychosocial development.[[9]](#footnote-10)

In the ACT, people with disability and parent support organisations consulted by ACTCOSS have raised concerns about early diagnosis and treatment timeframes.

For example, families awaiting a diagnosis for autism spectrum disorder (ASD), have experienced 6-12 month waiting times for private psychologists, only to have that psychologist leave or retire after a short period of time. Not having a choice of psychologists means that the child may not have an ideal therapeutic relationship with a particular psychologist. We also hear that child development services are reluctant to diagnose a young child with ASD. Worse still, some parents have been told the child’s behaviour is a result of their inadequate parenting. Such accusations break down relationships between parents and health care professionals and can result in missed opportunities to implement vital strategies, which can have devastating, lifelong impacts. The diagnosis and treatment of childhood disability needs to be understood as interconnected with family experience. It is vital to ensure adequate early support (disability identification and support) is available to all family members (including parents, children, other family members as needed). This can have positive impacts for children, both in terms of both child health and child safety.

## Children’s mental health: 8-12 – the ‘missing middle’ years

There needs to be a range of investments in children’s mental health. We note from the 2020-21 ACT Budget that the ACT Government is continuing to deliver the successful Adolescent Mobile Outreach Service (AMOS) (a community-based mental health outreach service that provides assessment treatment seven days a week for adolescents aged 12 to 18 years).[[10]](#footnote-11)

Disability and family peaks are currently advocating for increased ACT Government funding for investment in mental health supports for children – particularly early intervention with flexible outreach for children in what is often termed the ‘missing middle’ years: 8- to 12-year-olds. We encourage the Committee to read the Families ACT submission to the ACT Budget 2019-20 which highlights mental health as the ‘leading health concern’ for children aged 8 to 12.[[11]](#footnote-12) An intense focus on teen mental health means that children in the 8-12 age group are often overlooked, and vital years for early intervention are lost. A focus on the ‘missing middle’ years is particularly important as the ACT moves towards raising the age of criminal responsibility (see below).

## FASD and impacts of potential changes to the NDIS

The ACT Government will also need to remain vigilant about proposed changes to the National Disability Insurance Scheme (NDIS). ACTCOSS are very concerned that draft changes to the NDIS appeared to tighten the set of conditions which constitute developmental delay, including removing ones attributable to a physical and mental impairment. While this interpretation requires further analysis, we would be very concerned to see the removal of early intervention supports for conditions like foetal alcohol spectrum disorders (FASD) or acquired brain injury as suggested in media reports.[[12]](#footnote-13)

ACTCOSS agrees with statements from disability peaks that NDIS support should not be stripped away from target population groups which appeared to be one of the impacts of draft legislation released into the public domain earlier this year.[[13]](#footnote-14)

Further studies have proven that:

the range of cognitive, social and behavioural difficulties a person with FASD may experience can render them more susceptible to contact with the criminal justice system, and pose challenges at each stage of the criminal justice process.[[14]](#footnote-15)

ACTCOSS would like to see increased investment in early identification and support for children with FASD, particularly as part of the ACT’s program of raising the age of criminal responsibility. Failure to do so may see children appearing in acute circumstances, falling behind at school, or set on a path towards the criminal justice system when they could have been diverted away.

While there are disproportionate impacts of FASD across community groups, it is vital to address FASD is a whole-of-community issue. Addressing the issue broadly both reduces stigma any one segment of the community and ensures that at-risk youth across the whole of the ACT community are identified and receive appropriate support.

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| Recommendations* Fully fund and implement the Disability Health Strategy with a focus on ensuring families can access specialist diagnostic supports for more conditions in the ACT as well as improving general responses and health access for children with disability.
* Prioritise early diagnosis, especially for disability and early intervention responses.
* Significant investment in not-for-profit mental health and wellbeing services as part of prioritising early intervention and prevention – especially for children 8-12 years of age.
* Use relevant powers under bilateral agreements for the National Disability Insurance Scheme to resist any changes to eligibility and support access to children based on impairment type, especially FASD and other cognitive impairments.
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# Young people involved with the youth justice and out-of-home care systems

## Children in youth justice

Research has shown that conditions related to health and development in children can increase the risk of engagement with the criminal justice system.[[15]](#footnote-16) This is, of course, not because young people with disability or poor mental health are inherently more criminal, but because they are more likely to face socio-economic disadvantage and marginalisation.

There are many health determinants of offending, however, the ACT currently does not have accurate data on health issues faced by young offenders. A recent Healthy Centre Review of Bimberi Youth Justice Centre (the Review) notes that:

Bimberi does not capture data on young detainees who identify as having a disability and who require reasonable adjustments, nor whether a young detainee has a National Disability Insurance Scheme (NDIS) plan.[[16]](#footnote-17)

Anecdotal reports suggest that virtually all children in the Bimberi Youth Justice Centre have a disability. Overwhelmingly, children who receive youth justice sentences have unmet needs that we must respond to therapeutically. Even though young people with disabilities are overrepresented in the youth justice system, there is currently no clear screening mechanism to identify and support the needs of those young people at Bimberi. Bimberi does not currently provide adequate training in disability awareness for youth detention officers and there is no data collection on the health needs of young people at Bimberi, even though similar data is collected in other jurisdictions. As the Review notes:

Collecting data on disability to better understand and respond to needs could greatly improve Bimberi’s interaction with and models for working with young detainees with disabilities across health, education, and social engagement.[[17]](#footnote-18)

Enhanced health screening for Bimberi youth with disability and the collection of related data would greatly assist in identifying what health factors may be better diagnosed early and responded to therapeutically rather than through the criminal justice system.

The Review also found that ‘Bimberi lacks a comprehensive and coordinated throughcare approach.’[[18]](#footnote-19) Areas of particular concern include:

ensuring young detainees eligible for an NDIS package are supported, and ensuring young detainee have access to appropriate community-based health services.[[19]](#footnote-20)

Throughcare from the point of release may provide former detainees with supports to continue therapeutic treatment outside of detention and this may assist to reduce reoffending. Given the high rates of recidivism in the ACT, adequate investment in supportive throughcare programs is essential for the care and wellbeing of young people exiting Bimberi.

## Raise the age

The ACT is moving towards raising the age of criminal responsibility to at least 14 years of age. This provides a real chance of responding therapeutically to children’s needs and diverting them away from the criminal justice system. To ensure every chance of success, alongside raising the age of criminal responsibility, the ACT Government must continue to fund non-justice areas including health screening, early childhood services, child protection, youth homelessness, psycho-social disability and family violence.

## Children in the out-of-home care system

The Our Booris, Our Way review into the care and protection of Aboriginal children in the ACT made 28 recommendations to improve the ACT’s child protection system. The report placed emphasis on ways ensuring the safety of Aboriginal children and reducing the overrepresentation of Aboriginal children in out-of-home care (OOHC). The report highlighted the importance of an integrated response to child wellbeing and safety, including the health system. The report stated:

To maintain the possibility of restoration, families need to access services beyond child protection, across all other areas of government, particularly education, health and housing must engage to wrap around the key services for families.[[20]](#footnote-21)

While ACTCOSS contends that the ACT Government must implement all Our Booris, Our Way review recommendations, we would like to draw the Committee’s attention in particular Recommendation 14 which recommends that all Aboriginal and/or Torres Strait Islander children have the appropriate health assessment annually and receive appropriate preventative and primary health services in the ACT.[[21]](#footnote-22)

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| Recommendations* Ensure adequate health data collection at Bimberi Youth Justice Centre. Implement a youth justice throughcare program to be delivered in partnership with community organisations.
* Implement the Our Booris, Our Way review recommendations and ensure increased culturally safe and appropriate mental health support Aboriginal and/or Torres Strait Islander people/communities.
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Integrated care – a path forward for partnerships between health care providers, community services and families/carers

Community providers of health care supports - such as the Community Assistance and Support Program (CASP) which provides transport and in-home support, amongst other essential supports - play a vital role in facilitating access to services and alleviating pressure on the ACT health system. Integrated care projects, which work in partnership with community organisations, have the potential to address the broader social determinants of health and barriers to accessing health supports (such as transport).

This submission cannot be separated from the broader context of the current move towards commissioning in health. ACTCOSS is involved in the engagement process for the Coombs Family and Health Hub (the Hub) which we support. We understand the Hub will focus on maternal health, infant health and child health up to the age of 6 years. While we are aware that the project has encountered complications recently, we are encouraged by the ACT Government’s resolve to find a path forward and would urge that the ACT press ahead with the Hub. We are also encouraged by the involvement of general practitioners (GP), non-GP specialists and non-government, community-based organisations in the design and scoping phase.

*The ACT Approach to Commissioning (May 2021)* paper produced by ACT Health and the Community Services Directorate presents an example of the success of commissioning as:

People who need to access health or support services in the community in the ACT have CHOICE and can access the right support, from and in the right place, and time for them.[[22]](#footnote-23)

To achieve health choices and access for children/young people in particular, the role of the family cannot be overlooked. (ACTCOSS interprets the term ‘family’ in a broad sense, encompassing carers and care relationships also).

In recent years, the role of families as playing a vital role in health and wellbeing has been considered in academic literature. Families are increasingly being seen not only playing a primary role in preventing ‘disease or injury from occurring’[[23]](#footnote-24) but also secondary and tertiary roles of ‘early diagnosis and … rehabilitation’[[24]](#footnote-25) respectively. As recent studies have noted:

Failure to acknowledge the influence of the family as producers of health means an inability to develop and implement programs and policy that support and strengthen family functioning and produce conditions through which families can thrive.[[25]](#footnote-26)

Families and carers play a vital role. They are often required to transport or arrange transportation for their children to appointments. Families and carers can play a vital role in early detection illness and disability and often support children and young people to receive the necessary medical supports and intervention.

Integrated health projects such as the Hub have the potential to be a testing ground for a new relationship between health professionals and families and carers. It is vital to ensure that families and carers are equal partners in medical decisions, receive adequate early disability identification and support. Such support can have positive impacts for children, in terms of both child health and child safety.

The need to keep families front and centre will be even more the case in the context of the increasing uncertainty over the future of NDIS funding (given a push towards independent assessments and consideration of other cost-cutting measures at a federal level). Unless prevented, a scaled-back NDIS with reduced Territory influence will place additional pressure on families, the ACT community sector and the ACT health system.

These and other challenges mean a collaborative effort will be needed moving into the future. It is vital, therefore, to consider how the proposed Hub at Coombs and other integrated care projects may serve as a model for collaborative partnerships between health care providers, community service providers and families/carers.

The responsibility lies with government and community service providers to find ways of engaging at-risk families in the co-design of integrated health services. These services must create a strengths-based system of early supports which meet the needs of diverse families, including Aboriginal and/or Torres Strait Islander parents as well as parents with disability or mental ill-health. These groups need to be supported through decision making and early intervention, to avoid unnecessary contact with the Child and Youth Protection Services (CYPS).

In the case of Aboriginal and/or Torres Strait Islander families and carers in particular, *The ACT Approach to Commissioning (May 2021)* paper recognises:

There is self-determination of Aboriginal and Torres Strait Islander peoples through community-led solution development and implementation.[[26]](#footnote-27)

One useful path forward may be the expansion of Functional Family Therapy (FFT) programs in the ACT. ACT Government Child and Youth Protective Services publication *Working with Aboriginal and Torres Strait Islander Families: Providing Culturally Responsive Practice* already notes the importance of assisting families to ‘identify appropriate supports that will meet the needs of their child and family and address the safety concerns held by CYPS’ including ‘Functional Family Therapy.’[[27]](#footnote-28) This would ideally include staff training in culturally appropriate care as well as diversity training and training in trauma-informed practice and service design.

Compared with alternative treatments, Functional Family Therapy has lower rates of recidivism, reductions in substance use and reduces the risk of younger siblings offending.[[28]](#footnote-29) Increased investment in FFT is an important complement to health screening treatment and takes a holistic understanding of families and carers as an important partner in child/youth health screening and health care. However, FFT needs to be complemented by longer-term support for families with additional needs for families who are not supported by the NDIS.

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| Recommendation* Co-design integrated health care with families. Support families through early intervention, parenting programs, travel and recognising the benefits and necessity of whole-of-family supports to the wellbeing of children and young people, in particular Functional Family Therapy. A particular emphasis should be placed on support for families engaged or likely to engage with CYPS.
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# Conclusion

In the context of increasing pressures on the ACT healthcare system, it is clear that the way forward can only be through consultation and engagement between government and community stakeholders and families in a model of partnership, where each party has a role to play in facilitating better health outcomes.

Early intervention must continue to be a key focus whether it is access to the diagnosis of disease or early mental health support for children aged 8-12. Earlier interventions can assist families to better adapt and play a productive role in helping their child navigate health issues. Early intervention can also divert children away from the youth justice system and allow for therapeutic rather than judicial responses. Where young people do enter the child justice system, adequate screening and data collection will assist to ensure appropriate supports are put in place. For those leaving detention, a throughcare program (supported by strong community partnerships) is essential. Furthermore, whole-of-family programs such as FFT are an important means of reducing the risk of reoffending.

The issues the ACT health system faces are challenging – particularly in the area of child/youth health – but not insurmountable. A truly integrated health care system built on cooperation, genuine dialogue and mutual respect between health care providers, families and community service providers is the only path forward.

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| Summary of recommendationsWe recommend the following suite of initiatives, policy priorities and work areas to improve the health of children and young people in the ACT: * Implement key worker strategies to attract and retain health workers in partnership with the community sector where there are shared workforce goals.
* Commit to a real increase in spending on frontline ACT Government and community health services to raise ACT service standards up to those of other jurisdictions.
* Use relevant powers under bilateral agreements for the National Disability Insurance Scheme to resist any changes to eligibility and support access to children based on impairment type, especially FASD and other cognitive impairments.
* Fully fund and implement the Disability Health Strategy with a focus on ensuring families can access specialist diagnostic supports for more conditions in the ACT as well as improving general responses and health access for children with disability.
* Ensure adequate health data collection at Bimberi Youth Justice Centre. Implement a youth justice throughcare program to be delivered in partnership with community organisations.
* Prioritise early diagnosis, especially disability and early intervention responses.
* Significant investment in not-for-profit mental health and wellbeing services as part of prioritising early intervention and prevention, especially child mental health for children 8-12 years of age.
* Implement the Our Booris, Our Way review recommendations and ensure increased culturally safe and appropriate mental health support for Aboriginal and/or Torres Strait Islander people/communities.
* Co-design integrated health care with families: Support families through early intervention, parenting programs, travel and recognising the benefits and necessity of whole-of-family supports to the wellbeing of children and young people, in particular Functional Family Therapy. A particular emphasis should be placed on support for families engaged or likely to engage with CYPS.
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