Feedback Form

This Feedback Form has been developed to assist people providing comments on the Draft Plan. The Feedback Form is expected to take approximately 30 minutes to complete, subject to the amount of feedback you wish to provide. The Feedback Form is divided into four sections.

A. Comments on strategies or actions currently in the Draft Plan
B. Strategies or actions that you recommend are considered for inclusion in the Plan
C. Strategies or actions that you recommend are considered for removal from the Plan
D. Other Comments

Where the form indicates evidence is required, please outline any evidence supporting your comments in the relevant section of the Feedback Form and attach any supporting evidence to the email you send back to the Health Service Planning Unit at HealthServicesPlanning@act.gov.au. The evidence you include or attach may relate to:

- new information about significant new and/or emerging public health system issues, challenges or opportunities;
- a proposed change to a strategy, action or related timing (Short term or Medium term); and / or
- an implementation consideration.

If you wish to provide your contact details so that we can follow up any issues with you, please add them here.

Do you want your contact details to be treated confidentially? (Yes or No)

Your name	**Wendy Prowse**
Contact details	**ceo@adacas.org.au / 6242 5060**

A. Do you have any comments on the existing strategies or actions in the Draft Plan?

FIT WITH OTHER PLANS/IMPROVED PLANNING PROCESSES: Given that it is intended to be a Territory-wide health services plan, we ask – how does this plan fit with the other strategies/ reform measures in progress/process? (Integrated care planning, master planning etc)? We highlight also the need for better processes to ensure that this plan is truly territory-wide, strategic, responsive to need and covers all health services/areas of the health system.

ROLE OF NGOS/COMMUNITY: The current draft Territory-wide health services plan seems to largely be focussed on what public health services and the hospitals will do/not do. We would like to see also a greater focus on the entire health services system, including hospitals/public health services but also health services (including mental health services) delivered through NGOs, community services, GPs, allied health, pharmacists etc. In relation especially to mental health, but also to other domains of health - we would like to have seen this plan focussed also on developing better mechanisms/approaches to measuring (and share information with the relevant community/health services) around demand and projected demand. We would also have expected a focus on data and evaluation.

PATIENT/CONSUMER/CARER VOICES: How are patient/consumer/carer voices being included in the design/development of this plan? We would like to see further emphasis on the patient/consumer/carer experiences.

DESIGN FOR INTERSECTIONALITY: We particularly note the importance of health systems being designed with an expectation of intersectionality and intersectional life experiences, rather than people being expected to self-navigate across multiple silos or systems not designed to support their needs, during periods where people are experiencing ill health.

IMPLEMENT RECOMMENDATIONS/LEARNINGS FROM ROYAL COMMISSIONS AGED CARE, DISABILTY and PRODUCTIVITY COMMISSION MH etc: The Aged Care Royal Commission into Quality and Safety, made many recommendations that relate to health services across Australia. The Territory plan should acknowledge and reflect the proposed changes arising from those recommendations? Likewise, whilst we welcome the disability focussed initiatives, and acknowledgement that the Disability Health Strategy and strategies under the LGBTIQ+ health scoping study are expected to be relevant to the review and refinement of this plan, given the Disability Royal Commission that is currently in progress, and the known issues around diagnostic overshadowing, we would like to see further acknowledgement in this plan.

EQUITABLE ACCESS AND QUALITY OF HEALTHCARE: In our view this plan should be looking at both – equitable access to healthcare, but also equitable quality of healthcare for all patients, including (but not limited to) people with disability, people with mental ill health, older people,

carers, and many others. We would like to see this plan more fully recognise and seek to address the experiences of discrimination that many people with disability (and/or an array of intersectional experiences) in our community experience in health interactions and settings, and the consequent impact that discrimination can have on both access to and quality of healthcare.

BETTER OPTIONS FOR THOSE WITH SENSORY NEEDS ATTENDING EMERGENCY DEPARTMENTS: In 4.2j there is mention of appropriate care environments – we would like further clarification on this. We know, for example, that there was some work occurring around better support and environmental design that might better meet the needs of autistic people* and others with sensory needs, who are visiting the emergency departments in the ACT. We note however that many autistic people do not have co-occurring intellectual disability, and that it would not be appropriate to collapse this group into a heading that focuses on people with intellectual disabilities. We highlight that people with dementia may also benefit from opportunities to access quieter/calm spaces throughout the hospitals.

The Productivity Commission report on Mental Health made suggestions including to provide a calmer environment, sensory modification techniques, the use of staff skilled in de-escalating behaviours, and providing alternative settings to EDs. (Productivity Commission *Mental Health Productivity Commission Inquiry Report Volume 2* No. 95 30 June 2020 pp 29 and 602-603). We would like to see this and other Productivity Commission Mental Health report recommendations implemented.

(*Whilst in most instances ADACAS uses person-first language when describing people with disability, given the preference articulated by many autistic people for identity-first language, ADACAS seeks to respect that preference in our systemic advocacy when referring to autistic people. We do however additionally acknowledge that there are diverse preferences within also autism communities – that not all autistic people prefer identity-first language, and would always also seek to reflect individual preferences in our work with individuals).

IMPROVED WORD CHOICE: We also ask that the language “managing patients” be changed each time it appears (it currently occurs at 4.1c (“managing patients with dementia) and in various sections of 4.1l and 4.2j in reference to service for people with intellectual disability). Whilst we recognise that this in some ways is a minor correction – in other ways the current phrasing comes across as disrespectful and not upholding the human rights of the individuals concerned. I note that “managing patients” is not used in relation to people without dementia or intellectual disability.

OLDER PERSONS MENTAL HEALTH: ADACAS particularly draws attention to the support needs of people living in residential aged care who experience mental ill health, and for there to be concentrated effort to ensure equitable access and quality of support available.

RESTORATIVE PATHWAYS: ADACAS encourages that there also be avenues, effort on repairing relationships with people who have had negative experiences of healthcare/health support, with an especial focus on people in complex circumstances, including those with intersectional or other needs that have not to date been met. ADACAS has worked with people with complex health circumstances, especially around experiences of trauma, who seek to avoid all health services (sometimes to the significant detriment of their health/wellbeing) due to past bad experiences – what outreach or options would help re-build trust when it has been broken?

SEXUAL WELLBEING and the PREVENTION OF SEXUAL VIOLENCE: in ADACAS' view there is a role for Health in the health promotion aspects around sexual wellbeing, and also towards the prevention of sexual violence. We note that in other states/territories, health takes an active role towards work on such topics, in and across all settings. We would encourage connection with the work being instigated around sexual assault reform.

ADDRESSING KEY AREAS OF SERVICE DEMAND AND REFORM: we note that this section of the paper concentrates largely on demand as viewed in hospitals. Whilst this is clearly important, we note that there are demands (especially with regards to intersectional needs, and those of some priority populations) which are important and where support is needed, but where the needs might not be as immediately visible. In approaching establishing the needs to be addressed, we request needs analysis that take a broader and more inclusive/pervasive view (rather than solely focussing on need as is seen at the hospitals).

Theme	Key strategies and actions	Strategy number (from the Draft Plan)	Comment

1: Transitions of Care	Table 1.1: Short term	1.1a Paediatrics	We endorse the need for patient and family navigators, also for paediatric nurse liaison service.
		1.1b Mental Health	Intensive case management for people with complex mental ill health should be available to all those in the community that need it, including (but, importantly, not limited to) those presenting at emergency multiple times. This program should be co-designed with consumers, carers, service providers and also other relevant advocacy and representative bodies (ACT Mental Health Consumers' Network, Mental Health Community Coalition, Carers ACT as a starting point, but also other organisations working with people with mental ill health from various priority populations etc).
		1.1c Mental Health	We strongly endorse the need for more support to be made available earlier. We note the importance of working with the community peak organisations on such topics.
		1.1d Mental Health	Agreed – further improvements needed. We would like these points bolstered/further emphasised.
		1.1e Health System	We encourage seeking out First Nations people with experience in disability also to participate in these discussions. ADACAS is working with the

		1.1f Health system	First Persons Disability Network in relation to Disability Royal Commission submissions. ADACAS also emphasises the importance of involving people with lived experience of disability/ expertise around multicultural communities and disability, amongst those consulted. We express especial interest also in this topic.
	Table 1.2: Medium term	1.2a Health System	Please also include people with disability in addition to those with chronic conditions and older people.

2: Our role as a local, Territory and regional service provider	Table 2.1: Short term	2.1c Health System	Whilst improved information (including in accessible formats such as plain language, easy English etc) would be useful, additional support is also useful (we endorse the mentioned need for patient navigators, especially for those with complex circumstances/needs).
		2.1g Mental Health	We refer you to comments made by Mental Health Community Coalition with regards to needs in the mental health space.
	Table 2.2: Medium term	2.2c Palliative care	ADACAS notes the need for supported decision-making training, and also supported-decision-making support, to be made available to people with types of disabilities where cognitive ability might be impaired, who would like such support around end of life decisions. Given the importance of people having a voice in end-of-life decisions that impact on them, we draw attention to this topic.
		2.2e Sexual Health	See comments in overarching summary around the need for further health promotion efforts around sexual wellbeing in the community and in efforts to address/prevent sexual violence / abuse.

		2.2f Health System	ADACAS notes that any efforts to re-engineer attendance at local clinics need to take account of the need for equitable access to healthcare, and that there needs to be exceptions possible such that people in complex circumstances/with specific support needs that cannot be met at a closer location (perhaps due to relationship breakdown with closer services/ or closer services being unable to meet complex needs), can still access healthcare from other locations.
		2.2i Education and Training	ADACAS notes – it would be beneficial also for different types of training (perhaps delivered by NGOs if in their areas of speciality/expertise, e.g. on priority groups) also to be made more available to health staff
3: Strengthening Core Services	Table 3.1: Short term		
	Table 3.2: Medium term	3.2c Allied Health	We strongly support the need for equity of access to allied health services such as those mentioned – we were extremely pleased to see Older Persons Mental Health mentioned, although would ask that this be a focus not solely on the specific service that bears that name, but also on addressing the especial inequities around equitable access (and quality) of the full range of mental health services for older people, especially those living in residential aged care.

4: Addressing Key Areas of Service Demand and Reform	Table 4.1: Short term	4.1a Health system	We strongly endorse the need to work closely in partnership with Aboriginal and Torres Strait Islander communities (and in line with the agreements with the Coalition of Peaks) in closing the gap around health inequities. (We endorse this also in relation to other areas of the plan where it is highlighted).
		4.1c Care for older persons	We encourage a human rights based approach to responding to and working with older people, and encourage close work with the Office for the Senior Practitioner around minimising (and ideally removing) the need for restrictive practices. We also highlight the need for training and ongoing support for staff in how to ensure that they take supported decision-making approaches (thus seeking to uphold decision-making rights of older people). See also the paragraph re respectful use of language in the summary above (please don't use the term "managing" older people with dementia).
		4.1e Rehabilitation	ADACAS notes the need to ensure that rehabilitation is equitably available to people regardless of age or unrelated disability.

		4.1i Health system	We applaud the need to ensure better holistic care for people with co-occurring conditions. We emphasise the need to ensure that if there is a move to general wards, that there is not also a corresponding loss of access to specialist expertise/input (there is a continued need to ensure equitable access to and high quality of care). We encourage efforts to consider how the hospital could be better designed in light of an expectation of intersectional needs (to seek to avoid experiences of seeking to navigate multiple siloes of care)

		4.1l People with intellectual disability	We ask what is intended by "appropriate care environments"? Does this relate to being able to meet appropriate care needs for people who perhaps have co-occurring sensory or other needs, and might need quiet environments? If so – please name this. If a more general comment: ADACAS notes the need for work towards inclusion, not segregation as a general approach. We note the urgent need for staff to have ongoing training and support around how to work with people with disabilities in ways that uphold their rights. We emphasise the need to address issues of discrimination and also the need for all staff to build skills in making reasonable adjustments (and for there to be systems/policies/approaches in place which support and uphold this). Please refer to the paragraph re respectful use of language (please do not use the phrase: "managing" as is currently written in relation to managing patients with intellectual disability or ABI)

	Table 4.2: Medium term	4.2 j People with Intellectual disability	Please refer to our comments against 4.1l. Whilst we welcome specific efforts to address the needs of people with intellectual disability, we also draw attention to the needs of people with other types of disabilities – i.e. autism (neurodivergence), people with physical disabilities, people with sensory disabilities, people with learning disabilities (which are not necessarily intellectual disabilities) etc.
		4.2 k Anaesthetics and Pain Management services	We strongly endorse the need for there to be further access/capability/staffing in the pain management services arena.

B. Are there any new strategies or actions that you recommend are considered for inclusion in the Plan? Please outline or attach any evidence supporting your comments. Comments and new evidence received will be considered in accordance with the Draft Plan's four key themes.

Theme	Proposed new Strategy	Proposed new Action	Comment and evidence for inclusion of new strategy / action in the Plan
1: Transitions of Care	Please refer to information included in section D of this response	Please refer to information included in section D of this response	Please refer to information included in section D of this response
	Please refer to information included in section D of this response	Please refer to information included in section D of this response	Please refer to information included in section D of this response
2: Our role as a local, Territory and regional service provider	Please refer to information included in section D of this response	Please refer to information included in section D of this response	Please refer to information included in section D of this response
	Please refer to information included in section D of this response	Please refer to information included in section D of this response	Please refer to information included in section D of this response
3: Strengthening Core Services	Please refer to information included in section D of this response	Please refer to information included in section D of this response	Please refer to information included in section D of this response
	Please refer to information included in section D of this response	Please refer to information included in section D of this response	Please refer to information included in section D of this response
4: Addressing Key Areas of Service Demand and Reform	Please refer to information included in section D of this response	Please refer to information included in section D of this response	Please refer to information included in section D of this response
	Please refer to information included in section D of this response	Please refer to information included in section D of this response	Please refer to information included in section D of this response

B. Are there any strategies or actions that you recommend be considered for removal from the Draft Plan?

We do not propose to comment on topics that should be removed.

Theme	Key strategies and actions	Strategy Number (from the draft Plan)	Comment/ reason/ evidence to remove from the Plan
1: Transitions of Care	Table 1.1: Short term		
	Table 1.2: Medium term		
2: Our role as a local, Territory and regional service provider	Table 2.1: Short term		
	Table 2.2: Medium term		
3: Strengthening Core Services	Table 3.1: Short term		
	Table 3.2: Medium term		
4: Addressing Key Areas of Service Demand and Reform	Table 4.1: Short term		
	Table 4.2: Medium term		

D. Other Comments.

We list the following additional topics which need to be addressed:

- Access to bulk-billing GPs. In the ACT, it is currently difficult for many people who do not have financial means, to access a GP. We encourage territory action to find ways to redress this.
- Mental health services: the need for improved mental health services/systems does not seem to be sufficiently addressed in this plan. Some of the areas of intense need – planning for earlier support – which might include: development of mechanisms to ensure that the right mix of services is available to meet the needs of the ACT population (especially early supports to all that need it), and that those services are responsive to consumer/carer needs, with a view to providing support earlier, such that people have a better experience, but also that the demands on acute services are reduced. Given the acknowledged and increased demands in mental health support, much more extensive work is needed to plan on this topic. We highlight also the need for equitable access by all to mental health services, and to the need to address barriers which might be preventing equitable access.
- Equitable access to and equitable quality of care for people with disabilities, people in complex circumstances, and those with intersectional needs: Whilst we appreciate acknowledgement of the impending Disability Health Strategy, we would ask that work continues on planning for responses to already known issues (some of which include: need for quiet/sensory aware spaces throughout the hospitals, but especially in emergency departments, analysis to examine ways to address bias/structural discriminations/diagnostic overshadowing, embedding of trauma-informed care much more fully through the health systems, as well as other more specific issues outlined below, etc).
- Proactive coordinated healthcare and support for people with disability in relation to co-occurring health issues: People with disability often have co-occurring health issues that are common to people of that disability (e.g. people with down syndrome can also have heart defects, people with intellectual disability also experience higher rates of mental ill health etc). Many people with disability do not receive pro-active, coordinated healthcare which encompasses proactive care in relation to co-occurring (or potentially co-occurring) health issues. We recommend this be urgently addressed.
- Easier access to coordinated diagnostic and assessment processes: at the present time, if it is suspected a person has a health issue and/or disability but it is unclear what the health issue/disability is – it can sometimes be expensive, and very difficult to navigate access to appropriate diagnostic assistance (e.g. if a person's cognition is affected, but it is not clear whether this is related to mental ill health, autism, intellectual disability, neurodegenerative disease etc). Early identification and support when there is disability/complex health issues can make a very significant difference to peoples' lives. Access to allied health and medical staff (of individuals' choosing) is also important, for example, if a person needs a functional assessment to evidence substantial impact on functioning for NDIS entry purposes. What could be done to offer more access and more coordinated access to diagnostic and assessment processes?
- Holistic not siloed health care for people with co-occurring health issues: It is imperative that there is further work to prioritise person-centred care, and de-silo the way that healthcare is delivered in the ACT. For example - ADACAS has supported individuals in the ACT in situations where people have co-occurring physical health issues and mental ill health, and where the various wards/branches/hospitals are

arguing about which areas should accept responsibility for care (in effect – neither want to support the patient concerned). Whilst in many cases, staff recognise that healthcare and support is needed, the wards with expertise in the physical health issue/s typically argue that they do not have the capacity to support someone who is also experiencing mental ill health, the wards with mental ill health expertise typically argue that they do not have the expertise (or beds) to support someone who also is experiencing physical health issues. The patient/families concerned became increasingly distressed and the patient's health typically also deteriorates due to the stress and uncertainties about what is occurring. Whilst especially evident in situations where the health issues are as disparate as mental illness and a physical health condition, similar situations can also occur across other types of wards. This is a systemic issue within the way that, in particular, the hospitals are structured, and is clearly not good, person-centred, healthcare. We believe that the underlying issue sometimes involve demand, and/or reporting requirements/pressures on beds that contributed to situations where neither ward wanted their key performance targets stretched by someone with co-occurring health issues as part of their presentation. It is not acceptable that the hospital structures and systems have evolved in this way – we highlight the need for those issues to be urgently identified and resolved.

- Restorative approaches are needed both in situations where things have gone wrong, but also in situations where relationship with health/hospital systems have broken down, to seek to rebuild relationships such that individuals in those circumstances feel able to access healthcare systems. In 2019, the ACT government declared that Canberra is a restorative city[1] – given this focus – we encourage efforts to find ways to work together differently.

[1]ACT Government (2019), *Canberra as a Restorative City: Our Vision:* available via https://www.justice.act.gov.au/sites/default/files/2019-11/191381_JACS_6pp_Vision_Document_web.pdf, accessed in July 2021.

- Better support and pathways for those people with disability who are living in hospital beyond where acute care is needed, to appropriately resolve systemic issues both internal to hospitals that are extending stays, but also in working with other systems/structures external to hospitals to enable pathways to discharge to housing options wanted by the person with disability and that meet their needs. Living in hospital beyond where acute care is needed, can be dangerous to the health of people with disability, due to the increased risk of infectious disease (and death) in a hospital environment, an impact which can be magnified for people who might already be immunocompromised. ADACAS has worked with multiple patients who have died in exactly these situations (whilst we were advocating for solutions to the service and/or housing barriers that were preventing discharge). At the start of the COVID pandemic, we were advised that there were over 25 people with disability living in one of the hospitals, beyond when acute care was needed. Whilst there were some efforts at the time to seek to assist that specific group, further and targeted systemic work is needed to ensure better outcomes for all.
- Royal Commission Recommendations: Please refer to the comments at the start of this document, with regards to the need to ensure that Royal Commission recommendations are being included/planned for in territory-wide planning processes.
- Please refer also to other topics raised in overview at start of document.

Thank you for completing this Feedback Form.

Please return to *HealthServicesPlanning@act.gov.au* by COB 30 July 2021.