

The Yellow Brick Road: a path to the future of health advocacy in South Australia

HCA SA
Health Consumers Alliance of SA Inc



Consumers at the centre of health in South Australia

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28 February 2020 Consumers Health Forum of Australia (CHF)

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HCASA Workshop – Best Practice - Consumer Advocacy Models for South Australia
21 July 2020

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The Yellow Brick Road.ⁱ Introduction

When the SA Government chose to cease funding to the Health Consumers Alliance of South Australia (HCASA), it made the decision, that independent systemic health consumer advocacy was no longer necessary in South Australia.

Meaningful consumer engagement in health requires the capacity of expert partners and critical friends to inform and support health services to improve. A cultural shift is necessary to drive sustainable change to the health system that truly responds to the needs of the community and to position consumers at the centre of health.

HCASA has been the recognised peak voice for health consumers in South Australia for almost 20 years. As expert partners, HCASA have worked with consumers, health services and government to improve health outcomes.

With the pending closure of HCASA in September 2020, South Australia will be out of step with all other states, which have government funded, independent and systemic peak health consumer organisations, regardless of the governance arrangements between the State Health Department and Local Health Networks/Districts.

Internal systems within health services for monitoring compliance with minimum standards might tick some boxes, but frequently fails to drive true cultural change and innovation. South Australia has recent experience of the failure of its health system to achieve oversight transparently and accountably.ⁱⁱ

This White Paper reviews the key principles underpinning best practice in health consumer advocacy and explores a potential pathway towards a new model into the future.

The Wizard of Oz, is used as a metaphor for exploring a wicked problem,ⁱⁱⁱ and considering the future of health consumer advocacy in South Australia. It recognises that this path may experience obstacles, encounter unlikely champions, and find new ways of understanding and solving the problems ahead. To be successful, those who lead the way forward will need to be smart, show courage and above all have heart. This paper explores the following key drivers to ensuring health consumer advocacy in South Australia into the future:

- *The Wicked Witch. The Wicked Problem*
- *Glinda. The Guiding Belief*
- *Dorothy. Consumers Experience*
- *The Scarecrow. Be Smart*
- *The Lion. Take Courage*
- *The Ruby Slippers. Finding The Way*
- *The Tinman. With Heart*

Health Consumers Alliance of South Australia wishes to take this opportunity to acknowledge and thank the health consumers of South Australia. We acknowledge the many Consumer Advocates, who have given of their time, shared their experiences, provided invaluable ideas and perspectives, and have informed and influenced health policy to improve the health experience of all South Australians.

To our partners and key stakeholders, and health consumer champions, we hope this paper helps you start a new path forward in reestablishing health consumer advocacy in South Australia. Your combined voices will be imperative to ensuring consumers are at the centre of health in South Australia.

This leaves South Australia out of step with other states and territories which all have government funded, independent health consumers organisations

The Wicked Witch. The Wicked Problem

In a recently published article titled *Death of a Critical Friend in South Australia*, Paul Laris HCASA Board A/Chair presented the following perspective.^{iv}

Organisations advocating on behalf of those who otherwise have little say in the decisions which effect their lives can be seen as critical friends of government. They appear to be a threatened species – and we should be alarmed.

The Health Consumers Alliance is South Australia's only peak body advocating for the users of health care services. HCASA lost its state government funding in June 2018 after 19 years of continuous service. It has provided training for consumer advocates and for health care services, research and policy advice and most recently highlighted issues for health service users arising out of COVID-19. It has continued only through staff cuts limited, fee-for-service work and rent savings.

On September 30 2020 HCASA will be closing down. SA will then be the only state without a state government funded health consumers advocacy body. The HCASA's annual budget allocation from the SA Government was \$500,000. It is around 0.008% or one twelve thousandth of the SA Health budget for the current year.

But ignoring or eliminating critical friends has ominous implications. A social safety valve is lost. When governments pursue policies and procedures, which disadvantage and alienate those who have lost the voice of advocacy, we all suffer.

Inequity grows and social coherence crumbles. There is a risk then that defensive governments may respond with further restrictions on information, advocacy and criticism, further escalating polarisation. There is a price to be paid for the death of the critical friend.

When governments pursue policies and procedures, which disadvantage and alienate those who have lost the voice of advocacy, we all suffer

Implementation of sustainable consumer engagement policy and practices are often ad hoc across the broader health and care sectors and individual service providers, with many services having no consumer involvement in health service decision-making and limited opportunity for consumers to provide meaningful feedback and input.

The roles of the Commission on Excellence and Innovation in Health and Wellbeing SA in relation to peak level consumer advocacy remain unclear. SA Health services are focused on local consumer engagement and allocating their resources to support their own organisational outcomes.

The underlying premise in this decision is that, by implementing consumer engagement strategies, the need for systemic advocacy is diminished. The flaw in this thinking is that consumer *engagement* and *advocacy* are one and the same. This is fundamentally incorrect. It fails to recognise that whilst consumer engagement strategies, provide effective tools for consumer participation, systemic health consumer advocacy provides evidence-based consumer representation in health policy and identifies system-wide trends, issues and risks. In the absence of systemic advocacy this additional oversight will be missed, with potentially catastrophic outcomes for individuals and collective groups.

We are not strangers to such events. Oakden, medical mesh, chemotherapy under dosing – are all in South Australia's recent history. The need for independent health consumer advocacy has never been more essential.

Over the past year, since it's defunding and despite its best efforts, HCASA has already seen a trend in the establishment of siloed consumer registers, isolated rather than embedded consumer engagement, reduced consumer representation on statewide decision-making committees - all in the context of a largely unapproachable government. Systemic health consumer advocacy has become the inevitable collateral damage.

In the absence of a peak consumer body, consideration must be given to whether HCASA's mandate remains relevant, and if so, how and by whom, will this be met in the future?

Health consumer advocacy has become the inevitable collateral damage

HCASA mandate

- *Advocate for health and human rights of all South Australians that improves the health experience and outcomes for individuals and communities*
- *Ensure the issues and experiences of consumers inform the focus of systemic advocacy and policy and the work of the organisation*
- *Influence sustainable, positive change to health systems that support and respond to the needs of the community, including legislation, policy and service provision*
- *Promote the needs of consumers, carers and communities particularly those living with and experiencing health disadvantage*
- *Provide evidence-based consumer representation in health policy*
- *Build the capability of consumers to self-advocate and act as Consumer Advocates and Representatives*
- *Build the capability of health services to meaningfully embed consumer engagement into governance at all levels*
- *Build the capability and resilience of the health workforce and their authentic relationships with consumers and communities*
- *Monitor and report evidence of the benefits of consumer engagement*
- *Identify emerging issues, concerns and risks for consumers, carers and communities that could be addressed through systemic advocacy and work with government and health services to address it early to reduce or negate harm to consumers*
- *Record and share consumer stories as a platform for reflection, discussion and shared learning to drive consumer engagement in health service policy, research and practice*

Glinda. The Guiding Belief

To begin in determining what health consumer advocacy might look like in South Australia in the future, a commitment to core principles and beliefs that underpin health consumer advocacy is vital.

“Without informed, knowledgeable and articulate health consumers, health policy will always be unbalanced whatever the goodwill and idealism of governments and health providers. Mature consumer organisations are an essential part of the health equation”^v

Health Advocacy

Health advocacy is rooted in the belief that people (individuals and communities) should be able to determine what matters to them to ensure their health and welfare and enjoy a good quality of life. It involves active promotion of the interests of the individual or group, or a cause and is grounded in the principles of natural justice:

- *All people must be guaranteed equal legal and political rights as well as the capacity to exercise those rights*
- *All people should be able to participate fully in society and have input into decisions which affect their lives*
- *Economic and social inequality should be reduced so that people who experience disadvantage can participate in society^{vi}*

Health Consumer Advocacy

Health consumer advocacy builds on this premise to promote and enhance the consumer voice to ensure consumers are able to influence the health services that they pay for, use and expect.

The World Health Organisation *Declaration of Alma Ata* (1978) states that ‘people have a right and a duty to participate individually and collectively in the planning and implementation of their health care.’^{vii} In a health context this means that consumers have the right to participate in decisions about their own health and welfare, and be should be able to inform and influence health service planning, design, delivery and evaluation.^{viii}

Health consumer advocacy is a vital component of improving health outcomes. Health consumer advocacy is essentially an engineer – it helps build, strengthen and reinforce sustainable structures for consumer partnership and shared decision-making. For consumers, it helps build self-agency, health literacy and enables them to negotiate their own healthcare goals and expectations. For health service providers it helps build workforce capacity for engagement, opportunities for partnership and cultural and systemic change.

Health consumer advocacy lays the foundations that empower the consumer voice and better enable service providers to listen

Health consumer advocacy lays the foundations to empower the consumer voice and better enable service providers to listen. Health advocacy is often the catalyst by which laws, policy and systems are tested, challenged and changed. Consumers are able to inform health legislation, policy, corporate behaviours and community values and expectations shape the health environment, which in turn shapes the capacity to improve health care.

Enshrined by *Charter of Health and Community Services Rights*,^{ix} health consumer advocacy is predicated upon the rights of health consumers to:

- *Have access to health services that meet their individual needs*
- *Have their legal and human rights upheld and free from discrimination and harassment*
- *Receive safe, high quality healthcare*
- *Be treated with dignity and respect for their culture, beliefs and values*
- *Be provided with the information they need to make informed choices and decisions*
- *Actively participate in decisions that impact their health and wellbeing*
- *Be ensured of privacy and confidentiality and have access to their health information*
- *Provide comment and/or make a complaint about their health care*

Dorothy. Consumer Experience

The path to accessible health care is not always straight forward. The Australian health system is complex with multiple points of entry and multi-tiered and innumerable specialty areas. Effectively navigating the health system requires a high level of health literacy and active strategies by health services, to minimise barriers and increase access. Dorothy is an intelligent and resourceful person, but her way home is far from intuitive and access to the Emerald City is not available to all.

Many consumers and communities, particularly those living with health disadvantage, experience significant health inequity and for many this may be due to reduced autonomy and self-agency, and stigma and discrimination. Advocacy, both individual and systemic, can help reduce health inequity and provide a voice for people with least choice and most need.

Reduced autonomy

Many factors contribute to a decrease in autonomy, low health literacy, cognitive capacity, anxiety, lack of social support, lack of advocacy and voice. Consumers and communities who experience reduced autonomy may include but are not limited to; people with lived experience of mental illness; people with cognitive impairment; people living in supported accommodation; people living in residential aged care; refugees and people living in detention; people in prisons requiring healthcare; and individuals and communities experiencing stigma, racism and/or discrimination.

Self-agency

Fundamental to exercising self-agency and autonomy is the capacity to make informed choices and decisions and access to health services that best meet one's health care needs. A growing body of evidence supports that when consumers and community groups are engaged as equal partners with health services in shared decision-making, health outcomes are improved and health care is more targeted to meet individual health care needs.

Not all consumers and communities are able to exercise self-agency

Health disadvantage

Not all consumers and communities are able to exercise self-agency. Systemic and individual health advocacy is vital when consumers are not able to access the services they need, when health care does not meet standards of safety and quality and when consumers are unable to advocate for themselves to achieve the best health outcomes that meet their goals, needs and preferences.

Communities experiencing significant health disadvantage^x

Aboriginal and Torres Strait Islander people

Aboriginal people experience more life risk factors, poorer health and less acceptable outcomes in a range of life areas when compared to other South Australians.^{xi} As a result, Aboriginal people are among the most health disadvantaged population groups in the community.

People living with disability

People living with long-term disability are among the most disadvantaged and invisible groups in the community with comparatively poor health outcomes, social exclusion and lack of access to essential services and a health system that often fails to meet their needs.^{xii}

Culturally and Linguistically Diverse (CALD) communities

Migrants and refugees may live with long-term health conditions and disability. Many refugees have experienced trauma and torture and may be mistrustful of people in authority and service providers, including health services. Migrants and refugees are often reluctant or less able to raise a concern due to lower English proficiency.^{xiii}

People experiencing stigma, racism and discrimination

Many individuals and communities who experience health disadvantage also experience stigma, racism and discrimination related to their health condition, which can result in a reluctance to seek and/or access, needed health care. Stigma and discrimination has particularly affected people with lived experience of mental illness and LGBTQIA+ people who face significant barriers to accessing health care and are a key determinant of health for Aboriginal people.

Consumers and communities, particularly those who experience health disadvantage, are central to determining the future role and function of health consumer advocacy in South Australia. The experiences, views, needs and goals of consumers and communities who are at greater risk, are central to the design, delivery and evaluation of health care policy and services which impact them and to the alleviation of health inequality and inequity.

Health advocacy is a vital strategy to support the public interest and profile problems and emerging issues

South Australia must continue to be informed and influenced by diverse consumers and communities, their unique goals needs and experiences, and by their stories, which are singularly and together, powerful in their own right. Diversity and equity must also be considered as healthcare leaders work in codesign to eliminate disparities in care and outcomes and build trust with underserved communities.^{xiv}

In raising health system awareness of health inequity, health advocacy is a vital strategy to support the public interest, profile problems and emerging issues and support the health system to advance action and build the capacity of health services to improve care.

The Scarecrow. Be Smart

A new health advocacy model in South Australia must identify a core set of guiding principles to underpin and ensure a robust, quality approach to health consumer advocacy into the future. These guideline principles should reflect the following fundamentals.

Driven by consumer voice

Health consumer advocacy in South Australia must continue to be informed by consumers through their lived experience to ensure a health system that meets the individual needs of consumers and improves health outcomes for individuals and communities. Consumers and communities must have meaningful input into the development of a new advocacy model, in its codesign and in its ongoing role and function. A future health consumer advocacy model must also ensure that it works in a way that empowers, facilitates and supports consumer self-advocacy.^{xv}

Independent authority

As a fundamental premise, a future health consumer advocacy model must, through its funding and constitution, have independent authority. This independence is central to ensuring it is able to represent the voice of consumers, scrutinise the practices of service providers, challenge gaps and inequity in the health system and act with authority to influence and inform health service decision-making.

Evidence Based

Evidence based health consumer advocacy ensures the issues and experiences of consumers informs the focus of systemic advocacy and its priorities; provides evidence-based consumer representation in health policy; and meets the needs of consumers and communities as identified by their voiced goals, values and preferences. Strategies and partnerships that actively contribute to the development of best practice in health consumer advocacy and promote consumer-centred care should be prioritised. Feedback from consumers and communities should inform the monitoring and evaluation of performance and outcomes of a future health consumer advocacy model.

A future health consumer advocacy model must establish clear scope, parameters and limitations to clarify its role and purpose

A capacity to collect and analyse evidence forms the basis for setting priorities and underpins early identification of emerging issues, concerns and risks for consumers and communities. It sets the agenda for working with government and health services to address health inequity, reduce risk and inform quality improvement and performance measures.

Consumers should be partners in codesign of health and medical research to help ensure the focus of research priorities that best meets their needs. This ensures research questions are informed and framed as priorities for consumers and communities and not only those of interest to researchers.

Clarity of purpose

A future health consumer advocacy model must establish clear scope, parameters and limitations to clarify its role and purpose. This ensures that the model;

- Can operate effectively and efficiently within its resources
- Has staff that are appropriately trained, clear about their roles and have adequate knowledge and skills to undertake them effectively and to a high standard
- Provides clear information about what it can and cannot provide
- Ensures that the model does not inadvertently act to 'bandaid' and/or disguise health system gaps and failures
- Ensures funding is used precisely in the way it is intended and can identify and address resource deficits
- Measures and evaluates the benefits and outcomes of advocacy

Confidentiality

Confidentiality is a keystone of health consumer advocacy. It forms the trust relationship between the 'advocate', consumers and communities, and speaks to its credibility and reputation. Confidentiality demonstrates respect, protects consumer interests and provides a safe environment for consumers to tell their stories, share their experiences, raise their concerns, and discuss their views, perspectives and ideas. It ensures health consumer advocacy is based on informed consent, recognises and respects the rights of consumers and ensures consumers have control over their stories, their information and their advocacy.

Equality, accessibility and diversity

For some consumers, knowing how and being able to access advocacy can be complex and confusing. Finding the right advocacy that will best respond to their needs can be time consuming and frustrating at a time when a person may be at their most vulnerable and anxious. Strategies that actively engage with diverse communities ensures that their unique experiences and needs are not overlooked and ensures their diverse needs, preferences and barriers to accessing advocacy can be addressed and minimised.^{xvi} Advocacy must include the voices and experiences of the broadest range of individuals, groups and circumstances and reflect and meet the diverse needs of the South Australian community.

Accountability

Health consumer advocacy must be accountable for adhering to agreed health consumer advocacy principles, meeting its legal obligations and its agreed outcomes. Consumers and communities should be able to expect an advocacy model of the highest standard and have a clear and accessible route for feedback and complaints. A future health consumer advocacy model must be transparent and accountable to the South Australian public for the work it does and the way it uses the funding it receives.

Build capacity and resilience

Health consumer advocacy should continue to build the capability of health services to respond the needs of the community in a flexible and timely manner. It should develop methods to determine outcomes and measure the effectiveness of its role and function. It must work in a way that fosters consumer and community confidence, independence and agency. It is important to create a culture that promotes individual and community health literacy and empowers consumers and communities to advocate for themselves and others.

Health consumer advocacy must foster consumer and community confidence, independence and agency

A future health consumer advocacy model must continue to build the capacity and resilience of

- *Consumers and communities*: to exercise self-advocacy and enhance health literacy
- *Consumer Advocates*: to support, promote and defend the interests of health consumers
- *Health workforce*: to develop authentic relationships with consumers and communities to improve health outcomes and provide better care
- *Health services*: to meaningfully embed consumer engagement into governance and decision-making at all levels
- *Health systems*: to ensure consumer centred health policy that embeds consumer partnership in all aspects of healthcare

The Lion. Take Courage

Driving a new model for health advocacy in South Australia will require committed champions with the courage to challenge the current status quo. To be a powerful consumer voice a future model will need to evaluate consumer and community need into the future and position itself, in a potentially skeptical and resistant health sector. It is important to identify sympathetic and like-minded organisations and individuals to support and help drive the process.

What do we have the courage to achieve?

The key purpose of health advocacy is, and must be, to enhance the voice of consumers and to improve health experience and outcomes. To do that well it is necessary to engage effectively with consumers and communities and the health system. There is any number of options for a new health advocacy model, each with different strengths and weaknesses related to levels of funding; sustainability; reach; political support and independent authority.

Driving a new model for health advocacy in South Australia in the future will require committed champions with the courage to challenge the current status quo

In thinking strategically about how to set the scene for the development and implementation of a new model for South Australia it is necessary to consider each of these in the context of the needs of South Australians, the political context in which this happens and of the stakeholders who might be involved in carrying this legacy forward. Several options have been explored to offer a starting point for conversation.

What might a future health consumer advocacy model look like in South Australia?

Systemic Policy and Advocacy Model

A systemic policy and advocacy model is the predominant model across Australia. It ensures the continued partnership and strategic relationships between consumers and the health system (including the public, private, and community care sectors). It provides a platform to raise awareness of health consumer trends, risks and emerging issues and is the conduit for intersectoral collaborations such as private and public health service providers, disability and aged care sectors, community services.

There is a legitimacy of involvement of a health consumer peak body in informing and influencing health policy and decision-making and it is crucial to early identification and minimisation of serious mistakes.

Systemic health consumer advocacy acts as a catalyst for concerns and provides avenues to respond quickly to individual and collective consumer issues and needs. A systemic policy and advocacy model ensures a legitimate and expert central agency to focus on broad issues affecting the lives of health consumers. It provides a framework for working collaboratively with health services and government to build sustainable service systems that improve outcomes for individuals, monitor the effectiveness of these systems and highlight barriers and gaps that create risk.

Individual Advocacy Model

Individual consumer advocacy involves supporting people to exercise their rights by providing assistance to: voice concerns, access information, resolve issues or to identify available support options.^{xvii}

A 2018 HCASA survey report found that more than three-quarters of South Australian health consumers felt that their health care could have been improved with the support of a health advocate.^{xviii}

While there are other consumer advocacy services in South Australia, they support specific community sectors and groups such as consumers with a disability, aged persons, CALD consumers, asthma support services and other services supporting specific health conditions. This leaves significant cohorts of health consumers who are not part of these specific communities with nowhere to go.

An individual advocacy service, similar to the Western Australian model, could offer individual health consumer advisory and representation. Services could include: an advice phone service, 24-hour web and social media access and education and training for consumer advocates. Drawing from the evidence from casework, such a model would provide invaluable data to assist in identifying trends, patterns, issues and priorities for health consumer access and equity in health care and provide ongoing evidence to inform and influence health policy in South Australia.

Combined Systemic and Individual Model

A combined advocacy model providing both systemic policy and advocacy and an appropriately resourced individual health consumer advocacy service, would ensure systemic oversight and provide individual representation and support for consumers. This model could provide a transparent link between the consumer, the health service and external complaints bodies and focus on a rapid response to immediate need to minimise risk of adverse outcomes.

There are major advantages in a model with the capacity to span the continuum from individual to systemic advocacy

A combined model of health consumer systemic and individual advocacy would be independent of service delivery and free of any real or perceived conflict of interest; individually focused advocacy support delivered to health consumers, their families and carers and available to consumers at all points along the health care experience.

There are major advantages in a model with the capacity to span the continuum from individual to systemic advocacy. Issues that emerge at the individual level would inform service, organisation and statewide policy decisions. An advantage of a model that work at multiple levels is that each level supports and informs the others, so that action at any one level is boosted by the others.

Statutory Model

Health consumer advocacy has been the responsibility of a non-government organisation, with no legislated or real power or authority. Government has no direct accountability for ensuring health consumers have access to independent advocacy when the health system fails to meet their needs or does harm. The South Australian Government, like its national counterparts, has to some degree, met this obligation through its funding of HCASA. Unlike its national counterparts however, in ceasing this funding, the SA Government has ceased to ensure its accountability for health advocacy.

In South Australia;

- Health practitioner practice is regulated under *Health Practitioner Regulation National Law Act* and administered by the *Australian Health Practitioner Regulatory Agency (AHPRA)*.
- Health complaints are regulated under the *Health and Community Services Complaints Act* and administered by the *Office of the Health and Community Services Complaints Commissioner (HCSCC)*.
- The Public Advocate implements the provisions of the *Guardianships and Administration Act* and focuses on the needs of people who are mentally incapacitated.
- The *SA Health Care Act* provides for the administration of hospitals and health services and to establish systems to support the provision of high-quality health outcomes (amongst other provisions) but does not provide for health consumer advocacy should the governance of these systems fail to provide high quality health outcomes.

None of these regulatory bodies or legislations provide or have accountability or oversight for health consumer advocacy.

A long-term lobbying strategy could see a statutory health consumer advocacy agency with true systemic oversight and the authority to raise concerns and require change. It would ensure an appropriately resourced agency equipped to provide meaningful and measurable high quality systemic and individual health consumer advocacy. It would report directly to parliament and not the Minister for Health and Wellbeing or the Chief Executive Officer of the Department for Health and Wellbeing (SA Health) but be accountable to the public.

A statutory agency would operate within a legislative framework that ensures high standards of service, trained and qualified staff, robust methods for advocacy processes and outcomes, authority to ensure health service compliance and position health consumer advocacy and representation on high-level advisory and decision-making. A statutory advocacy model would ensure accountability for health consumer advocacy was transparent, protected and enforced in legislation.

A statutory health consumer advocacy agency with true systemic oversight and the authority to raise concerns and require change

Platform Model

A platform model would act to bring together like-minded and supportive organisations and individuals as a collective voice, to improve the health system with a focus on quality improvement. This model focuses on building an alliance of organisations and individuals, including health consumers, to build a high public profile and political acumen through public advocacy campaigns and involvement in health service design. The platform model would play a role in ensuring integrated health care and support health services to engage externally and be outward focused.

A platform of like-minded and supportive organisations and individuals might include

- Consumer and community organisations
- Other advocacy bodies (eg Disability, Aged Care, Mental Health)
- Consumer and community engagement experts
- Interested NGOs
- Human Rights and other Commissions and Coalitions
- Regulatory bodies (eg AHPRA, HCSCC)
- Centre of excellence – researchers and innovators
- Universities – eg schools of health
- Professional associations (eg AMA, APNA)
- Primary health networks
- Health service providers (public and private)
- Community service providers
- Private providers (eg training organisations, consultants)

Any and all of these models, and some not yet explored, have a critical role in enabling people to have a greater voice and greater control over their health. It is time to look beyond the current model of health consumer advocacy in South Australia and explore, with consumers and communities, what will best meet their needs into the future.

A transformative future advocacy model may look to consumers having greater power and expectation for greater choice, increased control over more individualised health care, and consumers and communities who take a more active role in driving and transforming health in South Australia.

Future Funding

Ensuring independent authority is vital when considering future funding models and sources. Whilst state government funding formed the basis of HCASA sustainability for almost 20 years, the funding agreement tied much of its work to supporting SA Health and funding was too limited to expand its support to the broader health and community services and sectors.

It should be noted that HCASA actively explored all of the following funding models in its attempts to secure ongoing and diversified funding into the future. The limited timeframe to achieve this within its existing reserves, and the advent of COVID-19 and its impact on immediate and potential long term priorities, failed to secure any of these funding options in the time available.

Government

Whilst all other state health consumer advocacy peak bodies, and the national health consumer body, receive recurrent government funding, it is becoming increasingly clear that long-term partnerships between government and its 'critical friends' can no longer be relied upon for secure and sustained funding. Never the less, to ensure a health consumer advocacy model that is able to achieve its core mission with legitimacy, core government funding is essential.

The Framework for the Management of SA Health Grants and Service Agreements with Non-Government Organisations Policy Directive identifies that a strong working relationship between SA Health and the non-Government sector, fostered through the department's various funding programs is essential in achieving Government policy objectives and targets.^{xix}

The power imbalance however, between government and the NGO sector cannot be overlooked. The apparent deviation between the current government's objectives and HCASA's mission has clearly impacted long-term security of the health advocacy peak body in South Australia. HCASA, whilst rich in social capital and legitimacy, has failed to influence government understanding of the important role of an independent health advocacy agency.

In the right context, as it has in the past, government funding has been complementary and mutually advantageous to both SA Health and HCASA. It has underpinned the legitimacy of the consumer voice, directly influenced health policy and decision-making and built the capacity for consumer engagement strategies across SA Health services.

To secure future government funding, a key strategy of a new health consumer advocacy model will need to reengage and reinvigorate the current government's understanding of and commitment to the role and benefits of health consumer advocacy, or work with a future government as part of its election platform.

Fee for Service

Although a potentially viable and perhaps only future funding option is fee for service. There are however significant risks associated with moving to a fee for service business model, which focuses energy on continuously attracting funds.

Mission drift is a real problem and arises when an NGO's priorities and activities are primarily determined by its funders, consequently, the NGO's functions diverge significantly from its original mission.^{xx} Inconsistent with its mission, this has the potential to create conflicts of interest when a fee for service is associated with the advocacy mandate to raise the health consumer voice and their right to health care that meets their needs, and when this fails, to challenge the failure.

A fee for service model can limit the ability for true independence and increase the risk of conflict of interest. Under what circumstances, for example, would HCASA have been sitting at the table in the Oakden review, if it relied on fee for service to be there?

The SA Health decentralisation of governance and subsequent amendments to the *Health Care Act*, have ensured local level consumer consultation and engagement is the responsibility of the Local Health Networks. The LHNs have made it clear however, that they have no interest, nor responsibility, in supporting a systemic health consumer advocacy body beyond discrete support, through fee for service, to assist them to implement local level consumer engagement.

Exploring a fee for service model will need to clearly identify the core mission of health consumer advocacy and what fee for services can be attracted to support and not detract from this mission.

Industry Levy

A levy model could be applied to state and federal health services across primary, secondary and tertiary health services. It could also act at the health interface with other care sectors such as disability and ageing and other sectors. It would need to support independent authority and function, integrity and trust of health consumer advocacy such as the levy similar on banks for funding the financial ombudsman. The economic benefit generated by including the voice of consumers and community could be recognised in a way that hasn't occurred before in South Australia. The contribution of funds is seen as an investment, not a cost.^{xxi}

A graduated levy model, incorporating a minimum levy, ensures levy costs are spread equitably between small and larger health services. It also acts to recover both direct and indirect costs associated with undertaking systemic policy and advocacy activities such as consumer and community engagement, consumer representation on statewide and national committees, advising government, preparing submissions and responding to health policy.

A graduated levy model, incorporating a minimum levy, ensures levy costs are spread equitably between small and larger health services

The premise of a levy model is that as all health services have similar access to the output of these systemic activities, the costs are shared across all health services. This is not achievable with a fee for service model. A combined levy and fee for service model would ensure core funding for systemic activities that benefitted all South Australians and all health services, with with a fee for service to support local health services and/or discrete projects.

Philanthropic

Advocacy is the basic tenet of democracy: a vital tool for surfacing the voices of marginalised or vulnerable citizens and for participation in the vital issues facing communities. It is a high-leverage, high-impact strategy with proven return-on-investment. If the philanthropic sector's role is to support a thriving democracy, it has a crucial role to play by funding advocacy.^{xxii}

Philanthropy has a vital role supporting civil society and shaping a better and more inclusive community. In doing so, it helps invigorate democracy, and ensure that the voices of the broader community, including those at the margins, are heard and given due regard in the development of policy.

Many philanthropic organisations fund 'on the ground' activities such as charities funding discrete service delivery programs. Often philanthropy plays a role supporting innovation, for example by funding new approaches to tackling social and environmental challenges.

Philanthropic funding that supports a peak systemic health policy and advocacy body, to raise the consumer voice is a sound approach to ensuring better health outcomes and improving health care and is consistent with philanthropic principles to shape a better and more inclusive community. Exploring philanthropic funding may provide a sound funding model in the absence of government support. This has been effective funding in other states but not so in South Australia.

The Ruby Slippers. Finding The Way

So what needs to happen next? If they could click their heels together three times, consumers, and stakeholders have identified the following concerns and immediate priorities in the absence of a health consumer advocacy peak body in South Australia.

Health Consumers' concerns and priorities

What are their concerns?

Recruitment

- How they will be informed of issues and opportunities for consumer engagement, and how they will be supported to develop their skills and knowledge through training, networking and mentorship.
- Potential lack of transparency in recruitment of consumer advocates and the fall-back position of 'cherry picking' and 'tapping friends on the shoulder' when health services are unsure or unskilled in recruiting and working with consumers.

Training

- Loss of independent, expert input into both the development and delivery of consumer advocacy and engagement training programs and the potential bias that will enter into local level, service-based consumer training.

Loss of independent, expert input into both the development and delivery of consumer advocacy and engagement training

Siloed participation

- Local level recruitment of consumers and the potential that consumer advocates will become siloed with one LHN or service, without opportunity for, or understanding of, broader levels of participation and involvement that could be available to them outside of a single health service.
- How they will be informed of other opportunities, including national opportunities and other community and care sectors, outside of LHNs and SA Health.

Their Rights

- Who will represent and support them when appropriate consumer engagement processes are not adhered to, such as payment of sitting fees; provision of training; lack of transparent recruitment; lack of recruitment of diversity; lack of role clarity or limited or tokenistic consumer and community consultation processes.

Representation

- How they will be ensured of representation to inform and influence state and national health and health service policy and transparent decision-making, without a central organisation to act as the conduit for this process.
- How will consumer representation occur within the Department of Health and Wellbeing and who will act as consumer representatives in the future in the absence of a health consumer advocacy peak body.

What are their immediate priorities?

A consumer advocates network

- To inform them on current issues, raise concerns, provide ongoing education information, network with each other, contribute to consumer advocacy and engagement work/projects, provide access to focus groups and consumer forums.

Consumer advocate recruitment opportunities

- To ensure access to information about consumer vacancies including LHNs, SA Health, other sectors, state and national bodies.

- To ensure appropriate, transparent recruitment processes free from tokenism and “cherry picking” (ie appropriate expression of interest recruitment and screening, orientation, lived experience, skills and ability based, sitting fees etc).

Ongoing consumer health consumer advocacy training

- To ensure new consumer advocates receive appropriate levels of training (from entry to leadership programs) that is skills-based, from an independent provider that ensures consumer advocates are trained and prepared and confident to contribute.

A central statewide consumer advocate network/register

- To ensure access to trained, experienced consumer advocates who have broader opportunities to develop advocacy skills etc and not solely aligned to individual organisations.

A central contact organisation

- To provide support, advice, offer debriefing, mentoring for consumer advocates independent of the LHNs and other organisations with which they are involved/aligned
- To represent consumers, independent of specific organisations/networks (ie LHNs, SA Health, SAHMRI).
- To establish health consumer advocacy and engagement policy, guidelines, resources independent of the health service providers.
- To maintain and expand relationships with communities and community organisations to ensure broader understanding and representation of diverse needs.

A central platform (website, social media page, hub)

- To provide access to recruitment opportunities, policy submissions, current research information, consultation processes (eg focus groups, surveys etc), consumer forums (state, national).

Stakeholders and service providers concerns and priorities

What are their concerns?

Health system codesign

- The loss of human centred design in SA health system and true codesign of services.
- How statewide consumer representation will happen and who will act as representatives
- No longer any systemic advocacy at a proactive level that pulls together consumer centred health policy and strategy to influence health system codesign.
- Who will provide a ‘big picture perspective’ of advocacy and policy at a high level.
- Where service providers will access support and mentoring in partnering effectively with consumers and the community in codesign – tokenism with only a small pool of consumers being involved.
- How they will have access to consumers from diverse backgrounds and communities and who experience health disadvantage. The health system does this poorly and struggles to connect with these communities.

Loss of human centred design and decision-making in SA health system and true codesign of health services

No driver for cultural shift

- The capacity to shift culture to meaningful consumer engagement.
- There is a significant and concerning lack of understanding, commitment and capacity of the health workforce for consumer engagement at anything more than a token level. Consumer engagement is not embedded in the health system or services with no true commitment or ownership from leadership or workforce. There is a great deal of resistance from the workforce to partner with consumers.
- Health services don’t know “what good looks like” and leadership does not recognise the importance or their role in building the capacity of the organisation.

Training

- Training for staff is imperative to build capacity for consumer engagement and to shift culture.
- Training for consumers should be the minimum standard when recruiting consumer advocates for governance committees, it properly prepares them for the role and helps ensure they are able to participate and contribute effectively.

Recruitment

- Health services struggle to recruit consumer advocates. This results in repeatedly using the same pool of consumers and forms the basis for tokenism.
- Health services struggle to recruit consumers from diverse communities including consummunities who experience health disadvantage.
- There is limited turnover and succession planning of consumer advocates who may sit on committees for many years. They often become institutionalised and no longer represent the lived experience of consumers currently using the services.
- The need for an appropriate and transparent recruitment process is important to address these issues.

Legitimate independent peak body

- No longer 'a go to place' to support health services, act as a sounding board and foster new ideas and ways to engage with consumers.
- The loss of the consumer movement in South Australia – the damage this will do has not been thought through and cannot yet be identified.
- The damage to South Australia – the only state without a health consumer peak body – leaves us open to scrutiny for lack of transparency and lack of engagement.
- Loss of a critical partner to government and health.
- Loss of the health consumer voice - creating an broadening gap between the needs of consumers and health system decision making in South Australia.

Loss of the consumer voice - creating an broadening gap between the needs of consumers and health system decision making in South Australia

What are their immediate priorities?

Centralised consumer advocate recruitment

- To ensure appropriate recruitment of consumer advocates who are 'role ready' (ie appropriate expression of interest recruitment and screening, orientation, lived experience, skills and ability based).
- To ensure consumer advocates are recruited from diverse backgrounds, lived experience, knowledge and skills and who have other opportunities to develop these skills through a range of recruitment opportunities.
- To ensure access to trained, experienced consumer advocates who have broader opportunities to develop advocacy skills etc and not solely aligned to individual LHNs or services.

Ongoing training (for both consumers and workforce)

- To ensure new consumer advocates receive appropriate levels of training (from entry to leadership programs) that is skills-based, from an independent provider.
- To ensure the training reflects current best practice and is provided by experts in consumer engagement and advocacy.
- To help build the capacity and capability of the health workforce to understand the benefits and implement consumer engagement at all levels of the health service.

Research and evaluation

- To gain a true picture of human centred codesign and health consumer engagement in South Australia – the rhetoric verses the actual.
- The need to ensure the continued recording of data regarding consumers who have contacted HCASA for issues and complaints – who will they go to now?
- The need to measure consumer advocates role experience in the absence of a peak body in SA ie in 3, 6, 12 months time

The Tinman. With Heart

Whatever the direction taken, whoever leads the charge, it must be done with openness, honesty, transparency and above all, with heart.

Advocacy at its core is meaningful, fair and just. It focuses on helping consumers and communities with pressing human need. It relies on a relationship of trust and integrity focused on improving the lives of individuals and communities.

By maintaining momentum now, we have the potential to shorten the path for others. Now is the opportunity to be buoyed by the readiness and willingness of consumers and communities. We must also identify those champions and allies who will work genuinely with consumers and communities to ensure sustainable health consumer advocacy in South Australia, into the future.

Health consumer advocacy is central to providing better opportunities for people:

- To access the health care they need and want
- To have greater control over their health and wellbeing
- To have greater access and equity for those who experience health disadvantage
- To demand and receive their health rights
- To improve their lives through improving their health

The obligation of health consumer advocacy is to strengthen the capacity of consumers and communities to raise their voice, and for the health system, its services, researchers and innovators, to respond to their health needs and continue to improve health care. This must be done with heart, health is a human service after all.

Putting consumers at the heart of health in South Australia

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