Think Human

HFI Trust Beneficiary Consultation

Final recommendations and project report

October 2020

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1. EXECUTIVE SUMMARY

1.1. Purpose

The HFI Trust Beneficiary Consultation engaged people living with disabilities, along with their families, carers, the local community and the broader public to explore the legacy of the Highgate Park site and the future of the Trust that owns it. In its 141-year history the Trust has always been for the benefit of people living with disabilities, specifically those who are unable to live independently without support. The consultation explored ways that its future could be relevant in its 21st century context.

Think Human was contracted by the Department of Human Services (DHS) to lead the consultation process with potential beneficiaries, their families and carers, as well as the local community and other stakeholders, including staff working in the disability and community sector.

DHS gave Think Human three clear priorities to work towards, as follows:

Financial sustainability of the HFI Trust
The recommendations needed to prioritise a sustainable future for the Trust, with maximum possible funds available to support beneficiaries

Community support
The preferred option needed to align with feedback from the community and particularly from people living with disabilities as the Trust beneficiaries, and their families and carers, whilst also respecting the legacy of the HFI Trust and the history of the site.

Improved assistance to beneficiaries & meeting unmet need for HFI Trust beneficiaries
The preferred option should enable an increased number of people with disabilities to benefit from the HFI Trust, including the potential to benefit rural and remote communities. The benefits provided by the Trust should not duplicate services and products provided by NDIS or other areas of Government.

1.2. Process

More than 360 people have been actively involved in this consultation, via interviews, workshops and surveys, including people from metropolitan Adelaide and regional South Australia, Aboriginal people living with disability and sector representatives, subject matter experts including people with lived experience and those working in the sector. The breakdown of participants across phases and categories of participants is provided in Figure 1.

Figure 1: Engagement of participants as a % of total across the three phases of the Consultation

1.3. Outcomes

The legacy of Julia Farr lived out through the Highgate Park site and the HFI Trust is held dear by many. There is a strong desire amongst the disability sector and the broader community to honour the work done by this South Australian innovator. There was a clear message that however this is done, it needs people living with disabilities to be at the centre of decision making.

Despite some strong connections to the site and a strong sense of local pride, in the detailed consultation discussions and deliberation throughout phases two and three of the consultation it was generally accepted that the value of the site to people living with disability is largely the monetary value it provides for the sustainability of the Trust into the future. At the same time, there is a desire to keep some portion of the land as a memorial to the service that has been provided there for more than a century.

With this in mind, beyond the sale of the land, the recommendations relate to people living with disability being at the centre of decisions about the Trust. By working with the government, this Trust is seen to be an exciting opportunity for South Australia to lead the way in supporting and advocating in the disability space in the way Julia Farr did over a century ago.

Recommendation one:

Sell the Highgate Park site but retain a small pocket of land to create an accessible space that honours the lives and experiences of people living with disability.

This is seen to be the best way to get value from the land since work to remediate and develop the site is expected to far exceed the money currently in the trust fund. But it was the strong desire of many to use some portion of the land to memorialise the site as a place that has served the disability community.

Recommendation two:

Once the site is sold, the Trust should become independent of Government, to be run by, with and for people living with disability.

While the general view is that the current Minister is acting in the interest of the people living with disability, there is an awareness that this will not always be guaranteed with changes in Government and Ministers. The expressed view is that there are many people with lived experience who also have the necessary skills and qualifications to run a Trust such as this and are therefore best placed to serve the disability community.

Recommendation three:

That the working group develops a clear articulation of the vision, focus, structure, beneficiaries, and roles for people living with disability in the Trust of the future.

Having a transition period where the Government works alongside skilled people living with disability provides time to establish clarity before making any changes requiring complex legal processes. With good governance established, the Trust could then be independent of government.

Recommendation four:

The Minister should adopt and hold the process of selling the site and the activity of the working group accountable to the guiding principles below, developed by people living with disability as part of the consultation process.

1. **"With us, by us, for us"**
   Key accountability question: Are people living with disability directly, actively and powerfully involved throughout the whole process?

2. **Inclusive, dignified, responsible**
   Key accountability questions: Does this enhance the dignity and inclusion of people living with disability? Are we including a range of perspectives from people living with disability, including new voices? Does this represent a responsible use of resources?

3. **Accountable, transparent, informed**
   Key accountability questions: Are financial decisions made in an accountable and transparent way? Are people living with disability fully informed?

4. **Respect the reason the Trust exists**
   Key accountability question: Does this honour the vision and spirit of innovation on which the Trust was founded?

5. **Remove barriers that hinder change and progress**
   Key accountability question: Does this decision hold back change? Does this maintain the status quo instead of prioritising progress? Are the quieter voices being heard? Are we hearing from new voices and are we having new conversations to progress new thinking?

1.4. Next Steps

- Explore options to sell the land and ensure that people living with disability are involved in decision-making that could impact the Trust and its assets moving forward, including the retained pocket of land. Site discussions should also involve Kaurna elders and community members as traditional custodians of the land. Likewise the local community voice will be critical in developing a master plan for the site moving forward.

- Make a Consultation Outcomes Summary available to everyone who actively participated in this consultation, to enable them to see the outcomes of their work.

- Ensure there is broad public communication about the decisions made as a result of this consultation and the final recommendations. This should include public messaging that provides important context about the history of the site and the Trust, including the ongoing work of JFA Purple Orange in continuing the legacy. Likewise there is a need for clear public messaging about the greater opportunities afforded by community living for dignity and self-determination amongst people living with disability.

- Continue to keep people living with disability involved and informed on the next steps in responding to these recommendations, particularly those who have been involved in this process and expressed an interest in staying actively involved and potentially contributing to a working group alongside Government.

- As the recommendations are considered and a response forumalted, adopt the principles developed during this consultation by people living with disability to inform and shape decision-making.

2. INTRODUCTION

This report will outline, in detail, the recommended future direction of the HFI Trust based on the results of the independent engagement process. The detail will provide context, and considerations to be taken onboard, when understanding the recommendations and how best to enact them.

Accompanying the recommendations will be insights from the data gained, forming the basis for the recommendations. These will be provided as *Key messages from people living with a disability* (and their allies); *Key messages from the local community*; and *Key messages from the Aboriginal disability sector*.

The process sought to gain broad input from across South Australia, not just metropolitan Adelaide. The central focus of the engagement was on the input of people living with disability. But to provide a wider perspective, the consultation included their families and carers, people working in the sector, and the general public (including the local community around the Highgate Park site). The approach taken, recruitment strategies, consultation methodology and general process will be described phase by phase. This will allow for transparency of how the data was collected and demonstrate how the recommendations were reached. Engagement methods were modified to respond to restrictions due to COVID-19 during the course of the Consultation project.

3. RECOMMENDATIONS TO THE TRUSTEE

There have been many insightful suggestions of gaps the Trust could focus on and creative ways it could be used. Their diversity speaks to the complexity of barriers faced by people living with disability in order to live full and equitable lives as members of society. It also demonstrates that a decision on what exactly the Trust *does* cannot be made without a number of the existing unknowns being resolved and without a response to the recommendations that are put forward as a result of the Consultation project. Critical unknown factors to determine what the Trust does into the future include the value of the land, the timescale of realising the value of any sale and the agreed governance of the Trust into the future.

The recommendations that follow address key questions to be answered by this consultation, namely what should happen to the site and what should happen to the Trust. However, they also address issues identified by people living with disabilities and their allies during the consultation process, namely what the governance of the Trust should be, and who the beneficiaries should be, into the future.

The recommendations that follow were developed directly by people living with disability, family members and friends and key subject matter experts and sector staff, many of whom also live with disability, and include representation from the Aboriginal disability sector. They seek to balance the three priorities provided by the Department of Human Service at the outset of this consultation:

F**inancial sustainability of the HFI Trust**
The recommendations needed to prioritise a sustainable future for the Trust, with maximum possible funds available to support beneficiaries

Community support
The preferred option needed to align with feedback from the community and particularly from people with disabilities as the Trust beneficiaries, and their families and carers, whilst also respecting the legacy of the HFI Trust and the history of the site.

Improved assistance to beneficiaries & meeting unmet need for HFI Trust beneficiaries
The preferred option should enable an increased number of people with disabilities to benefit from the HFI Trust, including the potential to benefit rural and remote communities. The benefits provided by the Trust should not duplicate services and products provided by NDIS or other areas of Government.

3.1. Recommendation one (site focus):

Sell the Highgate Park site but retain a small pocket of land to create an accessible space that honours the lives and experiences of people living with disability.

This is seen to be the best way to get value from the land since work to remediate and develop the site is expected to exceed the money currently in the Trust fund. In addition to the financial gain, for some this is seen as an important part of creating a fresh and hopeful start, acknowledging that the legacy of the site has become interwoven with the negative connotations of institutionalised care. But there was also a strong desire of many to use some portion of the land to memorialise the site as a place that has served the disability community.

3.1.1. Considerations:

A. The retention of the small pocket of land was seen as very important by the majority of stakeholders living with disability, as a site with a significant and historical connection with the disability movement. However, they emphasised the need to balance this with the financial impact and seek a settlement that has minimal negative impact on the financial benefit to the Trust when selling the site.
B. The priority of inclusive and accessible development should be embedded in the terms of the sale and priority be given to developers who embrace the accessibility agenda and universal design principles.
C. The process and decisions about the future of the site must involve Kaurna elders and the local Kaurna community at every stage, as the traditional custodians of the land.
D. The retained pocket of land, and subsequent use of that land, needs to represent a progressive expression of challenging barriers. The retention of the land is a way to embed the principle of honouring the reason for the Trust's existence - the work and vision of Julia Farr.
E. Participants are open to the idea of the government purchasing the asset from the Trust at a fair market rate if this will expedite the release of funds and the subsequent independence of the Trust.
F. If (E) is not pursued as the best option for sale, the working group (see Recommendation three) is involved in the ongoing discussions and decisions about the sale of the asset, particularly in relation to decisions about the retained pocket of land. Discussions and decisions about the use of the retained land need to involve Kaurna elders and local community members, as traditional custodians of the land.

Points to note:

- *Participants feel that, in recognition of the fact that the Highgate Park site, as the only Trust asset, has been used solely to deliver Government services since 2006, Government should pay all costs associated with its liquidation, in order to protect the existing funds in the Trust for the work of the Trust.*

- *There is a range of views amongst people living with disability, their families and carers, and the local community about how the legacy of Julia Farr should be memorialised. However, this should be clearly dissociated from the negative connotations of institutionalised care and should focus instead on the radical nature of Julia Farr's vision in her day, and her standing as a nineteenth century social innovator. Ideas include commissioned contemporary art work or sculpture that focuses on freedom and liberation, or art work that is co-created with people living with disability. Other suggestions include retaining a small memorial garden or the naming of streets, spaces or infrastructure that is built on the site.*

- *There were some concerns about the impact on the overall value of retaining a pocket of land. A minority felt the risk to value was too great to make this worthwhile to pursue; however, the majority who do wish to retain land do so with deep passion and conviction. Participants recognise that they do not have a sense of what sort of money is involved in this decision; consequently, the working group (see Recommendation three) should continue to be involved in the evolving decisions about the viability of this option. The majority did not feel that they would keep the pocket of land 'at any cost' and that there should be a limit set on this. However, without clear modeling of the impact of this aspect of the recommendation, they were unable to specify what that ceiling should be.*

- *A small number of stakeholders with a long and enduring connection with the Highgate Park site wished to see enough land retained to enable some accessible housing constructed on site for people living with disability. However, this did not represent the majority view.*

3.2. Recommendation two (Trust focus):

That the working group develops a clear articulation of the vision, focus, structure, beneficiaries, and roles for people living with disability in the Trust of the future.

While the general view is that the current minister is acting in the interest of the people living with disability, there is an awareness that this will not always be guaranteed with changes in Government and Ministers. The expressed view is that there are many people with lived experience who also have the necessary skills and qualifications to run a Trust such as this and are therefore best placed to serve the disability community.

3.2.1. Considerations:

A. A time-limited working group should be established as soon as possible, weighted towards people living with disability, to work with the government to guide the transition of the Trust into an independent structure with its own governance structure (see Recommendation three for more detail).
B. Until the site is sold and the asset liquidated, the Trust should remain in its current legal structure, with the Minister as sole trustee, but advised by the working group, with all decisions relating to the Trust driven by people living with disabilities.
C. The liquidation of the asset - including payment of any associated costs - should be undertaken by the Government on behalf of the Minister as the current sole trustee.
D. Participants are open to considering other legal structures other than a Trust for the future to best meet the needs and priorities of people living with disability. Likewise they have suggested consideration be given to amalgamating the Trust with another, established entity with similar values and ethos. These decisions should be guided by people living with disability.

3.2.2. Points to note:

- *There is high regard within the South Australian Disability community for the current Minister ("she is engaged and passionate") but overall people do not want the Trust to be entwined with government and political cycles in the future.*

3.3. Recommendation three (Trust focus):

That the working group develops a clear articulation of the vision, focus, structure, beneficiaries, and roles for people living with disability in the Trust of the future.

Having a transition period where the government works alongside skilled people living with disability provides time to establish clarity before making any changes requiring complex legal processes. With good governance established, the Trust could then be independent of government

3.3.1. Considerations:

A. Other legal structures could be considered if they better meet the identified purpose of the Trust and enable a more agile and progressive response to need and opportunity. The purpose as articulated by participants was 'to enrich and empower the lives of people living with disability.'
B. The working group should consist primarily of people living with disability as well as senior representation from government and other 'experts' as required.

C. The working group membership should be determined using a skills and experience matrix to guide recruitment (e.g. legal, financial, policy, disability sector subject matter experts, history and legacy of the site).
D. The working group should determine the vision, purpose and structure of the Trust (including options for affiliating with another Trust or body, or changing from a Trust structure). It would be tasked with developing the constitution and governing processes.
E. The working group should be given access to the full report from the HFI Beneficiary Consultation Project, which outlines the major needs and priorities identified by people living with disability
F. A co-design approach to the working group is critical.
G. Government should pay for and administer the working group and the legal process to change the Trust deeds.
H. The working group should determine who the beneficiaries are (e.g. by who is falling through the gaps, strengths-based) and define the focus and activity/investment of the Trust.
I. The working group should work with State and local government, Kaurna elders, and local community to develop a sensitive, inclusive and accessible option for the retained pocket of land, acknowledging the history of the disability movement on the site since 1879, and the perpetual Kaurna connection to and custodianship of the land.
J. The working group, and specifically people living with disability, should be involved in future conversations and decisions about the historical records and artefacts connected with the history of the Trust and the disability community that has been connected to the site since 1879.

3.3.2. Points to note:

- *In order to genuinely give priority to the voices of people living with disability, the working group process needs to be designed to be straightforward, not overly complex or demanding of large commitments of time and energy, yet giving time for people to express their views and opinions in ways that are accessible to them.*

- *The report from the HFI Trust Beneficiaries Consultation will provide important context for the working group, including more detailed analysis of discussions about the beneficiary definition and the focus of the Trust.*

3.4. Recommendation four (Trust focus):

The Minister should adopt and hold the process of selling the site and the activity of the working group accountable to the guiding principles below, developed by people living with disability as part of the consultation process.

"With us, by us, for us"

Key accountability question: Are people living with disability directly, actively and powerfully involved throughout the whole process?

Inclusive, dignified, responsible

Key accountability questions: Does this enhance the dignity and inclusion of people living with disability? Are we including a range of perspectives from people living with disability, including new voices? Does this represent a responsible use of resources?

Accountable, transparent, informed

Key accountability questions: Are financial decisions made in an accountable and transparent way? Are people living with disability fully informed?

Respect the reason the Trust exists

Key accountability question: Does this honour the vision and spirit of innovation on which the Trust was founded?

Remove barriers that hinder change and progress

Key accountability question: Does this decision hold back change? Does this maintain the status quo instead of prioritising progress? Are the quieter voices being heard? Are we hearing from new voices and are we having new conversations to progress new thinking?

4. KEY MESSAGES FROM PEOPLE LIVING WITH A DISABILITY

The single most agreed upon point, raised in every forum, was that people living with disability need to have a central role in the Trust, whatever form it takes in the future. This means having a pivotal role in decisions rather than just consulted on issues. Suggestions on how to achieve this ranged from a formal advisory committee to making up the majority, if not all, of the Trustees.

There were other concerns consistently raised by people with wide ranging disabilities. These were so clearly articulated in the first phase of consultation that we could group them into themes which held true throughout the project. The themes were:

4.1. Theme 1: Changes and Transitions in Life

Life transitions can be challenging for people with or without disability, but for those living with disability there are increased challenges. Further, at some particular points there are heightened needs that do not come under NDIS. A key transition period that came up in conversations was the transition from childhood to adulthood.

We have listed below a number of other transitions which were regularly raised. We note that some issues here are (or should be) funded and supported through State Government agencies and/or NDIS. However, we highlight them as they have a significant impact on the life opportunities of people living with disability.

- *Young people transitioning out of the care of the Department for Child Protection*. For this cohort, they experience an abrupt shift from a highly supervised and monitored life into NDIS, where they are required to self-advocate and self-manage their resources. Whilst this is a stark image, and one that some people no doubt receive some support to navigate, sector representatives and parents highlighted this as a time of real challenge for those young people.
- *Adults transitioning into NDIS*. Whilst it is acknowledged by many that NDIS is still in its early days and so there are many challenges that they hope will be smoothed out over time, people voiced real concern that there is inadequate support to navigate NDIS, to know what is available and to make it work well for each individual to really support the life they want to live.
- *Change in support workers*. This represents a far more significant change than simply a change in service delivery. It is not just an issue of competency, but one of trust. With many people being wholly or significantly dependent on support workers, this is a fundamental change.
- *Moving from the family home to independent living*. Not only is this a time of stress and upheaval generally, it is increased when there are complex health needs, mobility and transport limitations, greater distance from critical, natural supports.
- *Moving from NDIS to aged care*.
- *Transitioning from school to further education, work or training*. This is a period where families and young people living with disability have anxiety about opportunities available and, significantly, about the loss of vital peer relationships gained through school as peers may move interstate, take a gap year or move into vibrant adult social lives. People living with disability are afraid of being left behind.
- *Older parents of adults living with disability who are facing their own later life transitions*. There is deep anxiety for the later life transitions facing parents of adults with disability as they try to work out how and where they can all live safely and how they ensure their child is adequately supported when they are no longer able to be the primary support, or when they need support.

In discussing these transitions there were many suggestions and considerations around how it might influence the future of the Trust. Ideas involved pragmatic responses like education and support from peers, to testing out new approaches to ‘system transition', or targeted key moments to free people from a trajectory of segregation and isolation. Other responses were more conceptual, looking at defining approaches or guidelines to service provision. For example, ensuring there is a focus on holistic assessment of needs, especially during times of transitions.

4.2. Theme 2: Social Connections - Relationships & Social Resilience

A strong theme emerged, where people feel there is a significant gap that limits quality of life, is around social connection and genuine, caring communities. Some people living with disability find it hard to, or have never learned to, build & maintain genuine, deep, mutual relationships. For older people, this can be due to isolation during their youth and being separated from peers in the school system, or the low expectations of those around them and under-investment in them as equitable members of society. For younger people who are living in the community, there can still be segregation in how they spend their days and what is available to them, with much time still spent with other people with disabilities rather than with their age-group peers or people with shared interests.

Where there is community connection there was often lack of a sense of inclusion. This is seen to be because recreational/interest groups with a mixed and diverse society were not sufficiently equipped or skilled to cater for the more specific needs of people living with disability.

People living with disability and their family members highlight that there can be limited opportunities for genuine social connection. Whilst support workers offer ‘friendly’ relationships, for some people they end up being the most significant ‘friend-like’ relationship they have. Some family members voiced concern about this dependence and vulnerability, as the support workers will not be around for the long haul. They were concerned that their family members were not getting opportunities to learn the skills of mutual friendships, learning how to give and be needed by others. There was suggestion that the role of support worker should be used to facilitate and broker these friendships, not simply act as a substitute for them. It was also expressed that their family member was not getting an opportunity to explore their sexual identity or learn the skills for mutual, long-term sexual relationships.

Technology was raised as one area that has benefited the disability community in breaking down barriers. However, it was clear that this was supportive of social connections but cannot replace it.

People living with disability find NDIS does not easily support normative ‘extras’, which in fact are what most people take for granted as a normal part of life: the ability to buy a present for a family member, to host a party or to go to special events with friends and family rather than with support workers.

4.3. Theme 3: Advocacy, Education and Training

Many people who advocate on their own behalf expressed concern for those who have no family or friends to advocate for them so are dependent wholly on the formal channels. Low awareness of the availability of advocacy, coupled with perceived under-resourcing of advocacy services, leaves people living with disability vulnerable. Some wanted to see the establishment of an independent body responsible for supporting genuine disability inclusion. Others saw there a way forward in building communities of trust around people to advocate with them.

A recurring theme was the persisting low awareness amongst the general community of the needs, rights and values of people living with disability. This came across very strongly in the community responses on YourSAy and Facebook, where perceptions of the need to segregate, look after and institutionalise people living with disability is still very strong.

There seems to be a tacit assumption amongst the general public that people moving out into community settings equates to less support available for people, and less supervision of what happens in their lives.

This is echoed by people living with disability. Older people talked of life-long assumptions that they would not achieve much, or would achieve less than their peers. One or two said they felt they had defied people's expectations by still being alive and felt that all their opportunities had been limited by the assumption that their life would be short.

Amongst older people living with disability, who have self-advocated for many years, there was a sense of fatigue as they see attitudes in society still persist. Family members also shared this view, many of whom expressed similar fatigue in fighting for change and advocating to get the right support for family members. Likewise, people told us of ongoing physical barriers to getting out and being involved, like local council infrastructure, built environments that still were inaccessible or required people with wheelchairs to 'use the back door' (*see Theme #4*). Whilst local Disability Action & Inclusion Plans should address this, it will not happen overnight.

Part of this theme was a loud cry for challenging 'ableist attitudes". Part of the solution to this is real life education for the general public. This is seen as a pervasive problem that needs many approaches to address, including increased awareness and commitment to structural and policy change from governments, organisations, businesses and communities.

There was a loud call from people living with disability and their allies to challenge the currnet legislation and strengthen the Disability Discrimination Act which currently relies on people making complaints. However the system to lodge complaints is complex, onerous, overwhelming and often unsuccessful.

People living with disability feel there is a need for an independent mechanism, separate from government, to hold the system to account to make genuine inclusion a reality. Likewise, the need for an independent body that can genuinely focus on community education and shifting societal attitudes was raised by some people. Even within the disability support system people commented on significant gaps in awareness, knowledge and attention to genuine inclusion, with training for support workers in what it takes to support real empowerment being lacking, and limited accountability for staff to be agents and enablers of self-determination.

Finally, there is an ongoing need to empower people living with disability. This is seen to sit best outside the NDIS and government, as genuine empowerment will mean that people hold the system to account and will be powerful advocates for their own rights and the rights of others. People living with disability seek ways to be part of co-creating better futures for themselves and others living with disability, whilst challenging the norms, assumptions and prejudices that still run deep in society.

4.4. Theme 4: Buildings, Places and Spaces

This has already been touched on with reference to access to local amenities and communities with people living with disability reporting that there is still a long way to go to achieve a genuinely accessible built environment that allows them to live a normative, equitable life. However, it was also widely observed that there is still a significant shortage of suitable housing for people living with disability within communities and close to accessible public transport networks. This leads to adverse outcomes such as younger people with a disability ending up in aged care facilities because they have nowhere else to live that can provide them with even the minimum required support.

Along with appropriate housing, the limited choice and availability of holiday accommodation was raised on numerous occasions. And separate from holidays, the need for more respite accommodation for families to have a break from their caring roles.

Regional participants, however, focused on lack of short term accommodation when needing to come into the city (e.g. for multiple medical appointments, sporting or other events). People often need to accommodate support workers and/or family so end up staying in caravan parks or hotels which aren’t always adequately accessible.

People also expressed the need for more accessible infrastructure, including accessible community spaces, swimming and hydrotherapy pools, gyms etc. Likewise, the ability to access services that enable a normative lifestyle, such as dental and hairdressing services that are accessible, are limited at best, more often nonexistent. People living with disability do not want these to be set up as separate dedicated services and therefore segregated spaces and facilities, but rather that facilities are developed that are accessible *and* for universal access. The need for accessibility requirements incorporated into building codes and informed by people living with disability was brought up numerous times.

Whilst it is positive that local councils and other statutory bodies are required to have a Disability Action and Inclusion Plan in place, people commented on how woefully under-resourced and poorly executed these plans are. We heard repeatedly that the inclusion requirements under the current legislation fall far short of what is required to ensure people, particularly those in wheelchairs and with complex support needs, are genuinely included in society and able to access the services and venues they need and want. People highlighted that the process for changing this legislation relies on complaints, which as indicated above are incredibly difficult to lodge and follow through to successful outcomes. This widespread failure to commit to genuine inclusion leaves people effectively "stuck behind brick walls'; we heard people talk about community housing ending up like small scale institutions if in effect people are unable to get out due to inaccessible pavements and public spaces.

Young people with a disability shared with us their desire to live independently however many were fearful about moving out of home or sharing a house in case the situation did not turn out well and they would then end up stuck in an environment that didn't meet their needs. People with a disability highlighted their yearning for support to buy their own home and expressed frustration at the barriers they experience trying to enter the rental market. Those who have moved to community housing sometimes discovered that their home was not equipped with the necessary equipment to make daily tasks, like getting out of bed, easy for themselves or their support workers.

We heard many stories of how a simple kerb can ruin a day for a person living with a disability. There were multiple stories shared with us identifying that 'ableism' defines the built environment throughout our community and the subsequent strong need to educate architects, developers and planning approval authorities on the importance of considering functionality from the perspective of a person living with a disability. Universal design principles are not always incorporated and there is no incentive for their use. Architects and developers are not seeking advice based on lived experience and fail to facilitate connections with the community of end users to ensure co-design. People with disability believe it is essential for accessibility requirements to be incorporated into building codes to ensure a mandatory and consistent approach.

Technology is seen by people living with a disability as an opportunity for innovation to improve multiple aspects of living. We spoke with people with an acquired brain injury who were seeking new apps to support and extend their cognitive functioning and skills development and shared with us how technology had become essential during COVID to enable ongoing face-to-face communication with allied health professionals. There is also an opportunity to utilise technology in the development of smart homes. However, the cost of technology is a barrier for many people living with a disability and they shared their concern that it is difficult to access funding through NDIS.

4.5. Theme 5: Being Yourself and Citizenship

For young people with a disability there is a strong need to see positive and uplifting examples, from peers and/or role models, of what is possible for their life, like living independently with friends, studying at university, working in both small enterprises and large corporations -

things that people living without disability take for granted. There are too many deficit messages that they are exposed to repeatedly from society and at times fearful family members, who have also been exposed to deficit-based models and messages, that restrict their view of what is possible.

We regularly heard from older people with a disability that were working about the importance of having a ‘real job in real employment’ and how this is a catalyst for building a sense of inclusion and community, as well as earning an income that enables individuals to be financially independent and to live beyond the ‘reasonable and necessary’ limitations of the NDIS. Having a sense of purpose and being in a valued role - whether that is a volunteer, through initiating a small business enterprise or having a paid employment role - is critical to people’s sense of identity and facilitates social and community connection.

Family members clearly see a need for their loved ones to be able to experience everyday ‘moments of joy’ which create a sense of fun and connection. This includes things such as being able to go to the football with a friend, not a support worker; having opportunities to catch up with family and friends to celebrate life’s milestones; being able to go on a holiday with accommodation that provided all the necessary equipment as well as enough space to share with friends; and even the option of going shopping to buy a gift for a loved one without having to justify it. These everyday experiences are a vital part of life that is missing for people living with a disability.

For Aboriginal people living with a disability their sense of identity is embedded in connection to country, culture and spirituality. Many have lost their collective connection and shared with us their yearning to reconnect with their people and express their identity through appropriate programs delivered by indigenous people.

4.6. Other Key Concepts

With these themes come from the exploration of gaps in support, they were inextricably linked to possible solutions. However, through phases two and three, the future activity of the Trust became less of a focus, as seen in the recommendations. This is seen as the role of the transitioning working group. However, there were a few recurring concepts which were general in nature and/or attended to a number of the themes, so worth noting here.

The idea of a hub (not necessarily physical) came up regularly in different contexts with a variety of cohorts. It was usually described as a ‘place’ where people could connect to services, gain information, network with peers with and without disabilities. By being integrated in mainstream society, it would provide more opportunity for connection and an avenue for broader societal education and awareness building. This concept very much addresses all the themes uncovered in phase one.

Another concept that sits across all themes was the suggestion that the Trust should not be involved directly with service delivery. This automatically accounts for the expressed outcome of this project being that the benefits provided by the Trust should not duplicate services and products already being provided.

A final key concept which could sit behind any future focus, constraint or activity of the Trust is the importance of placing the rights of people living with disabilities at the fore. Rather than looking at limitations, deficits and diagnoses, people expressed the need for the emphasis to be on human rights as expressed in the National Disability Strategy and, ultimately, in the UN Convention of Human Rights.

5. KEY MESSAGES FROM THE LOCAL COMMUNITY

Highgate Park is a local landmark that residents strongly associate with a proud and long history of supporting people living with a disability and more recently providing transitional and respite care for older people in the community.

The local community needs to be reassured that people living with disability are receiving the support and care that they need to live in the community and that services have not been reduced as a result of the closure of Highgate Park. They also want to know that any financial gain from the sale of the property will be utilised to continue supporting people with a disability and not re-allocated by the government to fill any budget shortfalls. They seek transparency, accountability and ongoing communication about the outcomes of the Consultation process.

Any redevelopment of the site will be a cause of great concern for residents and ongoing engagement and communication will need to be managed in a sensitive, proactive and transparent manner.

As the Department of Human Services is aware there is keen interest in the site from a number of local stakeholders. While these stakeholders were invited to participate in the Consultation process, once they understood the focus was on the Trust, most declined, opting to wait for a future consultation process focused on master planning for the site. The exception was Concordia College who took the opportunity to engage with us and develop their understanding of the importance of co-designing with people living with disabilities in any future proposals pertaining to the site. Likewise some staff from Community Services in the City of Unley Council connected with us to share their perspectives and links to other service providers.

5.1. Key Message 1: The local community wants to be confident that people living with disability are receiving the support they need to live well.

The overwhelming message from the public in this consultation was that they wanted to see the Trust - and Government - continue to support people living with disability and build on the legacy of Julia Farr for many years into the future.

Within many of the comments received through the survey, Facebook and focus groups from people who do not have a direct connection with people living with disability there appears to still be a wide-spread community assumption that people living with disabilities need to be ‘looked after’. Some assume that congregate settings are still the best and ‘safest’ model for living for people with higher levels of disability. There seems to be a tacit assumption amongst the general public that people moving out into community settings equates to less support available for them, and less oversight and safeguarding of what happens in their lives. A few of the comments on the YourSAy survey were linked directly to the recent tragic events surrounding Ann-Marie Smith’s death; however, more broadly there seems to be an assumption that the closure of Highgate Park equates to less support for people living with disability.

Think Human sees an opportunity and a need for broader community education and information-sharing from Government to provide more context on what ‘living in community settings’ actually means, and to raise awareness that, done well and with appropriate personalised support, community living offers much more opportunity for people living with disability to live the lives they want.

5.2. Key message 2: The local community is proud of what the Highgate Park site represents and its long history of supporting people living with disability

There is a general perception amongst local community members, and the general public, that the Highgate Park site has been connected to ‘good work’ in the past. This is still largely connected to the name of Julia Farr, and there is a sense in the immediate vicinity that it speaks to the local community values. Local residents have talked about going to events there, and have a positive sense of having helped the residents and feeling good about that. There is a sense of pride in the site amongst local residents.

We have also spoken to and heard from a number of people who believe that the site cannot be sold, as well as a few people who assume that the site must continue to be used to support people living with disabilities.

There is an opportunity, echoed by people living with disabilities and reflected in the final recommendations, to mark in some way on site the long history and legacy of the site. Likewise, Think Human sees an opportunity for Government to raise public awareness of the evolving legacy of Julia Farr's work, including the separation of the Highgate Park site and original Trust from the Board of the Julia Farr Centre, with the resulting significance of JFA Purple Orange in carrying on and making contemporary the vision of Julia Farr for radical inclusion.

5.3. Key message 3: The local community wishes to see sensitive development of the site, with most wishing to see some or all of the site retained to support people living with disabilities

Most local residents elected to respond to the consultation by survey. However, in those who did participate in-person none were aware that the site is in fact owned by a Trust, and that whatever happens to it equates to direct impact on people living with disability. Most local people assumed the site was owned by the Government, with a small number believing it was owned by 'Julia Farr' (JFA Purple Orange). There was a fear expressed by local residents, and by other stakeholders, that selling the land would equate to 'government flogging it off to make money'.

There is uncertainty locally about what will happen to the site and nervousness that the site will lie vacant for long periods of time, increasing the risk of vandalism and crime.

Most local people and wider community members wished to see the site continue to be used to support people living with disabilities. Whilst this is not financially viable with the small amount of capital currently in the Trust and the importance of releasing the capital held within the site to enable the Trust to support people again into the future, Government should be aware of this strong local sentiment and do all it can to ensure the site is sold and redeveloped as quickly and as sensitively as possible.

6. KEY MESSAGES FROM THE ABORIGINAL DISABILITY SECTOR

Across all three phases of this consultation Think Human engaged with Aboriginal people living with disability and leaders and staff from the Aboriginal disability sector, including staff with direct involvement in service delivery on the Aṉangu Pitjantjatjara Yankunytjatjara lands, where people living with disability represent a huge percentage of the population.

6.1. Connection to culture is critical and is currently underserved under NDIS

A key message, from both metropolitain and remote Aboriginal stakeholders, is the critical need to connect people to country and culture, something that the NDIS only does under 'community needs'; however, stakeholders highlighted that it requires its own focus. One Aboriginal leader emphasised that this neglect of culture within the NDIS is true for culturally and linguistically diverse populations as well, some of whom seek support through Aboriginal-led organisations. One stakeholder referred to this as people being "culturally denied, with a loss of skills and development". For Aboriginal people, spiritual connection is multi-layered and includes connection with land, family, future, children and relationship to nation.

6.2. There is a need to build real empowerment and leadership amongst and alongside Aboriginal people living with disability

Whilst the message about empowerment was shared by both Aboriginal and non-Aboriginal people living with disability, in the Aboriginal context the needs and the 'vacuum' of genuine empowerment and leadership is even more profound. Stakeholders spoke of needing to genuinely shift power but that this requires resources and investment to make it real, otherwise it is demoralising. Whilst NDIS offers some resourcing around this, its focus on the individual over the collective is problematic in Aboriginal communities where a pooled approach to resourcing would be more culturally appropriate. When asked what the Trust could do, one respondent from the Aboriginal disability sector said, "Co-creation!" That's what NDIS can't do. It's still doing 'to' and it's individualised…"

6.3. Many Aboriginal people living with disability do not know what is available and how to access services, particularly around times of transition.

Aboriginal leaders identified a gap in people's awareness about NDIS and what it can offer and believe there are many more people who could be getting services who aren't.
Another area of need is around the transition from 18 into adulthood, particularly from children who have been in the care of the Department for Child Protection as they transition out of a heavily regulated environment into independence and have to navigate NDIS for themselves. Stakeholders also commented that whilst some people received substantial plans under NDIS, often the family does not understand the plan and how it works, with little consideration given to language and cultural appropriateness. Linked to this, there is a significant need around staff training, which in the Aborignal context includes trauma-responsive and culturally sensitive training.

7. ENGAGEMENT APPROACH

Much care was taken to ensure the methodology of the engagement was accessible to ensure people living with disability were truly at the centre of the consultation. This meant having sufficient support for people using technology like video conferencing; accessible venues when COVID restrictions eased; and a variety of tools to enable people to engage as effectively as possible.

7.1. Phase 1

7.1.1. Methodology

The first phase of engagement sought to get insight into people's connection with the site from both people living with disability, former staff of Highgate Park, and with the broader community (particularly those living in or involved in the local area around the site). Along with considerations of the site, early consultation aimed at understanding the needs in the disability sector. This was considered both generally and within the context of what the future of the HFI Trust could be. Again, people with lived experience were the focus of this alongside families, carers and others who worked in the sector. The hierarchy of stakeholder engagement for this consultation is represented in figure 2.

As this phase would shape the remainder of the consultative process, it was important to get input from as many people as possible. With the assistance of DHS we published a YourSAy survey and a Facebook engagement to capture a wide audience and community representation. The Facebook engagement reached almost 10,000 people and generated 95 comments.

To ensure people living with disability were at the centre of the engagement, we recruited people through advocacy groups, service providers, government agencies, DHS staff and community houses, sector-wide e-bulletins and social media channels and targeted friends and family networks through a number of service providers. In addition, we contacted local businesses, the City of Unley Council and carried out a letter box drop to capture the input from the local community. There was also focused attention in outreach to CALD and Aboriginal community organisations.

Due to the on-going impact of the pandemic, the majority of consultation in phase one was undertaken remotely using video conferencing technology, online surveys and phone calls.

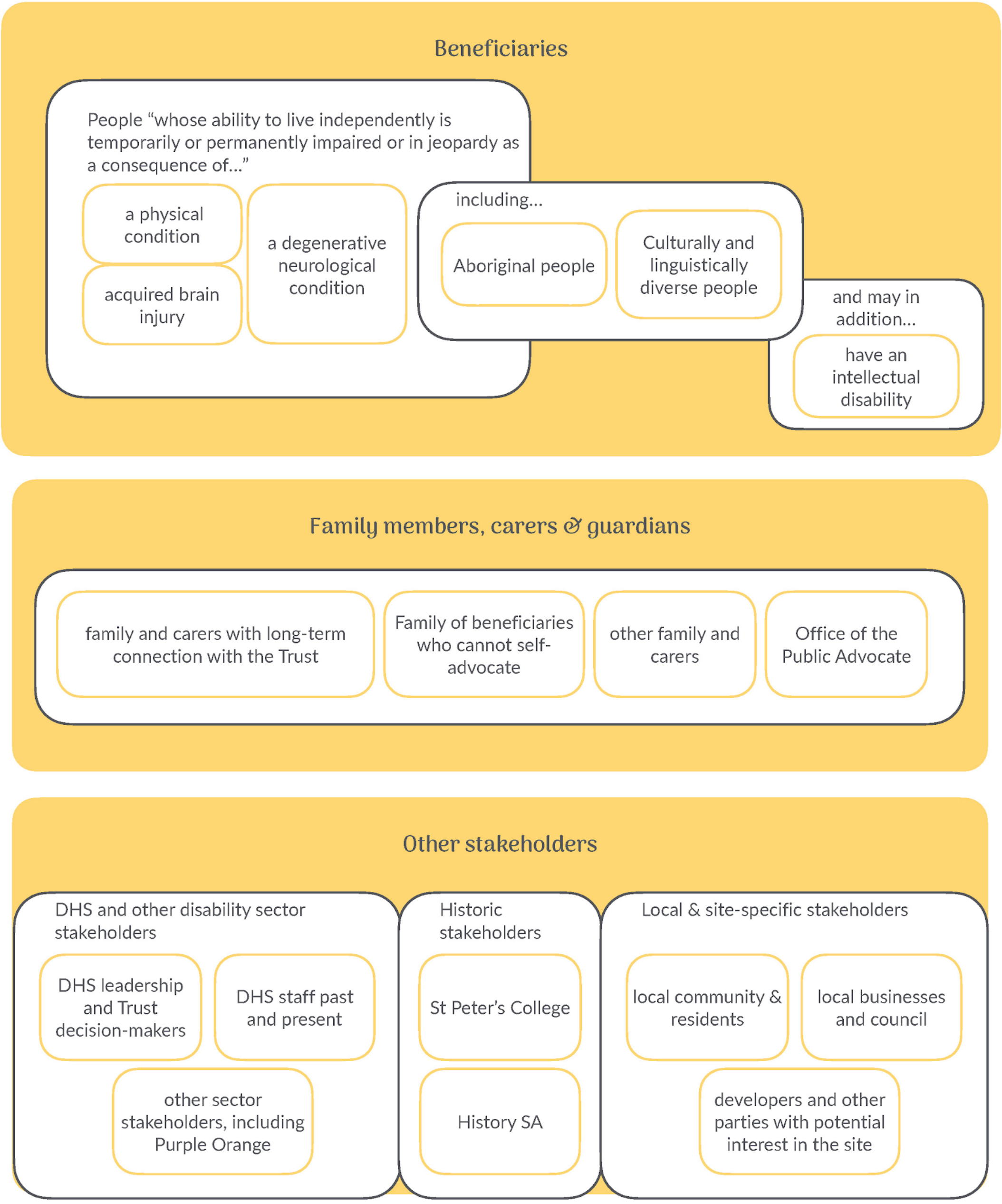

Figure 2: Engagement hierarchy for the HFI Beneficiary Consultation

7.1.2. Participants

A total of 277 people participated in phase one, broken down across channels of engagement and category of respondent as shown in table 1. This is represented as a percentage of total respondents in figure 3. It should be noted that the number of people living with disability recorded throughout all three phases should be read as a minimum number and only represents those who chose to identify as living with disability. It is possible that there are others who participated throughout the consultation who chose not to specify that they had a disability.

Phase one						
	interview	YourSAy survey	YourSAy forum	direct contact (email/submission)	Facebook comment	Total
People with disabilities	14	13		7	2	**36**
Family members/friends	10	16		1	1	**28**
Sector experts / current & former staff	15	22				**37**
local residents/businesses	6	32		2		**40**
history and legacy interest	0	11				**11**
other/unknown	0	17	15	1	92	**125**
TOTAL engaged	277					

Table 1: Phase one engagement overview

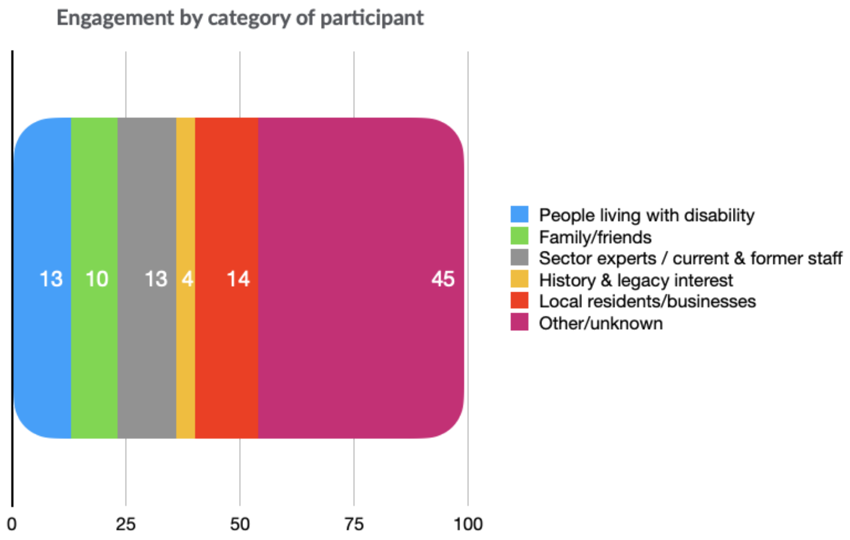

Figure 3: Category of participants as a % of total for phase one

7.1.3. Insights Gathered

Phase one led to the identification of the needs and gaps as expressed in the themes in Section 4: Key messages from People living with disability. Participants also suggested a range of ideas and concepts for what the Trust could do under these themes, which are summarised below.

A key priority from the Consultation was to ensure that the Trust focus did not replicate NDIS or other existing Government support or responsibilities; however, a key message from phase one was the fact that the support ecosystem is still in a state of transition itself, which makes it hard for individuals to know what is and is not available. In an environment where many people are still not getting their basic needs adequately met, it is challenging to consider what role a Trust can play that sits outside these ongoing needs. However, it is clear that this is not the Trust's role, nor would it have the capacity to deliver at that sort of scale. Below we have consolidated some of the possible focus areas that could be relevant and appropriate for a Trust in the future.

Opportunities to focus on peer roles and volunteering

Many participants spoke of the gap in volunteer and peer support left by the transition to NDIS and its focus on individualised funding models. Peer support and role models can provide a vision of hope and a sense of what is possible, as well as being able to provide practical advice and navigation support from someone who has 'been there before'. Participants also felt that there were increasing levels of support workers taking the place of friends and saw opportunities to use the Trust to explore befriending and peer mentoring models such as exist in the UK.

Opportunities to focus on research and innovation

There was widespread agreement that the current model of the NDIS is far from perfect; likewise, current models of community housing are also not fully enabling the vision of people living vibrant lives embedded in their local community. In fact, in almost every area of the current system people could see opportunities missed, and ideas that could be explored. Consequently a recurring idea for the future focus of the Trust was in research and innovation, particularly approaches that favoured co-design and co-creation with people living with disability, where people could be actively exploring and testing new models and opportunities to genuinely enhance life opportunities with and for people living with disability.

Opportunities to focus on empowerment and self-determination

The strongest message across all phases of the Consultation, including phase one, was the priority for people living with disabilities to be at the centre of decision-making that impacted their life and future. Across the disability community the opportunities for this, and how it could be achieved, vary hugely. There could be an opportunity for the Trust to explore progressive and emerging models of how this can be done well. Advocacy and safeguarding came up regularly as areas requiring focus; however, this is a grey area with what is the responsibility of government and what lies outside the current statutory service ecosystem. People saw an opportunity for the trust to play a role in holding the system accountable for its responsibilities from a community empowerment perspective.

Opportunities to focus on systemic and societal change

Whilst participants recognised that any one of the themes described in Section four could provide rich ground for the focus of the Trust, there was widespread agreement that no one theme, if addressed well, would on its own lead to systemic change. Indeed, the insights and needs across themes are so interwoven that it is hard to unravel them; this was particularly expressed by Aboriginal stakeholders who talked of the broader complexity of life and society that disability sits within.

As a result, a recurring possibility for the Trust, despite the probability that it would be quite small, was to focus at a societal and systemic level, to contribute in some way to shifting societal attitudes and misconceptions about disability and developing new and hopeful narratives of life's potential. These narratives would be for the dual purpose of providing examples and inspiration for people living with disability of what a good life could look like, and to transform the false narratives still held in society about people living with disability, many of which we heard first hand in phase one.

7.2. Phase 2

We moved into phase two in mid August. Phase two explored the themes expressed in phase one in more depth. This moved from identifying needs to determining ways these could be responded to. Then, by using the lens of the Trust, we could shape these into the beginning of recommendations with beneficiaries, families and other sector experts.

7.2.1. Methodology

Phase 2.a - Deepening workshops

The start of Phase two involved a set of workshops to test and deepen the themes emerging from Phase one and to explore the viability of options for the future of the Trust's relationship with the site. The aims of this phase were to:

- Identify if there was an overarching focus for the Trust, for example, if there was one theme that was more important than others to people living with disability, or that clearly stood out as sitting outside the current NDIS scope
- Explore more deeply the implications and viability of keeping or selling the site

There were five workshops in total, involving both face-to-face and video conference sessions, with participation from people living with disability, family members, sector staff, subject matter experts (some of whom also live with disability) and local community members.

Phase 2.b - *Towards recommendations* workshops

In phase 2.b we ran six online workshops to work towards developing some draft recommendations. In addition we had four one-to-one interviews to work through the same process with people who could not attend the workshops. The issues addressed in these sessions are outlined below, with the main issues and points for discussion that emerged from phase 2.a.

The future of the site
A decision is necessary as the value of the Trust is wrapped up in the site. The Trust does not have the financial resources to re-develop the site itself which makes retaining the whole site unviable.

Workshop participants were asked to consider what other options are available. For example, perhaps part of the site could be sold and part retained to explore shared development opportunities with other financial partners, or all of the site could be sold to a developer with any money released to the Trust.

The governance of the Trust
Currently there is one trustee (the Minister) which dates from the period when the Trust's sole focus was on the work of Highgate Park. Throughout Phase 1 and 2.1 of this consultation project, people living with disability, subject matter experts and families have consistently expressed concern that the Minister remain as sole Trustee in perpetuity.
With Highgate Park now closed participants feel it is timely to re-examine this to decide if still appropriate.

Workshop participants were asked to consider a range of governance options that enable people living with a disability to express their interests on an ongoing basis to influence decision making.

The role of people living with disability
Feedback from the consultation process is clear and strong that the voice of people living with disability needs to be at the centre of all decision making. The closure of Highgate Park represents an opportunity to ensure that people living with disability are at the centre of decision making about the Trust's future structure, direction and activity.

Workshop participants were asked to consider ways that people living with disability could influence decision making and whether their role is alongside, advising, guiding or replacing the role of the Minister.

The focus of the Trust
The Trust was established in 1879 and was last reviewed in 1997, prior to the commencement of NDIS. The purpose of the Trust needs to be clearly defined and agreed to ensure the longevity and relevance of Trust now and in the future. The consultation process has identified a broad range of needs and opportunities within the context of NDIS but without knowing how much money will be in the Trust it is hard to define the activity of the Trust.

Workshop participants were asked to consider potential trust purpose statements and activities which could support the themes identified in Phase 1 of the consultation process.

The beneficiaries of the Trust
Julia Farr's vision was to support the 'destitute' and 'incurables', terms that today are outdated. Clarity is needed to know exactly whom the Trust is for in a 21st century context that reflects contemporary understandings of the social construct of disability.

Workshop participants were asked to consider definition options for 'beneficiaries' to ensure the Trust is inclusive and accessible and that the definition has longevity in the evolving context of disability.

The name of the Trust
The current name, "The Home For Incurables (HFI) Trust" is outdated, discriminatory and exclusionary. The name should reflect any changes in the beneficiaries, purpose and activities of the Trust.

Workshop participants were asked to consider name options based on discussions from Phases one and two.

7.2.2. Participants

A total of 67 people participated in phase two, broken down across categories of respondents as shown in table 2. This is represented as a percentage of total respondents in figure 4.

Phase two	
	Workshop/interview
People with disabilities	33
Family members/friends	10
Sector staff / subject matter experts	24
local residents/businesses	0
history and legacy interest	2*
other/unknown	0
TOTAL engaged	**67**

Table 2: Phase two engagement overview

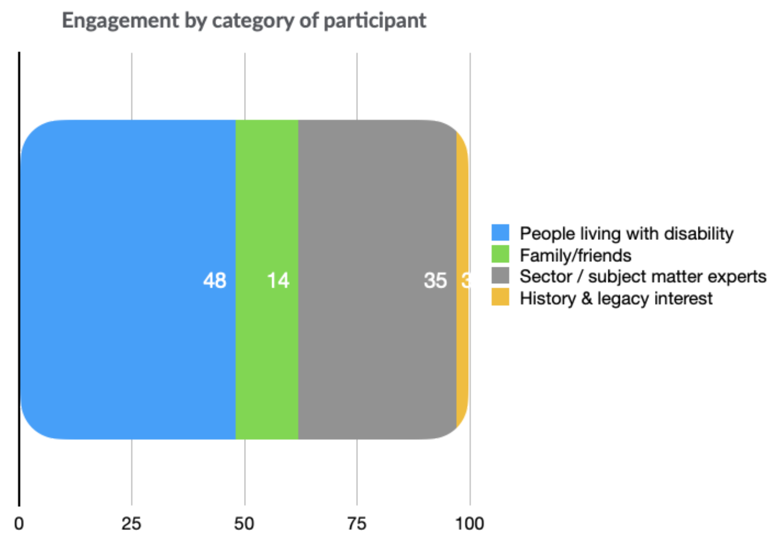

Figure 4: Category of participants as a % of total for phase two

7.2.3. Insights Gathered

At the end of Phase 2.b, the consolidated feedback of all participants led to the development of a set of draft recommendations, with some key decisions still to be made in Phase three.

The Future of the Site

"Sell the Highgate Park site to get as much money as possible to put into the Trust."

There is not enough money in the trust to redevelop the site, nor is there a sense that this is the most accessible or best-located site even if the trust wanted to build something in the future. There is a strong feeling from some in the disability community that this land has such strong connections with a past of institutionalised care that it should not be the site of any future disability investment.

Key decisions to be made in phase three:

1. **Keep a small parcel of land, sell everything else**
   Use as a memorial space e.g. garden or sculpture. It would be a place to go when something significant (good or bad) happens in the disability space. Would also be a place to reflect on the fact we stand on the shoulders of the people who have gone before.

2. **Sell all the land to start afresh with the land**
   Legacy of institutional care. A place of separation and segregation, based on good intentions but the underlying assumption that people needed to be protected from the world.

3. **Sell all the land but hold an event**
   The event would recognise the good of Julia Farr's contribution and the people who have gone before for whom the site was home. It would also look to the promise of what is ahead.

4. **Sell all the land but commission a piece of art e.g. sculpture to install elsewhere**
   The piece of art would honour the bravery and freedom narrative of the disability community, not the legacy of institutional care.

The Governance of the Trust

"The government establishes a strategic working group involving people living with disabilities, relevant subject matter experts (ideally with lived experience), and government to guide the transition to a new governance structure for the Trust. People living with Disability will be key decision-makers at the centre of the structure."

There has been a unanimous view expressed that the Minister should not continue as the sole Trustee and that people living with disabilities need to be involved as active and powerful decision-makers. This is in line with the principle of 'nothing about us, without us.'

Key Decisions to be made in phase three:

1. **Recommend a working group is set up to work with the Minister/Government to transition the Trust into a new governance model with people living with disabilities at the centre**
   Whilst people living with disabilities and their allies are clear about not wanting the Minister to remain as *sole* trustee, and about people living with disabilities being *actively involved* in leadership, there is still much to do to determine what the final structure could or should look like e.g. amount of money may be small; if there is an ongoing role for the Minister it may make sense for it to remain connected to government. There could be the recommendation that a set of guiding principles be adopted (perhaps those we will use in the workshop), and/or recommendations for breakdown of membership and working group focus.

2. **Recommend the Trust moves forward with changing the Trust deeds to a shared power arrangement between government and people living with disability and other relevant allies**

3. **Recommend the Trust moves forward in changing the Trust deeds to an independent governance model outside government involving people living with disability and other relevant allies**

4. **Recommend the Trust is amalgamated with a larger trust.**
   This could support greater credibility, exposure, and audience and may be a more cost effective option by bringing economy of scale. But it would require identifying an appropriate, values-aligned entity to partner with and assumes the other party would be interested.

The focus of the Trust

No individual theme emerged to override the others, with participants agreeing that all the emerging themes had merit and were important to supporting people living with disability to live their best life. As a result, participants were unable to form a draft recommendation on the focus of the Trust and the key decisions below reflect this.

Key Decisions to be made in phase three:

1. **Make a recommendation for the focus of the Trust aligned to one or more of the above themes**
   Whilst the actual activities of the trust cannot be defined until the amount of money it holds is confirmed (at some point in the future) it may be possible to define the broad focus area based on priorities of people living with disability and areas of unmet need.

2. **Recommend that the Trust focuses across the themes on co-design research and innovation to shape a more inclusive future for people living with disability**
   Given that the service and policy landscape will continue to evolve and change, the trust could focus more on emerging ideas and innovation to shape the future of society, policy and the service landscape. Given the strong messages from participants about the role of people living with disability being critical and central in all decision-making, adopting a co-design and collaborative approach to research and innovation aligns with this sentiment.

3. **Recommend that the Trust focuses in the short-term on scoping and viability of the Trust itself**
   Focus initially on reinventing the trust itself, based on a set of guiding principles and working with people living with disability, through which the ultimate focus and future activity of the Trust will be defined

The Beneficiaries of the Trust

Participants in the consultation have highlighted that they wish to make a recommendation to clarify and update the definition of beneficiaries for a 21st century context. The spirit of Julia Farr's initial vision was to support people who had no other support or were 'falling through the cracks'. However, defining beneficiaries by listing types of disabilities is fraught, as definitions change over time and it sets up a deficit model. Likewise, defining beneficiaries by gaps in the current system is fraught, as this will change over time as the NDIS and government roles evolve. As a result, no consensus was reached on what a new definition of beneficiary could be going into phase three.

Key Decisions to be made in phase three:

1. **Suggest a new definition of beneficiaries**
   This could be using social/strengths based approach (National Disability Strategy; UN Convention of Human Rights); or it could be a new definition of 'beneficiaries' that stretches beyond simply beneficiaries to encompass the spirit of collective action, partnership approaches, and a Trust that is by/with/for people living with disabilities

2. **Keep the current definition in the short term**
   Suggest that a new definition of 'beneficiaries' be developed collaboratively over time, but recommend a set of principles that should be upheld in the process

The name of the Trust

Participants agreed that they could not form an opinion on renaming the Trust until the issues above were resolved and key decisions made about the sale of the land and the future focus of the Trust.

7.3. Phase 3

7.3.1. Methodology

Phase three was focused on developing the final recommendations that are included in this report. Participants were provided in advance with the draft recommendations and options as outlined above and had the option to discuss these with someone else in advance of the final recommendations workshop to help them think through their response. 36 people were invited to attend the final recommendations workshop or participate in an interview; all 36 had participated in phase 2.b and had contributed to the draft recommendations. Everyone had the option of providing written or verbal feedback prior to the final workshop if they could not attend in person.

In the final workshop, participants worked in small groups to go through the draft recommendations and formulate their preferred options, and why. We then worked with the group to try to resolve any differing opinions through a process whereby each person could express any aspects of the discussion where they felt strongly one way or another and together worked to find a recommendation that everyone could accept.

7.3.2. Participants

A total of 27 people participated in phase three, broken down across categories of respondents as shown in table 3. This is represented as a percentage of total respondents in figure 5.

Phase three		
	Workshop/ interview	**written submission**
People with disabilities	11	
Family members/friends	3	3
Sector staff / subject matter experts	6	2
history and legacy interest	2	
TOTAL engaged	27	

Table 3: Phase three engagement overview

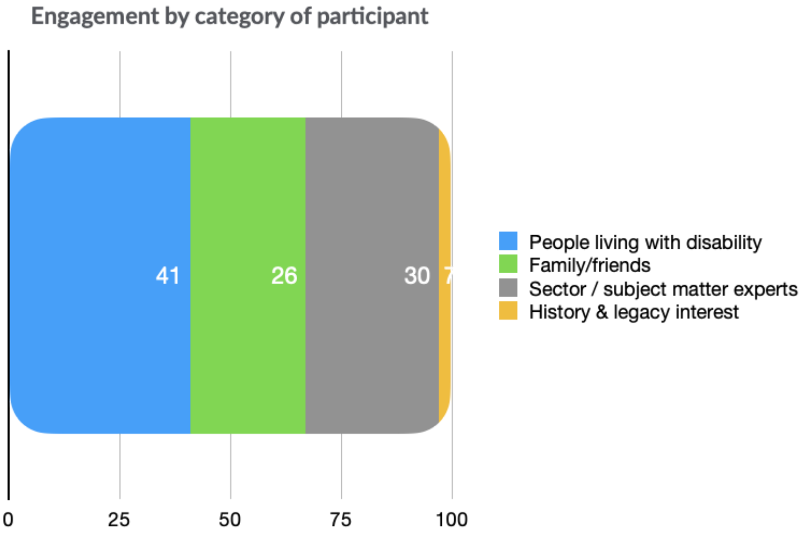

Figure 5: Category of participants as a % of total for phase three

7.3.3. Insights Gathered

The outcomes from this phase are captured in the final recommendations, which form the first part of this report. The commentary below is to provide additional context to the recommendations.

People understand that options for the future of the site and the trust are constrained by economic viability.

Whilst in an ideal world many participants were excited at the prospect of keeping the site and redeveloping it to be a fully accessible community hub, people were also realistic and sought to make recommendations that had the potential to be viable within the economic realities facing the Trust. Likewise, despite the nervousness with letting the site go, as a relinquishment of a current asset, there was also general agreement that, even if in the future the Trust sought to build a physical asset, the Highgate Park site was not the most central or accessible place to service the South Australian disability community. The recommendation to release the capital was also acknowledged as the best way to widen options for what the trust can do, which may or may not require a physical site in the future. In relation to the potential negative impact that the COVID-19 pandemic could have on the value of the land, and whilst there was discussion about putting off sale of the land until the economy was more stable, people could also recognise that holding the site indefinitely carried its own risks, including the potential devaluing of the site through vandalism or simply as a result of prolonged market volatility.

People's desire to see the Trust led by people living with disability is backed up by a willingness to get personally involved.

Throughout the consultation Think Human staff have heard from skilled, insightful and experienced people living with disability who would gladly be part of shaping the future of the Trust, beyond the life of this consultation process. Whilst people recognise that there will be a requirement for specific skills and experiences on the road ahead, including financial, legal and governance expertise, they wished to see priority given to people living with disability working in these fields, with other 'allies' being drawn in only when people living with disability could not fulfil the needs of the process. There was a genuine desire to work collaboratively with Government, with some expressing a desire to see Government adopt a bipartisan approach to developing the future of the trust, in acknowledgement that the Trust needs to be designed to outlast political cycles.

People's desire to honour the legacy is based in hope, bravery and optimism

Throughout the 140 years of the Trust that owns Highgate Park there have of course been multiple highs and lows in the experience of people receiving services at the site, and in the experience of those leading the Trust. For every positive anecdote we heard a negative one; for every person who wanted to see the building retained and reused, someone else wanted to see it razed to the ground. Whilst some felt strongly that the site should not be memorialised, by phase three of the consultation there was agreement that a pocket of land could be retained. However, the use of this pocket of land is to be for the purposes of future-oriented inspiration rather than retrospective nostalgia. The legacy focus should be about bravery and courage amongst 'those upon whose shoulders we stand', acknowledging the lives that have been lived on site and the freedom from paternalistic models of care that the closure of the site represents. It is also important to re emphasise the overarching desire expressed by Aboriginal stakeholders that the traditional cushions of the land, the Kauran people, be involved and acknowledged.

'How' the process moves forward is as important as 'what' the Trust becomes

The principles described in Recommendation four were developed participants in phase three in order to guide their own decision-making. Having found them useful to resolve challenges and differences of opinion in the consultation process, they wished to recommend that these be adopted to guide the next steps, as the Trustee develops her response to the recommendations. Participants recognise that there may be valid reasons why some recommendations cannot be upheld; however, they wish to be fully involved and informed about this along the way, and feel that the principles, if adopted, will provide a safeguard around the process moving forward.

8. NEXT STEPS

In response to this report, and in addition to the recommendations in relation to the Trust, Think Human makes the following recommendations for the next steps in the process:

1. Explore options to sell the land and ensure that people living with disability are involved in decision-making that could impact the Trust and its assets moving forward, including the retained pocket of land. Site discussions should also involve Kaurna elders and community members as traditional custodians of the land. Likewise the local community voice will be critical in developing a master plan for the site moving forward.

2. Ensure everyone who actively participated in this consultation is kept informed of the outcomes.

3. Ensure there is broad public communication about the decisions made as a result of this consultation and the final recommendations. This should include public messaging that provides important context about the history of the site and the Trust, including the ongoing work of JFA Purple Orange in continuing the legacy. Likewise, there is a need for clear public messaging about the advantages of community living over institutional care settings in offering dignity and good lives for people living with disability.

4. Continue to keep people living with disability involved and informed on the next steps in responding to these recommendations, particularly those who have been involved in this process and expressed an interest in staying actively involved and potentially contributing to a working group alongside Government.
5. As the recommendations are considered, and a response formulated, adopt the principles developed during this consultation by people living with disability to inform and shape decision-making.

9. CONCLUSION

As stated at the outset, the public of South Australia, and particularly those with a connection to the site, care passionately about what happens at Highgate Park, formerly the site of the Home for Incurables and the Julia Farr Centre. Whilst there is a strong desire locally to see the site retained for people living with disability, the majority of people living with disability themselves, when given an opportunity to explore the issues, opportunities and constraints in detail, see the greatest benefit being in selling the majority of the land to ensure the Trust remains viable into the future. However, whilst selling all the land would ensure most money be released into the Trust for the future, their desire is that a small pocket of land be retained, as both a memorial to the legacy of those who have gone before them in the struggle for dignity and equity and as a sign of hope and a sanctuary for the future. This view was echoed by Aboriginal stakeholders, who in addition would like to see the land in some way acknowledged as Kaurna land first and foremost. This will be important not only for considering the possibility of retaining a piece of land but also for the ongoing planning for the rest of the site.

Whilst this report does not make clear recommendations for the final shape and focus of the Trust, this is because there are still many questions that remain unanswered, not least of which is, once the land is sold, how much money remains in the Trust to be used to support people living with disability. What is clear, however, is that people living with disability wish to be centrally involved in all aspects of decision-making and leadership moving forward.

This is an exciting opportunity for the future of the HFI Trust and for the Minister for Human Services to reinvent a genuinely innovative fund to strive towards radical inclusion of people living with disability in 21st century South Australia.