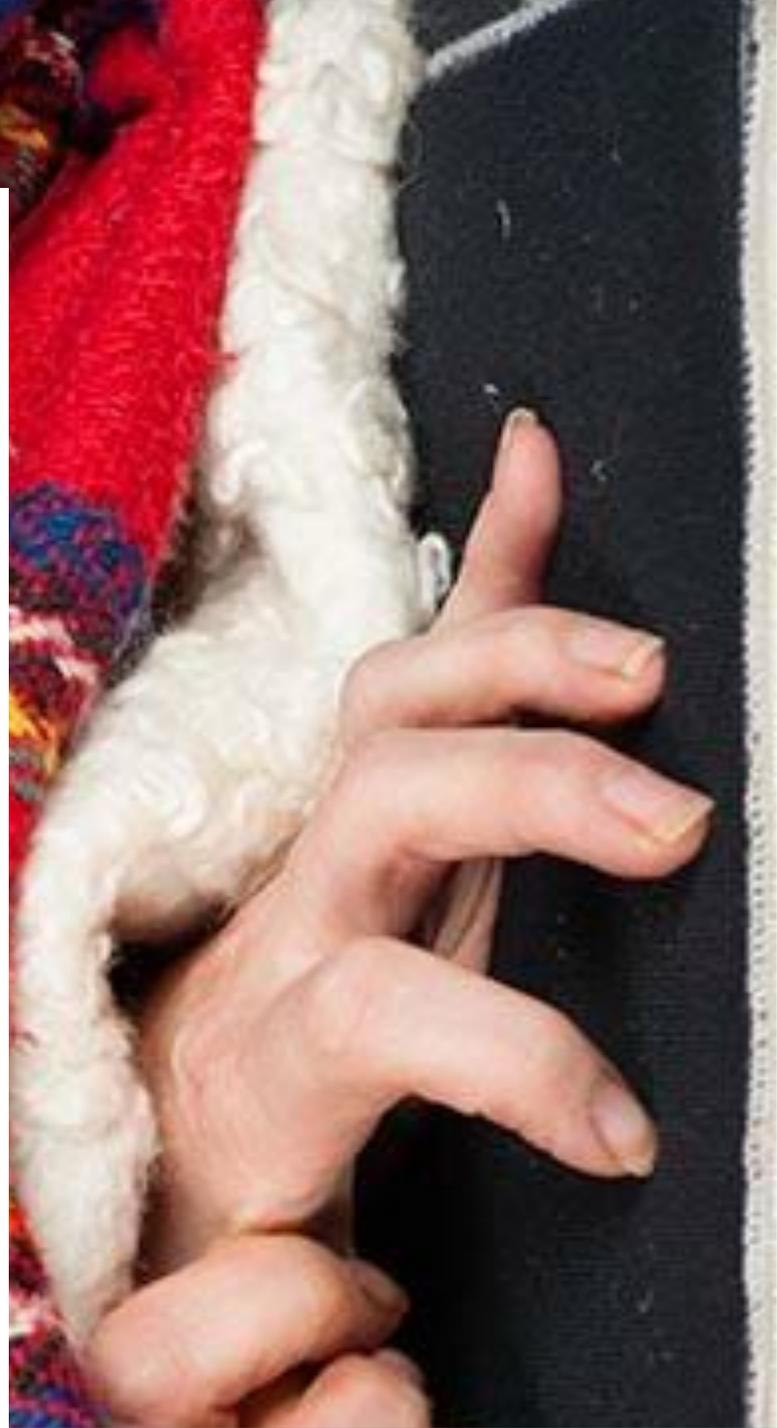


SA woman dies from long-term abuse and neglect:

*A DISABILITY COMMUNITY
RESPONSE*



MAY 25 2020

Independent Disability Research & Education

Dr Betty-Jean Dee-Price
Researcher/Educator/Advocate

A South Australian woman dies from long-term abuse and neglect: A disability community response.

“This was clearly a case where the system failed on so many levels.” (survey respondent)

Acknowledgements

This report acknowledges the life of Ann Marie Smith and the profound impact the news of her death has upon the community. This survey is dedicated to Ann Marie Smith and to those who hope for a better future for people with disabilities and their families.

Acknowledged are the 136 people who generously and thoughtfully responded to the survey - the majority of whom are people with lived experience of disability. Gratitude is also extended to peer supports from Flinders University and the University of South Australia who offered encouragement and advice in the planning and preparation of this report.

A note about language

A range of language is used to describe people and roles within the disability field. For the purposes of this paper the term 'people with disability' is used unless it is in the context of a direct quote by a respondent.

Respondents have used varying terms to describe people who provide paid personal care and/or other type of assistance. The words 'carer,' 'support worker,' and 'attendant' are used throughout.

Glossary & Acronyms

ABC Australian Broadcasting Commission

Ableism is discrimination and social prejudice against people with disabilities or who are perceived to have disabilities.

CP Cerebral Palsy

CVS Community Visitor Scheme

HREC Human Research Ethics Committee

NDIA National Disability Insurance Agency

NDIS National Disability Insurance Scheme

PWD Person with a disability

Respondent Person(s) who answered the survey

RN Registered Nurse

SA South Australia

SA Health the South Australian brand name for public hospitals and state health service administration

Survey Monkey is an online survey development cloud-based software as a service company

About the Author

Dr Betty-Jean (B-J) Dee-Price is a researcher and, published author. B-J is a humanist, disability advocate, sessional lecturer and holds full academic status in the College of Medicine and Public Health at Flinders University South Australia. Her primary research interests include disability health and education, complex disability, severe communication disability and inclusive research methods. B-J participates on a number of disability committees and is the Flinders University representative on the South Australian Health Performance Council Disability Project.

Contact

Email: bjdeeprice@flinders.edu.au

Phone: 0434192392

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Background

This investigation began as a survey post on social media, with the intent of capturing the response of the community (in real time) to the news of the death of South Australian woman Ann Marie Smith. As described in the media post, the information gathered was to be used to give voice to the community on the various platforms of advocacy on which the author participates. An ABC news article (see references) preceded the posting of the survey.

It was hoped the survey would receive around 20 responses; however, within a few hours of posting there were more than 60 detailed responses. The survey was kept open for 48 hours obtaining over 90% completion-of-survey rate by a total of 136 respondents. Responses were detailed and of high quality. After extensive consultation, a decision was made to formally publish these findings as independent research.

Survey design

Survey Monkey was used to obtain anonymous on-line surveying to capture the responses of people on social media (Facebook). The survey used a combination of multiple-choice questions, sliding scale and open questions. There was a total of eight core questions, five of these contained a second open question requesting respondents to provide detail on their decisions or to add additional issues or topics that may have not been adequately included in the survey questions. Filters were applied to highlight detail within responses, comparing answers across the different types of respondents.

Introduction

‘The only friends my daughter has are my friends. When we go [die] her world goes. This is my greatest fear. It chills me to my core.’ (survey respondent)

The experiences and responses of people ‘in real time’ when critical events come to light, are often outside the grasp of structured research. Research proposals, submissions to Human Research Ethics Committee (HREC) and so forth can take many months. The news of what happened to Ann Marie Smith, a South Australian woman was released on Friday 15th May 2020. Within 48 hours of the news being delivered, a survey was created and posted on social media. A further 48 hours after that, 136 people, mostly people with lived experience of disability, answered the survey, providing a total of 470 comments ranging, in length, from single words to page long statements. The analyzed contents of the survey, in receiving input, advice and support from experts at Flinders University and the University of South Australia, are shared in this report.

‘Sadness’, ‘outrage’, ‘worry about the future’, and ‘despair in the delivery of services’ formed the tone of survey responses. Due to the generosity of the people who responded to the survey and their willingness to answer it despite the confronting nature of the content, there is enough data to provide a sample of the issues facing people with disabilities in relation to their care and wellbeing in the community.

'It was a systemic failure. How can one human be overlooked by so many? The carer, the carer's agency, the NDIS, SA Health, community, police.' (survey respondent)

Key messages

- 'Not Surprised' received the largest aggregate of responses to the question *How surprised were you by the news of a woman dying in such circumstances?*
- The majority of respondents believe abuse happens often.
- While there were noted comments about the behaviour of the 'carer' the focus was on systemic change with many respondents describing the implications of health, NDIS and the interface of State and Federal bodies.
- There is little confidence that the current Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disabilities will deliver the changes needed.
- Recommendations for improvements formed three key themes. 1) Broad Government 2) Service Provision 3) Community awareness and community development.
- The majority of respondents support the appointment of a South Australian Disability Commissioner who is independent of Government/political interests, has lived experienced of disability, has powers to investigate and is accountable to the community.

1. Respondent Categories

There was a total of 136 respondents with the greatest contribution from people with lived experience of disability. Respondents indicating 'Person with a disability' or 'Parent of a child with disability' combined were 59% of the cohort. A further 12% indicated they were a family member of someone with a disability.

Attendant/carer/support worker, works in the disability sector and those with associated interests in disability combined to represent 19% of all respondents.

Close to 10% of the cohort were people who ticked the 'None of the Above' box.

Table 1. *Respondent types (numbers)*

Person with a disability	39
Parent of a child with disability	40
Family member of someone with a disability	16
Works in the disability sector	9
Attendant/carer/support worker	9
Associated interests in disability	8
None of the above	13
Total	136

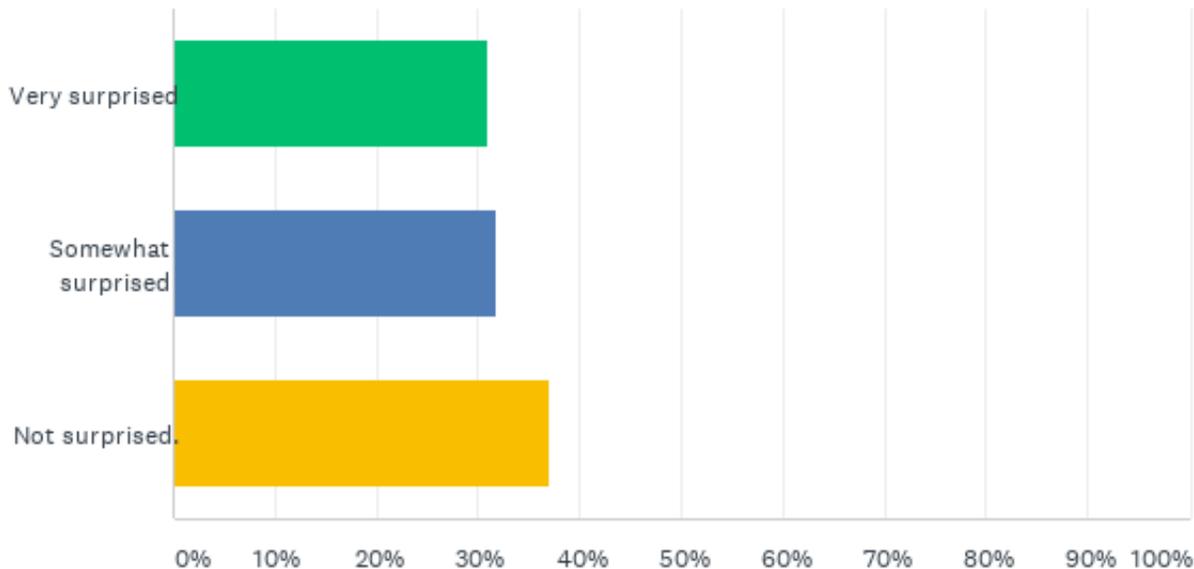
2. Surprise response / news of a woman dying in such circumstances.

'The fact that people are surprised by this.

The ignorance and ableism in our society is so ingrained.' (survey respondent)

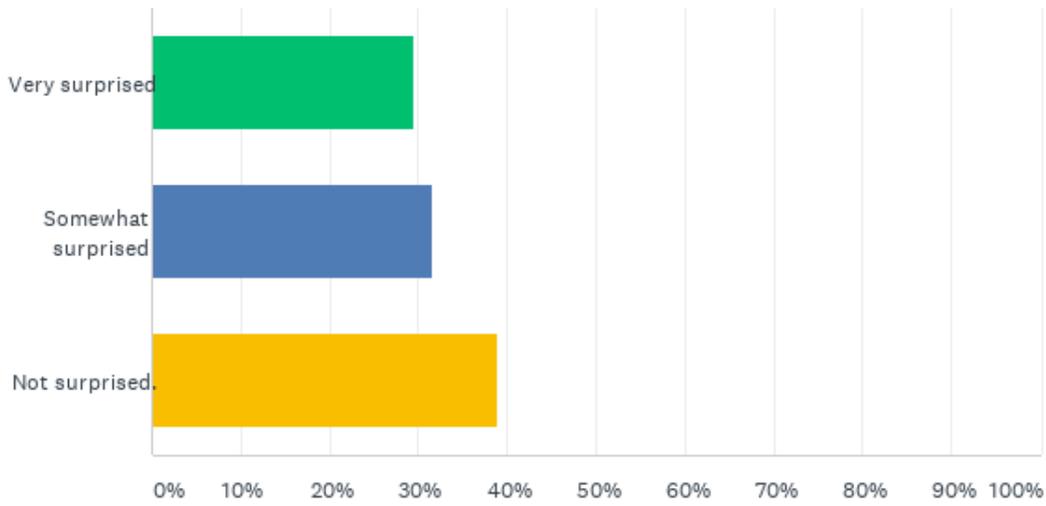
A total of 134 of the 136 respondents answered the question *How surprised were you by the news of a woman dying in such circumstances?* Graph 1 provides an illustration of the answers provided. *Of the 134 responses -*

- 41 (30.60%) indicated they were 'very surprised'.
- 42 (31.34%) indicated they were 'somewhat surprised'.
- 51 (38.06%) indicated they were 'not surprised'.

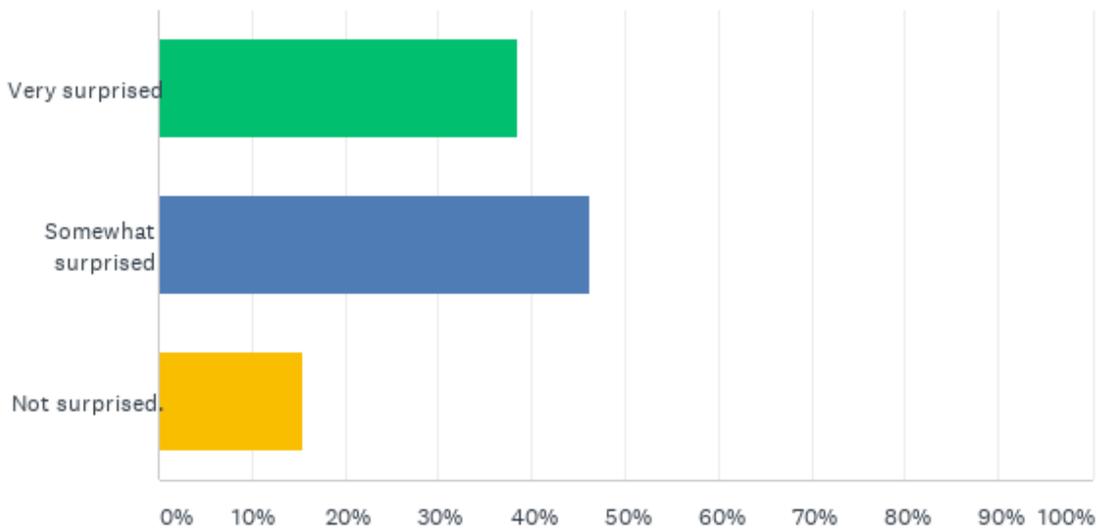


Graph 1. *Surprised responses (total cohort 134)*

The study compared answers across the *types of respondent* groupings. This was done by applying a filter to the categories of respondent types. Graph 2 and 3 (p. 11) suggest a sharp distinction in responses to this question according to the disability orientation of the respondent. The lowest number of responses to the category 'not surprised' were from those who selected 'none of the above' in the list of respondent types (i.e. they didn't have lived experience of disability). 'Parent of a child with a disability' indicated the highest proportion of 'not surprised' very closely followed by the 'person with a disability' filter.



Graph 2. *'person with a disability' 'parent of a child with disability' 'works in disability sector' 'attendant/carer/support worker' n. 95*



Graph 3. *'none of the above' respondent type n.13*

The highest scoring selected option was 'not surprised' with 46 respondents providing comments for why they made this choice. Approximately half said these responses were in reference to their direct experience. Examples of typical responses are included below.

Respondents indicating 'Person with a disability'.

'Unfortunately, as someone with quadriplegia and hence reliant on the same kinds of services that this young lady was, I have both seen and been subject to abuse far too many times. So unfortunately, no, hearing about this latest case has not surprised me.'

'Because it's happening to me for 3 years.'

'Unfortunately, abuse by support workers is known in the disabled community as not uncommon.'

Respondents indicating 'Works in the disability sector' or 'Attendant/carer/support worker'.

'There is no oversight of carers. I know this because I am one!'

'I am an RN and have seen shocking things over 21 years of nursing which I have reported.'

'Worked as a psychologist in the disability sector for over 20 year and have always been aware of the severe risks to people with disability.'

There were also a few comments which extended notions of poor care to aged care.

'Have first-hand experience of neglect in aged care & disability care.'

Comments referring to system gaps within care agencies, health services, the National Disability Insurance Agency and other related systems formed the next highest grouping of responses.

'That people are surprised that this happens shows how little people care about people with disabilities and indicates that they will forget about it straight away. Nothing will change.'

It's easy to churn out surveys and wave a report as proof that something's being done but it's fake-proof as often the only thing that's been done is a survey. Nothing changes. The vulnerable pay the cost.'

'Segregation of people with disability, starting from school aged'.

3. Most disturbing aspects

There were two parts to the question – in the first part respondents were invited to provide a ranking-order in response to the question *What disturbed you the most about this story?* A list of options drawn from the ABC media article such as ‘alleged behaviour of the carer’ and ‘the woman’s complaints were ignored’ etc. was provided. The second part asked – *Is there anything else that disturbs you about this story?* All 136 respondents answered the ranking question and 103 provided written responses to the *open question*.

A decision was made to exclude the results of the ranking question for several reasons. Some respondents described their frustration with not being able to rank one or more responses equally. Two respondents stated that if they had the opportunity to do so they would have given the highest ranking to all of the options provided. There was some confusion as to whether the ranking was from lowest to highest number or vice versa. Some core disturbing factors brought to light in the second question were not part of the ranking process.

The most disturbing aspects of the story are therefore listed collectively and in alphabetical, not rank order, with examples of typical comments made:

- Absence of authority over care agencies

There is no government body who is assigned to regulate and check in unannounced to these agencies ...’

- Absence of family and friends

‘So many PWD live on their own with no family.’

‘Many family and friends scattered when my daughter was born. It’s not an easy life and most of them didn’t want to be part of it. ‘

- Absence of connection with neighbours

‘The lack of community care. Neighbours didn’t seem like they checked in on her or had friendships with her. ‘

‘Neighbours noticed nothing at all. Nothing? Are we so disinterested in each other?’

- Alleged behaviour of the carer

‘Care is so haphazard. I have worked with other support workers who are abusive, either verbally, physically or mentally.’

- Complaints, by Ann Marie Smith, were ignored

‘No surprises hospitals etc. didn’t follow up on her complaints. ‘

‘I’m disturbed her complaints were ignored for so long. ‘

- Implications of the carer agency

‘I worked in the industry, companies don’t follow up on care maintained or carer audits.’

-
- Inadequate advocacy / governance protecting the interests of people with disability
'Independent review of all public systems and statutory/policy/complaints mechanisms.'
 - Language used by journalists in reporting the story of Anne Marie Smith
'Some of the reporting has been upsetting to me as someone who has CP, such as suggesting Ann Marie died of complications of cerebral palsy which is simply untrue and appears to minimize the actual cause of her death.'

· 'Media saying the lady was "suffering" from cerebral palsy .'

'...Chair-bound ??'
 - Role of the National Disability Insurance Agency (NDIA)
'She's not the first person to have died this way since the NDIS started.'

'There are many issues with NDIA and access to appropriate funds for care levels.'

SA Health's handling of the healthcare of Ann Marie

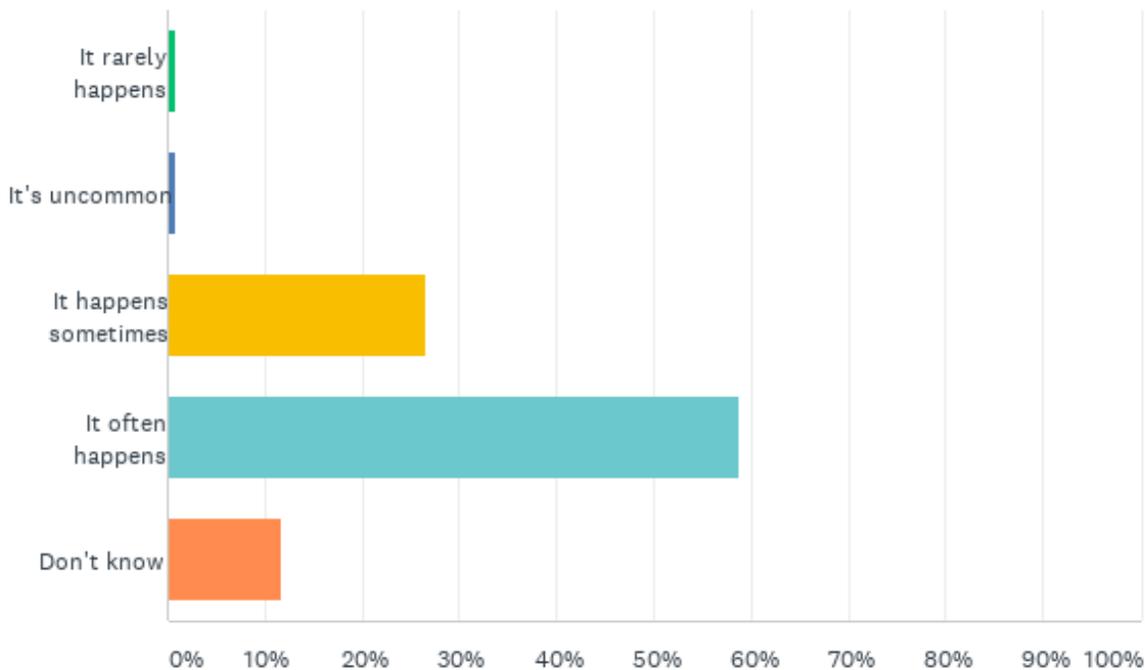
- 'I don't think the health system cares that my mum exists and I can confidently say the same for Anne.'*

'..hospitals in SA are not properly set up for people with disabilities.'

4. Perception of how common abuse/harm is within the community.

'It seems to happen quite a lot. The Royal Commission made that clear.' (survey respondent)

Respondents were asked this question. *In your opinion, how common is the problem of 'poor care' where the recipient of care may be harmed physically or mentally by person(s) responsible for their care?* All 136 respondents provided a response with the major response being 'it often happens'.



Graph 4. *Perception of abuse/harm*¹

These results gave a clear indication of the respondents' perception of 'poor care', which may lead to physical and mental harm, being a common occurrence.

¹ In this question use of 'it rarely happens' and 'it's uncommon' was not optimal as they share very similar meanings. However, this error did not have a bearing on the data outcome.

5. Perception of the Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disabilities

Respondents were asked to apply a sliding scale from 0% to 100% to the question *How confident are you that the current Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disabilities will deliver the changes needed?*

The mean average of the 133 respondents who answered the question was 37%.

6. Recommendations

Respondents were asked the following question: *In your opinion, what needs to happen to prevent situations of poor care, violence, abuse, neglect and exploitation for people with disabilities?* Of the 136 total respondents, 129 answered the question. Clear themes emerged from the data which could be categorized as having implications in three areas:

- **Broad Governance**
- **Service provision**
- **Community awareness/development**

The words 'checks', 'audits', 'monitoring', 'needs', 'care', 'agency', were used with frequency within the descriptive responses.

Broad Governance

Survey responses indicated strong interest in calls for over-arching safeguards and better co-ordination between the South Australian State Government and Federal Government systems. Improved systems of accountability where Government Departments, State and private service agencies must report on standards, audits and evaluation.

'Overarching safeguards in place (either government or NDIS management).

'Re-working of the CVS (sic - community visitor scheme) to include checks on people who don't want to live in state-based care homes. Isn't that why the NDIS was set up, to give people choice?'

'The agencies, the state government bodies and NDIS all need to work together.'

'An independent disability commissioner with powers to investigate Government and private sector services is needed.'

Comments related to legislation also arose within the theme of 'Broad Governance'.

'Possibly specific criminal legislation, and consequences from a statutory body with Investigative and prosecution powers.'

'Tighter governance of organisations and service providers. Harsh penalties.'

Service provision

Comments from respondents highlighted a need for greater accountability of service providers in both care support and health/allied health services. Effective recruitment of staff who are trained and personally orientated towards care work; not just doing a job were frequently emphasised in comments.

'There needs to be a greater duty of care performed by the service providers.'

'Support worker should all be trained with empathy. They should experience from their peers what it feels like to be transferred from wheelchair in a hoist, have someone take their jumper off, put food in their mouth, wash their face, clean their teeth. Feel what it feels like.'

'There also needs to be regular face to face checks with the person being cared for particularly if there are no friends and family being able to monitor the level of care.'

'Co-ordinators or managers of these places should regularly visit the person in their home and get their feedback, if needed with an advocate present.'

Community awareness/development

Among the comments in the survey were recommendations for building stronger communities and increasing disability awareness.

'Community education starting with the media.'

'We need to start investing in our neighbourhoods.'

'Stop segregating and hiding people with disabilities away from the rest of the community by doing all the stuff NDIS promised but hasn't delivered.'

7. Disability Commissioner (SA) question

116 people responded to the question - *Does South Australia need a Disability Commissioner?*

Table 1. *Does SA need a Disability Commissioner?*

Yes	89
No	2
Unsure	5
Not known	20

Note: 16 of the 20 responses classified as 'Not Known' still provided comments of desired qualities in a disability commissioner.

Extensive detail was provided in response to the question - *What qualities would you expect that person/role to have?* Common themes were of 'lived experience', 'empathy,' 'strength' and 'understanding'.

'YES. Qualities needed are a strong focus on human rights, social justice, and empathy; a strong communicator with a person-centred strength-based approach who can appreciate having a disability, and get 'stuff' done. '

'Guts, no more Government pleasers, someone with the strength to hold their ground and drive change'.

'Yes, good understanding of disability, courage to take on carer businesses and carers when poor caring happens, authority to speak up for disabled, authority to work with the police to investigate abuse, assault, sexual abuse.'

'Abuse is happening but we are only made aware of the extreme situations.' (survey respondent)

Summary

There was enough data collected within the survey to provide a sample of the types of concerns and issues which surround the death of a South Australian woman from long-term abuse and neglect. 136 people, mostly people with lived experience of disability, gave their time to answer a survey aimed at understanding why this traumatic situation occurred, and more importantly what might be done to prevent poor care in the future.

As a final note, there were comments made by respondents indicating ongoing poor care and abuse for people with disabilities and in aged care. If a positive step forward could be made on behalf of Ann Marie Smith it would be that the experiences of poor care and abuse, as captured in the descriptions of respondents, might be addressed. The thoughtful and generous recommendations made by the community offer a sound beginning.

References

(2020). Retrieved from <https://www.abc.net.au/news/2020-05-15/police-investigate-death-of-chairbound-woman-in-adelaide/12253326?fbclid=IwAR29ktXOAuILO14es3RFqjXJ73j5ddBOUQrq9lsqgh50pMCdQKI taJ0W-Mg>

<https://www.abc.net.au/news/2020-05-15/police-investigate-death-of-chairbound-woman-in-adelaide/12253326?fbclid=IwAR29ktXOAuILO14es3RFqjXJ73j5ddBOUQrq9lsqgh50pMCdQKI taJ0W-Mg>