

**ABC AUDIENCE AND CONSUMER AFFAIRS
INVESTIGATION REPORT C54507-16**

'It's like she's a three-year-old': What life's like when your children never grow up
published by ABC News Digital on 11 December 2016

Complaint

The Disabled People's Organisations Australia (DPOA), an alliance of four national Disabled People's Organisations (DPO's), has complained that the article *'It's like she's a three-year-old': What life's like when your children never grow up* (<http://www.abc.net.au/news/2016-12-12/at-home-with-the-hilliers-caring-for-adults-with-disabilities/8098976>) by reporter Margaret Burin was in breach of the fundamental rights to privacy, respect and dignity of the two women featured. The DPOA states that all people with a disability, including those with intellectual disability, have the right to make informed decisions about every aspect of their lives, and questions whether the young women concerned were afforded an opportunity to give their informed consent.

The DPOA states that the story is not consistent with the ABC's editorial standards for privacy and harm and offence, and that it humiliates and denigrates the two young women. While the DPOA acknowledges the need for support for carers, *"it is grossly unethical, unprofessional and inherently cruel to openly exploit two women with intellectual disability to highlight issues relating to lack of services and support"*.

The DPOA requests that the content be removed and recommends that the ABC instigate as a matter of urgency human rights training for all ABC staff.

Assessment

The DPOA states that the story may have breached a number of human rights treaties which it lists; consideration of these treaties is outside the remit of Audience and Consumer Affairs. The complainant also notes that the ABC is committed to respecting human rights in its content; as the ABC's Corporate Responsibility website states, the freedom of expression and portrayal related to human rights are demonstrated in the ABC's Editorial Policies.

Audience and Consumer Affairs have carefully considered the matters raised by the DPOA; reviewed associated coverage and social media; sought information from ABC News Digital and assessed the content against the relevant ABC Editorial Policies for *privacy* and *harm and offence*.

Privacy

6.1 Intrusion into a person's private life without consent must be justified in the public interest and the extent of the intrusion must be limited to what is proportionate in the circumstances.

ABC News Digital have advised that the reporter discussed the story at length and in detail with the parents Sue and David Hillier. It was made clear during the discussion that the story would appear in different formats across ABC platforms and on social media; that there were significant privacy and

consent considerations; and that it was likely there would be some criticisms of the article. The story was undertaken with the full consent of Sue and David Hillier and the article, including the photographs, was agreed with them prior to publication.

On the issue of consent from Kara and Jenna, ABC News Digital have advised: *“Sue and David explained who Margaret was and where she was from prior to her arriving at the house. Kara and Jenna understood she was from the ABC and would be taking photographs When Margaret arrived Sue said to the twins “Remember I told you Margaret was coming from the ABC”. Margaret then said “Hi Kara and Jenna, I’m Margie from the ABC, I’m here to do a story on you and your family”.* During each photograph and video, the reporter ensured that all parties were aware at all times that she was present.

Audience and Consumer Affairs note that the reporter also undertook photography at the Mulleraterong Centre and Stay, which Kara and Jenna attend. ABC News Digital have provided the following information on the reporter’s liaison with these centres:

Photographs of Kara and Jenna were taken inside the Mulleraterong Centre and Stay with the full knowledge of the operators of those centres. The initial story idea was first raised with the CEO of the Mulleraterong Centre (Annette Read), which is a day centre for people with disabilities. Margaret also told Maree Sandford, the CEO of Stay, where the twins also attend, about the fact she was doing a story on the Hilliers and would be spending a couple of days with them.

Approval was given by both centres to take photographs in their locations. Ms Sandford was with Margaret while she was taking photographs inside Stay and staff were briefed of her presence. At Mulleraterong staff were briefed by Ms Read on what Margaret would be doing during her time there. At no stage did Ms Read or Ms Sandford raise any concerns about what Margaret was doing.

Audience and Consumer Affairs further understand that both Ms Read and Ms Sandford made supportive comments about Sue Hillier as the parent and guardian of the twins, and that they also both made clear that Sue Hillier is a respected member of the community.

Audience and Consumer Affairs are satisfied that the reporter made thoughtful and reasonable efforts to ensure that informed consent for the story was sought and provided. Notwithstanding this, Audience and Consumer Affairs have also considered whether the intrusion into the lives of the Hillier family was proportionate to the public interest aspect of this story.

The situation of Sue and David Hillier as full time carers, when as the story states there is a ‘desperate need for disability housing’ is highly newsworthy. It is explained that:

The twins are on the Department of Human Services disability support register waiting list. That would mean they'd live in a residential home with 24-hour care.

But that seems like a long way off yet, and Sue isn't sure how much longer she can cope.

And

There's a huge demand for supported accommodation for people with disabilities in Australia.

While many hope the NDIS rollout will bring some relief, the scheme faces a [huge shortfall in disability housing](#)

The article links to a news story from June 2016 which states:

The National Disability Insurance Scheme (NDIS) faces a huge shortfall in disability housing when it is fully rolled out in 2020.

The National Disability Insurance Agency (NDIA), which runs the scheme, says costs to meet demand have been factored in to its \$22 billion budget.

It estimates at least 27,000 people eligible for the scheme will require specialised disability accommodation (SDA), however most of that housing has not yet been built.

The title of the story *'It's like she's a three-year-old': What life's like when your children never grow up* encapsulates the focus of the content: it is established as a piece highlighting the lives of carers. This is further explained in the text of the story:

Sue and David are private people, so welcoming a photographer into their home to capture their family's day is a big deal.

But after many years of hiding their lives away from people, the couple say they want to share the reality of caring for adults with disabilities.

Audience and Consumer Affairs are satisfied that the story was of high public interest and framed specifically from the viewpoint of the carers, who represent a principal and relevant viewpoint in matters relating to disability support and the NDIS.

The complaint only refers to one specific image as being an intrusion into privacy: the shower scene is described as a breach of the *"fundamental rights to privacy and appear(s) to be deliberately denigrating dehumanising and humiliating"*. ABC News Digital have advised that this image was carefully considered and that it aimed to illustrate the fact that Sue and David Hillier are required to look after their adult daughters' care in every way, including bathing. Audience and Consumer Affairs notes that the photograph is carefully framed to minimise visible nudity, and that it demonstrates how Sue Hillier gets into the shower with Jenna to assist her, and how she is still available for Kara, who looks on.

Audience and Consumer Affairs have also considered this image more broadly in the context of the photo essay. The photographs represent the daily lives of the Hilliers and include mealtime; showering and dressing; behavioural issues; and the twins' various interests in TV commercials; old magazines and op shops. The shower photograph captures a very intimate family moment, but Audience and Consumer Affairs are satisfied that it is a discreet image and that overall in the story there is no undue emphasis on any one aspect of the care of Jenna and Zara.

The text and photographs describe and show the daily routines and challenges of the Hilliers; a family on the waiting list for supported accommodation for people with disabilities. The photo essay is a truthful depiction of the role that Sue and David Hillier play in the lives of their daughters. Concerns surrounding disability support and the roll out of the NDIS, and the people whose lives will be directly affected by it, are highly newsworthy. Audience and Consumer Affairs are satisfied that to the extent that there was any intrusion into the privacy of Kara and Jenna's personal life without consent, this was proportionate to the important public interest in this story.

Finding: No breach

Harm and offence

7.1 Content that is likely to cause harm or offence must be justified by the editorial context.

And

7.7 Avoid the unjustified use of stereotypes or discriminatory content that could reasonably be interpreted as condoning or encouraging prejudice.

The complainant has raised sections 7.1 and 7.7 of the ABC's editorial standards, but has not explained specifically how they believe these standards have been breached. Without explanation from the complainant on how they believe the content to be stereotypical or discriminatory we are unable to assess their concerns against standard 7.7. However, as the complainant claims that the young women were exploited to highlight issues relating to lack of services and support, we have assessed the content against 7.1 and considered whether the story was *likely* to cause harm or offence to the audience, and more specifically to the Hillier family themselves.

The complainant is particularly offended by the depiction of Kara and Jenna in the photographs which are described as disrespectful, and "appear to be deliberately denigrating, dehumanising and humiliating" of the two women. On review of the images and the information provided by ABC News Digital there is no evidence to support the notion that the photographs have been selected or manipulated in some way to support a particular view of Kara and Jenna. The photographs are a mixture of posed images and candid photographs which together represent an authentic depiction of the day to day lives of all members of the Hillier family.

Audience and Consumer Affairs accept that some audience members would find some of the photographs challenging and at times uncomfortable, particularly those of a more intimate or private nature. However, any likely offence is justified by the editorial context of this story as explained in the privacy section: the highly newsworthy issue of disability support and the roll out of the NDIS.

With regard to possible harm or offence caused to the Hillier family, as noted previously the reporter had lengthy discussions with the parents; these discussions included the possibility that the article may lead to questions of whether Kara and Jenna could consent to the story; and might prompt comments about Kara and Jenna's appearance on social media. ABC News Digital and Sue and David Hillier made the decision that the importance of the story, which would be carefully handled, justified any limited harm or offence it was likely to cause.

ABC News Digital advise that the reporter has spoken with Sue Hillier three times since the story was published, and that she has repeatedly made clear that she remains happy with her decision to take part in the photo essay. Although Sue Hillier is aware of some of the criticisms of the story, she has advised ABC News Digital that she has also experienced a wave of support from people in the community and those further afield; and that people have expressed compassion and empathy towards the whole family.

Audience and Consumer Affairs further note that the story has prompted numerous supportive comments on the ABC News Facebook site. ABC News Digital have also provided an example of the supportive comments the unit has received:

comments: What a beautiful and sensitive article portraying the love and dedication by two exhausted parents, for their twins. I am a psychologist and wish there were more articles around like this that raise so many important issues. For me, one of the things I hope it helps with is highlighting the need for respite and a plan for those with significant disabilities under the ACAS/older adult age limits. Services and care for these people is so limited. Kara and Jenna, David and Sue, thank you for allowing us to see a snapshot of your life.

There is no evidence to suggest that the story has caused harm or offence to the Hillier family. It is relevant to note that Sue and David Hillier have both expressed the view that the story is within the public interest, and that change in disability services will never happen if stories like theirs, confronting for some as they may be, continue to be hidden away.

Finding: No breach

Conclusion

For the reasons set out above, Audience and Consumer Affairs has concluded that the story *It's like she's a three-year-old: What life's like when our children never grow up* was in keeping with the Corporation's standards for *privacy* and *harm and offence*.

5 January 2017