

## Disability Health Network

## Carer video transcript

Visual: Deb, headshot, facing camera

Text: 'Debra, Disability Health Network member'

"Hi I'm Deb and I have a brother with a learning disability who is now almost 50 and who lives in a group home with Nulsen Disability Services.

Visual: Deb, headshot, facing camera

"As a sibling looking out for my brother I try to get an understanding of what is going on with his life, what sort of things affect his life, what his healthcare plan is, so that if I understand it I'm better able to support him.

"Without that knowledge you're not able to support them.

"Because I am a carer and a sibling who's had the longest relationship, life relationship with each other, we grew up together so we know each other very well. That life history of a person with a disability for a healthcare worker is very important. We can save them a lot of time.

"I would have hoped there would have been more open communication between his treating specialists and me or us as his siblings and be provided with more information.

"And when I ask questions I have an expectation of me being able to ask as many questions as I want so I fully understand what's happening to him, what the treatment plan is, what the care plan is, what the medication is about for I don't think that without knowing the whole story I can be in a position to support him as much as he needs.

Visual: Zoom in, photo of Deb and her brother

"You have to be proactive, consistent and you have to...

Visual: Deb, headshot, facing camera

"Sometimes it feels like you're digging a road to China in trying to the get information so you feel competent in understanding what's happening because if you're ever called on in a role to make an informed consent I don't think you can really do that effectively unless you know the ins and outs of everything.

Visual: Deb, walking towards camera

"I think they're recognising his disability, they treat him with respect which is important.

Visual: Deb, headshot, facing camera

They put him first and foremost in their thoughts – he's the person they have got to obviously look after first and his well-being is number one priority.

"I just wish that carers were recognised more and had more of an input and were treated as a member of a cohesive health team that communicates with each other effectively because if you don't do that there's going to be unhappy team members and disgruntled team members aren't going to contribute to supporting him in having a good life which is what is very important to me.

"My big wish for my brother is that he has a cohesive network, a team of medical professionals whether it's the specialists, the GP, the dental therapist, the support team...

"Nulsen Disability Services has a health network team that surrounds him but it's going outside of that that sometimes causes more angst than I would have hoped.

"I want him to be supported.

"We all have this fundamental right to be involved in the planning of our own healthcare and I don't see that that's any different for him.

"I think that with the support around him he's quite capable of doing just that and I just hope that that would just happen.

"And sometimes I don't think that is as effective as it should be."

Text: 'WA Health News health.wa.gov.au'

End of video

## This document can be made available in alternative formats on request for a person with a disability.

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