Presenter ([00:00](https://www.rev.com/transcript-editor/shared/9iPcELCJvDBdZ5GPHgO_Ok7w-XdySKLbuOYk08hI04BNT0u3hENPbpc1RC_CBnuGGeJ9Oh1vf9hBrYfMe7rX2db3Fzk?loadFrom=DocumentDeeplink&ts=0.81)):

Welcome to the National Disability Services Podcast on identifying and responding to deteriorating health NDS sector consultant Heather McMinn is interviewing Reese Adams on this topic. This recording took place on the lands of the Wurundjeri Peoples of the Kulin Nation. NDS pays respects to the elders, past, present, and emerging, and any community members listening today.

Heather McMinn ([00:26](https://www.rev.com/transcript-editor/shared/CXVgeEIpmiKiqcFIdc7Hgv9ZL5iwyUpSt3JtQQBqbtkTxNhsj89aDYqBlUXr5VB83cdQkL77Ho0IgwMG1DwAMmCOA5o?loadFrom=DocumentDeeplink&ts=26.58)):

Welcome to the National Disability Services Podcast. My name is Heather McMinn, and I'm a Disability Sector Consultant with NDS, the Peak Body for Disability Service Providers in Australia. Today I'll be speaking with Reese Adams, Head of the Center for Developmental Disability Health part of Monash Health about how to identify the deteriorating health of individuals in residential disability settings. Reese has worked in the field of developmental disabilities for the past 18 years in varying capacities. Originally trained as an occupational therapist. He continued his career into research with the Center for Developmental Disability Health prior to becoming the head of the center in 2019. Good morning, Reese, and thank you for joining us today to talk about identifying deteriorating health in disability settings.

Reece Adams ([01:24](https://www.rev.com/transcript-editor/shared/aLDArPqstHoLc6b21oM1afDIEgRj8xnelMhgAn6qacUpgOsxiXtfUMWxelIpYWLGnbqSvlSnf3lSYaUTvKgVXZWV110?loadFrom=DocumentDeeplink&ts=84.9)):

Morning, Heather. Thank you for inviting me.

Heather McMinn ([01:27](https://www.rev.com/transcript-editor/shared/PTgxv_AguUHOIJBPZVTEZvBlYF_vbceSmq5qAaQPP7g9e1PB1dnGPWX_fxIsn0yTaXZnWB87Nk7nV_kqB56EFZ3ws8s?loadFrom=DocumentDeeplink&ts=87.03)):

Before we begin the conversation, I do want to note for the people who are listening, that they'll be able to look at the podcast show notes to get details about the resources we talk about, including a deteriorating health poster, and there will also be added links to all the supporting information for easy access to these particular resources. Reese, to start off with, can you tell us a little bit about the Center for Developmental Disability Health and the work that you do there?

Reece Adams ([02:00](https://www.rev.com/transcript-editor/shared/cSmp2CXU_EsrJdSJ-k9NrrTKydWA1iCHHU2MM0gXUqo7LaiLmrhiM6g3--ds5vAu0RPMLfoNC2jlzAneIxJidh0xHGo?loadFrom=DocumentDeeplink&ts=120.42)):

Yeah. The Center for Developmental Disability Health is a statewide health service here in Victoria. Our service provides three particular functions for clinical servicing, so specialists, medical and nursing support for our primary care partners, so general practitioners allied health, etcetera in the community. We also provide education and support to workforce, but also for students in universities. And we also participate and lead research and innovation activities. The center itself has existed for just over 30 years. The center started back in the early 1990s around the time of de-institutionalization here in Victoria. So it's played a really important role for the continued advocacy

Heather McMinn ([02:52](https://www.rev.com/transcript-editor/shared/ABorG6oHZVyATZf2ZzeTuO6UjFNQx0osQtBtlhpL_GDA1Pkkj3D8vM4Tifw1cXcEDMKsMA_SM3V269MFGLLuw631KsQ?loadFrom=DocumentDeeplink&ts=172.71)):

Thank you Reece, and for listeners, we will be providing a link to the Centre for Development Disability Health because I've looked on there and there's lots of resources, there's lots of opportunities for education and training, and it's a really important resource that exists for any workers and providers who are supporting people who are living with an intellectual disability. You were consulted in the development of the poster for disability workers around managing deteriorating health, and I understand the development was a partnership between the Disability Services Commissioner and Department of Families Fairness and Housing. And this poster will be used to display in group homes and include supporting documentation with discussion points for workers. Prior to people looking at that, I think it's really important that we actually explore what is deteriorating health and how might support workers actually identify the signs that someone might have deteriorating health.

Reece Adams ([04:02](https://www.rev.com/transcript-editor/shared/6chZ7vlFtsWSv9M_WozOYGGB8AToTpe75GBJ-BZeCPZe8WDYR0pP-IB1CUzRVlJgyPYlUmgoB43uTcM893Pfas77L2Y?loadFrom=DocumentDeeplink&ts=242.32)):

I think the most important thing to start with is that we acknowledge the fact that people with intellectual and developmental disabilities often present to our hospital systems in crisis. And we know that through anecdotal experience, but also through our evidence in literature and research that has been conducted before. And the reason that this data is so important is because it tells us a story about in the timely manner in which people address their health needs. So when we start to talk about deteriorating health, it's really important for all those who support a person who cannot maintain or support their own healthcare, that they're aware of when a person changes and when I talk about changes, it could be as little as things as they've lost their appetite or they've stopped going to the toilet like they would normally have done. And so it's really important to pick up those symptoms really early with people with intellectual disability, for example

([05:01](https://www.rev.com/transcript-editor/shared/Cr2F_5ncpceaTt5mr26U89I_Ly7nghisYAYOPn6G_18J858VbSISO70Z1dcCl_CTa27f3lBv47NlpkP5THqvBjuh0uM?loadFrom=DocumentDeeplink&ts=301.75)):

we know that there are certain conditions that are much more prevalent than that in the general population. So for example, constipation, gastro reflux aspiration where fluids or food or non-air related things go down into our lungs, and that's what can cause recurrent chest infections for individuals. So there are certain chronic or complex conditions that can be quite recurrent for people with intellectual disability. So when you're supporting a person with an intellectual disability, it's really important to be aware of how they're managing. And the other component is their presentation, their behavior, their participation in their usual daily activities. So aside from just picking up those things like coughing, for example, when they're eating, which might just seem like the old saying, oh, it went down the wrong pipe, that's not a good thing. We need to make sure that they get assessed in a timely manner for their swallowing. But we might also see other symptoms like someone starts to become a bit more withdrawn and want to just stay in bed, or they might not be able to participate in their usual, you know, daily routines than what they normally would've. And that can all be signs of someone who might be in pain or discomfort, may be unwell. So we always need to ask the question, what is happening?

Presenter ([06:28](https://www.rev.com/transcript-editor/shared/qbyUKuo3g1vz96fb0im6qkc2URlCUc3namjx6VS4Bdr5h_085tL0Enm2FDlSMgUGTA6E0qbYeXPyQh1TNMmbCqQ05JQ?loadFrom=DocumentDeeplink&ts=388.43)):

As this podcast has discussed to identify deteriorating health? Remember to look out for coughing, vomiting, shivering, or sweating attempts at self-injury, unusual fatigue, chest pain and discharge or fluid from nose or mouth. And to keep a close eye on changes in a person's eating or drinking, skin changes such as a rash, swelling or blisters change to skin or lip color, whether that be blue or gray, behavior, toilet habits, sleeping patterns, mobility, facial expressions, body movements and mood such as tiredness or aggression. Remember, minor illness or change in health can quickly become life-threatening for a person with disability. This is especially important for people with swallowing issues. Always seek advice and support if you are unsure.

Reece Adams ([07:24](https://www.rev.com/transcript-editor/shared/2KR6LD4QCWG3ZY_BxasUX8Cx0BLGtEI0ul4BHDxriP0yQI5euIdl710c_FXyfEWAfEl7BjuM72284A5B0wVkfQ6JGV0?loadFrom=DocumentDeeplink&ts=444.59)):

And so the next part is actually understanding, well, what has changed? And we start to look at their health changes. And that's when those questions around, has their appetite changed? Maybe we should make an appointment with the gp. And again, we don't, we should not be waiting for the GPS availability. We need to see a GP sooner rather than later. I know it's really important to try and see a regular gp, but if their regular GP is not available, it's really important that they consider seeing alternate medical services, and that could be potentially the emergency department if they're that concerned. But what we also want to see is that good communication of those changes in symptoms when in the residential facilities. What we want to see is good documentation amongst the staff because staff change from shift to shift to shift. And if we don't hand over those changes, what happens is that the person's symptoms are not known.

([08:22](https://www.rev.com/transcript-editor/shared/6IJaLXZ_yJb8OsBEzkXDfkOFoC-BrVWuUC1wYdIzYGtmnCbY7IL3IWeE9kCtYajgIoknlG5Dl6i1MtvdBONPSN9OdyU?loadFrom=DocumentDeeplink&ts=502.58)):

And so when the person does actually hit crisis, as we might say, and their health is significantly deteriorated only within a short span, and when I say a short span, it can take as short as a couple of days, three days even, particularly if someone's had an ongoing constipation that may not have been picked up well before. And so all of a sudden they're deteriorating within a very rapid short period of time. And so those symptoms aren't communicated. The person goes to hospital with that person and they dont know what to tell the workforce, the health staff what's happening because they're not known. And that can be really challenging from our healthcare workers to then assess. So while I talk about this very long journey of a person in deteriorating health, it's really important to understand why our support workers, particularly in the residential facilities, have such an important role to play in observing, communicating and documenting.

Heather McMinn ([09:18](https://www.rev.com/transcript-editor/shared/9C0Rgbn0kozO19EIdzmpHaaMlnmq12NqfUAOAv6KVspJ9fMpkQ3vgjsBgVsiceGTZoO9NHkk45laf3UvhKMhj_QBig4?loadFrom=DocumentDeeplink&ts=558.99)):

Thank you Reese. It really is about getting to know that individual and noticing when something's not quite right and being prepared to actually say even to colleagues or to the individual or to the health practitioners, something's not quite right. Can we actually investigate it further and see if there's anything that needs to be addressed? What are some of the challenges do you think that exist in that disability accommodation setting in regards to managing that deteriorating health situation? I don't know whether you've got any examples or further thoughts around that.

Reece Adams ([09:59](https://www.rev.com/transcript-editor/shared/7aUkMJvNNzsPi7oXWZZVwluuKRD1hU9IiWzb7hjkP2KNpNx_qcW6Q02yfvOvWqa0D7woMXR9BDinSTnq4mc-lP1Wan4?loadFrom=DocumentDeeplink&ts=599.38)):

Look, it's very variable and every setting is different and every organization is different. And one of the things that we've learned through more recent times with the introduction of NDIS has been that as service providers, while we've got the regulations through the commission, a lot of service providers still have their own tools and reporting systems and so forth in which their workers used to communicate or to document information and to track or chart information as well. So I think in recognizing that, I think some of the challenges are around people's familiarity with these tools. I think that's number one. And really comprehensively understanding how to use and why it's important to use those tools. And that can be really challenging for some of our workforce, particularly when they're new. But we also have to be cognizant or supportive of that workforce that are coming in, that not everyone has a lot of health literacy or health background.

([11:05](https://www.rev.com/transcript-editor/shared/uBXpBLHYujteFQKEKej5HpZ3hFfpjL69Ffanus1WnZz20VV62CiKcfGHaMpYe63m_KjyiDt4Gk6MPuUS0Vo99ITwl1Y?loadFrom=DocumentDeeplink&ts=665.01)):

They may not know much about, constipation and what that means and how that might impact an individual. They may not even really know much about at, 18, 19, just coming out of school, wanting to start their career as a support worker. And then, they're being thrust in with a lot of the responsibility for looking after another human being and that can be quite daunting. So it's around recognizing that, that everyone has different skills and knowledge and experience that sits behind them. And I think when I think back to when I was a disability support worker, back in the day when I was at uni, one of the things that I remember vividly, and even now sometimes through practice, you meet some people who have worked in the field for so many years and they know the person, because they'd worked in that house for 10, 15, 20 years.

([12:02](https://www.rev.com/transcript-editor/shared/4ty0syue8l5alBLJYHjlXeuu3lv_Z1UOr4omeqZIJcrutlZ07XrKXLerkOnOSpsra0xz3uzW1fV-bnaxZGxikUdHAWs?loadFrom=DocumentDeeplink&ts=722.17)):

And so any changes, they were able to pick it up on, but it was instinctive for them. And I think we need to recognize that these systems like the chart tools that is a way for us, creating an equality or a consistency that everyone in the workforce can participate in supporting that documentation. And the last thing that I'd probably say is the challenges or barriers around the unknown. The fear of being reprimanded if you do something wrong or you don't act quickly or you pick up something and it's not acted upon. I think one of the concerns I hear from some support workers when they come through our service clinically is that real concern that you, well, we can't have them on too much medication. We can't support too many needs. If they change their needs, they have to go to hospital because we currently support them so much. And I think that concern around their role and their responsibility needs to be addressed and spoken about more comfortably and supported. Because we recognize that health is very challenging and we recognize that health can be very time consuming. And so we just need to support our support workforce to be more aware.

Heather McMinn ([13:18](https://www.rev.com/transcript-editor/shared/sCyHWNR8cK949QdAB0oRaEz1ue6bs7EExwoEXc6C6C2v6GqlsRSc9YlIGvvcfhNREVQ5FyjIfezlayqU1MvkqidFFVY?loadFrom=DocumentDeeplink&ts=798.97)):

It also highlights the onus on the providers to be making sure that their workforce is supported, that new workers do have mentoring or training access to these resources. They won't necessarily know where to just access them individually. And so it is a shared responsibility within each of the organizations and across that workforce. And I also used to work in disability residential accommodation settings. So yes, I'm familiar with, you know, a lot of what you were saying reminded me back of my time there. I look, I know that the focus for this podcast and the actual poster has been disability, residential accommodation, but it is a resource and, and this podcast and the discussion we've had can be used by anyone, can be used by in-home support workers can be used by family members such as myself but also I'm thinking day service providers. There's the same responsibility for workers to be aware of whether someone they know is showing signs of deteriorating health. We're coming to the end of our podcast. Is there any more resources or services that you haven't mentioned that you'd like to note now? again, we will put any links to these at the end of the podcast and video.

Reece Adams ([14:51](https://www.rev.com/transcript-editor/shared/YSvvl0H4K-tYjsx1_XGk2E5i0bLTLOoie8dRnCHpPRSPWsYs9JUClSlGnVIIB5kNc8E_KGUpuYsQmDyZcoSg0wN_nvw?loadFrom=DocumentDeeplink&ts=891.29)):

There's many different centers across Australia that do work in this space and look at resources. So for example, the Center for Intellectual Disability up in New South Wales. for our program we're about to launch a national website for intellectual disability and mental wellbeing called My Lived ID that has just been launched on the internet. And I'll share the link to make sure that gets around. And again, it's around looking very holistically at an individual, even though it is looking at mental wellbeing, but our health deteriorations can impact our mental health as well. there are many different universities that are trying to do work in this space. So really what I would say for most people, if you have a person with a certain type of disability, so Down syndrome for example, going to their peak bodies is always a great start.

([15:44](https://www.rev.com/transcript-editor/shared/adnT9tsnmEfGEVH6Il5RG6eiQWM9US8rN_gSZgfAxboABIMf6TFKVBSWjUBWy0mC3Udxo19WPo08QJV-sNlZvhqIRy4?loadFrom=DocumentDeeplink&ts=944.99)):

And asking what resources do you have? Where can you point me in the right direction? As I said, our center's a statewide health service. We're the only statewide health service of our type, so we're very much here to help Victorians and they're always welcome to. But equally, we work back into a national system as well. And not every state has services like ours, but we're always willing to help coordinate or support people to access at least resources, information, education. and that's one of the functions actually of the My Lived ID hub for services. People can type in their postcode and try and find services in their region. So we're really actively trying to connect people more and more as time goes on and looking at ways to centralize that it's a growing process, but it's definitely making sure that people reach out to people like ourselves at the Center for Developmental Disability Health. We will do our best to help support people and link people into those support networks.

Heather McMinn ([16:42](https://www.rev.com/transcript-editor/shared/fb7SqSiJZcbQAygbsjkhP2_NwhlqLZeDepZ_uW2jUjhizFj7tPW-9CtRaJWHpCyUdIUA9XwbEgpdBK9Mg6Td5RQIxUg?loadFrom=DocumentDeeplink&ts=1002.68)):

Thank you, Reese. I think we could talk for many hours about all the different resources and peak bodies and supports that are actually available and we will make sure that they're added at the end of this podcast. So I thank you for your time. We look forward to your national website, another resource that's available to workers and workers can also contact the National Disability Services Australia. And we will link them with each of you if they're having any kind of trouble making that contact. So thank you for today. We appreciate your time.

Reece Adams ([17:22](https://www.rev.com/transcript-editor/shared/FbwkDHXhttbzZyI1CBehGnGyGXIxFy0dL7nEMONVCkvhsFZf2q_jfCKZEL3yUhRGx-uHtA-XKDudA2ZPBXhGQTBBEvk?loadFrom=DocumentDeeplink&ts=1042.55)):

Thank you very much.

Presenter ([17:24](https://www.rev.com/transcript-editor/shared/Gga0HpteyVxBi8U52Vt_6QEvVcgLRvkdxIEXkf7WnUklpiL-ssRYgdPaDAg39w5T6HVOvZ2lES7E6dv_qt6Pimo72Ro?loadFrom=DocumentDeeplink&ts=1044.44)):

Please find in the description of this podcast the links to the two Deteriorating health posters that were discussed in this podcast presentation. The posters offer advice and particular steps on how to best support a person with deteriorating health. These links, as well as all other websites discussed, will be included in this podcast description. This podcast was produced by National Disability Services with funding from the Victoria State Government.