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Socio-environmental models of allied health disability support: an exploration of narrative experiences in the Australian National Disability and Insurance Scheme

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Supplementary Material

Table S1. Example topics and prompting questions

Topic 1: key differences between allied health practices and models of care in the health and disability sectors.	Topic 2: learning's from working as an allied health professional in the disability sector.	Topic 3: experiences working as an allied health professional in the disability sector.
Question Prompt 1: What do you identify as the key practice and model of care differences between the health and disability sectors?		
Question Prompt 2: Are you able to provide examples of these differences in real practice settings? Can you please describe the key differences in the professional language used between health and disability?		
Question Prompt 3: Are you able to provide an example of when differences in language use have been important in a practice setting?		
Question Prompt 4: Can you please elaborate on how the concept of risk is managed in disability compared to the health sector?		
Question Prompt 5: Are you able to provide an example of how the idea of risk has been managed differently in a disability practice setting, and how you feel the same example would be managed in a health setting?		
Question Prompt 6: Can you please explain the difference in communication styles between health and disability?		
Question Prompt 7: Are you able to provide an example of where using different communication approaches have been used in your practice?		
Question Prompt 8: Can you please talk to any differences in proactive and reactive practices between health and disability?		
Question Prompt 9: Are you able to provide an example of a reactive/proactive approach used with a client?		
Question Prompt 10: Can you please describe the focus on formal and informal training between the health and disability sectors?		
Question Prompt 11: Are you able to provide an example of where informal/formal training has been used in your work in disability?		
Question Prompt 12: Can you explore your role as an educator for staff, clients, families and carers in disability and how that differs to health? Are you able to provide an example of where you have taken an educator role for either staff, clients, families and carers in your disability sector role?		

Supplementary Material Text S2a: Interviewee 2 - Dignity of risk case example: Karen

Karen is in her early 50's and lives with her family in a metropolitan location. She experiences difficulty swallowing (dysphagia) as a result of a stroke a few years ago, and often coughs when drinking thin fluids. Before her stroke, Karen enjoyed sharing a Friday evening wine with friends and family. She requested a speech pathologist to review her swallowing, with the goal to return to drinking an occasional wine.

The speech pathologist assesses Karen's swallowing; identifying Karen is at high risk of aspiration when drinking thin fluids, including wine. Therefore, the speech pathologist recommends Karen only consume thickened fluids and suggests a number of options for thickening wine prior to consumption. Karen does not enjoy the taste and texture of thickened wine. Considering the risks outlined by the speech pathologist, Karen decides she would still prefer to drink an occasional un-thickened wine.

Using their clinical judgement, the speech pathologist informs Karen of the risks associated with drinking thin fluids, such as wine, and explores potential risk minimisation strategies. Karen and the speech pathologist develop a risk management plan, which includes strategies to reduce the risk of aspiration and what to do if this does occur. Karen is able to make an informed decision with the assistance of the speech pathologist and approves the risk management plan. Given the nature of this process, the speech pathologist requests Karen provides written informed consent, and all relevant information is documented.

Karen was able to achieve her goal by accepting the risks involved with consuming thin fluids. She considers this to have improved her quality of life. The speech pathologist

reflects on the concept of dignity of risk and recognises how another professional in the same situation may not wish to assist Karen in consuming thin fluids.

Supplementary Material Text S2b: Interviewee 2 - Models of care case example: Ashley

Ashley is in her early teens and has a diagnosis of Cerebral Palsy with a Gross Motor Classification System (GMFCS) Level IV. She is unable to communicate verbally and is a member of a local scout group. Ashley's NDIS plan includes 10 hours of speech pathology to support her goal of improved inclusion and participation in scouting.

The speech pathologist begins with an assessment, liaison with Ashley's family, and observation at the scout group. It is agreed that the 10 hours of speech pathology may be better directed towards training for the Ashley's family and scout leaders around inclusion, as well as developing resources for the group, rather than spending 10 hours in one-on-one therapy sessions with Ashley. As a result of training and resource provision, Ashley's scout leaders and group have improved skills to promote and work towards her goal of inclusion. Ashley is now able to be activity engaged in scouting activities, as the scout leaders have the skills and knowledge to design appropriate activities.

This type of capacity building differs to the kind of therapeutic work the speech pathologist regularly engages in. However, it is identified that this was likely the best way for Ashley to achieve her goals. Another therapist may have chosen to provide therapeutic services directly to Ashley with the aim of improving her non-verbal communication skills. But this would be focussing on Ashley's impairment, rather than identifying potentially disabling socio-environmental barriers which could be more efficiently addressed with the limited hours of support available.

Supplementary Material Text S2c: Interviewee 1 - Considerations when working in the supported persons environment case example: Olie

Olie is in his early 20's and has autism spectrum disorder*. He lives with his mother and younger sister in a regional/rural location. Olie's mother has an intellectual disability and his younger sister has an acquired brain injury. Olie's NDIS plan includes 12 hours of individualised funding for occupational therapy sessions to support his goal to improve personal care and hygiene.

A referral is made to an occupational therapist, where early contact is made to ensure Olie is happy with the therapist and to arrange an initial home visit. The occupational therapist performs a risk assessment prior to the home visit, where it is identified that Olie's home environment includes high levels of hoarding and low levels of hygiene. The family has a history of interactions with various government agencies and have historically disengaged when recommendations are made to change their living environment. The occupational therapist decides to engage with Olie in his home environment, on consideration of how social and environmental factors will affect the attainment of his goals.

Olie, his mother and sister, and the occupational therapist meet during an initial home visit. Upon visiting their home, the therapist notes the environment poses a risk to the health and wellbeing of Olie and his family, due to hoarding and hygiene issues. There is no clean surface to sit or place documents; and the occupational therapist is conscious of safety risks when positioning themselves in the room. The occupational therapist is aware that this is Olie's home environment, and that he and his family have indicated no desire to change it. In developing a plan to achieve Olie's goal, the occupational therapist makes efforts to ensure their own personal judgements are not brought into this situation. However, the

occupational therapist acknowledges that it will be difficult for Olie to achieve his goal of improved personal care and hygiene within this environment.

After 12 hours of occupational therapy, Olie was only able to achieve small gains towards his goal. In reporting to the NDIS in a person-centred and respectful way, the occupational therapist identifies Olie's home environment limited the ability to achieve his goal.

* It is acknowledged that some people may prefer person first or identify first terminology.

Supplementary Material Text S2d: Interviewee 2 - Informed choice and informed consent case example: Avery

Avery is in her early 40's and has lived with a degenerative neurological condition for a number of years. She resides with her partner and two children in a metropolitan location. A referral for speech pathology and physiotherapy has been made to assess and provide supports for her progressive speech and functional mobility decline.

Avery usually experiences slowed speech and walks with two forearm crutches. Her condition generally fluctuates, and after a recent relapse she is now slurring in her speech and is requiring a four-wheel frame to walk. Avery's goal is to reduce slurring and return to walking with two forearm crutches. She develops a plan with the speech pathologist and physiotherapist and provides informed consent in relation to the support services provided. In developing this plan, it becomes evident that Avery's partner would like to begin planning for future relapses in her condition, specifically for when she eventually loses the ability to speak and walk. Avery has made it clear she does not wish to engage with goals

that involve future planning, as she is not ready to face the thought of losing her independence.

The speech pathologist and physiotherapist recognise the importance of planning for future relapses and reduced independence from Avery's partner's perspective. However, they also recognise their role in facilitating Avery's choice and that she has not provided consent to pursue future planning goals at this point in time.

Supplementary Material Text S2e: Interviewee 2 - Goal oriented work case example: Jordan

Jordan is in his early 30's and recently moved back to his parents' home in a regional/rural location after an acquired brain injury left him unable to independently care for himself. Jordan recently became eligible to receive funded supports through the NDIS. Subsequently, physiotherapy and occupational therapy supports were requested as part of his NDIS plan.

The physiotherapist and occupational therapist meet with Jordan and his parents to review his goals and make a plan regarding supports required to achieve his goal. During this meeting it became clear that Jordan's goals do not align with his parents' wishes. Jordan intends to continue living with his parents indefinitely, however, his parents would like him to return to independent living. Under the current NDIS funding arrangements, the physiotherapist and occupational therapist are limited to providing support services to achieve Jordan's goals, which do not align with independent living.

Jordan's acquired brain injury affected his cognitive functioning and decision making. Although, he has retained capacity to make decisions according to a recent

neuropsychology assessment. During peer supervision, the physiotherapist and occupational therapist reflect on the challenges arising in this situation, particularly regarding the conflict between Jordan's wishes and his parents' wishes in the setting of current NDIS funding models, and their clinical decision making.

Supplementary Material Text S2f: Interviewee 1 - Reactive and flexible plans case example: Rowan

Rowan is a teenager with autism spectrum disorder*. He lives with his parents and attends a 'mainstream' school in a regional/rural location. Rowan's parents provide all his care needs, and he generally only leaves the house to attend school and visit his grandparents. Rowan received early intervention services during his early childhood but has not had any supports outside of school attendance for a number of years. Funding for support services has been available to Rowan for a while, however, he and his family have only recently had an NDIS plan developed, which includes occupational therapy and speech pathology supports.

A referral is made for 10-hours of occupational therapy and speech pathology respectively, with an NDIS plan and goal for learning to surf. The therapists are unsure why they have received a referral for this goal, as it is not a support they provide. The occupational therapist and speech pathologist meet with Rowan and his family to review their plan and goals. It soon becomes clear that Rowan and his parents are not sure what services can be provided by occupational therapy and speech pathology, and how they could match their family wants and needs. The family also reports not being sure why surfing is in Rowan's support plan and do not perceive this as their goal.

Rowan and his parents are planning to travel to Europe for six months to visit family once he has completed high school. The occupational therapist and speech pathologist identify the family travel plans as an important long-term goal. However, in order to achieve this, there are a number of community safety and anxiety goals to work on before Rowan will feel confident to engage in environments outside of home, school, and his grandparents' house.

Using a reactive and flexible approach, Rowan, his family, the occupational therapist and speech pathologist develop a plan to request approval of additional support hours and change his documented NDIS goal to something that is more person-centred. This request is designed to work towards a new goal for Rowan and his family to travel in Europe for six months after high school completion.

* It is acknowledged that some people may prefer person first or identify first terminology.

Supplementary Material Text S2g: Interviewee 1 - Training and education role case example: Morgan

Morgan is in her 20's and experiences approximately 100 seizures per day caused by severe epilepsy. Morgan requires high levels of care supports that are provided by a team of disability support workers. The team of support workers provide personal hygiene supports, which includes washing in a bath.

A referral is made for occupational therapy and physiotherapy to review the disability support workers manual handling process during washing, and recommend any

improvements that can be made to reduce potential risks to Morgan and her carers. Upon meeting with Morgan and some of the support workers, Morgan expresses that she feels vulnerable during bathing and worries she might drown if she has a seizure while in the bath. Together a plan is made to achieve Morgan's goal of improved safety while washing. This includes bathroom modifications and purchase of equipment, including a wheel shower commode, as well as manual handling training for the support worker team.

The occupational therapist and physiotherapist make attempts to arrange manual handling training for all the disability support workers providing care supports for Morgan. It is difficult to organise all the carers to attend at the same time, particularly as they work for a different organisation to the therapists. A few of the support workers who regularly provide care for Morgan are able to be trained together, and a training handover form was amended to include actions to take and a defined feedback loop to the support workers line manager if something unexpected happened during washing.