

THE RELATIONAL NATURE OF PLANNING WITH PEOPLE WITH INTELLECTUAL DISABILITY AND COMPLEX SUPPORT NEEDS

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Person-centred planning

While it is true that we all make plans, few of us create a formal document to do so, beyond perhaps our last will and testament. In contrast, people with intellectual disability have had their lives and activities documented in written plans for the last 30-40 years since individual service, education and health plans were introduced. Since the 1970s, the term 'person-centred planning' has been widely used in this context based on the work of John and Connie O'Brien in the USA (O'Brien & O'Brien, 2002). The intention of person-centred planning is to create a positive life plan by building on the individual's valued relationships, aspirations and capabilities (Mansell & Beadle-Brown, 2004; O'Brien & O'Brien, 2002). The development of person-centred planning was in reaction to the previous deficit-based focus of traditional planning processes about, rather than with, an individual with intellectual disability (O'Brien & O'Brien, 2002). At its core, person-centred planning is an approach to support the person to explore their goals and make decisions about the services that can help to achieve them (Mansell & Beadle-Brown, 2004).

For people with intellectual disability eligible for the Australian National Disability Insurance Scheme (NDIS), a plan is the basis on which funding is allocated and hence a vital mechanism to ensure people's choice of, and control over, the 'reasonable and necessary' supports and services they require (Walsh & Johnson, 2013). Research we have undertaken at the Intellectual Disability Behaviour Support Program at UNSW, Sydney has highlighted the challenges people with intellectual disability and complex support needs may encounter when engaging in NDIS and other social care planning (Collings, Dew & Dowse, 2018; 2017; 2016; Dowse & Dew, 2016). Conducted over the past three and a half years, our research was undertaken in partnership with people with intellectual disability and complex support needs, family members, practitioners including planners, and inclusive of those from Culturally and Linguistically Diverse (CALD) and Aboriginal and Torres Strait Islander backgrounds.

Complex support needs

The term 'complex support needs' encompasses the interplay of intellectual, psychosocial, and/or physical health conditions in conjunction with adverse environmental factors, such as, behavioural risks, substance misuse, criminal justice contact, insecure housing, cultural or intergenerational disadvantage, or a history of violence, trauma and abuse (Dowse, Cumming, Strnadová, Lee & Trofimovs, 2014). Typically, complex support needs have both breadth and depth as they may span multiple domains and/or involve high levels of need in one or more areas (Rankin & Regan, 2004). Given the inherent complexity of effectively engaging with people with intellectual disability and complex support needs, our work and that of others has identified the need for more frequent and intense contact between the person and their planner. Also important is the role of those within an individual's informal network

– family and friends - who may help them to identify and articulate the goals they wish to include in their plan. However, the very nature of the complexity inherent in their lives means that not all people with complex support needs have informal network members to assist them in this way. Nonetheless, individuals with complex support needs typically require assistance with the planning process to occur over a longer period of time than may be required by others with less complex support needs (Collings, Dew & Dowse, 2018; O'Connor, 2014; Soldatic, van Toorn, Dowse, & Muir, 2014; Rosengard et al., 2007). These aspects have proven to be challenges for planning in the NDIS in that people with intellectual disability and complex support needs may be further disadvantaged by engaging in a time-constrained and/or impersonal planning process.

Relational nature of planning

A key component of our work is a focus on the relational nature of planning from the perspectives of people with intellectual disability and complex support needs, their family members and the practitioners who work with them (Collings, Dew & Dowse, 2018; 2017; 2016). As highlighted in our work, these relational aspects are the crux of effectively planning with this group: having a consistent, trusted, skilled, knowledgeable, and helpful person to guide and support the person with intellectual disability and complex support needs through planning. In Figure 1 we have illustrated the relational domains of planning identified across the IDBS work in New South Wales with people with disability, family members, practitioners and planners. Nine relational planning domains are identified grouped under three headings: 1. Building rapport involving taking time, listening and being respectful; 2. Connecting at a personal level involving developing trust, showing understanding and being culturally aware; and 3. Having skills involving imparting knowledge, providing choice, and being consistent. As represented by the matrix lines in Figure 1 we see each of these domains as interdependent rather than discrete.

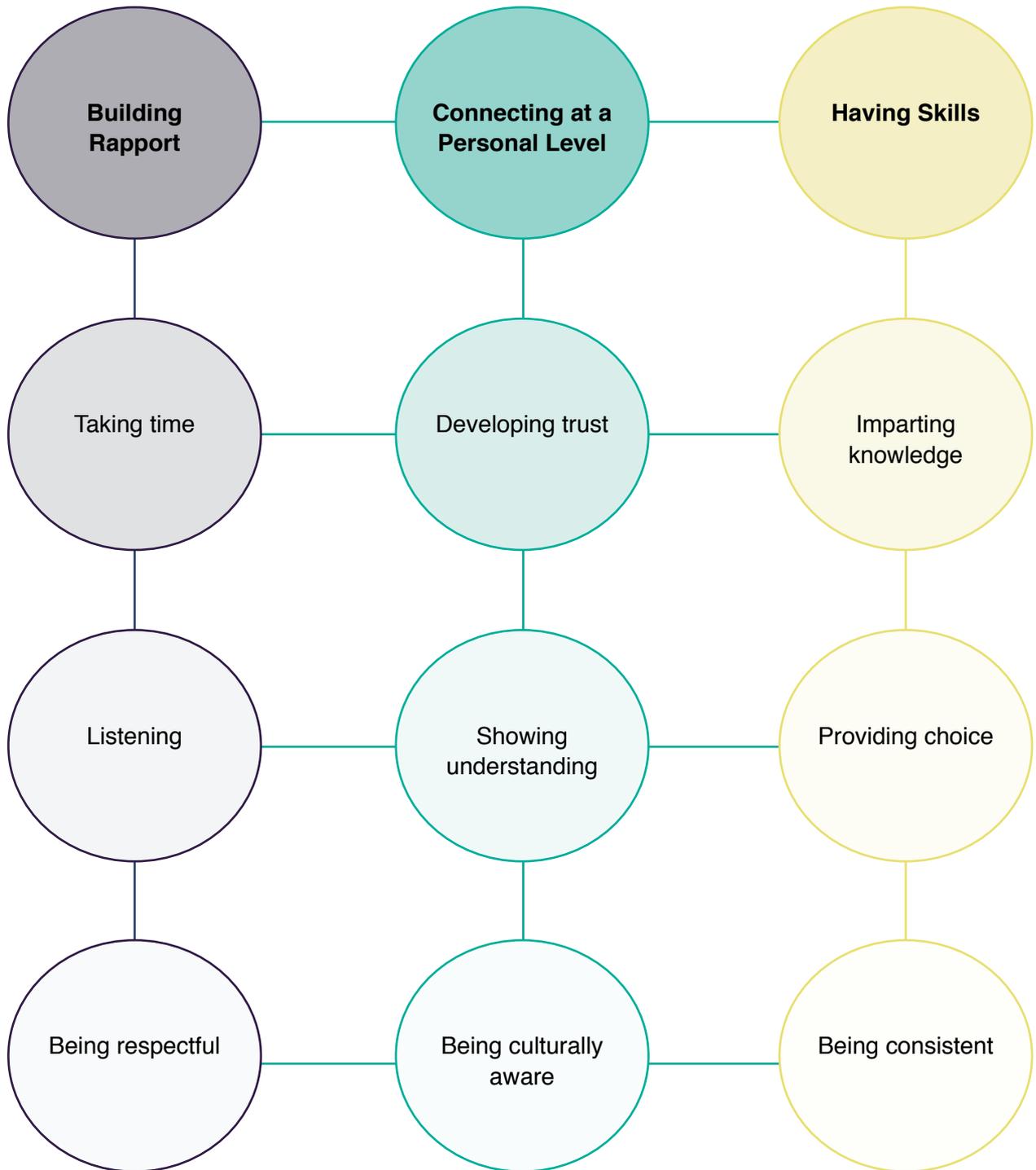
Building rapport

Building rapport between the person with intellectual disability and complex support needs and the planner is an essential relational planning component mentioned by all participants in our work. Building rapport does not happen in one meeting but rather develops over time through multiple interactions during which the planner earns credibility and the pair establishes a working relationship. For people with complex support needs related to disadvantage, discrimination, and marginalisation, building rapport may be inhibited due to past negative experiences with governments, professionals and service providers. Listening is also important and participants with intellectual disability were highly attuned to identifying planners who really listen as opposed to those who come into the meeting with preconceived notions of what the plan would contain. A planner's ability to build rapport and really listen are indications of the level of respect shown by the planner was towards the person. Feeling respected was particularly highlighted by Aboriginal and Torres Strait Islander community members with disability and their carers and is linked to planner's understanding the impact of colonisation and displaying a non-judgemental attitude about people's lives and life choices.

Connecting at a personal level

Connecting at a personal level may seem obvious; however, participants told us that this is often overlooked within a planning context where the focus is on identifying and recording the person with disability's needs. Connecting at a personal level includes the development of trust between the person and planner so that the person feels comfortable discussing with the planner private and perhaps intimate aspects of their lives around which they wish to make plans. Sharing a lived experience of disability either personally or by having a family member with disability was identified by people with disability as aiding this personal connection. A participant described this as "they need to be able to have

Figure 1 Relational Domains of Planning



walked in our shoes” (Collings, Dew & Dowse, 2017, p. 8). Rapport and trust are closely aligned with the planner’s understanding of the person and his/her goals. For participants from CALD and Aboriginal and Torres Strait Islander backgrounds, planner’s cultural awareness is a fundamental aspect of demonstrating connection as imposing dominant cultural values and expectations on people from CALD or Indigenous backgrounds was viewed as both insensitive and perpetuating a dominant culture paradigm.

Having skills

Having skills to work effectively with people with disability was also identified by all participants and reflected a sense of frustration on the part of some that not all planners had knowledge about disability and about relevant, available supports and services. Skilled service providers, many of whom worked with individuals over a long period of time, reported being excluded from the planning process. While some understood this was an attempt to focus planning on the person and remove perceived coercion for the person to continue using their service, they also felt their exclusion, particularly for some people with complex support needs, meant the person was unsupported in planning meetings without family, or service provider involvement. Planner knowledge is also linked to the ability to present and discuss choices with people with disability. A lack of knowledge on the part of planners was perceived as limiting choice for the person as discussions may only occur around known supports and services without consideration of other, less well known, options. Being consistent relates to people’s preference for engaging with the same planner over time so that subsequent planning encounters build upon, rather than have to initiate, the relationship between person and planner.

Summary

Our body of work around planning with people with intellectual disability and complex support needs reinforces the importance of the relational nature of planning as fundamental to ensuring good outcomes for this group who are often excluded or exclude themselves from supports and services due to past poor experiences. Taking the time and having the skills necessary to build rapport and connect personally has been identified as essential to maximising the planning process so that the outcome is a positive life plan that encapsulates the person’s goals and aspirations. Practitioner, person with disability and Aboriginal and Torres Strait Islander specific planning resources developed by the IDBS team can be downloaded for free from: <https://www.arts.unsw.edu.au/research/intellectual-disability-behaviour-support-program/resources/>



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