

Making the most of the NDIS

by Jane Sherwin



When people with Down syndrome gain meaningful skills that enable them to fulfil valued roles, instead of basic life skills, the person is more likely to have a better chance of achieving a positive future.

The introduction of the NDIS has been greeted with much excitement and hope. For some people it is seen as the panacea to the shortcomings in the service system. For others, it is seen as giving equity of opportunity.

This article draws on a theory called social role valorisation (SRV) in providing suggestions for making the NDIS as fruitful as possible. SRV is a helpful thinking framework because it has, as its central idea, that if someone with a disability wants a lifestyle that is meaningful and brings participation and belonging in community life, then being in valued roles will be a crucial path to that lifestyle. This article also comes from a place of caution. Many people speak and act as if having money, choice and a plan are the answers to all the problems related to disability. Let's start at a place of possibility and explore how the potential of the NDIS might be realised: a better life through the NDIS is more likely if each person with a disability is supported to have valued roles.

Courage and other virtues

All parents have dreams for their children before they are born. Each person typically has dreams about what they might like to do when they grow up, shaped by what they see their brothers and sisters do and what they see in broader life. This is true for people with disabilities too, however, there are many dynamics that get in the way of these dreams becoming real life. Working for a better life, a life of richness and meaning, a life of purpose, a life that includes relationships with a range of people who aren't paid to be there is likely to be the better, although harder path.

Making dreams of a better life into a reality requires drawing on various human qualities, such as the virtues of courage, tenacity and creativity. These virtues will be familiar to many people with disabilities and to their families because it is likely that they've already had to practise them when, for example, arguing for decent health care or walking down the street and ignoring stares, or while keeping their heads held high when the principal says your brother without a disability can come here but you need to go to somewhere *special*. Drawing on these inner strengths is an essential first step in order to reconnect with the dreams prior to knowing about the disability.

Conscious planning for valued roles

In planning, the first step is to have a clear sense of what a positive future, outside of services, might look like. This requires a focus first and foremost on the potential, the gifts and the talents of the individual, being mindful of needs but not focusing on deficits.

There are three further ideas to keep in mind:

1. Think valued roles when thinking about a good life.
2. Have roles in mind when naming your goals.
3. Plan to meet each role goal by identifying how the person can best learn the role and become socialised into the role.

1. Think valued roles

The good things in life—for an adult for example—typically include things like having a home, having a job, continuing to learn, having friends, opportunities to contribute, having a spiritual life, and having a sense of identity that brings respect and dignity.

Being in valued roles makes it more likely that those good things of life are possible. At home, the roles could be of homemaker, neighbour, a hobbyist of some sort and family member. At work, the roles could be an employee, a colleague, a tax payer and social club member. Contribution and purpose could be through various volunteer roles, or as an employee, parent or good neighbour. It is through roles that there is a sense of identity, status, respect from others, and self-respect.

There are also age appropriate roles: for example a three-year-old might be in the role of the daughter, adored grandchild, cousin, and Wiggles lover. A twelve-year-old might be in the roles of son, brother, student, football player, guitar player, and library member.

Also, if acceptance and belonging is important, then being in valued roles is an essential path because it is through valued roles that people participate in community life and become known.

Being in a role is very different from simply having activities. For example, when a young person leaves school, there can be *make-busy* activities done to fill in time such as going on outings, doing life-skills training and crafts at a day service. One problem is that in five years' time the person might be stuck in those same activities with limited growth and opportunity. In contrast, for example, before a young person leaves school the question should be asked, 'how does any other young person create a meaningful week once they leave school?' That question gives rise to the roles of, for example, part-time student, volunteer, part-time employee, gym goer, library member, and contributor to the home lifestyle such as through cooking a regular evening meal.

What this means

Become clear about the vision for a positive future and identify the sorts of roles for an individual to have a good life. Any specific needs should be met within the context of pursuing valued roles and the good life. For example, the need to be skillful in personal care or to have manners should be met within the larger roles that those skills are necessary for, such as employee or tertiary student. Secondly, negotiation with a service will be necessary as to whether they have the where-with-all to actually assist someone into a valued role. This is very different from someone being admitted to a group home or expecting a service to find activities and outings for them.

2. Have roles in mind when naming goals

The sorts of goal areas include:

- building skills—for example, building coordination skills so that the person can be a soccer player
- developing a new role—for someone who loves to play the drums, the role could be drummer in the school band
- expanding or strengthening a current role—a person who has moved into their own home and is a neighbour could be encouraged to be a good neighbour through offering to bring in the mail or water the plants of a neighbour
- moving out of negative roles—for example, if someone has learnt to act like the *eternal child*, they could move out of this negative role by learning age appropriate skills for a valued role.

What this means

Being in valued roles will be helpful in getting a rich and meaningful life.

3. Plan to meet each role goal by identifying how the person can best learn the role and become socialised into the role

Who and what surrounds a person conveys expectations of the role to the person. A teacher and other students shape a student role. Being surrounded by desks and chairs sends strong messages of role expectations. A fisherman can only be in that valued role if they actually spend time fishing. These examples show the importance of how socialisation into a role occurs through the *role communicators* which are the people in the social environment, the activities that are done, and those things in the physical environment. All of those communicators convey messages about what is expected in the behaviours and the responsibilities that are called for within a role.

When planning for roles, there may be unhelpful habits of thinking that lead to a *sort of a valued role but not quite*. For example, the role of employee is less valued at a sheltered workshop than at a real workplace where there are other employees who have valued status. The role of tenant is less valued in a group home than in a typical house with housemates who are there not on the basis of impairment.

When planning for a valued role each of the role communicators becomes a decision point. Decisions about each of the following need to be made:

- Where is the most valued place likely to be? A cleaner in a respectable hotel, for example, has more status (and therefore more likely to bring more respect) than a cleaner of the local park toilets.
- What is the most valued grouping likely to be? If we think *typical*, then the most valued grouping for the role of student guitar player is with other students who are learning guitar on the basis of that interest, rather than being grouped because they happen to have a learning difficulty as well. One of the reasons that this is so important is because it is the other students who also become role models.
- What are the most valued activities likely to be? This decision point gets us to identify activities that are the tasks and the responsibilities of the role, for example, the role of tenant and homemaker would include paying the rent, cooking, shopping and cleaning.
- What appearance is consistent with the role? For example, a child care worker would wear neat casual clothing that allows them to bend, sit on the floor and lift children comfortably.
- What timing is consistent to the role? For example going to church would typically happen on a holy day, not at a time that is simply convenient for the minister to visit a facility.

It is important to have all of these factors in place before or as early as possible when someone enters a new role.

What this means

If there isn't a fit between all of these decision points, then it is more likely that the person won't become socialised into the role and that they will look different. If all of these decision points are attended to well, then it is more likely that the person will learn the role in a way that is likely to lead to others perceiving them to be truly in that role and to the person learning the requirements of the role. This also means that the person is more likely to have a better chance at having a positive future.

Cautions

Just as money will not buy happiness, it will also not necessarily buy better lives for people with disabilities. The NDIS should be about getting a life, not getting a service. Frankly, what matters is what the money is spent on. If the money is spent on more group homes and more day services, then it is likely that people with disabilities will continue to live life on the margins of ordinary community life. Clearly this article recommends spending money on assisting people to have real valued roles and getting a real life.

A second caution regards *choice*. There are four reasons why we should be cautious about the mantra of *choice*. Sometimes choices are made with low hope and expectations about what is possible. Other times, choices are made with no or little information about the possibilities. Thirdly, if choices are based on what someone has always known and if what they have known has only ever been the traditional congregated, segregated service life, then *choices* might lead to someone being further stuck in a separate lifestyle. Finally, many services provide a menu of options that are decided upon—not in consultation with—individuals, or even necessarily with the individuals in mind: a *choice* from a pre-determined menu approach is not a sign that people have authority over their own lifestyles.

Planning is said to be a key process within the NDIS system. The caution here is that if planning is deficit based, the focus is on what the individual can't do and is shortsighted. A deficit-based approach is less likely to lead to a lifestyle like others typically take for granted. It is more likely to lead to a service life where the main role of the person with a disability is that of client of a service.

These cautions are offered so that people with disabilities and families do not become stuck in the client role, dependent on the system.

Finally

A good thinking framework like SRV can help people turn the possibilities offered by the NDIS into probabilities. May you find the richness of community life that all people deserve, courageously, consciously and cautiously.

References

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