

NDIS supports for independence

Executive Summary

At the 17 June meeting of the Intellectual Disability Reference Group (IDRG), member Ms Judy Huett, Speak Out Tasmania described experiences of younger people with intellectual disability in Tasmania receiving too much support under the NDIS and are consequently losing life skills and increasing their dependence. The first section of the paper summarises Ms Huett's evidence and the questions she poses.

The scenario described challenges the whole philosophy and paradigm of the NDIS and has potentially deleterious impacts for both participants and the Scheme. This second section of the paper argues that the situation has developed over a long period of time and reflects legacy models of disability. This includes: how people with disability have been treated in the past, how families have been treated, and how families treat their family member with disability, approaches to early intervention, education, and specialist services. Lastly, this section considers *Factors in the NDIS* that may be a barrier to an appropriate focus on independence.

The third section of the paper identifies what is required to ensure that all stakeholders promote and work together toward increased independence of people with disability. The fourth and final section provides recommendations for the Agency.

1. Background

At the 17 June meeting of the Intellectual Disability Reference Group (IDRG), member Ms Judy Huett, Speak Out Tasmania described experiences of younger people with intellectual disability in Tasmania receiving too much support under the NDIS and are consequently losing life skills and increasing their dependence.

Ms Huett reported:

- An increase in support workers going to activities with clients when support is not required.
- Support workers speaking on behalf of participants where the participant could speak on their own behalf.
- Support workers not understanding their role as supporting independence and facilitating relationships. They see themselves as paid friends.
- Examples of greater dependence include participants no longer:
 - catching buses independently as they travel by car with their support worker
 - going to the doctor alone; and
 - going to town shopping with real friends, having friends over or hanging out with friends

- Service providers going to planning meetings with the person, encouraging more rather than less support; and
- Service providers writing into the service agreement that the support person will represent the participant with the Agency.

Ms Huett posed the following questions:

- How can the NDIA make sure service providers are actually working on skill development and working towards a person's goals?
- How can the NDIA stop service providers influencing plans?
- If a person doesn't reach their goals, how can the NDIA make sure this is looked at during a plan review? Questions need to be asked, but the person with intellectual disability must not be 'punished' by reducing their hours
- How can the NDIA measure goals and make sure service providers are supporting clients to reach them?
- People with intellectual disability need to be reminded of their goals regularly, how will the NDIS do this?

The aim of this paper is to provide preliminary notes to understand the issue and possible solutions.

2. How did we get to this situation?

This situation arises from factors in participants and their families' lives, including their experience in the early years and in school, factors in services and factors in the NDIS.

Factors influencing people with disability

- People with disability lack a vision of how they can be more independent; they often have not had exposure to people like themselves leading ordinary lives.
- Lack of education regarding 'what is possible' under the NDIS
- People with disability have not had the opportunity to enhance skills.
- Families without a vision have been over protective
- Services have not provided support for independence.

Factors in families

- Lack of vision of an ordinary life
 - Seen in families of young children perceiving that a full time teachers' aide in childcare and school represents success
 - Families have no idea how a person with significant disability can be involved without a paid person velcroed to their side
- Families have little idea of how to use paid staff to compliment informal support
- Families often need support in 'the art of asking'
- Families need guidance to plan for personal safeguards for their family member so that they can visualise increased independence without compromising safety
- Families experience distrust as a result of years of capped support in state systems

- Families have learnt to ask for as much support as possible because they may never have another opportunity
- There is not yet trust in the NDIS that support will be there when needed
- Once the support is in place, families perceive the danger that “if you don’t use it you will lose it”

Factors in early childhood intervention

- Traditional early intervention teaches families that their children only develop through the skilled work of professionals. This leads to:
 - The perception that more therapy is better than, for example, time in childcare
 - Lack of confidence in the incidental learning from participation with other children and through ordinary family activities
 - The reinforcement of the perception that their family member with disability must always have someone with them.

Factors in schools

- Schools lack vision of a truly inclusive education where all are welcomed and support structures are systemic, not attached to the individual.
- There is a lack of expert support for teachers including:
 - lack of specialist consultancy support; and
 - lack of planning time for teachers to adjust curricula
- These factors result in a perception of the need for a full time teachers’ aide ‘just in case’ to compensate for the lack of educational planning and specialist support.
- A full time teachers’ aide restricts opportunities for a student to be independent or learn to be independent, including students with disability learning how to ask peers to assist where required (i.e. developing informal support). Full time teachers’ aides unintentionally reduce the opportunities for friendship.

Factors in disability services and staff

- Services do not have the knowledge and skills to build independence or how to facilitate the development of relationships.
- WHS and risk mitigation strategies lead services to be over protective.
- Most staff work in a ‘maintenance’ support model, at best supporting participants to maintain their skills. They do not see a role in developing participant capacity and facilitating relationships.
- There is no training, development and support for this much more challenging role.

Factors in the NDIS

Context

- There is limited demand from people with disability, families and carers for increased independence beyond the early years. People have difficulty visualising

how they could be more independent. They are constrained by the stereotypic perceptions (including self-perception and those of others) of their capacities related to their disabilities.

- There is a limited market of services to implement the NDIS vision of increased participant independence and increased informal support.
- Most providers of capacity building support have little experience in increasing independence, facilitating relationships and enhancing social and economic participation.
- The demands of surge make real engagement with participants a challenge. The issues raised in this paper can only be dealt with in the context of a relationship that in the main is prevented as a result of the volume of work.

Planning:

- Are NDIA planners and community partners encouraging participants to think about increased independence and facilitating informal support?
 - Challenge: when professional strangers try to encourage people in unfamiliar directions e.g. to use less support, to be more independent, they are perceived as bureaucratic cost cutters. People and their families have to come to the view themselves and to have the confidence that more will be available when and if required
- Is capacity building towards independence being included in plans?
- Are participants and their families encouraged to think about increased independence and more relationships and are they being encouraged to highlight these goals in their discussion with potential providers.

Implementing the plan - Support Coordination Framework:

- NDIS allocates Support Coordination sparingly because it is expensive, however in a few hours per month for a few months, the NDIS has the unrealistic expectation that a Support Connector will 'build a network of informal and mainstream supports'
- In general, the level and duration of Support Connection and Support Coordination do not reflect what is required to 'build informal supports' and promote independence
- Most providers of Support Coordination lack experience building independence, facilitating relationships and enhancing social and economic participation
- Most providers of Support Coordination do not help participants to think about what increased independence might mean for them and do not negotiate with support providers in relation to the goal of, or support provided to, increasing independence and facilitating relationships.

Provider registration

- Provider registration processes do not require evidence of skills and experience in building independence

3. The way forward: Promoting and supporting independence

People with disability

What do people with disability need to do to achieve greater independence?

- Build a vision that increased independence is possible and how it can be achieved.
- Take up skill building opportunities.
- Build and maintain an appetite for risk taking.
- Staff who understand their role as supporting independence and facilitating relationships.
- Empowering peer support to provide role models.

What can the NDIS do?

- Frame planning conversations about what the participant can do and would like to do to maintain and increase independence.
- Ensure there is targeted capacity building in relation to independence, including how to negotiate with services, direct staff to promote goals of independence and facilitate relationships.
- Develop a national network of peer networks with clear expectations as to their role.

Families

What do families need to do to enable their family member with disability to be more independent?

- A vision for their family member.
- Capacity building:
 - that increased independence is possible
 - how to support their family member to become more independent (promoting positive risk taking) without compromising safety; and
 - how to guide and direct staff to promote independence.
- Mentoring support as families take steps.

What can the NDIS do?

- ILC capacity building for families.
- Peer networks for families (as opposed to 'carer groups')
- Use of appropriate parent training in NDIS Support Catalogue.

Providers

What do providers need to do to assist participants to be more independent?

- Recognition that all support should be provided in a skill enhancing way through implementation of approaches as Active Support for all domains of life.
- Incentives to work on participant skill development.
- Framework that assists providers to work with participants to identify and measure progress toward goals.

What can the NDIS do?

- Reflect increased expectation and skill in pricing catalogue.
- Talk with NDS on how to persuade providers to focus on independence.

Workforce

What needs to happen so that workforce development focuses on promoting independence in their clients?

- Recognition that the fundamental role of the support workers is to assist participants to be more independent.
- Recognition that supporting participants to be more independent requires different skills.
- Change Disability Support Worker Certificate 3 and 4 training to provide skills in assisting people with disability to be more independent.
- Provide training and reward staff who help participants be more independent.

What can the NDIS do?

- Negotiate with training authorities to amend support worker training to focus on building independence.
- Reflect increased expectation and skill in pricing catalogue.
- Demonstrate to services that they will do better when their staff are trained in Active Support which will reflect the changed role expectations.

NDIS processes

Information and capacity building

What is required of information and capacity building to focus on independence?

- Prioritise focus on independence and what it means in practice for people of all ages and capacities and for families.
- Capacity building of people with disability and families to visualize and demand increased independence. Products and resources of the NDIA need to take account of the diversity of disability and lived experiences. Use of people with whom participants can identify is critical

- Empowering peer support.

What can the NDIS do?

- Prioritise independence in all NDIS material especially NDIS readiness.
- Require organisations seeking funds in the ILC to demonstrate how their work will support participants to be more independent.

Planning

What is required of the planning process to focus on independence?

- Goals for independence to go into all plans.
- Support participants to value independence:
 - enable participant to share / be proud of and report areas in which they are independent
 - alert participants to danger of decreased independence
 - identify goals / next steps in enhancing independence; and
 - monitor for achievement of goal of increased independence
- Discuss in planning and frame participant goals in terms of independence.
- Refer people with disability to peer networks.
- In plan review, reflect back on steps for independence in first plan, monitor progress and identify implications for next plan.
- Encourage participants to renegotiate agreements with providers to focus on independence.

What can the NDIS do?

- Have less focus on drop down menus and more focus on discussion
- Provide training materials to NDIS staff, outsourced planners and LACs about focus on independence and how it is achieved.

Plan implementation

What is required of the planning implementation process to focus on independence?

- Focus on independence
 - highlight in service agreement; and
 - enhance capacity of participants and families to hold services accountable to supporting independence.
- Ensure brief to Support Coordinator focuses on independence.

What can the NDIS do?

- Amend the Support Coordination framework.
- Amend registration process to ensure providers demonstrate skill in promoting independence.

- Expert guidance and support to participants and their families in moving towards greater independence. Ensure Support Coordinators and other capacity building providers have:
 - knowledge, skills and experience at supporting independence and social and economic participation; and
 - ability to work directly with participants and families to mentor their growth and development.

4. Recommendations for the NDIS

In relation to information

That the Agency prioritises independence in all NDIS materials.

ILC

That the Agency:

- Requires organisations seeking funds in the ILC to demonstrate how their work will support participants to be more independent.
- Provides capacity building that enables people with disability and families to visualize and demand increased independence including:
 - how to enable and support independence in safe and safeguarded ways; and
 - how to negotiate with services, direct staff to promote goals of independence and facilitate relationships
- Develops national network of peer networks (including peer networks for families) with clear expectations as to their role.

Planning

That the Agency:

- Provides training materials to NDIS staff, outsourced planners and LACs that focuses on independence and how it is achieved.
- Frames planning conversations about what the participant can do and would like to do to maintain and increase independence.
- Refers people with disability to peer networks.
- In plan review, reflects back on steps for independence in first plan, monitor progress and identify implications for next plan.

Reasonable and necessary support

That the Agency:

- Ensures goals for independence go into all plans.

- Ensures capacity building for independence goes into all plans (including capacity building that assists families to support independence).

Plan implementation - Support coordination

That the Agency:

- Amends Support Coordination Framework to strengthen its capacity building elements.
- Amends registration for Support Coordination to ensure Support Coordinators have the:
 - knowledge, skills and experience at supporting independence and social and economic participation; and
 - ability to work directly with participants and families to mentor their growth and development.
- Ensures the brief to the Support Coordinator on behalf of the participant focuses on independence.
- Supports participants to value independence including:
 - enables participants to share / be proud of and report areas in which they are independent
 - alerts participants to the danger of decreased independence
 - identifies goals / next steps in enhancing independence; and
 - monitors for achievement of goal of increased independence.
- Facilitates a service agreement that:
 - highlights independence
 - encourages service and participant to work together to identify and measure progress towards goals; and
 - enhances capacity of participants and families to hold services accountable to supporting independence.

Market and sector development

That the Agency:

- Takes whatever steps are available to assist providers to recognise that all support should be provided in a skill enhancing manner that maintains and enhances independence. This may include:
 - amendments to the registration process to ensure providers demonstrate skill in promoting independence
 - support for the introduction of training in Active Support in all domains of life to reflect changed role expectations; and
 - work with National Disability Services to change expectations of the sector in relation to promoting independence.
- Recognises that support for independence requires a different skill set and provides incentives and rewards for services to work on participant skill development including:

- increased expectation and skill of support workers enhancing participant independence to be reflected in pricing catalogue.
- Negotiates with training authorities to amend support worker training to focus on building independence.

Belinda Epstein-Frisch

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Supporting NDIS participants to be more independent

